Exploring of stroke survivors’ information needs for an Information and Communication Technology based home stroke rehabilitation plan to facilitate self-care

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Abstract

Background: To improve self-care in home-based stroke rehabilitation, the access of information that the stroke survivors’ needs is crucial. Currently there is a limited support of collaboration which contributes to restricted access of information and involvement in the care. Information and Communication Technology-tools can facilitate collaboration whereby increasing access and sharing of information. Nevertheless, a number of systems have failed due to a poor user requirement elicitation and analysis.

Objective: The general aim of this study is, to explore and understand information needs of stroke survivors’ for Information and Communication Technology based home stroke rehabilitation plan to facilitate self-care.

Methods: An explorative qualitative study using document analysis, focus group study and prototyping

Results: Through focus group interview the information needs that stroke survivors’ have to facilitate self-care during home-based rehabilitation were elicited. The information needs provide motivational, educational, reminding, social, personal health and general information support. ICT –tools can provide access of information needs timely to stroke survivors’.

Conclusion: Stroke survivors’ information needs, during home-based stroke rehabilitation includes some health information and the available support services for daily life in addition to rehabilitation plan. Thus, this study revealed that identifying and understanding end user information needs is crucial prior to and during the development of a system.

Keywords: Stroke rehabilitation, Information and Communication Technology, self-care, qualitative study, stroke patient, information
Acknowledgements

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Finally to the Creator, for giving me the strength throughout the journey of my life!!!
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Appendix A: Paper Portfolio

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List of Abbreviations
ICE – In Case of Emergency
ICT – Information and Communication Technology
PHR – Patient Health Record
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1. Introduction

Stroke is the most significant global cause of mortality and disability, however in developed countries the primary and secondary prevention of stroke has decreased mortality [1]. The global prevalence of stroke survivors was estimated to be 62 million in 2005 and to project from 67 million to 77 million in year 2015 and 2030 respectively, which increases the demand for rehabilitation [1].

Stroke survivors incur different types and degrees of disabilities like physical, cognitive or emotional function alteration. Based on the stroke related disabilities the duration of rehabilitation and involvement of neurology team varies. Stroke rehabilitation begins at the acute stage where the patient is medically stable and commonly continues to outpatient or home, the patient’s own environment. The primary aim of rehabilitation for the stroke survivors after acute phase is maximizing the functional and cognitive abilities [2] to reduce impairment and enhance independence in daily activities.

As the number of chronic diseases and health expenditure is increasing rapidly focus is growing to bring a positive health outcome in long term conditions [3]. Rosewilliam et al states about the focus of rehabilitation stroke outcome ‘Improving outcomes from stroke rehabilitation is a national priority’ [4].

Patient-centered rehabilitation practice and sharing of important information between patients, family caregivers and the multidisciplinary team contributes to a better outcome [5]. Nevertheless the reality of a multi-professional rehabilitation team involved in the care makes access to and sharing of information difficult.

The use of Information and Communication Technology (ICT) empowers patients by facilitating access and sharing of information in rehabilitation [6]. The Swedish National strategy for e-health recommended in 2006 the development of ICT for a safer, accessible and efficient health care service [7]. In 2010 the Swedish National e-health focused on the provision of interactive personal eServices based on individual needs and desires. The idea behind was, in order for
individuals to have access of information on health and social care as well as previous individual histories which increases the benefit of ICT to individual level [7]. Generally, for patients to monitor [8], check the progress of their illness [9] and a better collaboration [10] in chronic condition the use of an ICT tool is recommended.

This study is part of a PhD project “My Care Plan”, which focuses on exploring information needs of patients, family caregivers and the interacting health care professionals. The objective is to design a health information system, an electronic personalized plan to improve collaboration, patient participation, autonomy and self-care for patients suffering from chronic condition. The project, “My Care Plan” currently focuses on stroke survivors. Thus, this study being part of “My Care Plan” focuses in exploring information needs and understanding how the information needs facilities self-care of stroke survivors during home-based rehabilitation.

The success of a tool is met when it satisfies the intended purpose. In order to identify the information needs end users’ participation and involvement in the development process of a system is vital [11]. As mentioned above, in this study, stroke survivors’ information needs are elicited and understood how to improve self-care in home rehabilitation.

1.1 Stroke

The World Health Organization defined stroke as “rapidly developing clinical symptoms and / or signs of focal or global disturbance of cerebral function, with symptoms lasting 24 hours or longer or leading to death, with no apparent cause other than of vascular origin” [12].

The arteries that carry oxygen and nutrients to the brain are affected in stroke. Ischemic and hemorrhagic stroke are the two types of strokes classified by the cause. Ischemic stroke occurs when the flow of blood to the brain is obstructed by a clot whereas hemorrhagic stroke occurs when a blood vessel ruptures. In both types of stroke, part of the brain where the arteries are affected cannot get blood. The brain being a complex organ which controls various body functions makes the disabilities of post-stroke diverse.
Depending on the part of the brain affected the types and degree of disabilities incurred by the stroke survivors varies. Disabilities differ but can include physical disability (like problem of mobility), cognitive impairment (like difficulty in communication) and psychosocial impairment like depression. The disabilities bring life-style changes which have long term consequences to the stroke survivors and increases burden to their family caregivers [13, 14].

According to Swedish National Quality Registry for stroke care (Riks-Stroke), in Sweden 30.000 people are affected by stroke every year with a total cost of 18.3 billion kroner per year [15].

Post-stroke rehabilitation is aimed at improving function and/or preventing deterioration of function, and to bring highest possible level of independence, physically, psychologically and socially.

1.2 Stroke rehabilitation and rehabilitation plan

Stroke is a lifelong disease process, the rehabilitation starts from acute inpatient setting where the patient get medically stable to outpatient or at the patient’s own environment, named as home-based rehabilitation. Starting rehabilitation early and proceeding to the late phase is crucial for a commendable outcome [16]. The focus of this study is specific to home-based stroke rehabilitation.

Rehabilitation is defined by Wade DT et al ‘as a process that is iterative, active, educational and problem solving based on patient’s disabilities. A rehabilitation comprises of four components i.e. assessment, goal setting, intervention and evaluation’[17]. These four parts are also mentioned in Scottish national clinical guideline as the conventional approach to rehabilitation [18]. The primary goal of rehabilitation is complication prevention, impairment minimization and function maximization however the secondary goal is prevention of stroke recurrence.

Every stroke is different and people are affected in different ways. Stroke survivors receive rehabilitation care from a neurology team based on the type of disabilities they incur. In the care and rehabilitation of stroke survivor depending on the disabilities the involved health care
professional, might include one or a combination of physiotherapist, occupational therapist, speech and language therapist, a counselor, physician and/or nurse.

The neurology team identifies the disability/ies and sets a goal together with the individual stroke survivor for possible improvement. Interventions are provided for the achievement of the goal and the progress is evaluated against the agreed goal. However studies have shown that recovery or positive outcome differs when specified by stroke survivors and a rehabilitation team. Stroke survivors are satisfied by measuring recovery from the point of pre-stroke state, while the rehabilitation team measures recovery with the occurrence of the stroke [4, 19].

Stroke survivor’s rehabilitation needs changes over time based on the progress of the disability. In order to guide to a patient-centered outcome, increased patient participation and caregivers collaboration during a rehabilitation goal setting process is essential[3,4,19,20].

Providing stroke survivor plan about the rehabilitation and graded system of goal achievement increases the patient’s motivation and participation in their rehabilitation process [21, 22]. In order to have a better post-stroke outcome the rehabilitation plan needs to be tailored and addressed to the specific need of the stroke survivor.

1.2.1 Self-care and behavioral change

Stroke is a long term condition where the survivors have a desire to manage their daily life activities and a need to cope with their disabilities. In rehabilitation, stroke survivors are expected to take action according to the intervention provided, based on the goals set which needs behavioral change [23]. Self-care is defined as the action individuals ‘take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents’ [24].

In order for a targeted behavior to happen a person need to be motivated, have sufficient ability and effective trigger according to Fogg
He stated that all the three parts need to happen in integration for a behavioral change.

1.3 Paper portfolio for stroke rehabilitation

In Stockholm County a paper portfolio [see Appendix A] which includes stroke rehabilitation plan has been provided to individual stroke survivors by a neurology team since 2010. The paper portfolio was provided to the stroke survivors by the stroke nurse or the neurology team immediately after the patient was diagnosed, in acute unit. If the stroke survivor need home rehabilitation, the neurology team comprising of two physiotherapists, two occupational therapists, one counselor and one speech and language therapist gets informed.

The portfolio was designed by a neurology team, with the aim of increasing patient participation and self-care in their rehabilitation and collecting individual patient related rehabilitation information compiled in one document. In addition, the portfolio aimed to facilitate communication and collaboration between the stroke survivor, different caregivers and neurology team involved in the patient’s rehabilitation.

While using the portfolio, a patient set individual goals together with the neurology team. Accordingly the planned and performed activities together with the outcomes were documented by the patient, the family caregiver or the neurology team in the portfolio. The paper based patient rehabilitation plan was shared with family caregivers and health care professionals with the will of the patient.

The portfolio was evaluated one year after the stroke survivors used it. The preliminary evaluation of the study suggested that the portfolio has an advantage of collecting information from the neurology team in one portfolio. The other advantage was information about a patient rehabilitation was able to be shared between the patient and their family caregivers. Furthermore stroke survivors were interested in reviewing back past rehabilitation history and a part of the portfolio facilitated the access.

Some of the limitations of the paper portfolio were, one or part of the document might get lost and patient involvement in their
rehabilitation care was questionable [26]. Besides, as the disease condition need long term rehabilitation, information needs changes over time and updating the information timely was a challenge.

1.4 ICT-tools and users’ information needs

ICT tools empower patients with chronic condition [5] by facilitating access to personal health related information. Person-centered health record enables persons to access their own personal data and information related to the disease which empowers patients. Patient empowerment increases the involvement of patients in their care and rehabilitation process [27].

Patient-centeredness, the provision of care based on the patient individual preference, needs and values, is one of the sixth aims that were recommended for the improvement of health care [28] according to Crossing the Quality Chasm. Patient-centeredness increases patient involvement in their care [29]. Lober et al state about Personal Health Record (PHR) as ‘PHR are proposed as a strategy to make health care more patient centered’ [30].

In order to improve outcome of chronic condition, patient’s participation in their rehabilitation is crucial. As mentioned in crossing the quality of chasm as the ten simple rules for the 21st century, health care system which would result in better patient outcome is that the patient as the source of control shared decision making and have control of their health records [28].

Currently PHR has a functionality of information collection and sharing [31]. PHR to present patient centered information, user of the system need to be involved in the design [32] to clearly understand their information needs.

1.5 Problem analysis

In stroke rehabilitation, the patient’s participation, self-care and sharing of information with family caregivers and neurology team is crucial for a positive outcome as mentioned above. When patients get empowered their involvement in their care and rehabilitation increases [27] but to be empowered they need to be enrolled in shared decision
making and be provided with information about their specific disease condition so as to be knowledgeable. However, currently there is a limited support of collaboration which contributes to restricted access of information and involvement in the care process [10].

As mentioned above, ICT tools can facilitate the access of health related information and increase collaboration of patients, family caregivers and health care professionals. Even though patients have been provided a PHR, few solutions are designed other than the ordinary tool for appointment booking [33]. Most PHRs are designed to store health data rather than making patient to actively interact in their care process. Besides they are not designed from patients’ perspective in order to provide the basic knowledge to the patients. Koch stated that ‘PHRs mostly represent a snapshot of the provider’s Electronic Health Record without redesign’ [33].

The success of a tool is met when it satisfies the intended purpose. A number of health information systems didn’t fail due to a flawed technology rather due to a poor user requirement elicitation and analysis [34, 35]. In order to identify the requirements, participation of the user of a system is vital in the development process of a system [11].

Stroke survivor’s information needs changes over time even during rehabilitation. In order to facilitate patient participation, self-care and sharing of information with family caregivers and neurology team in home stroke rehabilitation a tool needs to be designed [7, 8, 36]. Therefore, it is crucial in this study to gather and understand information needs of stroke survivors’ before designing a tool.

1.6 Previous studies

Stroke survivors have substantial information needs which changes over time. As mentioned above provision of information has an advantage of improving the knowledge of the survivors whereby motivating them to participate actively.

Though currently, the productions of information materials are increasing, stroke patients still have unmet needs. Stroke survivors
want timely up-to-date and relevant information which is tailored to their needs.

The idea, about the need for accessing sufficient amount of information that stroke survivors at different stages have, is not new. Though, not much is done about provision of information needs of stroke survivors to facilitate self-care using ICT-tools in general during rehabilitation, especially home-based rehabilitation from the patient’s perspective.

Information needs of stroke survivors changes through time. Studies [4,17] suggest that, participating in goal setting and having a clear goal facilitates involvement in rehabilitation. Understanding the diagnosis was the information need of stroke survivors at two days of diagnosis [37]. Information needs like medical issues, consequences of stroke, stroke association, insurance information, assisting aids and social support are some of the identified information needs of post stroke patients [38]. Other study mentions that the demand for information about stroke diminishes through time [39].

1.7 Research aim and objective

The general aim of this thesis is

- To identify and understand how the information needs of stroke survivors can facilitate self-care in home rehabilitation using ICT-tools.

The objectives set to reach the overall aim of this thesis:

- To identify stroke survivors’ information needs
- To analyze and understand the information needs of stroke survivors to facilitate self-care.

1.8 Research Questions

The research question that will be answered in this study is:

- What are the information needs of stroke survivors’, who participate in home-based rehabilitation to facilitate self-care using ICT-based rehabilitation plan?
2. Methods

An explorative research was conducted in this study to explore and understand information needs of stroke survivors’ for home-based rehabilitation. Starting from the beginning of the study, the research was designed by conducting a thorough literature review. The review focused on background study of the specific subject area and possible alternatives of methods to be chosen.

The research was conducted based on qualitative approach. The justification being the aim of the study, where information needs was elicited and understood from the study participants. As a data collection tool a couple of focus group interviews were conducted. General interview guide, were followed to elicit requirements from the focus group participants. Paper prototype were designed and presented based on the information needs elicited. The qualitative data collected were transcribed and analyzed based on content analysis and presented in the result section of this study.

2.1 Study setting

Stroke survivors, who are members of stroke patient association, with experience of rehabilitation were recruited as the study participants. All participants of the study were recruited from Stockholm, Sweden. Three consecutive focus group interviews were conducted at Karolinsk Institutet, Solna. Each focus group interview had duration of two hours with an interval of two weeks.

In addition a two hours focus group meeting was conducted with neurology team in one of the Stockholm County’s Healthcare Center, where they use the paper portfolio. The meeting with the neurology team was held prior to the focus group interview with the study participants.

2.2 Research methodology

Research methodology is a systematic way of conducting a research, which includes all the possible choices of methods and techniques included to solve the research problem with the logical justifications behind [40, 41].
Scientific research can be categorized as explorative, descriptive or explanatory based on the objective of a project. Explorative research is conducted when trying to generate initial personalize ideas about certain procedure, phenomenon or when evaluating or testing the extent of a phenomenon. It is conducted in early analysis phase in order to elicit attitude and perception of participants. Descriptive research is when describing the characteristic of something or a phenomenon. Explanation research gives explanation to the how and why question in order to give answer to a specific phenomenon operates [42].

This study follows explorative research methodology. As mentioned above the aim of this study is to explore and understand the rich descriptions of stroke survivors’ information needs prior to the design of electronic home-based rehabilitation plan.

2.3 Research approach

Qualitative approach was performed in this study, the justification behind was the aim of the study which answers the research question. Qualitative approach deals with subjective assessment of attitudes or opinion and it produces a narrative and textual description of the given phenomena whereas, quantitative approach is concerned with assigning numerical value to phenomena [40]. Qualitative and quantitative approach differs in the type of research questions they answer.

The aim of this study as mentioned above is gathering and understanding stroke survivors’ information needs prior to the design of an electronic home rehabilitation plan. The choice of the approach was determined by the research question. In this study the research question tried to gather and understand patients’ subjective attitude, insight about home-based rehabilitation. So, in order to get a rich descriptive response for the research question a qualitative approach is the best choice.

2.4 Selection of Participants

A sample is a subset of a population selected to represent and draw inferences about that population [43]. Participant in qualitative research are chosen based on the relevance and relationship to the topic under study.
The participants of the first focus group interview were recruited by convenience sampling technique, non-random sampling technique, where participants are selected based on availability [41]. An invitation letter containing the research purpose and some more detailed information was announced to the members of stroke survivor association through the representative of the association. Besides an invitation letter [see Appendix B] was uploaded in a stroke survivors’ Facebook group, for a recruitment of younger (less than 65 years) voluntaries. Finally, three voluntary participants were involved in the first focus group interview.

The second focus group interview was conducted two weeks after the first and two more participants were recruited by snowball sampling, again a non-random sampling technique, where participants of the study find potential research participant [41]. The second focus group interview was held with the two new participants and a participant who had participated in the first focus group interview.

The third focus group interview was held with four of the respondents who had already participated in the earlier focus group interviews.

The participants of this study are all respondents because they give subjective response/ feedback in the focus group interviews. Only one of the respondents had a chance of owning the paper portfolio under the rehabilitation period.

**Table 1: Characteristics of the study participant**

<table>
<thead>
<tr>
<th>Respondent</th>
<th>Age</th>
<th>Gender</th>
<th>Time since first stroke</th>
<th>Language of Interview</th>
<th>Currently follow-up in rehabilitation</th>
<th>Usage of Internet</th>
</tr>
</thead>
<tbody>
<tr>
<td>R1</td>
<td>61</td>
<td>Female</td>
<td>19</td>
<td>Swedish</td>
<td>Yes</td>
<td>Social network and more</td>
</tr>
<tr>
<td>R2</td>
<td>61</td>
<td>Female</td>
<td>17</td>
<td>Swedish</td>
<td>No</td>
<td>Social network and more</td>
</tr>
<tr>
<td>R3</td>
<td>58</td>
<td>Male</td>
<td>11</td>
<td>Swedish</td>
<td>No</td>
<td>Social network and more</td>
</tr>
<tr>
<td>R4</td>
<td>66</td>
<td>Female</td>
<td>18</td>
<td>Swedish</td>
<td>No</td>
<td>Social network and more</td>
</tr>
<tr>
<td>R5</td>
<td>48</td>
<td>Female</td>
<td>4 1/2</td>
<td>Swedish</td>
<td>Yes</td>
<td>Social network and more</td>
</tr>
</tbody>
</table>
2.5 Data collection tools

A combination of primary and secondary data collection techniques were used in this study. In order to get the necessary responses to the research question qualitative data was collected from the participants of the study using focus group interviews.

Document analysis was used as a secondary data collection tool. In addition, focus group interview was chosen as it is mostly used in the early analysis phase in order to elicit attitude and perception of a group of study participants. Within the focus group a general interview guide was followed to collect the primary data.

Figure 1: Data Collection processes

2.5.1 Document analysis

In order to understand the current routine of stroke rehabilitation and rehabilitation plan, focus group meeting with the neurology team and document analysis was done. Document analysis is a method used for systematically reviewing or evaluating documents, in this case the paper portfolio and the preliminary evaluation of the paper portfolio were reviewed.
2.5.2 Focus group interview

A focus group interview is a qualitative method of data collection technique involving a small group of people on a common topic. Focus group interview is unstructured interview where a researcher wishes to explore issues that are important according to the priority of the specific study group. Focus group meeting motivates discussion due to the fact that not being rigidly constructed interview [44].

Focus group interview has an advantage of being relatively fast and inexpensive data collection tool. In a single focus group interview a number of interviews are done when compared with individual interview. Besides, numerous topics can be discussed and many insights can be gained within the group when compared to an individual interview [44].

Facilitating focus group interview and as the same time documenting or analyzing data is difficult. So the interviews were recorded with the informed consent [see Appendix C] of the participant’s, for the purpose of facilitating the data analysis process.

Stroke survivors experience and perception of home rehabilitation and rehabilitation plan were tried to be thoroughly understood and gathered from the participated focus group interviews.

In two consecutive focus group interviews the problems that the study participants face during rehabilitation process were clearly discussed and identified. Discussion about the contents of a rehabilitation plan was made with the participants before and after presenting the paper portfolio. In general the information needs that will facilitate the participant’s self-care in their rehabilitation were discussed.

2.5.3 Prototyping

In the final focus group interview, a paper prototype [see Appendix D] were designed based on the information needs gathered. Paper prototype has an advantage of involving users in brainstorming, to identify additional suggestions by visualizing how an interface might look like.

In this focus group meeting, an early confirmation of the already identified information needs was performed, and further information needs elicited.
Table 2: Topics discussed and participants of each focus group interview

<table>
<thead>
<tr>
<th>Focus group 1</th>
<th>Topics discussed</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- The participants’ experience of stroke rehabilitation</td>
<td>R1,R2,R3</td>
</tr>
<tr>
<td></td>
<td>- Their experience of rehabilitation planning</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- The motivations of stroke survivors’ to participate in rehabilitation and self-care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- The problems that stroke survivors experienced in rehabilitation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- The paper portfolio was presented and discussed</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Their information needs, to be included in an ICT-based rehabilitation plan was discussed</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Focus group 2</th>
<th>Topics discussed</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- The same topics as the first focus group was discussed at the beginning of the meeting</td>
<td>R2,R4,R5</td>
</tr>
<tr>
<td></td>
<td>- Stroke survivors ideal rehabilitation plan was discussed and information needs elicited</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Focus group 3</th>
<th>Topics discussed</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Paper Prototype was presented to the stroke survivors and the additional information needs they have were discussed</td>
<td>R2,R3,R4,R5</td>
</tr>
</tbody>
</table>
2.6 Qualitative content analysis

A qualitative research approach results in collection of large volume of information. In this study the data collected from the focus group meetings were translated from Swedish to English and transcribed verbatim at the same time by the author. The transcribed data was analyzed using content analysis, in order to increase understanding and generate knowledge or a broad description of the phenomenon under study.

Content analysis is ‘a research technique for making replicable and valid inference from texts (or other meaningful matter) to the contexts of their use’ [45].

The analysis of the data was done manually using content analysis using the following procedures stated by Elo et al [46]:

**Preparation phase**

1. Selecting the unit of analysis: - the transcribed data was matched with the corresponding participants while transcribing.
2. Making sense of the data: - the data were read in depth, to identify and list all the information needs.

**Organizing phase**

3. Open Code: - The data was organized according to the type of information needs discussed.
4. Creating categories- The data was categorized based on how these identified information needs can support self-care.
5. Reduction of the categories- the categories was grouped under the same heading

**Reporting phase**

6. Finally the findings were presented in the result section

2.7 Ethical consideration

Every research has ethical issues. Research ethics is considering the participant and the information with care.

In this study the participants were provided with all the relevant information prior to the focus group interview. General information
about the researcher like who the researcher is, which institution does the research study, researcher’s purpose of undertaking the research.

In addition the participants were informed about the general aim of the study and about the anonymity of the participants. It was clearly mentioned that they won’t be described by name in the result or the study in general.

The confidentiality of the data gathered was mentioned. That the data will not be passed to any third party, it will only be accessed with the involved researchers and if needed that the participants will be asked for permission.

Informed consent was signed [see Appendix C] that the participants voluntarily enrolled in the focus group interview and a voice recording made based on the willingness of participants to facilitate analysis of the data. They were also informed that the data will be kept secured and deleted after analyses. The participants were told to leave whenever they feel like discontinuing the interview and that it doesn’t affect them in any way.

In addition, the research “My Care Plan” has been approved by the regional ethical review board [REF Diarienummer 2011/2093-31/5].
3. Result

The results of this study focus on the participants’ opinions and suggestions regarding stroke survivors’ information needs and how ICT tools can support self-care in home-based rehabilitation planning. As mentioned above, content analysis method was used to analyze the data collected from the focus group meetings. Five themes were identified by analyzing the characteristics of the information needs that the participants’ of this study have. Each of the following five themes requires different information to support stroke survivors’ self-care during follow-up of home-based rehabilitation.

- Theme 1 – Motivational support
- Theme 2 – Educational support
- Theme 3 – Informational support
  Category 1- Personal Information
  Category 2- General Information
- Theme 4 – Reminder/ Memory support
- Theme 5 – Social support

3.1. Motivational support

Motivational support refers to the information needs which the participants of this study desired to facilitate self-care by increasing motivation and to get involved in their rehabilitation.

In home-based rehabilitation the stroke survivors are expected to involve in the interventions (activities) even in between the follow-up with the neurology team. However, it is difficult for stroke survivors to bring a new behavioral change based on the incurred disability. Thus, a motivational support was requester to facilitate self-care. The overall objective of being motivated and managing self-care is to promote their health while they are under a follow-up of home rehabilitation.

i. Clear and well defined Goal

Rehabilitation plan in stroke is designed based on the disabilities or complaints of the survivor. A goal is set to improve or minimize deterioration of the disabilities or complaints. Setting a goal together and describing it in a clear and understandable way was found to be
encouraging or motivational by the participants of this study. The respondents expressed, having a goal documented makes their plan of success more structured. They even mentioned that in order to achieve the goal, they might have the chance of sub-dividing the goal which makes it simpler to them.

“I feel so good if rehabilitation have a well-defined goal to work in favor of it... in my case it is the goal that motivates me ... dividing the goal into sub-goal and attaining the sub-goal really motivates me ... I can see in that way that my condition is improving ” [R3]

“I believe goal is also a structure against the biggest chaos one have in mind ... it gives a structure that one can divide the goal by himself/herself or together with the neurology team into sub-goals and one can achieve the sub-goal and continue with the rest attain the biggest one” [R2]

Setting a clear goal and describing the goal visibly was desired by some of the participants as a motivating factor. Knowing what to do in order to change the situation that they are in, after stroke is highly valued by the respondents.

“...if I have a clearly explained goal that means I know myself what I need to achieve... so I can communicate with myself... above all it is me who need to work to achieve it... so a clear goal is excellent... I will feel better if a rehabilitation plan includes a goal...” [R3]

ii. Individually tailored interventions at home

In rehabilitation to accomplish the goal that is set, the provided exercises or activities by the rehabilitation team need to be implemented into action by the stroke survivor. The respondents expressed the benefits of having the exercises/activities at the computers they have at home when possible. They said that they can exercise whenever they have the possibility, courage and motivation. Moreover, they described that nowadays there are so many exercises on the internet but either they are too long or extreme to meet their personal needs. What they preferred was to have activities tailored specifically to their problem based on their abilities so as to be motivated to accomplish the tasks.

“When I was in rehabilitation I used so many electronic supports for training of my memory ... for me if I got good help from the
professionals it is so simple to follow and exercise so much by myself... if I get the instructions ... and if I get the access at home ... but I wasn’t given the access at home, the exercises were only available in the rehabilitation clinic and they had two local computers at the clinic and they were locked at the evening ... what I hate is the accessibility at night .. I would have continued exercising when I felt like doing it...” [R3]

“When we talk about training I have so many of them left undone because the free transportation ticket is not enough. My doctor says that I need to exercise 2-3 times a week and I know ...when I exercise my mind is very ...very much better ... I cannot travel 2-3 times a week the transportation ticket is not enough but having a training program at home on the computer is so nice...there are training programs outside where you can buy but for me I think it is excessive, too much information ...and it is also too long... I cannot manage that kind of things” [R5]

Individually tailored intervention provided at home for a stroke survivor during a follow up in home-based rehabilitation is motivational since it encourages them to get involved in their self-care by their own initiative.

iii. Evaluation Results

The respondent also declared that not only providing the training programs but also follow-up of the stroke survivors at different periods of time by the neurology team has an effect in the outcome of the rehabilitation. Evaluation results from the neurology team visualize for stroke survivors the changes they have achieved thereby motivating them to further activities.

“Seeing an evaluation really motivates... sometimes I can see some clear changes but not always a clear and visualized evaluation from, may be my speech therapist or a physiotherapist shows me my real progress... knowing which steps I have come across gives a real motivation for me in addition to the clearly mentioned goal” [R3]

“...it is not easy to see the change... I used to say nothing is happening...my relatives can tell me that I am improving but I can see the changes like...ok so I wasn’t able to eat by myself... so evaluation
and having it seeing it documented is very important I think even about my feeling”[R5]

“Really good to have evaluation but the problem is at measuring the qualitative, quantitative and subjective goals…” [R3]

Observing the change that the stroke survivors have from the information about evaluation results makes them more motivated and active in participating in their self-care.

iv. Diary

Documenting or writing down what they have done every day or after a long period of time, was the solution taken by a majority of the respondents for the memory problem they have and due to the fact that they are easily forgetful. They write a diary for different purposes concerning rehabilitation e.g. to get motivated at their daily activities by looking back at what they have documented in the past. In addition they get involved in their care by getting a kind of trigger or reminder about their different personal information.

“I have done like …something special... Milestone...every year I have written what went good for me ... I wasn’t like looking only at the problem description ... like ... to have a feeling like ...ok... so I can perform this ...I have done this every year and I think it was after like ... 5years ... something like that...the list was so long...at the beginning the text was short ...to observe after sometimes that you can do something different makes you feel much more better...” [R4]

“I have a black book and sometimes when I see it I didn’t write anything for months...by the time I had a follow-up with neuro-psychologist and when I told her that I was so tired those days... I remember she told me that I had done (I had taken care of) so many things, by that time ... she saw it from what I already wrote down... but for me .... I felt that I haven’t done anything” [R5]

Some will write what has happened, whether it’s an improvement or deterioration and the other might write what they can achieve or what they are able to perform. A majority of the participants will also like to go back to different times and glimpse what they have documented.

“For me to have this at home ...I have been working my entire life with IT and if I would get a rehabilitation plan and support services
electronic it would have been so comfortable... I would take my little ipad and write the information about what has happened so that I can read back whenever I want ... for me it is convenient” [R3]

“I think it is good to write what I have done not only how I have improved... if I write what I have done ... sometime in the future I can go back to what I wrote and read and it feels good... seeing back the changes motivates at current stage” [R2]

In summary, the following information was desired by the participants of this study as a motivational factor to take responsibility of their own health and well-being and get involved in their rehabilitation activates:

- clear and well-defined goals providing information on what to achieve;
- access to interventions tailored individually to their abilities at a relevant time;
- evaluation results by showing the change they have achieved; and
- a diary providing personal information and reminding them,

Stroke survivors need to self-care since they have a long term condition to cope with the disabilities they have and maintain or promote their health.

The above four information categories were also available in the paper portfolio, which was designed by a neurology team. In the focus group the participants’ of this study confirmed by demanding for it again.

3.2 Educational support

Educational support refers to the information needed by the participants of this study to facilitate self-care by providing sufficient knowledge about the disease condition.

i. Stroke information

The respondents suggested having information about stroke, different stroke related disabilities and the related neurology teams duties and responsibilities. Having knowledge about the disease condition or the disabilities most of the time encourages patients to get involved in their care process. The respondent elaborated that knowing about the neurology team roles and responsibilities would have given
them a chance to manage their conditions by asking for the kind of help they can receive.

“I didn’t know that I had a brain damage, I was 2 or 3 months home after my stroke when I looked for day rehabilitation care and I was looking for stroke rehabilitation and I couldn’t find anything and when I asked for help they told me that it was written on the wall and it says brain damage and only by that time and means I knew I had a brain damage.” [R5]

“My physician wrote in my journal that I didn’t need help from a counselor by that time which I saw recently... it is like this... normally I didn’t know what a counselor can do for me, I thought a counselor was a person who can talk with me and have an education lower than a psychologist and I didn’t even know anything about occupational therapist... I didn’t even know that there is a neurologist... if I had known that then I would have asked for help from them.” [R4]

“There are so much information about stroke ... for example if you can’t walk, if you can’t use your arm ...but there is no enough for those problems which are hidden... when you mind doesn’t function... cognitive ... whenever I was with my psychologist and when they asked me how it went I threw my head back and said ... ahhhh So that is how it felt ...It is because I felt so heavy...but there was no one ... never a single person...who told me that it is because of the stroke ....information about stroke is important to have” [R5]

In long term condition like stroke knowledge about the disease condition, health risk and benefits of self-care can be a precondition for a change in behavior. Having sufficient knowledge about the disease condition empowers patients and facilitates self-care to prevent disease or promote health as suggested by the stroke survivors and ICT can provide access of the information anywhere and anytime. Information about stroke, as well as about the different roles and responsibilities of different healthcare professionals, was asked for by the participants of this study, which was not available in the paper portfolio.
3.3 Informational support

Informational support refers to those information needs that support, by providing person related or general health information in order to facilitate self-care to the participants of this study.

3.3.1 General health information support

In this section general health information needs that stroke survivors demanded that facilities in the support of their self-care are presented.

i. Assisting devices

One of the basic information need for the participants of this study is the concern to know about assisting devices. Since assisting devices helps them in their daily life due to the disabilities they have incurred, they would like to know where they would find and how to access the assisting devices, and whom to contact. The participants’ demanded for the information of other stroke survivors’ suggestion concerning assisting devices and different games too.

“I used to play so many games on the internet which will train my memory.”[R1]

“I have mental tiredness that means I don’t have the energy to do so many things at a time... so my mind stops all of a sudden... so I need something which makes me relaxed”[R2]

“There are times which feels like your mind is so dizzy...it is good to have some kind of game may be which might take away your concentration sometimes... we are sometimes disturbed by taking in so many things going on at once...so we get so stressed ... and when I get focused...after some time I relax...so...Yeah something like a game which takes all the focus away from me...and it need to be easy...I doesn’t need to be demanding.”[R5]

“I need to take away the thing that makes me worry so I can concentration...something which is a totally different way ... somewhere like in my own world... so I can relax my mind.”[R4]

“...I know there are some helpful instruments but I don’t know everything and I don’t have access to ... I remembered it took me time to find out when I needed a shower chair ... I gave a called to the county and asked whom to contact...” [R5].
ii. Stroke associations

Associations related to stroke were suggested by the participants of this study to be important to them. They mentioned that they got vital information from the association and members of the association which helps them in self-care.

“This one is .... the last part... each and every information is crucial... think if I had something like this I would have known where I could turn to get the help that I wanted.” [R3]

“What saved my life when I got my first stroke was that, there was information in Vårdguiden about stroke associations ... it is not there now ... it was taken away... but then you could find the telephone number and give a call and get advice... it saved our lives for us stroke survivors.”[R4]

“...I didn’t have someone to compare with... even though the doctor was explaining everything to me ... I thought that I was only lazy, not doing anything, that I only slept... but when I went to an association... I talked with the persons who had a stroke ... and I was assured that I wasn’t lazy... that I wasn’t crazy ... I wasn’t alone ... everyone have the same symptom as I have.”[R5]

iii. Important organizations

As mentioned by the respondents’, stroke survivors have a need of communicating with different organizations in order to take care of their personal businesses after the onset of stroke. Therefore, in the focus group meeting they mentioned the need of having contact address and links to some of the most important organizations they usually communicate with.

“I was 90% blind and wasn’t able to talk at all ... after I went home I couldn’t see anything or read anything... I was the one who had searched for rehabilitation because I didn’t get a chance to communicate with health care, social services or rehabilitation...I searched and applied by myself, It took me 3 months to get to a rehabilitation center” [R3]

“...I had a meeting for planning my condition with social insurance agency (Försäkringskassa) and employment agency (arbetsförmedling) and then I went for work training...” [R2]
“The hospital had the responsibility of contacting the primary care when they send a person home...In my case I was just sent home from hospital no communication with rehabilitation or primary care” [R3]

“Many of us don’t know how to search for and get rehabilitation” [R1]

The three general health information needs; assistive devices, stroke association and important organization facilitates self-care in stroke survivors by providing them with general information. Information in general has an advantage of creating awareness and empowering long term condition patients. In order to meet their social, emotional and psychological needs stroke survivors collect information form stroke association, members and different links and take action as needed. In the paper portfolio there was a part which provides information about stroke association but the remaining information needs i.e. assistive devices and important organizations were demanded by the participants of this study in the focus group meetings.

3.3.2 Personal health information support

In this section personal information needs that stroke survivors expressed could facilities their self-care are presented.

i. Medicine list

The respondents described the advantage of having their medication list from different departments. If they come across any emergency situations, which might include being unconscious, they believe that having the medication lists might facilitate their care and treatment to be faster and safer.

“When I was diagnosed with stroke ... the physicians said it would have been easier for them to diagnose me so much earlier than the time they did if they would have seen that I was taking a contraceptive pill...but the health information system they have and the one where all my medications was written wasn’t the same so they missed my stroke... so I recommend that... ” [R5]

“I was in emergency and I had a card which says I am a stroke survivor, which medications that I take and in case of emergency contact....but the nurse refused to look at it ... it was Christmas Eve and you know that is not a good time... but I believe it would have been a good help.... what dose of medication a person need to have in case of emergency is visible
in that card ... I don’t need to take lower dose than I deserve to have” [R4]

Having personal information is one form of preventing accident and maintaining health. The respondents wanted to care for themselves by having access to their personal health information.

ii. My health history

A majority of the participants expressed the advantage of having their own information (health history) written down and compiled in one document. The respondents expressed that even though that they are often too tired, when they meet a new health care professional or a person at any organization they are expected to explain about themselves. There are times that they preferred to have a document describing their health history and be able to share it rather than explaining again and again.

“Whenever I meet a new person I need to explain my problem again and again... because it is not visible...so I don’t need to explain again and again, I wished to show to them something collected in one place ... when I try to explain...sometimes I get tired and can’t find the words to express my thoughts (feelings) and I ended up telling them that I am tired....” [R5]

“I want a possibility of sharing my history and everything for the person who is involved in my health process... I don’t want to talk about same thing repeatedly at different times...and I don’t want to take care of everything by myself ... because nowadays everywhere they write me a paper everywhere and I am expected to manage everything by myself... there are also so many who have more disability than we have so it’s not easy for them to communicate with the people around” [R5]

Some of the respondents mentioned that they couldn’t communicate as a consequence of the stroke and they didn’t have the written information about themselves available at. When they went to a social service, social insurance agency (Försäkringskassa) and different offices, it was so difficult to explain and manage (process) the circumstance as they desired. One of the participants has clearly explained that he was the only one who had all the information in his
head but he couldn’t see and talk, so taking care of his personal businesses was a big problem for him.

“I wasn’t able to talk...So difficult to be like this, I was the one who were affected by stroke and I was the only one who was taking care of all my stuff, nobody had an overview of what had happened... it was only me who had all the information loaded in my brain.... that is the biggest problem I faced... when I wasn’t able to communicate” [R3]

“After a year I began to talk but I had ... I didn’t have any... I learned everything again, I didn’t know that this was a chair and that was a table. But I knew what it was... I mean I knew how to use it but I had to learn again to call it a chair.... I got help to say same things instead of saying the word I used to say ‘can you move that thing where a person sits’ and when you said to me ‘do you mean the chair’ I said ‘yes’ ... that way I learnt that it was called chair...that is how I lived and it was so difficult to communicate with health care , with social insurance agency when you couldn’t talk at all...” [R3]

In order to cope with the disabilities they incur without the support of any health-care provider or a family care giver and take care of some businesses they have, stroke survivors expressed a need of being able to access their documented personal health information.

iii. Neurology team contact address

In stroke rehabilitation a neurology team is involved and managing to access a certain professional team was a challenge for the participants of this study. A majority of the respondents expressed the difficulty in searching for the address of the neurology team.

“After I went home from the hospital I was the one who took care of everything and had to get in touch with all professionals at health care, hospital that was the difficult period when I had the biggest disability when I couldn’t say a single word...aaa... It was so tough” [R3]

“I had 32 healthcare contacts in outpatient settings” [R4]

During the rehabilitation care process, stroke survivors used to have an appointment at different durations and for different purposes but clear address of the professional wasn’t always available. Having the name and the address of the professional was considered as an advantage by the respondents.
“When we think of the shortages we can talk about health care contact information shortage” [R3]

“It is like this... even the special needs changes a lot in stroke survivors based on the problem and after a year for example may be the survivor realizes what kinds of problems the person has and when the person needs to work and needs to plan further, the person need contact in order to increase the trainings to a higher level. Or in another solution the person need a professional it can’t be anyone like the outpatient, the person need to meet the professional who knew the problem from the beginning so the person doesn’t have to explain himself again... so it is good to have a name there...” [R4]

“It would have been wonderful... I remember one professional... he gave me his number and it was so easy to remember it until now I had a good feeling for it... the name of the professional is also so important... otherwise it was me who really need to work hard to find that information “ [R4]

Since a number of health care professionals provide care for patients who have chronic condition, managing name and address of all the health care providers involved in their care is not easy. Their day to day life will be facilitated by having access to such information.

iv. Emergency Contact address (ICE)

Having a contact address of someone to be contacted in case of emergency (ICE) was given focus by the respondents. The respondents supported one another’s suggestion as to the recommendation of a contact address. They related the issue with their disease condition and mentioned that a stroke survivor might end up in any emergency situation at any time and confirmed the importance of having ICE contact address.

“And there is something ... it would have been good to have the three letters.... ICE... in case of emergency... You don’t know where you end up and if you end up in emergency they can look for ICE contact if the person is unconscious” [R5]

"yes... In case of emergency... someone to contact in case of emergency” [R4]
In long-term condition one of the self-care goals is to meet their social, emotional and psychological needs. Stroke survivors requested for the emergency contact address prior to accident to be prepared ahead. They are trying to meet their psychological need in this way, to feel safer and more prepared.

v. Stroke card

In the focus group interview a majority of the participants suggested the advantage of a card or a pin which visualizes that they are a stroke survivor. They mentioned that it have different advantages like if they end-up in an emergency situation or daily situation when their hidden disabilities can be challenging, such as when they are expected to wait in a long queue.

“I have a card for example if I stand in a queue in a supermarket I can show the people that I cannot stand there half an hour.” [R5]

Participants’ of this study tried to meet their social, emotional and psychological needs by trying to possess personal health information. Medication list, stroke card and ICE contact address are mentioned in this section as a facilitator of their self-care by providing vital information to them or to an authorized person in charge of their care, including in emergency care at an accident. My History and Neurology team contact address are needed to practically ease their day to day life.

Out of the five information needs, only the neurology team contact address was included in the paper portfolio the rest was demanded by the participants of this study.

3.4 Reminder/Memory support

These are the information needs that the participants of the study demanded in order to be reminded to take action in their daily life.

i. Disabilities/Diagnosis

Most of the participants’ of the study mentioned that they want to have their disabilities or diagnosis in a written form. They mentioned they forget easily so that it is good to have it.

“The goal that I have might be one... may be to go up the stairs but the disabilities that I have can be many ... it might be physical or cognitive disabilities...so it is really nice to have my disabilities or diagnosis” [R3]
“I had a problem in my left foot and because of that I ended up in a serious complication and when I looked back at what the problem was I realized that I was working against the intervention. To remember to exercise ... like to press down and use my big toe ... I was rather waking my finger up. To press the floor using my toe finger it took me so many years to use my mind and remind. The moment I left home I walked in a wrong position... so it is so important to have your disabilities written down” [R4]

In order to prevent deterioration of function or to improve function in rehabilitation stroke survivor need to take action as part of the provided intervention. So a reminder could have an effect in facilitation of self-care by working against the forgetfulness, acting as triggers to self-care.

ii. Calendar

From what a majority of the respondents expressed, they have problems of memory loss and get easily tired and stressed while taking care of several activities at one time or even during a single day. They desired a calendar which might give them a chance to visualize a single day or several days, weeks and months in order to schedule several daily activities (plans) according to their wish.

“I asked why do I write when I was at... with a psychologist and I got the answer... like... so that I can go back and check... ok...that is why I was tired now and I see that there it is too much now.... I have everything in my mobile now as everybody else...but I don’t have a whole view ... but if I get a calendar I can see weeks and months... I see time in my mobile and when people call me and talk about some appointments; I am forced to hang up the phone because I cannot see the calendar when I talk on the phone” [R5]

“There are so many apps in my ipad where I can write activities which is like sticking in a sticky note so when I see the whole picture of the week I can move the sticky notes from the day which is busy to where I see that I have a free time ... I don’t need to write the whole list again...and I can see the whole picture ... because for me time span is a problem...that is why I don’t have a good mind for time” [R4]

“To see the whole picture of my everyday activities is an important thing in my life... otherwise I will schedule too tight programs and will end up stressing” [R4]
The other demand of the participants of the study to facilitate self-care was to have a reminder. In behavioral change, in order to take action trigger has an effect.

From the two information needs, the demand for the information disabilities or diagnosis was made by the respondents during the presentation of the prototype. However, the calendar was already available in the paper portfolio.

3.5 Social support

Social support refers to one of the information needs the participants of this study have. It included the psychological and informational supports that they get from each other. To get information, motivation or be reminded in long-term condition support from people having the same condition was considered very positive.

i. Social network

The other suggestion of the participants was a social network like Facebook, where they get direct comment from stroke survivors.

"Another type of support system is Facebook, stroke survivors communicate through Facebook and there is so much sorrow, smile and so many feelings... it is another type of supporting tool using internet."[R3]

"Using Facebook we give tips to each other so much... we provide different links telling what and where to find... there are so many who help people this way when they want something."[R2]

"...all the information that I have today and all the things that I know today... I didn’t get it from health care rather I got it from other stroke survivors."[R5]

"...when we stroke survivors had stroke and we went to rehabilitation... we were still unconscious... cannot remember anything... I remember when I took over my room from one stroke survivor and he told me his experience... I don’t remember the first three days what the professionals talked with me about, the only thing what I remember was him... the first person that I trusted was him... physician only tells you what you can do."[R5]

The demand for social network was not available in the portfolio.
All the identified information needs are presented in table 3. Information needs available in the paper portfolio, those elicited form the participants of the study were mentioned.

**Table 3: Information needs with the respective identifies document and methods**

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<thead>
<tr>
<th>Information needs</th>
<th>Paper portfolio</th>
<th>Focus group interview</th>
<th>Prototype</th>
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<td><strong>Motivational Support</strong></td>
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<td>Intervention</td>
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<td>Evaluation</td>
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<td>Diary</td>
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<td>Stroke information</td>
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<td><strong>General health information support</strong></td>
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<td>Assisting devices</td>
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<td>Social network</td>
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4. Discussion

This section includes discussion of the results, methods and limitations of this study besides, recommendation of further research.

4.1. Discussion of results

The focus group meeting with the stroke survivors’ allowed the identification of their information needs to facilitate self-care during home-based rehabilitation follow-up.

Taking action or involving in the provided intervention and attaining already set goal is essential for a better outcome, during rehabilitation follow up. For stroke survivors’ self-care is more than involving in the training programs. Self-care is taking action in their daily life activities to meet their social, emotional and psychological needs.

The finding of this study revealed that stroke survivors need motivational support to facilitate self-care. Tailored intervention and clearly set individualized goal are some of the identified information needs which provide motivational support. Studies also suggest [17, 47] that stroke survivors have a need for an individualized and clear goal to be motivated.

Increasing knowledge of chronic condition patient about their disease in general empowers them by creating awareness. Two of the participants of this study demanded for information about the general disease condition i.e. stroke. Involvement of patient in their management of health condition increases with empowerment. Studies show that long term condition like stroke demands for general information about their disease decrease through time [39]. Further, study is suggested to understand about the recommended needs.

Even though the topics discussed with the participants was mainly about rehabilitation and self-care during rehabilitation follow-up, the respondents demanded for personal health information for example medication list and my health history. These information needs were unique compared to the paper portfolio which was designed by the neurology team.
Stroke survivors’, who mostly have a memory problem, desired their diagnosis/disabilities documented so as to be reminded or triggered. Tham et al stated about importance of the awareness of stroke survivors disabilities in the outcome of their rehabilitation [48]. Respondents of this study also desired to have disabilities documented especially if an intervention (activities) is specified to facilitate self-care.

Most of the information needs elicited from the participants of this study was also available in the paper portfolio which was designed by a neurology team. However, additional information needs were elicited from the participants of this study as summarized in the result section.

Paper-based storage system also makes sharing of information difficult [29]. While discussing self-care of long-term condition it might include the involvement of a multidisciplinary team and/or family caregivers. ICT-tools can provide access and sharing of all the information needs identified timely. However, the biggest challenge will be designing the system by considering the different disabilities and age of stroke survivors.

4.2. Discussion of methods

Explorative, qualitative research methodology was used since the objective of the study was to explore stroke survivors’ information need. The methods, document analysis, focus group study and paper prototyping, used to conduct this study are thought to be an appropriate choice as compared to the available resources as time.

The alternative method would have been an individual or group case study, where continuous observation and interview would have been done to elicit and understand the information needs of stroke survivors.

The selection of participants in this study was done by convenience and snowball sampling which might have a bias in the result. The best suitable sampling technique would have been purposeful sampling. But due to shortage of time and unavailability of participants lead to convenience sampling. The other limitation is it was only one of the respondents that had the paper portfolio. In this type of qualitative study
the number of participants has an effect, but in this study only five respondents were involved.

The best way of confirming the information needs would have been good if the users started using the system and evaluate it. But in this study an early confirmation of the information need is performed prior to the design of the system by using the paper prototype.

Validity checks the extent to which the finding is generalizable and reliability refers to the consistency of the finding. The aim of this study was not to generalize the finding into a large group of people. Reliability measures if the finding can be replicated again if the research question is done following the same method. Using a combination of methods in a research ensures validity. Since a limited number of participants were involved in the study it might affect the validity. The aim of this study wasn’t to generalize into a larger group. However, the study can be transferable to other chronic conditions by using the rich description.

4.1 Further studies

A focus group interview with stroke survivors’, who had a chance of using the paper portfolio, would be a good beginning.

Then, since collaboration of neurology team and family caregivers have a contribution on the better outcome of stroke survivors during rehabilitation. Eliciting and understanding information needs of the neurology team and family caregivers would been recommended.

After that, conducting a thorough review or study how to present the evaluation of the goal and then developing a system based on the gathered information.

Finally, preliminary evaluation is recommended to be done after the implementation and usage of the system by users.
5. Conclusion

The research question addressed in this study was:

- What are the information needs of stroke survivors’ who participate in home-based rehabilitation to facilitate self-care?

To reach to the main findings, document analysis and focus group meeting with a neurology team was conducted for the purpose of understand the current routine about rehabilitation planning and the information needs available in the paper portfolio.

Then the focus group meeting with participants of this study, stroke survivors, was conducted. Motivational information needs which were available in the paper portfolio, such as clear and well defined goal, individually tailored intervention and evaluation were identified from the participants of the study as well.

Information needs that give support to the participants of the study by reminding, were identified during brainstorming in the focus group meeting while presenting the prototypes.

An additional information needs that was not available in the paper portfolio were identified from the participants of this study such as the information needs which fulfills their psychological and social needs i.e. social support. Besides the rehabilitation plan, the participants had information needs of available of medication list and support services.

This showed stroke survivors’ information needs during rehabilitation are not only restricted to rehabilitation plan rather health information and available support services.

In general, the study revealed that end users involvement for the identification and understanding their information needs are crucial prior to development of a system.
References


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Appendix A: Paper Portfolio

| 1 | Min rehabilitering  
Rehabiliteringsplan, träningprogram,  
utskrivningsmeddelande, blankett med mina  
rehabkontakter |
<table>
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<td>2</td>
<td>Rehabdagbok och reflektion</td>
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<td>3</td>
<td>Schema/almanacka</td>
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| 4 | Övriga insatser  
Hemtjänst, distriktsköterska, färdtjänst,  
personliga assistenter etc |
| 5 | Information  
Rehabaktörer, patientföreningar, broschyrer |
Appendix B: Patient Invitation Letter

Förfrågan till strokepatienter och närstående om deltagandet i en studie för att identifiera samverkansbehov för informationsutbyte och kommunikation mellan patienter, närstående och vård- och omsorgspersonal vid vård i hemmet

Bakgrund och syfte

'Min hälsoplan' är ett dataprogram som kan användas av stroketeamen, patienter och närstående för att planera, rapportera och följa upp strokevård och rehabilitering i syfte att förbättra samarbete mellan patienter, närstående och vård- och omsorgspersonal.

Dataprogrammet är tänkt att kunna nås via olika typer av hårdvara, t ex en vanlig dator, en dator med pekskärm, en TV eller en bärbar enhet som en iPhone. Kunskapen vi får genom att utveckla denna egenvårdsapplikation kan i framtiden även användas för att bygga liknande applikationer för andra kroniska sjukdomar.

Hur går fokusgruppmöten till:

Du tillfrågas att delta i en serie på 3 möten som kommer att hållas i en lokal i Karolinska Institutet och varje möte beräknas ta ca 2 timme. Dessa möten spelas in och anteckningar görs av den medverkande forskaren. Syftet är att diskutera strokepatienters och/eller närståendes informations och kommunikationsbehov och granska och bearbeta olika designskissar i grupp.

Vad är riskerna?

Deltagande i projektet medför inga direkta hälsorisker. De ämnen som tas upp under fokusgruppsträffarna kan upplevas som privata eller personliga då vi kommer att diskutera vilka problem man stött på som strokepatient eller närstående och vilka behov av stöd man har. Det är dock helt frivilligt hur mycket av sina privata erfarenheter man diskuterar i gruppen och alla deltagare har möjlighet att när som helst avbryta.

Finns det några fördelar?

Strokepatienter och närstående som deltar i projektet får möjlighet att lära sig mer om hur ny teknik kan underlätta deras delaktighet i vården, hur de kan få stöd i egenvård och rehabilitering och hur IT-system kan utformas för att stödja deras kommunikation och samarbete med olika vårdgivare. Projektet erbjuder också ett forum för att diskutera problem och svårigheter i kommunikation med vården och tillgång till relevant information, både med forskargruppen och andra patienter och närstående i en liknande situation. Vi kommer också att diskutera de närståendes roll i vården och hur de kan stödjas i vårdprocessen.

Hur får jag information om studiens resultat?

Efter att studien är avslutad och resultaten analyserade, kommer en rapport på svenska att skickas till dig som deltagit i studien.

Försäkring och ersättning?

Du som patient omfattas av patientförsäkring och reseersättning betalas ut i nära anslutning till forskningstillfället.

Frivillighet

Det är givetvis helt frivilligt att delta och du kan avbryta studien när som helst. Är du intresserad av att delta i studien eller önskar du ytterligare information om projektet är du välkommen att hör av dig via telefon eller e-post till någon av nedanstående personer.

**Maria Hägglund**, doktor i medicinsk informatik vid Centrum för Hälsoinformatik, Karolinska Institutet      Telefon: 08-524 836 87, 070-718 0421, e-post: maria.hagglund@ki.se

**Nadia Davoody**, doktorand i hälsoinformatik vid Centrum för Hälsoinformatik, Karolinska Institutet      Telefon: 08-524 864 86, 0700 778 188, e-post: nadia.davoody@ki.se
Appendix C: Patient Consent Form

Centrum för Hälsoinformatik vid Institutionen för Lärande, Informatik, Management och Etik (LIME), KI

Samtyckeblankett

Deltagande av strokepatienter och närstående i fokusgruppstudie gällande 'Min hälsoplan'

Jag har tagit del av den skriftliga deltagarinformationen för fokusgruppstudien som syftar till att identifiera samverkansbehov för informationsutbyte och kommunikation mellan patienter, närstående och vård- och omsorgspersonal vid vård i hemmet. Jag har dessutom fått information om syftet med projektet 'Min hälsoplan - studier kring att stödja egenvård och samarbete i strokevården genom informations- och kommunikationsteknologi'. Medverkande personal har informerat mig om studiens utformning och jag har haft möjlighet att ställa frågor angående fokusgruppstudien. Jag har samtyckt till att delta i studien och är medveten om att mitt deltagande är frivilligt, samt att jag när som helst kan avbryta mitt deltagande utan att ange några skäl.

Ort och datum: 
Namnförtydligande 

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Jag har informerat ovan namngivna deltagare om utformning av studien.

Ort och datum: 
Studierepresentantens underskrift:
Namnförtydligande:

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……………………………………………………………………………………………………
Appendix D: Prototypes

Front page Overview 1

Hello Kaale!

MIN SIDA

STROKE

HÅL MEDEL

KONTAKTEN

PATIENTFÖRENM HÅLL SOCIALA NÄTVERK

STROKE-KORREKT

FRIDAG 5 APRIL 2013
Diary and History Overview
History in a calendar overview

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[Diagram showing a grid with various emojis and labels]
Rehabilitation plan overview