

Structuring and Designing Web Information System for Stroke Care: A Malaysian Perspective

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The rapid development of information technology is a powerful instrument for organizational problem-solving to help with establishing general information systems behavior. The choice of medium is important to insure the success of message delivery. The Internet plays an important role in providing information in a timely manner and in a way that can reach a large geographical area. Internet/web systems mean that business, government, or consumers can access the information (Walter and Scott, 2006). Nowadays, an important use of the Internet is to spread information with an emphasis on health. For more than thirty years, clinicians, health service researchers and others have been investigating the use of advanced telecommunications and information technologies to improve healthcare as mentioned by Hawkey et al. (2007). Health information includes stroke and cancer awareness to inform the public about how to detect and cope with situations related to these two diseases.

This research focuses on stroke because it is a leading cause of morbidity, the third leading cause of death in Malaysia and a major reason for adult disability. According to World Health Organization (2000), stroke is also a major cause of death in developed countries. Many people are not aware that stroke is actually preventable and that stroke survivors can live a normal life again. Raising awareness is therefore one of the main agendas of this research.

Throughout the world, government agencies have provided online information to remind the public how important it is to understand stroke, which can affect anyone at any age. Unfortunately, research shows that this information is too vague to allow people to prioritize the information that they really need and to discard what they need less (Younbo et al., 2006), most likely because most information was provided as paper pamphlet with badly organized sections. Two general issues that this study aims to tackle are: 1) the appropriate medium for delivering the information and 2) the organization of the information and its appropriate content. Currently, most of the information about stroke is available online in English, which disadvantages those who are not familiar with English, such as lowly educated Malays.

In addition, published information about stroke rehabilitation and coordinated rehabilitative programs is scarce, especially for use by patients and caregivers. Community-based services such as home visits or classes have been successful in improving the patient's and caregiver's knowledge about stroke and may assist stroke survivors and caregivers in making effective decisions about treatment. In Malaysia, however, owing to the limited human resources, only selected hospitals provide home care nursing services. Passive formats (such as pamphlets) have been used to provide information for stroke survivors and caregivers but they are not as effective as educational interventions.

This paper is divided into five sections. The first section introduces user requirements for the four target user groups. The second section reviews existing stroke information systems. The third

section describes the study we performed. The fourth section discusses the outcomes of the study. The fifth section gives the hierarchy of website navigation and concludes with a summary of what users can get from this information system and possible future enhancements.

Characteristics of the Information System's Stakeholders

In Malaysia, for years caregivers and rehabilitation centers struggle to get the right information to help them address the needs of stroke survivors. Upon initial interview, it became apparent that they need an information system with a flexible and extensible medium for content delivery. Through the initial interview, four groups of users of such information system are identified: stroke survivors, stroke caregivers, stroke rehabilitation centers and therapists.

Stroke survivors' characteristics

Even though stroke survivors will not become one of the stakeholders in this research, their opinion is important because they are the main reason why we need to develop the system. The aim of the research is to help stroke survivors cope with their situation. As Hawkey et al. suggested, successful technology begins with identifying human needs and then tailor the technology to the target audience based on relevant human factors or needs. Through the initial interview, we gathered some requirements if stroke survivors are to be able to use the designed information system. Specifically, a third of stroke survivors suffer from aphasia, a cognitive disorder that impairs speech and language. This means that in many cases stroke survivors will have to rely on other people to understand any information.

Stroke caregivers' characteristics

Caregivers in Malaysia vary in terms of background, age and race as they range from the spouses, children, grandchildren of the stroke survivors, to hired helpers. It should be noted that the stroke survivors (and caregivers) that participated in our study were from low to middle income families, and therefore, some of them had never used computers before. This means that, whatever information we provide, it should be simple enough for novice computer users to learn quickly.

Rehabilitation centers' characteristics

Rehabilitation centers provide physical and language rehabilitation programs for stroke survivors and how to care for stroke survivors for stroke caregivers. Most of these centers have their own websites. Therefore, the information system that we design should seamlessly integrate with their websites.

Therapists' characteristics

Most rehabilitation centers are manned by three types of therapists: occupational therapist, speech therapist and physiotherapist. These therapists are usually very familiar with Internet technology, speak English well (and therefore can use stroke information in English) and most work in several rehabilitation centers, thereby are not always available in one particular rehabilitation center.

Existing stroke information systems

Websites that aim to aid stroke survivors and caregivers are widely available, albeit mostly in English. Table 1 shows some of those websites. As Table 1 shows, only one website provides the information in Malay.

Table 1: Stroke web resources

URL	Users	Country	Organization	Video	Downloadable document	Language
www.strokeassociation.org/	Therapists, stroke caregivers rehabilitation centers	US	American Heart Association	No	Yes	English
www.nasam.org/	Stroke caregivers rehabilitation centers	Malaysia	National Stroke Association of Malaysia	No	No	English, Malay
www.stroke.org	Stroke caregivers rehabilitation centers	Africa, US	National Stroke Association	No	No	Spanish, English
www.stroke.org.uk	Stroke caregivers rehabilitation centers	UK	Stroke Association	No	Yes	English
www.strokecenter.org	Stroke caregivers rehabilitation centers	US	Barnes Jewish Hospital and Washington University School of Medicine	Yes	Yes	English

User Requirement Gathering Methods

Three methods were employed in the development of our systems: interview, focus group and card-sorting. The study was conducted at a rehabilitation center and stroke survivors' homes.

Interview

Interview is one technique we chose to discover user requirements. In such a context the use of interviews is common and recognized as the major technique for ascertaining the requirements of the actors in the organization (Kantola et al., 2007). Three therapists, three stroke caregivers and two stroke survivors were interviewed.

Focus Group

In this research, the focus group combines the ideas that we gathered from the interviews conducted earlier. What focus groups do best is offer 'an opportunity to collect data from groups discussing topics of interest to the researcher' (Ragupathi, 1997). Two groups participated in the focus group sessions: a Chinese group and an English group.

The English group is a group of people who can speak English and involves four stroke survivors. The Chinese group is a group of people who can only speak Chinese and involves eight stroke survivors. The translation process was done by one of the stroke caregivers who works at the rehabilitation center. Two questions that form the basis of the focus group discussions were:

- What problems are they facing at the rehabilitation center?
- What information do they need in addition to the information given by the rehabilitation center?

Card-Sorting

Card-sorting activity is a knowledge-elicitation technique often used by information architects, interaction designers and usability professionals to establish or assess the navigation hierarchy of a website as mentioned by Hudson (2005). Card-sorting requires a few people to select the card which they really think is necessary for them. The content of these cards comes from interview and the focus group treated earlier. The total number of cards that we created is 120 from the information people said they required in the previous focus group sessions. Three caregivers and one stroke survivor did the card-sorting activity.

Results

From the interviews, the following requirements were gathered:

Therapists' requirements

The therapists we interviewed suggested that an online pamphlet consisting of guidelines on how to take care of stroke survivors, which they can distribute to stroke caregivers, would be useful. They also stated that an online communication medium through which they can interact with the stroke survivors (to follow up on treatments) and other stroke therapists (to share ideas) would be helpful. One of the therapists suggested that a VCD with movies of step-by-step exercises be provided for stroke survivors to help them to do rehabilitation at home.

Caregivers' requirements

The stroke caregivers' issues that need to be addressed through the designed information system are:

- Caregivers do not have access to the information on how to take care of stroke survivors, especially during the early days of recovery.
- Caregivers have tremendous emotional burden as they had to cope with their own emotion as well as that of the stroke survivor.
- They need to communicate with other caregivers to share their experience.
- They need to know whom they should see, where they should go and what they should do when they are in an emergency situation.
- A directory of doctors, rehabilitation centers and therapists is needed.

Stroke survivors' requirements

The stroke survivors' requirements were gathered from both interviews and focus group sessions. In the interviews, surprisingly some stroke survivors requested online communication medium to communicate with the therapists. They also suggests a website in which they can choose and shop for rehabilitation equipment that do not cost a fortune (one example that was given was, during early recovery, a stroke survivor's house needs to be fitted with handle bar. Using common handle bars that can be purchased from any home improvement shops costs a quarter of specialized handle bars, and the common bars do the job as well as the specialized ones). They also emphasized that they need to communicate with other stroke survivors to share stories, tips, advice, etc.

From the focus group discussions, it became clear that caregivers are stroke survivors' lifeline. Another finding that kept getting mentioned was, they would like the public to know early signs of stroke and risk factors that can lead to stroke (fatty food, certain ethnicity, stroke in the family, etc).

Card Sorting Activity

Consolidating the requirements and the requested information from all the stakeholders, 120 topical items were gathered. Four respondents (two caregivers and two stroke survivors) did the card sorting. We then merged the results of the card sorting activities. The following is the hierarchy of the sorted cards.

1. General information about stroke
2. Emergency and education for patient
 - i. Emergency
 - Helpline for emergency and questions regarding stroke
 - What MUST be done daily
 - Therapy that the patient needs
 - ii. Education
 - Getting support for post-stroke
 - Information on communication and swallowing
 - Market-place for modification tools (budgets, where to get)
 - Finding supplies (bed)
 - Financial resources
 - Social welfare support
 - Stroke survivor personal stories
 - iii. Videos
 - Video on how to carry stroke survivor
 - Video on how to help patient swallow food
 - Video on how to move patients from bed
 - Video on how to take care of patient's shoulder
 - Video on how to turn patient around
 - Video on how to walk in a correct way
3. Life after stroke
4. Rehabilitation and regaining independence
 - i. Therapies
 - New and alternative therapies
 - What to expect in rehabilitation
 - When to begin rehabilitation
 - Chart from initial step to final step in rehabilitation
 - Occupational therapy
 - What programs of rehabilitation are available
 - Highlighted activities (dos and don'ts for stroke survivor)
 - Speech therapy
 - Steps in speech therapy
 - Therapy that the patient needs (different types)
 - ii. Effect
 - Warning signs of stroke
 - Information to the effect that family history is a predictor of stroke
 - Media statistics
 - Media stroke news

- Stroke connection magazine
- iii. Preparation of home for patient
 - What to prepare in the house
 - Mobility aid application (e.g. people living on fourth floor of an apartment)
 - Sample picture of bathroom modification
 - Step-by-step guidelines for bathroom modification
 - Step-by-step guidelines for stairs modification
 - Example picture of stairs modification
 - Step-by-step guidelines for kitchen modification
 - Sample picture of kitchen modification
 - iv. How to avoid another stroke
 - Exercise and fitness
 - Diet plan
 - Improving patient care
 5. Information from professionals
 - Information on advice center by professionals
 - Psychiatry/psychology information to handle stroke
 - Motivational talk by professionals
 - Motivational talk by doctors
 - Motivational talk(by volunteers)
 6. Connecting others
 - Common thread Pen-Pals
 - Patient feedback to therapists
 - Pediatric stroke resources (links for family who experienced strokes)
 - Discussion board for speech therapy
 7. Caregivers
 - Information on national organization for empowering caregivers
 - Educational information or caregivers
 - Discussion forum for caregivers
 - Caregivers' personal stories
 - Handling emotion for caregivers
 - Support group for caregivers
 - Information on the caregiver's marketplace
 - Caregiver's health management
 - Information on national organization for empowering caregivers
 8. Research findings
 9. Program provided
 - Program organized for stroke survivor and caregivers
 10. Downloadable
 - Downloadable information on rehabilitation center (e.g.: NASAM,MIND)
 - Downloadable information on daily activities at home
 - Downloadable information that they need at home
 - Downloadable information on schedule of diet plan
 11. Contact
 - Links to government hospitals and rehabilitation centers
 - List of donors
 - Directory of nursing homes

- Directory of volunteers
- Directory of doctors
- Directory of care centers

Conclusion

This research proposed a combined technique to get at user requirements from Malaysian perspectives in developing an information system for stroke care.

The approach using card-sorting activities is a first step to obtaining an idea of the hierarchy of the web structure. We are currently planning on testing the stakeholders to navigate around the created information system to detect navigation problems.

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