

# Advances in Geriatrics

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## Culturally Sensitive, Senior-Friendly Health Information for Caregivers of Veterans With Stroke

**S**troke—the leading cause of serious, long-term disability in the United States<sup>1</sup>—can cause abrupt, devastating changes not only in the lives of patients but also in the lives of patients' family members. Following a stroke, the patient's family members often must take on new caregiver roles, in which they are expected to manage the stroke survivor's multiple physical and mental issues while at the same time dealing with personal stress and uncertainty.<sup>2</sup> Thus, in order to care properly for stroke survivors, family caregivers need information that covers the full spectrum of the stroke recovery trajectory—from diagnosis to rehabilitation—as well as methods that help caregivers manage their feelings during the recovery period.

The *VA/DoD Clinical Practice Guidelines for Management of Stroke Rehabilitation*<sup>3</sup> emphasize the importance of patient and caregiver education. Clinicians need up-to-date and

easily accessible patient education materials since caregivers frequently turn to their health care team for support. Stroke-related information may be even more critical for caregivers whose preferred language is Spanish. Currently, the majority of health education materials related to stroke are written in English, despite the fact that Hispanic Americans have a higher rate of mortality from stroke than white Americans.<sup>4</sup> Recognizing this need, investigators from the North Florida/South Georgia Veterans Health System Geriatric Research Education and Clinical Center (NF/SGVHS GRECC), Gainesville, Florida, conducted the study, "Web-Based Informational Materials for Caregivers of Veterans Post-Stroke." The NF/SGVHS GRECC originally was opened in 1984, with one of its primary foci being the rehabilitation of veterans with stroke and other chronic diseases. Since that time, the NF/SGVHS GRECC has had several clinical approaches in conjunction

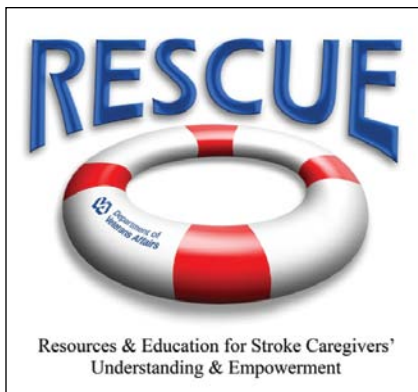
with the VA Rehabilitation Outcomes Research Center (RORC) and the VA Brain Rehabilitation Research Center (BRRC) to assist older veteran patients in the recovery process.

As part of our study, our collaborative investigative team developed and evaluated a Web-based information system that would provide patient education materials to stroke patient caregivers with the intention of increasing their confidence and supporting them in their new roles. Our investigative team included members from the NF/SGVHS GRECC, the NF/SGVHS RORC, the VA Caribbean Healthcare System (VACHS), San Juan, Puerto Rico, and the Clement J. Zablocki VA Medical Center (CZVAMC), Milwaukee, Wisconsin. Members of the VA Stroke Quality Enhancement Research Initiative (QUERI) and the Richard L. Roudebush VA Medical Center, Indianapolis, Indiana, served as project consultants. The project aligns with the NF/SGVHS GRECC's goal to encourage patients and family

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The VHA's Geriatric Research, Education and Clinical Centers (GRECCs) are designed for the advancement and integration of research, education, and clinical achievements in geriatrics and gerontology throughout the VA health care system. Each GRECC focuses on particular aspects of the care of aging veterans and is at the forefront of geriatric research and clinical care. For more information on the GRECC program, visit the Web site (<http://www1.va.gov/grecc/>). This column, which is contributed monthly by GRECC staff members, is coordinated and edited by Kenneth Shay, DDS, MS, director of geriatric programs for the VA Office of Geriatrics and Extended Care, VA Central Office, Washington, DC.





members to become more active participants in their health care.

### DESIGNING AND EVALUATING THE MATERIALS

The first step in providing stroke patient caregivers with patient education materials was to identify the specific informational needs of these caregivers. We examined previously funded caregiver research data, as well as performed a critical review of caregiver information on the Internet and in the published literature. For each need we identified, we created a senior-friendly fact sheet (44 total) and grouped the fact sheets into the following 9 categories: general stroke information, obtaining good health care and information, understanding how caring for a loved one affects you, caring for someone with emotional and behavioral needs, helping your loved one become more independent, keeping your loved one healthy, caring for someone with physical needs, finding community resources, and managing financial and legal issues.

Using established guidelines,<sup>5-8</sup> we created low-literate and senior-friendly patient education materials that use an interactive format, bullets, and statements that are direct, brief, and positive. We used the Flesch-Kincaid readability score tool<sup>9</sup> to ensure the materials were at a 7th-grade reading level or lower. The writing team and additional clinical

experts reviewed the fact sheets for accuracy.

Each fact sheet was translated from English to Spanish by a certified translator and then revised and verified by 2 to 3 Spanish-speaking investigative team members. During this process, we went beyond simply ensuring accurate translation from one language to another; we sought to ensure the fact sheets were culturally sensitive to the Hispanic American population served by the VA.<sup>10,11</sup> To do this, we invited health care providers who had experience with caring for Hispanic American patients to take part during the design phase and used photographs of Hispanic American individuals within the materials.

With a launch date goal of November 2010, we designed a prototype Web site (<http://www.rorc.research.va.gov/rescue>) to house the fact sheets and other self-care documents. Once completed, caregivers

survivors, their family caregivers, and their friends. The theme of RESCUE is that caregivers act as “lifeguards” who are responsible for the safety and well-being of those under their watchful care. In accordance with this theme, the image of a life preserver was used as a branding image and integrated throughout our informational and promotional materials (Figure).

To gauge perspectives of providers and caregivers from different geographic regions and cultural groups, we conducted focus groups that discussed the Web site and the fact sheets. The provider groups included 10 clinicians from NF/SGVHS, 12 from CZVAMC, and 10 from VACHS. We conducted face-to-face interviews with 47 caregivers from these same sites.

Feedback from the providers and caregivers who participated in the focus groups and interviews was overwhelmingly positive. Some general comments included that the Web site

*The theme of RESCUE is that caregivers act as “lifeguards” who are responsible for the safety and well-being of those under their watchful care.*

and providers will be able to download printer-friendly fact sheets from the site, which also will be linked to the VA’s health care portal, My HealthVet.

The goal of the Web site, which is named Resources and Education for Stroke Caregivers’ Understanding and Empowerment (RESCUE), is to provide helpful information about caregiving and the challenges it poses to VA staff as well as veteran stroke

and fact sheets looked professional and were comprehensive, accurate, and user-friendly. Respondents appreciated that the medical terms and content were written in easy-to-understand language. In the feedback, the providers and caregivers also made important suggestions for improving the materials—such as including additional topics, providing pronunciation help for medical terms, and placing a search feature on the Web site.

## SPREADING THE WORD

Recognizing that the success of the project depends on whether health care providers and stroke patient caregivers use our future Web site, we are implementing a multipronged promotional campaign to “spread the word” about the project. We have developed bimonthly RESCUE newsletters designed to improve health care providers’ knowledge regarding caregivers’ roles, to highlight the progress of our project, and to increase interest in our future Web site. We disseminate these newsletters using 3 formats: HTML e-mail, Web page, and portable document format (PDF) files. The newsletters also are featured on the My HealthVet Web site. Each newsletter addresses an important caregiver issue, such as sex after stroke or long-distance caregiving.

We also promoted the Web site at VA events during May 2010, which is National Stroke Awareness Month. Ten VA medical centers, all with a high population of stroke survivors, are distributing fact sheets, newsletters, caregiver tools (such as aphasia pocket cards and medication logs), and promotional “giveaways” that display the Web site address. Results of a Web-based evaluation showed that 85% of the newsletter recipients found the content to be informative and 54.3% of recipients shared newsletter content with a coworker, patient, or family member. From March 2009, through May 2010, there were 5,394 Web page views and approximately 3,838 PDF file downloads of the newsletters.

## THE IMPORTANCE OF PARTNERSHIPS

Building and maintaining partnerships with VA professionals and other stakeholders has been a key element of this project. The most valuable and influential partners have been My HealthVet, the VA National Center for Health

Promotion and Disease Prevention (NCP), and the American Stroke Association (ASA). These partners provided information for the fact sheets and newsletters and, through their endorsements of the project, helped build our credibility as a leader in education for stroke patient caregivers. Most importantly, these partners have promoted the project and future Web site to their large, national audiences.

## THE NEXT STEPS

We will make final refinements to the Web site after usability testing and in-depth face-to-face interviews with 4 to 6 caregivers that will be

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conducted during the fall of 2010. The official launch of the Web site, in November 2010, will coincide with National Family Caregivers Month. Prior to the site’s launch, we will increase promotional campaign activities, the culmination of which will be announcements about the new Web site on the VA Home Page, VHA/VA Facebook Fan Pages, VHA/VA Twitter, VA employee’s paystubs, and My HealthVet. The ASA will feature the project and Web site in their *Stroke Connections* magazine. A printed book of the fact sheets (intended for caregivers who lack Internet access or computer skills) will be available late in 2010.

The last phase of the project will be the summative evaluation that includes an online survey for site users and a telephone survey of health care providers. We also will collect Web site statistics, such as number of

page views and downloads. Although the funding for the project will end in 2011, the VA Stroke QUERI will review the content of the fact sheets at least annually and, in collaboration with My HealthVet, will continue to maintain the Web site.

A natural extension of our project is the development of Web-based support for other veteran patient populations. The materials and methods used herein specifically for stroke patients may enjoy broad applicability. For example, without a burdensome degree of modification, the materials and methods can be used among younger cohorts of veterans (such as

among those who have experienced traumatic brain injury).

## LESSONS LEARNED ALONG THE WAY

Over the course of the project, our skill in designing materials for this specific patient population greatly improved. Although creating materials for a low-literate, older population can be challenging, authoritative sources (such as those used in our project) can be helpful. They provide recommendations for the entire design process, such as the type of writing style to use, how the materials should be organized, and what size and color of font are most effective.

Similarly, developing culturally sensitive materials can be a challenge. Engaging members of various cultural groups was critical to the success of our project, as we learned that the creation of Spanish-language

materials often involves more than finding a talented translator. It is important to allow plenty of time for revising and refining the language and content in patient education materials.

We also learned the value of applying the concepts of health marketing.<sup>12</sup> A strong promotional campaign ensures that patient education materials are used and valued. Key components of a strong promotional campaign include developing partnerships, using consistent branding, and delivering your message through several venues (such as online content, printed brochures and newsletters, and promotional giveaways at events).

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*The authors report no actual or potential conflicts of interest with regard to this column.*

#### Disclaimer

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#### REFERENCES

1. American Heart Association. *Heart Disease and Stroke Statistics—2010 Update*. Dallas, TX: American Heart Association; 2010.
2. Greenwood N, Mackenzie A, Cloud GC, Wilson N. Informal carers of stroke survivors—Factors influencing carers: A systematic review of quantitative studies. *Disabil Rehabil*. 2008;30(18):1329–1349.
3. Duncan PW, Zorowitz R, Bates B, et al. Management of adult stroke rehabilitation care: A clinical practice guideline. *Stroke*. 2005;36(9):e100–e143.
4. Ellis C, Zhao Y, Egede LE. Racial/ethnic differences in stroke mortality in veterans. *Ethn Dis*. 2009;19(2):161–165.
5. US Department of Health and Human Services, Centers for Disease Control and Prevention, Agency for Toxic Substances and Disease Registry. *Scientific and Technical Information—Simply Put*. 2nd ed. Atlanta, GA: Office of Communication, Centers for Disease Control and Prevention; April 1999. [http://www.cdc.gov/DHDSP/cdcynergy\\_training/Content/activeinformation/resources/simpput.pdf](http://www.cdc.gov/DHDSP/cdcynergy_training/Content/activeinformation/resources/simpput.pdf). Accessed August 25, 2010.
6. Health Education Resource Exchange. *Guidelines for Developing Easy-to-Read Health Education Materials*. Washington, DC: US Dept of Health and Human Services; June 2000. <http://www3.doh.wa.gov?here/howto/images/easy2.html>. Accessed June 6, 2010.
7. Clear and simple: Developing effective print materials for low literate readers. National Cancer Institute Web site. <http://www.cancer.gov/aboutnci/oc/clear-and-simple>. Updated February 27, 2003. Accessed August 25, 2010.
8. National Institute on Aging. *Making Your Printed Health Materials Senior Friendly—Tips from the National Institute on Aging*. Gaithersburg, MD: National Institute on Aging, National Institutes of Health, US Dept of Health and Human Services; October 2007. [http://www.nia.nih.gov/NR/rdonlyres/D8994383-6F06-4C07-B560-2A32247D3991/9571/NIA\\_Health\\_Materials\\_TipSheet51308.pdf](http://www.nia.nih.gov/NR/rdonlyres/D8994383-6F06-4C07-B560-2A32247D3991/9571/NIA_Health_Materials_TipSheet51308.pdf). Accessed August 25, 2010.
9. Kincaid JP, Fishburne RP II, Rogers RL, Chissom BS. *Derivation of new readability formulas (Automated Readability Index, Fog Count and Flesch Reading Ease Formula) for Navy enlisted personnel*. Research Branch Report 8-75. Millington, TN: Naval Technical Training, US Naval Air Station, Memphis, TN; 1975.
10. Doak CC, Doak LG, Root JH. *Teaching Patients With Low Literacy Skills*. 2nd ed. Philadelphia, PA: Lippincott; 1996.
11. Sabogal F, Otero-Sabogal R, Pasick RJ, Jenkins CN, Perez-Stable EJ. Printed health education materials for diverse communities: Suggestions learned from the field. *Health Ed Q*. 1996;23(suppl):S123–S141.
12. Bernhardt JM. Improving health through health marketing. *Prev Chronic Dis*. July 2006. [http://www.cdc.gov/pcd/issues/2006/jul/05\\_0238.htm](http://www.cdc.gov/pcd/issues/2006/jul/05_0238.htm). Reviewed February 27, 2009. Accessed August 25, 2010.