



# Journal of Applied Sciences

ISSN 1812-5654

**science**  
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## Deriving the Navigational Structure for Stroke Information System Based on User Perceptions

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**Abstract:** The aim of this research is to insure that all the included information given through the internet is what the stroke patients really need. This research discusses several methodologies and techniques applied in eliciting the requirements of users in Malaysia and insuring the correct result are given to them. This research uses interviews, focus groups and card-sorting activities been conducted among Malaysian users. This research covers three groups of users: stroke caregivers, stroke rehab centers and therapists who treat stroke patients. The study presents a website as the medium to deliver the information as decided by the user, including a user-defined of two-level hierarchy of web navigation structure based on Malaysian perspectives.

**Key words:** Stroke survivors, card-sorting, interviews, focus group, mobile

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### INTRODUCTION

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 also important to insure the success of message delivery. The internet plays an important role in giving useful information to keep the communication going. Internet/web systems mean that business, government, or consumer clients of a company can interact through internet connections, or that a company's own functional areas can interact through intranets (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. Health information includes stroke awareness for needs and satisfaction for whereby the public know the importance of having the right information at hand to deal with them as discussed by Park (2007).

Research conducted by Smith *et al.* (2008) studied on why the stroke patient and career did not have enough information and lack of guidance in order for them to handle the stroke patient after discharge from the hospital. This research focuses on stroke because it is a leading cause of health morbidity, the third leading cause of death in Malaysia and a reason for adult disability. Many people

do not realize that stroke is actually preventable as well as the fact that a lot people, who suffer from stroke can live a normal life again. Regan and Drummond (2008) stated that life expectancy has increased significantly for people around the world with intellectual disability which resulting in a rising incidence of age related illnesses that also applied for stroke. The awareness of this information needs to be increased so that people know that stroke can be prevented and cured in many different ways.

Governments have provided online information to remind the public how important it is to know about strokes, which can attack 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. Two general issues that we are concerned with and the medium that is going to choose for delivering the information and secondly the organization of the information and its exact content. Currently, most of the information about stroke is available online for non-Malaysian people. Malaysian people do know that awareness of stroke is very important but fewer people know that stroke can attack more than once if we do not have the right information to prevent it happening. Lack of information and the wrong medium of delivery are the reasons to develop the system.

In addition to this, published information about stroke rehabilitation and coordinated rehabilitative programmes 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 patients 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 patients and caregivers but they are not as effective as educational interventions. Knowledge and information are among the most important factors in purposeful health care work. As mentioned by Hakkinen and Korpela (2007), there is very important in today's activity networks that share the same customers and involve several stakeholders and organizations that should cross various boundaries between the actors that may fully aware of each others' actions and plans for health care puposes.

This research covers the information targeted on the groups of users directly involved with stroke patients. This includes finding the correct medium of communication to deliver the information based on user needs. By using the medium chosen, we need to prioritize the level of the information content and a site navigation menu provided by users.

A study conducted by Kaufmann *et al.* (2004), described what type of information that the stroke caregivers and stroke patient really need and how they want the information to be deliver in a real life. This study showed that they have insufficient and limited information they required on after discharge from the hospital. For years, caregivers and rehab centers have struggled to get the right information to help them with stroke patients where they require an information system with a flexible and extensible medium for content delivery. In recent years, the interest in the role and well-being of stroke victims in today's society has become a centre of attention for researchers from different academic fields. By including participants of different ages and with different disabilities in requirements engineering enhances the quality and quantity of input and ideas (Sustar *et al.*, 2008). Three groups of people making use of the information are identified: stroke caregivers, stroke rehab centers and therapists.

Even though stroke patients 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 patients handle their situation depending on the level of stroke. From this study, most of the stroke patient is an adult. Older people are a large market group with

various needs and preferences that designers, developers and engineers must take into account when creating products (Sustar *et al.*, 2008). Despite of this, we must take into the consideration that stroke patient is vary from their background. This research was conducted to find out how the stroke patient can use the internet as their medium for information with regard to accessibility. Human factors engineering is the area of engineering positing that design of technology should begin by identifying human needs and then tailor the technology to the target audience based on relevant human factors or needs on. As regards the characteristics of stroke patients, however, they are often unable to read and understand the information published on the internet to help them. That is why this research focuses on giving caregivers and stroke rehab centers the right information for them to handle the stroke patient base at the appropriate stroke level. Taken into consideration is the stroke patient characteristic, aphasia which is a cognitive disorder that impairs speech and language. From interviews with aphasic individuals, their caregivers and speech-language pathologists, the need was identified for a daily planner that allows aphasic users to manage their appointments independently. The stroke caregiver will become the person in charge who can help them manage the daily planner that includes the health information required.

Caregivers have an important role in the care of people with a cognitive disability, such as stroke patients. Caregivers provide essential support to these individuals when they return home with varying levels of physical and cognitive difficulty' (Cameron and Gignac, 2008). Caregivers vary in terms of background, age and race. As study conducted in Japan, Muraki *et al.* (2008) prepared a set a questionnaire with the purpose on understanding caregiver's background. Caregiver's experience in handling the stroke also is important to see how it helps them to get the information that they acquire to assist stroke patient as discussed by Persson and Wennman-Larsen (2007). Analyzing their background helps us to know what information they need in order to help them handle the stroke patient. This is to insure that they can understand and practice the information given through the medium chosen. The internet is one medium of communication that they normally use to interact with other people and get more information (Sullivan, 1991). Websites can be one such choice to publish information for caregivers and give them directions on how they can really take good care of a stroke patient. In fact, the internet as mentioned by Sacile (2000) is the correct medium to give the right information, but studying all the

websites available can mean that they strain their eyes and take longer to receive the correct information. It means that even if the correct information is on those websites, its accessibility does not reflect user needs (Walter and Scott, 2006). This research evaluates the feasibility of an information appliance with the goal of alleviating repetitive questioning behavior and contributory factors to caregiver stress. One of our major interests is to obtain the caregivers' ideas to make sure that they really get what they want in terms of information with a correct medium of delivery.

Rehabilitation centers provide rehab programs for stroke patients to help them handle the stroke. As registered centers, they have their own website to publicize information about themselves and give news about stroke itself. When they work independently, however, they need more information from the government side to help introduce themselves to stroke patients who, after treatment at the hospital, need continuous rehab. Even though useful information is published on their websites, they only provide online communications to each other, which is one-sided communication.

Therapists are people, who act as the professional back-up to the medical side. There are three different types of therapist: occupational therapist, speech therapist and physiotherapist. These three therapists use the internet as their daily communication between themselves and stroke patients. Most of them work independently and receive information about the stroke patients online

In recent years, many tools have been developed to aid the stroke patient regardless of who is taking care of him/her. For stroke caregivers, an online handbook is required which they can download from the internet to see what they really can do when dealing with stroke patients. Rehab centers, need information about stroke patients and pamphlets which they can download and distribute for stroke patient for the purpose of rehabilitation.

Meanwhile, according to stroke therapist characteristics, what they require most is an online communication between them and the stroke patient. This research tries to enable all stakeholders to connect with each other.

Lin and Yeh (2008) have studied seven website design elements in order to achieved user-centered approach as a guideline for developing a website. In this study, an investigation of several online web sources discovered information for people in certain countries such as the UK, the US, Africa and Malaysia. Table 1 shows the comparison of online web sources that provide information about stroke. The information provided motivates us to develop an information system for people in Malaysia which is usable by all. This is to insure not only that the stroke patient is aware of stroke disease but also that the people around them who look after them are aware about stroke and the rehabilitation programme.

From the web sources shown in Table 1, we compare the various elements such as user, country, organization, professional resources, video, downloadable documents and language used. Most of the web sources identified above are dedicated to stroke caregivers, rehab centers and therapists. Looking for the different level of stroke patient and their impairments, we ignored stroke patients as users in this research, but stroke patients who able to speak, listen and understand are included among our respondents to make sure the views coming from other stakeholder are reliable.

Table 1 shows that developed countries such as the US, UK and Africa have an adequate amount of information about stroke. The government of the country itself makes an effort to develop information for the public. Professional resources mean that experts such as doctors can find therapist information included on the web. Only one web source contained videos about stroke. Pamphlets that can be downloaded from the web are also important in improving the site's usefulness. Most of the web sources chose the English language to deliver the information: one of them offers a choice between English

Table 1: Comparison on different stroke web sources

Language	Downloadable documents	Video	Professional resources	Organization	Country	User	URL
English	Yes	No	Yes	American Heart Association	US	Therapist, stroke caregivers, rehab center	<a href="http://www.strokeassociation.org/">www.strokeassociation.org/</a>
English, Malay	No	No	No	National Stroke Association of Malaysia	Malaysia	Stroke caregivers, rehab center	<a href="http://www.nasam.org/">www.nasam.org/</a>
Sparyol, English	No	No	No	National Stroke Association	Africa, US	Stroke caregivers, rehab center	<a href="http://www.stroke.org">www.stroke.org</a>
English	Yes	No	Yes	Stroke Association	UK	Stroke caregivers, rehab center	<a href="http://www.stroke.org.uk">www.stroke.org.uk</a>
English	Yes	Yes	Yes	Barnes Jewish Hospital and Washington University School of Medicine	US	Stroke caregivers, rehab center	<a href="http://www.strokecenter.org/">http://www.strokecenter.org/</a>

and Spanyol. The Malaysian website in Table 1 has dual language but no videos, downloadable documents or professional resources. Because the research is from the Malaysian perspective, it tries to develop the information in two languages, English and Malay, to match stakeholder characteristics.

## **MATERIALS AND METHODS**

In order to obtain an information system that fulfills user needs, there are several techniques introduced to let users pick and choose what they really need from the information system. In earlier research, issues of concern include design and development of applications, acceptance testing, integration with existing technology and standards. In later research, they include confidentiality, ethics, privacy, security and user-friendly interfaces' (Raghupathi, 1997).

For this research, we make an assumption to deliver the information. We try to propose to employ mobile as the medium to deliver the information and the target user is the stroke patient only. But the result from the methodology is different from what we expected. In this approach, we proposed user involvement, to assist users to attain an acceptable or improved level of performance and usability of the web information system developed for stroke. These approaches are intended to uncover user centered needs by gathering material created by the user or recording the user's doings and sayings by integrated structure and functionality system designed into the user requirement's as discussed by Jeschke *et al.* (2008).

As also mentioned by Ahmad (2008), requirements elicitation, systematically extract and identify the requirements of the system from a combination of human stakeholders, the system's environment, feasibility studies, market analyses, business plans, analyses of competing products and domain. This research had three stages based on human factor design which are the human stakeholders for the system. The three are interview, focus group and card-sorting. The objective of implementing these three techniques is to insure that every item on the information system is user-driven with the right method. This study took place at a rehabilitation center and stroke patient home at National Stroke Association of Malaysia (NASAM), Selangor and Kuala Lumpur from December 2007 until April 2008.

Interview is one technique that is chosen in order to discover user views as mentioned by on stroke

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 as mentioned by Sampaio *et al.* (2006). This interview session involves three groups of people: therapists, stroke caregivers and stroke patients. A set of questionnaires is prepared for these three groups of people to achieve the same objectives from different perspectives. The interviewees involved are three therapists, three stroke caregivers and two stroke patients.

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 (Raghupathi, 1997). This focus group involves two groups, a Mandarin group and an English group. The English group is a group of people who can only speak English and involves four respondent stroke patients. The Mandarin group is a group of people who can only speak Mandarin and involves eight respondent stroke patients. The translation process was done by one of the stroke caregivers who came to the rehabilitation center. Two questions that have been asked of these groups are:

- What problems are they facing at the rehab center?
- What information do they need instead of the information given by the rehab center?

The third technique is card-sorting activity which 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). Computerized Winconssin card sorting also applied for Children and Adolescents with Asperger Syndrome applied for group of participants in large and complex environment as described by Kaland and Mortensen (2007). 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 are 120, endorsed with the information people said they required in the previous sessions

Three respondent caregivers and one stroke patient did the card-sorting activity. The background of the respondents was taken into account when they did the card-sorting and gave us different ways of arranging the cards.

## RESULTS

The results of the techniques were then combined to produce user requirements in Malaysia. The first one was the interview session with the therapists. What they need are an online pamphlet consisting of guidelines on how to take care of stroke patients which they can distribute to stroke caregivers. They also required an online communication through which they can interact with the stroke patient and other stroke therapists in order to share ideas. One of the therapists needed to have a VCD provided for stroke patients to help them to do rehabilitation at home. For the medium of communication, they are not comfortable using mobile phones as their source information because of the size and they could not afford to buy a PDA to provide a large screen. They also mentioned that the stroke patient did not use mobile phones because of their disability.

The stroke caregivers' issues are:

- Caregivers do not have access to the information on how to take care of stroke patients
- Caregivers have conflicting emotions whereby they need to face the problem with the stroke patient and themselves
- They need to communicate between themselves 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, rehab centers and therapists is needed in order for them to contact all the professionals

From the stroke patient perspective, the general information that they need is online communication between the therapists. They require also the right equipment and other things in order to fight the stroke. They also emphasized that they need to communicate with each other to share stories.

From the focus group discussions involving 12 respondents from the stroke patient group, what we see is a common idea on what they need. Even though there are only two questions we asked, they needed to take a long time to answer because of the difficulties of communication between them. We conclude that what they require are:

- They need more help from caregivers to do tasks
- They rely on the caregivers to find the information for them to help them do what they want

The second group of users involved are the stroke caregivers, who have different perspectives on the two questions given:

- Caregivers act as their hand to help the stroke patient
- Caregivers need to know the signs of stroke better

From the card-sorting activity, we combined all the cards arranged by respondents to produce a site navigation menu. The total number of cards was 120 cards and we split the cards into two halves. One of the four respondents was able to arrange 120 cards, but the other three were only able to arrange sixty cards each. The combined results of the card-sorting are:

**Step 1:** General information about stroke

**Step 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 patient personal stories

(iii) Videos

- Video on how to carry stroke patient
- 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

**Step 3:** Life after stroke

**Step 4:** Rehab 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 patient)
- 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

**Step 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)

**Step 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

**Step 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

**Step 8:** Research findings

**Step 9:** Program provided

- Program organized for stroke patient and caregivers

**Step 10:** Downloadable

- Downloadable information on rehab 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

**Step 11:** Contact

- Links to government hospitals and rehab centers
- List of donors
- Directory of nursing homes
- Directory of volunteers
- Directory of doctors
- Directory of care centers

From the cards that respondents arranged, we came out with a general hierarchy which becomes the first step of stroke site navigation as shown in Fig. 1.

## DISCUSSION

From those three techniques for gathering the combined user requirements, we can manipulate and use all the information provided by users starting from the interview until it reaches the site navigation structure. This approach gathered all the requirements needed by

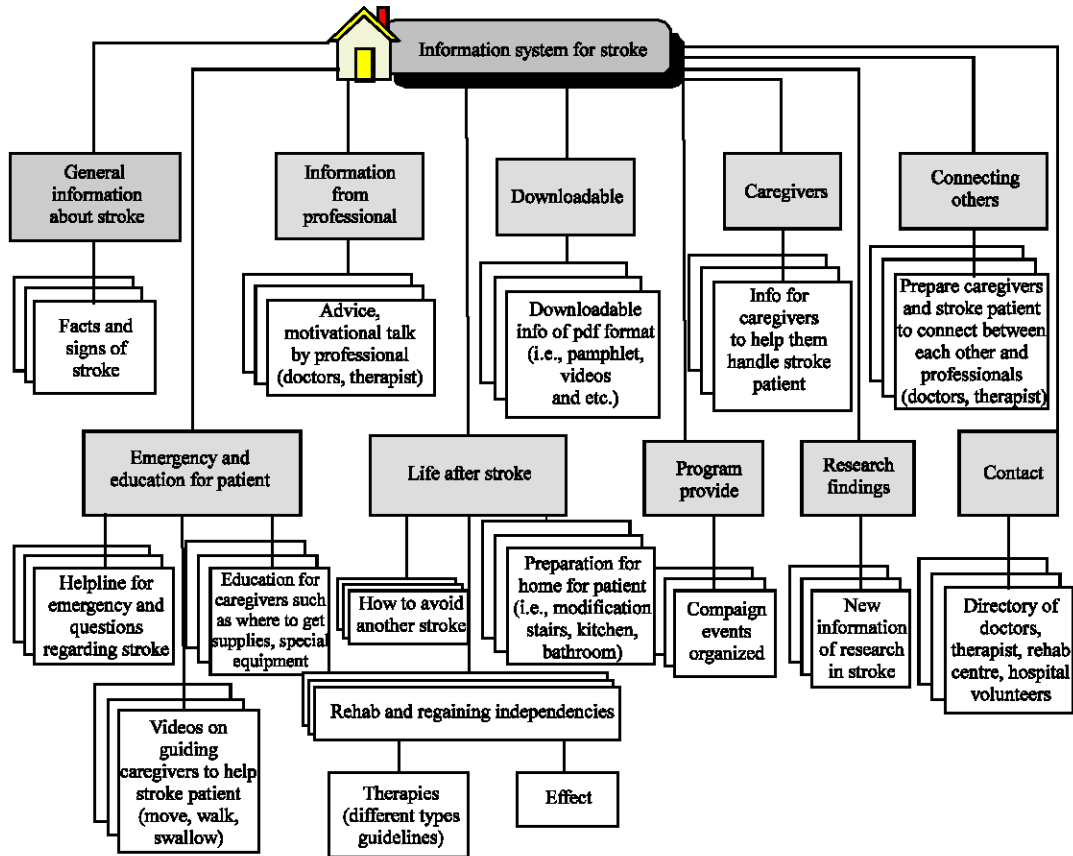


Fig. 1: Two-level hierarchy of web navigation structure

three groups of users involved in three different types of techniques focusing on user-centered design for Malaysian people.

The methodology showed that respondents refuse to use mobile phones for their information delivery. Instead of that, they prefer to use the internet as the medium to publish all the information that they require. Considering the user opinions and the usability of the internet to deliver the information, we chose a web information system as our medium for content delivery.

This hierarchy from the card-sorting activity is a combination of those three decisions made by respondents. In order to reach the site navigation, the prioritization of user was decided by looking at their background. Priority in this chosen technique was given to the respondent of stroke patient who came from a computer science background. The reason why we chose her was because she was familiar with and could understand all the wording written on the card and understand the site navigation structure better than the other three respondents. Furthermore, the respondent is the only person who was able to do all the cards, which

is divided in two because of the time constraints and the ability of the stroke caregivers to understand the contents of the cards

### CONCLUSION

This research proposed a combined technique to get at user requirements from Malaysian perspectives. Through the approach, we can see the user views from different aspects. Unnecessary information can also be eliminated from the content of the website.

The approach using card-sorting activities is a first step to obtaining an idea of the hierarchy of the web navigation structure. Further studies are necessary in order to enhance and improvise this site navigation structure because this research involves only a few people. The consideration of the different backgrounds of people involved in the card-sorting activities is necessary to make it more usable. The pattern of the hierarchy will change in the testing phase. Different methodologies used in this context are very helpful in order to achieve a hierarchy on one site.



## ACKNOWLEDGMENTS

First and foremost we would like to express our gratitude to the Almighty, who gave us the chance to complete the research work successfully. Secondly, we would like to forward our deepest thanks to colleagues, lecturers and technical staffs from the Department of Software Engineering for their endless assistance, technical advice and co-operation. We would also like to thank NASAM, which is a rehabilitation center for stroke patients and which provided us with details about stroke. We are deeply grateful to those stroke patients and caregivers who contributed to and spent time on this research.

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