Disability and Rehabilitation, 2008; 30(19): 1506–1512

informa
healthcare

REHABILITATION IN PRACTICE

Stroke rehabilitation information for clients and families: Assessing the quality of the *StrokEngine-Family* website

ANNIE ROCHETTE[1,3], NICOL KORNER-BITENSKY[2,3], VALERIE TREMBLAY[2,3] & LORIE KLODA[4]

[1]*Faculty of Medicine, School of Rehabilitation, University of Montreal, Quebec,* [2]*Faculty of Medicine, School of Physical and Occupational Therapy, McGill University, Montreal, Quebec,* [3]*Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR), and* [4]*Life Sciences Library, McGill University, Montreal, Quebec, Canada*

Accepted August 2007

Abstract

Purpose. This study: (i) Identified the availability of scientifically-based information on the internet regarding stroke rehabilitation intended for those who have experienced a stroke and their families; and, (ii) assessed the usability of a newly created website on stroke rehabilitation for laypersons, *StrokEngine-Family*.

Method. First, an extensive systematic search was undertaken to identify and appraise existing stroke rehabilitation websites. Seventeen websites met specific inclusion/exclusion criteria. Although some addressed stroke rehabilitation interventions in layperson language, none discussed the numerous treatment options based on scientifically based information. Thus, *StrokEngine-Family* was developed and its usability assessed with individuals who had experienced a stroke and family members.

Results. Seven respondents aged 43 – 68 years participated in the pilot testing of the newly developed *StrokEngine-Family*. All except one indicated overall satisfaction with the website: The one respondent rated it as somewhat user-friendly mainly for aesthetic reasons including the need for darker colors and larger font. In addition, respondents requested specific information regarding emotional support and local community referrals to this type of support. Based on the feedback, minor changes were made including a greater use of short phrases, bulleted notations and the addition of a depression module.

Conclusions. The systematic review provided support for the development of *StrokEngine-Family*. In pilot testing, *StrokEngine-Family* was easy to use and valuable in content.

Keywords: *Internet, stroke, patient information, knowledge translation, website*

Introduction

In Canada alone there are between 40,000 and 50,000 new strokes each year – one every ten minutes [1] resulting in 300,000 Canadians living with stroke-related sequelae that impact on participation [2] and on family functioning [3 – 5]. Because of its sudden onset, stroke changes life from one day to the next, and often has a multiple systems effect that impacts on speech, physical, sensory, cognitive, visual-perceptive, and behavioral functioning [6]. Consequently, there is a need for individuals with stroke and their families to have access to high quality information about stroke rehabilitation and what is, and what is not, effective in terms of intervention. Such information is necessary to lessen the burden of stroke and empower families to seek the best possible interventions. In support of this notion, the World Health Organization advises that, 'patients have a right to be given factual, supportable, understandable and appropriate information'. Indeed, Coutler and collaborators [7] insist that clients be given necessary information to ensure a participative approach in decision making about their treatment options.

Even those of advance aged are increasingly turning to the internet for medical information [8,9]. The question we were interested in answering

Correspondence: Annie Rochette, PhD, School of Rehabilitation, Université de Montréal, C.P. 6128, Succursale Centre-Ville, Montréal, Québec, H3C 3J7, Canada. Tel: +1(514) 343 2192. Fax: +1(514) 343 2105. E-mail: annie.rochette@umontreal.ca
Annie Rochette undertook this work as a Post-doctoral fellow at McGill University, Montreal, Quebec, Canada.

ISSN 0963-8288 print/ISSN 1464-5165 online
DOI: 10.1080/09638280701615220

was: Is scientific information on stroke rehabilitation easily available to clients and families on the internet? If not, we were prepared to create and pilot test the usefulness of a stroke-rehabilitation layperson website. Thus, the purposes of this study were two-fold. First, we conducted a systematic review of websites to identify those that provide scientific information on stroke rehabilitation in a format useful for laypersons. As the search revealed no suitable website, *StrokEngine-Family*, a website focused on stroke rehabilitation was developed and its usability was assessed with individuals who had experienced a stroke and their family members. The term 'usability' is defined as 'the effectiveness, efficiency, and satisfaction with which users can achieve tasks in a particular environment. High usability means a system is: Easy to learn and remember; efficient, visually pleasing and fun to use; and enables quick recovery from errors' [10].

Materials and methods

The two phases of this study are presented separately.

Searches on the Internet for a website on stroke rehabilitation

Searches were conducted in Microsoft Network (MSN) search engine and Webcrawler, the latter being a meta-search engine that regroups Google, Yahoo, Ask Jeeves, About, LookSmart and Overture FindWhat. The following search terms were used: 'stroke rehabilitation', 'stroke AND rehabilitation' and 'stroke OR physiotherapy OR physical therapy OR occupational therapy'. To be included, websites had to be in English or French and available free of charge. Each website was reviewed independently by three individuals including two researchers with expertise in stroke and a health sciences librarian with expertise in consumer health information. When a website was identified it was reviewed for inclusion/exclusion using the following criteria of elimination: (i) Duplicate; (ii) presence of advertisement to sell products (e.g., medications, services); (iii) not specific to stroke; (iv) not readily accessible to clients and families (i.e., terminology aimed primarily at health professionals); and (v) no mention of stroke rehabilitation interventions.

Assessing the usability of StrokEngine

Design. A methodology combining quantitative and qualitative approaches was used where open-ended questions were asked whenever a score of dissatisfaction was given on a close-ended question. A telephone interview was used to elicit information on usability of the website. While ethics requirements were reviewed with the Institutional Review Board of McGill University, Montreal, Quebec, Canada, a formal ethics review was deemed unnecessary as individuals were free to review the website or not and contacted us if interested in doing so. No personal information or identifiers were used in the reporting of results.

Development. StrokEngine-Family (www.strokengine.org) provides information on an 'A to Z' of topics related to stroke rehabilitation (e.g., acupuncture, aids and adaptations, constraint-induced therapy, driving after stroke) in a web-based format targeting the layperson (see Figure 1). The content is based on rigorous scientific review of the evidence as developed by an international group of experts on stroke rehabilitation. Each module is organized in a similar format for ease of use and worded, whenever possible, using layperson terminology (see Figure 2). Prior to website posting each module is read by a group of experts in stroke rehabilitation and by laypersons. Printable versions are available for clients and families who may prefer to read from a hard copy. There is no charge for use.

Development of the questionnaire. While there are numerous instruments to elicit information on the quality of health information available on the web, when a number were reviewed, none was found to be easily usable by those with stroke and their families [11]. Therefore, we designed a questionnaire to measure usability of *StrokEngine-Family*, based on an extensive literature review in which we identified the components that are important to measuring usability in terms of design and content. We based our questionnaire on one previously developed to assess *StrokEngine*, the companion website that is geared to health professionals. Prior to its use, the adapted questionnaire and procedure for data collection were pilot-tested on three individuals without known medical conditions. Minor modifications were made based on this first step, and the questionnaire was pilot tested further with two individuals to confirm its acceptability.

Each item on the questionnaire is scored on a five-point Likert scale from 'not at all' (1) to 'extremely' (5), where a higher score indicates a greater satisfaction. For example, items included, 'How satisfied are you with the appearance of the text (size, type of writing, spacing, etc.)?' or 'How satisfied are you with the visual presentation (organization of content)?' Each time a score of three or below (a low satisfaction score) was indicated for a particular item, the participant was asked to specify their concern or dissatisfaction by giving a specific

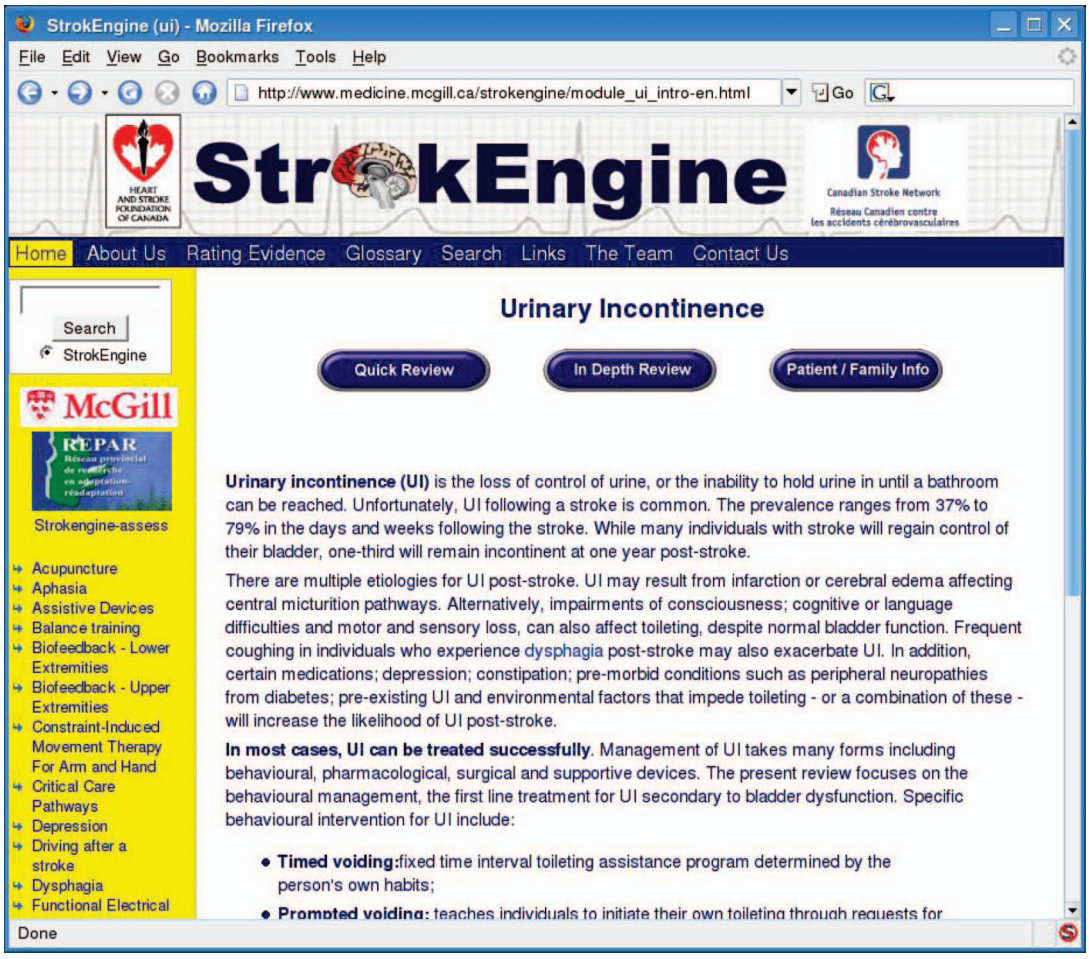

Figure 1. Home page of urinary incontinence module of *StrokEngine*.

example. This procedure allowed participants to express themselves on aspects that might not have been covered by the close-ended portion of the questionnaire. Also, at the end of each section, there are open-ended questions such as 'apart from what you mentioned earlier, what do you (1) like, (2) dislike and, (3) what other information would you like to see included into *StrokEngine-Family*.

To validate participants' recommendations, subsequent participants were asked for their feedback regarding the potential modification or suggestion.

Participants

A purposive convenience sample of individuals who had experienced a stroke, and family members of those with stroke, was recruited. Special attention was given to finding individuals of varying ages, gender, skill with internet use, time since stroke, side of stroke and timing in the process of care to ensure variability in the characteristics of the sample. Individuals with severe cognitive impairments or expressive aphasia were excluded.

Recruitment and data collection procedures

An invitational letter explaining the purpose of the study was sent by a provincial stroke support group to its members and distributed in three hospitals in Montreal, Quebec, Canada and surrounding regions. Individuals who were interested in hearing the details of the project were asked to contact the research team. Those who contacted us had the study explained, and if the individual met eligibility and was interested in participating, a telephone interview was scheduled.

Information on socio-demographic characteristics was collected and participants were asked to choose two of four possible modules to review during the interview by picking from one of the following: Acupuncture, constraint-induced movement therapy for the arm and hand, driving or urinary incontinence. If specific modules turned out to be of greater interest than other modules, they were no longer offered as potential choices to later participants to ensure all four modules were critiqued. The order of module allocation was randomly assigned such that one module was not always the first module

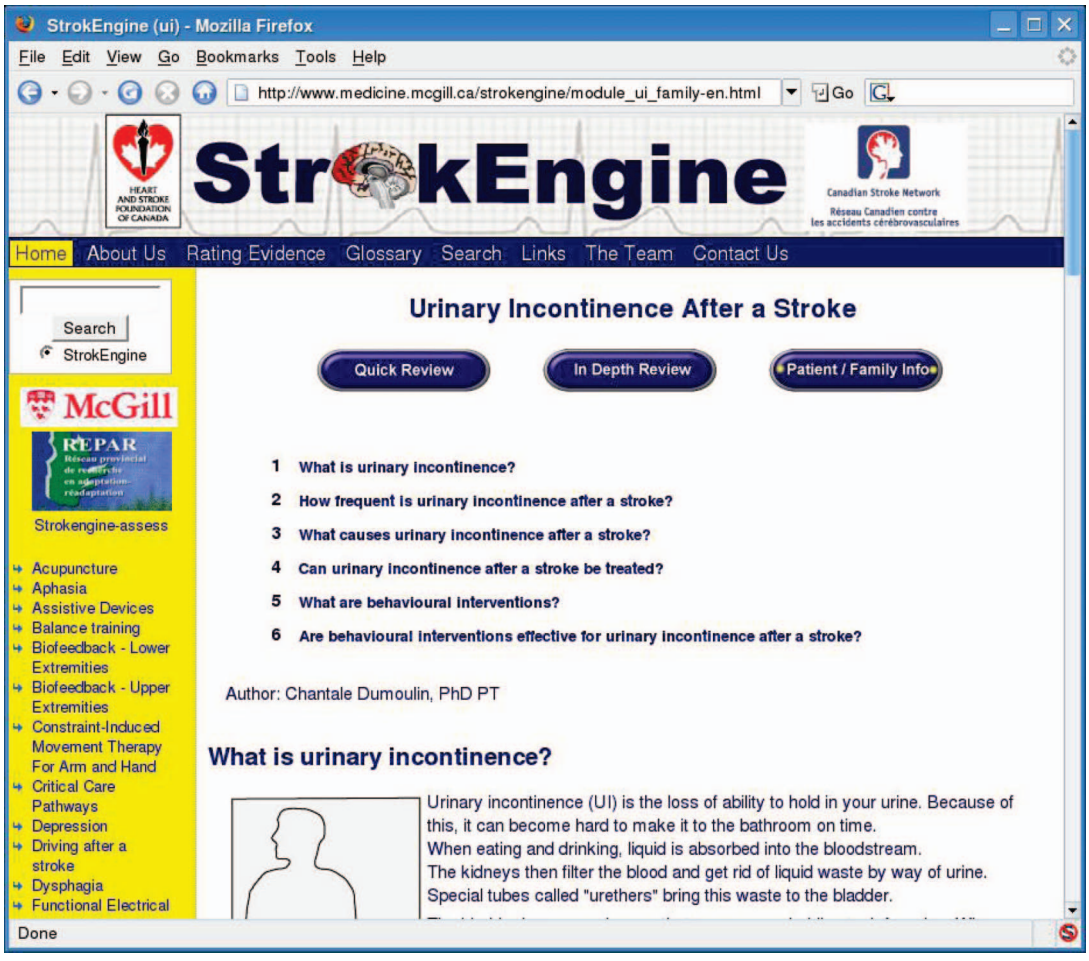

Figure 2. *StrokEngine* Patient/Family information module about urinary incontinence.

reviewed as this may have resulted in biased results – specifically, some modules appearing to be easier to maneuver when it was the effect of being the second module perused. It was also emphasized with participants that questions would be asked, not about their knowledge or learning of the information posted in the module, but rather on how friendly, easy and accessible it was for them to use and navigate within *StrokEngine-Family*.

At the time of the interview, the participant was first asked to take a few minutes to look at the home page of *StrokEngine*, and then to go to the first of the two modules chosen. He or she was informed that the interviewer would call back in 20 min at which time he/she would complete a questionnaire on usability. The participant was provided with the telephone number of the interviewer and told to call if he/she had difficulty accessing or maneuvering within the website. Following the appropriate delay, the interviewer contacted the participant and administered the usability questions related to the home page and the first module. Next, the participant was instructed to review the second module and another 20 min was provided (or shorter or longer as requested by the participant). The interviewer then continued with questions regarding the usability of the second module and the participant's general appreciation of the *StrokEngine-Family* website, along with any other comments or sentiments regarding their experience.

Results

Searches on the internet for a website on stroke rehabilitation

The systematic search revealed 105 websites using Web crawler and more than 2 million websites using MSN. The first 300 websites we perused and a decision was made to conduct an in-depth study of the first 100 as the remaining sites consisted primarily of duplicates or those that were not relevant to our query. After applying the exclusion criteria, 17 websites remained (see Table I). While some addressed stroke rehabilitation interventions in lay-person language, the information was very general or was specific to one intervention, and none of the sites discussed the various treatment options, their

advantages and drawbacks. Based on this review, we deemed it relevant to develop and pilot test the usability of a detailed, rehabilitation-specific, scientifically based stroke website for laypersons.

Pilot testing the usability of StrokEngine

Seven respondents aged 43 – 68 years participated (see Table II). All seven respondents indicated being very or extremely satisfied with the different components of *StrokEngine*, including its ease of use (see Table III). Regarding the home page, one respondent suggested the use of darker colours and bigger fonts and another suggested putting the left-sided menu across the top of the page. One respondent was at first confused as to what to do with the A to Z menu but figured it out for herself. The two respondents who answered somewhat on the usefulness of information in regards to specific modules would have liked a decision tree as to who could benefit most from a specific intervention – those in the acute, sub-acute or chronic phase. Another suggestion was to incorporate bullet formatting with short phrases to make the text simpler to follow.

Two respondents had difficulty finding the first module but all could easily find the second (see Table III) supporting an ease of learning when using *StrokEngine-Family*. In general, respondents indicated appreciation for the website, especially given its availability from home where they could access information at their own pace. Two respondents who had their stroke more than 10 years prior remarked that they wished that this kind of tool had been available back then. All three family members of stroke patients showed a particular concern regarding information about how to handle crying, cognitive and personality changes, as well as information on where to access specific resources within their community, such as emotional support. Also, one family member who was still fresh from the experience of a loved one experiencing a stroke found that the site gave her hope and encouragement, especially to see that so many different rehabilitation approaches exist and could be tried.

Table I. Websites including stroke rehabilitation information using layperson terminology ($n = 17$).

Name	URL
American Hearth Association	http://www.americanheart.org/presenter.jhtml?identifier=4713
• American Stroke Association	http://www.strokeassociation.org/presenter.jhtml?identifier=1200037
National Stroke Association	http://info.stroke.org/site/PageServer?pagename=HOME
• Stroke TIA	http://www.stroke-tia.com/stroke-tia/rehabilitation2.html
The Stroke Association	http://www.stroke.org.uk
National Institute of Neurological Disorders and Stroke	http://www.ninds.nih.gov/disorders/stroke/poststrokerehab.htm
Internet Stroke Center	http://www.strokecenter.org/pat/ras_toc.htm
Hearth and Stroke Foundation	http://ww2.heartandstroke.ca/Page.asp?PageID=24
Stroke Survivor	http://www.strokesurvivors.ca/index.php?nav=arm_and_hands
The Canadian Stroke Network	http://www.canadianstrokenetwork.ca/
Stroke-information.net	http://www. stroke-information.net
Family Doctor	http://familydoctor.org/151.xml
Staten Island Heart	http://www.siheartdocs.com/recovering_from_stroke.htm
The Stroke Information Directory	http://www.stroke-info.com/
National Stroke Foundation	http://www.strokefoundation.com.au/
SAFE – The Stroke Alliance For Europe	http://www.safestroke.org/index.html
SAFE – Stroke Awareness For Everyone	http://www.strokesafe.org/

Table II. Description of respondents.

Respondent type	Age	Age (stroke)	Time since stroke	Side of body affected	Module 1	Module 2
Spouse	62	60	28 years	Right	A	C
Stroke	45	n/a	8 years	Right	C	A
Stroke	64	n/a	4 years	Left	A	UI
Stroke	68	n/a	13 years	Right	D	A
Stroke	47	n/a	19 years	Right	C	A
Daughter	43	71	2 months	Right	C	UI
Daughter	42	70	3 months	Right	C	D

Module: Acupuncture (A).
Constraint-induced movement therapy for arm and hand (C).
Driving (D).
Urinary incontinence (UI).

Table III. Responses* regarding usability of *StrokEngine-Family*.

	Somewhat (n)	Very or extremely (n)
Home page		
Easy to find	1	6
Satisfaction with visual presentation (organisation of content)	3	4
Satisfaction with appearance of text (size, type of writing, spacing)	1	6
Satisfaction with colors	2	5
Module 1		
Easy to find	2	5
Satisfaction with visual presentation (organisation of content)	2	5
Satisfaction with appearance of text (size, type of writing, spacing)	0	7
Usefulness of information	2	5
Module 2		
Easy to find	0	7
Usefulness of information	2	5
General appreciation		
Satisfaction with general appearance	1	6
Easy to use	0	7
Satisfaction with time required to open pages	0	7
How user-friendly	1	6
Overall satisfaction	0	7

*No respondent indicated a response of *not at all* or *a little* on any question.

Discussion

The results of our systematic review showed that although there are numerous valuable websites on stroke on the internet, none are designed specifically to provide scientific information on the range of rehabilitation interventions available for clients or families. Websites with stroke-related educational material that have been evaluated for their quality and suitability [12] also do not focus on stroke rehabilitation. Although some valuable websites might have been omitted with our search strategy, we are confident that if we did not find them after extensive efforts, they would not be easy to find by layperson users.

StrokEngine was designed to be an empowering website that provides accurate information on stroke rehabilitation with the hope that clients and their families can get involved and participate fully in decision-making regarding the interventions that are effective and in which they would be willing to participate. Its purpose is to provide understandable information that enables individuals to seek out scientifically accurate information and enables a dialogue with healthcare professionals as to the best approach to use for a given individual. This is one reason why it was decided that *StrokEngine-Family* would be located on the website targeted for health professionals. It was deemed that this would allow better congruence between the family/patient information and the health professional information. In turn, it is hoped that this format will ensure a true participative approach between stroke healthcare providers and those seeking stroke-related rehabilitation services [7].

A possible limitation of the second phase of this study is the small sample size. However, given the use of both a quantitative questionnaire and a qualitative approach where any proposition to improve the website was validated with subsequent participants, we were able to reach saturation, that is, no new comments or suggestions were proposed by the last two respondents. Another possible limitation of this pilot study is that only four modules were tested.

Results from the usability study are encouraging. An effort will still be required to ensure widespread awareness and implementation of *StrokEngine-Family* as a knowledge translation tool. Future avenues include collaboration with researchers from other countries to adapt *StrokEngine-Family* to meet the needs of the international community, not just by providing the site in different languages, but also by respecting the diversity in international treatment options and differences in healthcare delivery systems.

Conclusion

A new tool providing information specifically on stroke rehabilitation is currently available and was welcomed by individuals who have had a stroke and their family members. *StrokeEngine-Family* was found to be easy to use and valuable in terms of content. Challenges remain including the need to translate this website into multiple languages for international use and for use in differing cultures and healthcare systems.

Acknowledgements

This project was funded in part by the Heart and Stroke Foundation of Ontario, the Canadian Stroke Network (CSN), the Réseau provincial de recherche en adaptation réadaptation (REPAR) through a summer fellowship to V. Tremblay, and the Centre de recherche interdisciplinaire en réadaptation du Montréal Métropolitain (CRIR). A. Rochette was funded by a post-doctoral fellowship from the Canadian Institute of Health Research (CIHR) and N. Korner-Bitensky through a senior career award

from the Fond de la recherche en santé du Québec (FRSQ).

References

1. Fondation des maladies du coeur du Canada. 2005. Accessed at: http://ww2.fmcoeur.ca/
2. Mayo NE, Wood-Dauphinee S, Cote R, Durcan L, Carlton J. Activity, participation, and quality of life 6 months poststroke. Arch Phys Med Rehabil 2002;83:1035–1042.
3. Anderson CS, Linto J, Stewart-Wynne EG. A population-based assessment of the impact and burden of caregiving for long-term stroke survivors. Stroke 1995;26:843–849.
4. Bethoux F, Calmels P, Gautheron V, Minaire P. Quality of life of the spouses of stroke patients: A preliminary study. Int J Rehabil Res 1996;19:291–299.
5. Scholte op Reimer WJ, de Haan RJ, Rijnders PT, Limburg M, van den Bos GA. The burden of caregiving in partners of long-term stroke survivors. Stroke 1998;29:1605–1611.
6. Geyh S, Cieza A, Schouten J, Dickson H, Frommelt P, Omar Z, Kostanjsek N, Ring H, Stucki G. ICF core sets for stroke. J Rehabil Med 2004:135–141.
7. Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: Is the information good enough? BMJ 1999;318: 318–322.
8. Ullrich PF Jr, Vaccaro AR. Patient education on the internet: Opportunities and pitfalls. Spine 2002;27:E185–188.
9. Shuyler KS, Knight KM. What are patients seeking when they turn to the internet? Qualitative content analysis of questions asked by visitors to an orthopaedics web site. J Med Internet Res 2003;5:e24.
10. Hyperdictionary. 2000–2005. Accessed at: http://www.hyperdictionary.com/
11. Bernstam EV, Shelton DM, Walji M, Meric-Bernstam F. Instruments to assess the quality of health information on the worldwide web: What can our patients actually use? Int J Med Inform 2005;74:13–19.
12. Griffin E, McKenna K, Worrall L. Stroke education materials on the worldwide web: An evaluation of their quality and suitability. Top Stroke Rehabil 2004;11:29–40.