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ORIGINAL ARTICLE



Exploring future possibilities of using information and communication technology in multidisciplinary rehabilitation after stroke - a grounded theory study

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ABSTRACT

Background: Using Information and Communication Technology (ICT) could increase the intensity of rehabilitation, the level of patient activity and participation in everyday life after stroke and is in line with having a person-centred approach.

Aim: To explore how healthcare professionals use and could potentially use ICT to enable a person-centred rehabilitation process after stroke.

Methods: Six individual and two focus group interviews were conducted with a group of healthcare professionals working within rehabilitation after stroke. A grounded theory approach was used to collect and analyze the data.

Results: The professionals described their current use of ICT as well as their vision of how ICT could be incorporated as a tool in rehabilitation for sharing in four categories: (1) Sharing of information, (2) Collaborating from a distance, (3) Having transparency in the documentation and (4) Supporting patients' use of ICT.

Conclusion: Professionals state that using ICT solutions in rehabilitation after stroke could increase sharing between professionals and their patients and increase patient participation in the rehabilitation process.

Significance: This study highlights the importance of developing ICT that healthcare professionals could use along with a person-centred approach. The results will be used to develop an ICT-supported multidisciplinary intervention for rehabilitation after stroke.

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KEYWORDS

Neurology; ICT; technology; participation; activities of daily living; qualitative method and grounded theory

Introduction

Stroke is an umbrella term that includes infarction or hemorrhage in the brain, which can result in reduced performance capacity due to impaired mobility, cognition, speech, sensation or vision [1,2]. A stroke often leads to reduced life satisfaction and participation in everyday life for those affected and their significant others [3,4]. In many cases, the need for healthcare services and rehabilitation remains for years [1,5].

The Swedish national guidelines for stroke care are available to ensure that rehabilitation after stroke is based on the best available evidence [6]. The guidelines include recommendations that rehabilitation after stroke should be provided by a well-coordinated multidisciplinary team [6]. Rehabilitation after stroke in Sweden is usually initiated in the acute stroke unit at the hospital, sometimes followed by a short stay at an inpatient rehabilitation unit. However, long-term rehabilitation is provided in the form of outpatient or home-based rehabilitation in neurological rehabilitation teams in primary care [6]. Healthcare professionals within rehabilitation usually work in teams comprising occupational therapists, physiotherapists, speech and language therapists and medical social workers [6].

The Swedish national guidelines for stroke care also recommend that the teams should use a personcentred approach [6]. Some of the key components of person-centred care include forming a partnership, listening to the person's narrative and documenting the narrative, goals and plan so that they are

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B Supplemental data for this article can be accessed here.

accessible to the person [7]. In order to be personcentred, the therapists should have a holistic view and take into account the person's whole life situation, not just their medical needs [8,9]. Additionally, professionals and patients should share decision-making and goal-setting in order to increase the patients' involvement in the rehabilitation process and participation in everyday life [7,8].

The Swedish Association of Local Authorities and Regions and the Swedish government have created a vision (Vision e-health 2025) and action plan to become a global leader in the use of e-health solutions, including the use of Information Communication Technology (ICT), by 2025 [10]. Several ICT patient-directed solutions have already been developed across the country, for example, various self-management programs that aim to achieve equality in health and participation [10]. However, within Swedish health care and rehabilitation professionals primarily use ICT (i.e. their computers) to read and write medical records, communicate with colleagues and perform other administrative tasks. In order to meet the goals for the vision e-health 2025, there is a need to develop secure, effective and useable ICT solutions within rehabilitation, as well as within other areas of health care [10].

The possibilities of using ICT within rehabilitation include the potential to monitor and support patients from a distance during their rehabilitation process. This could serve as an addition to regular rehabilitation [11,12] since the use of ICT in rehabilitation after stroke and other chronic conditions has proven to be both cost-effective and to also facilitate communication and feedback [12,13]. Previous research has shown that people with acquired brain injury could learn to use ICT, for example, memory aids, to support participation in their daily activities [14]. However, the technology might be perceived as being difficult to handle for people with acquired brain injury, including stroke, due to cognitive deficits. Thus, it is important for professionals to note whether additional support is required [15–17].

The present study was performed as part of a larger project within the HELD research group [18] at Karolinska Institutet. The long-term objective of the larger project is to develop a person-centred multidisciplinary rehabilitation intervention after stroke supported by ICT. The development, testing and implementation of the new intervention are guided by the Medical Research Council's (MRC) guidelines for developing and evaluating complex interventions [19]. According to the MRC's guidelines, the creation of evidence together with identifying the evidence base are key elements of the development before new, complex interventions can be modeled, tested and eventually implemented [19]. As part of the development of theory, a previous study was performed which showed that people 6-12 months after a stroke had the drive and need to use ICT in their everyday lives, despite having physical and cognitive impairments resulting from the stroke [20]. Another previous study within the research group showed that occupational therapists and people after a stroke emphasized the importance of "sharing and transparency" during the rehabilitation process in order to facilitate a person-centred approach [21,22]. The concept of "sharing" included building a therapeutic relationship, sharing professional knowledge and sharing an understanding of the patients' experiences, activities and goals [21]. Transparency was defined as the participants' ability to visualize and follow the rehabilitation process [22]. Previous research has shown that ICT like mobile phones, computers and tablets can be used within rehabilitation to improve the performance of daily activities and participation in everyday life [23,24]. Our assumption is that ICT could also be used to enhance sharing and transparency between professionals and patients during the rehabilitation process.

Even though there is increased use of ICT in society at large and within health care and rehabilitation, knowledge of the potential barriers and facilitators to implementing ICT within person-centred, team-based rehabilitation after stroke is sparse and needs further exploration. This current study will contribute with knowledge on how professionals use and could use ICT as an effective and secure tool within the entire rehabilitation process after stroke, from acute rehabilitation to long-term primary care rehabilitation.

The aim of this study was to explore how healthcare professionals use and could potentially use ICT to enable person-centred rehabilitation after stroke.

Method

A grounded theory (GT) approach was used during data collection and analysis and included a constant comparative method and memo writing [25,26]. The use of GT allows the researchers to be flexible and add data along the way when needed in order to saturate the emerging categories [26]. Ethical approval was obtained from the Regional Ethics Committee in Stockholm (2013/1808-31/5).

Table 1. Participants characteristics.

	Profession				Place of work	
Interview group	Occupational therapist	Physio-therapist	Speech and language therapist	Medical social worker	Acute stroke unit	Neurological rehabilitation team in primary care
Individual	2	2	1	1	3	3
Focus group 1	4	2				6
Focus group 2	3	2	1			6

Participants and recruitment

This study was based on individual and focus group interviews with a group of professionals working in rehabilitation after stroke in Stockholm, Sweden. The initial theoretical sampling of participants was strategic in order to achieve variation in professions and workplaces [26]. One person working at an acute stroke unit was contacted and asked to recommend professionals (occupational therapists, physiotherapists, speech and language therapists and medical social workers) from different workplaces within rehabilitation after stroke (acute and primary care rehabilitation) who could be invited to participate in the study. Participant characteristics are described in Table 1.

Six professionals (three from acute rehabilitation and three from primary care rehabilitation) were informed about the study and all agreed to participate in individual interviews. The initial analysis of the individual interviews guided the theoretical sampling and revealed that there was a need to collect additional data in order to saturate the emerging categories. In the individual interviews the participants described their current use of ICT. However, their views of potential future use needed to be further explored. Within focus group interviews, the dynamic discussions between the participants can create new in-depth knowledge [27,28]. Thus, two focus group interviews were held at Karolinska Institutet in Stockholm in conjunction with a seminar organized for neurological rehabilitation teams within primary care. Before the seminar, all the participants received information about the study and an invitation to participate. Twelve professionals from nine different neurological rehabilitation teams accepted the invitation and agreed to participate.

Data collection

The first six individual interviews were conducted by the second author from April to October 2015 at the participants' workplaces. Two focus group interviews comprising 12 participants in total and two moderators in each group (the authors plus an additional researcher from the research group) were conducted in November 2015. All participants received written and oral information about the study, were guaranteed confidentiality and informed that they could withdraw their consent at any time.

The data collectors and moderators were researchers with several years' clinical experience of rehabilitation after stroke. As recommended by Charmaz [26], an interview guide was developed by the authors containing a few open-ended questions based on the aim of this study (Supplementary Appendix 1). The questions regarded the professionals' perception of the potential barriers and facilitators for using ICT within rehabilitation after stroke. The interview guide was used as a flexible tool that allowed the participants to reflect on the topic and tell their stories rather than merely answer questions [26]. All the interviews were audio recorded and transcribed verbatim.

Data analysis

A constant comparative method, moving back and forth in the material, was used to analyze the transcribed interviews. [25,26]. NVivo software was used to sort and organize the data [29]. Memos were written throughout data collection and analysis to assist in the analysis process and to capture developing ideas around the material [26].

Analysis started during data collection in accordance with the GT approach and the first stage was initial coding through comparison on an incident-byincident basis [26]. Analysis of the transcribed interviews was mainly performed by the first author. However, it was continually discussed by all authors throughout the process. The constant comparative method was used as an analytic tool throughout the study to guide the data collection and create a new understanding of the collected data [25]. The initial codes were kept close to the text and organized into 11 categories that described different areas in which ICT was used in rehabilitation. For example, for communication, assessment and providing information (see Supplementary Appendix 1). When progressing to focused coding and integration of the categories, the categories were revised. The seven new categories created at this stage reflected the reasons for using ICT within rehabilitation after stroke. For example, the professionals' use of ICT to enhance collaboration with patients and significant others, coordinating the rehabilitation and assessing the patients' need to use ICT during the rehabilitation process.

In order to further deepen the conceptualization and describe the relationship between the categories, a theoretical coding was used [26]. The results from previous studies that describe the importance of sharing and transparency in a client-centred intervention for rehabilitation after stroke [21,22] were used to create the four categories presented in the results. The coding frame is presented in Supplementary Appendix 2.

Results

Four categories were identified from the analysis, describing how and for what purpose the professionals currently use ICT and their vision of how ICT could be incorporated into rehabilitation in the future: (1) Sharing of information, (2) Collaborating from a distance, (3) Having transparency in the documentation and (4) Supporting patients' use of ICT.

Sharing of information

Sharing information was one of the areas in which the professionals saw a potential for ICT to be used in order to provide essential information to patients and their significant others, to help them feel in control of the situation and to own their rehabilitation process.

The professionals noted that managing and understanding information regarding their medical care and rehabilitation was problematic for many of the patients. This was evident during both acute stroke care and when adjusting to life at home after discharge. Overall communication and information to patients and significant others were primarily provided orally through face-to face meetings or via telephone and through written information. There were no ICT-based systems for sharing information. One of the professionals commented: "They get one paper here, one paper there, one paper somewhere else. If this information could be collected together for the patient, I think that would be great!"

The professionals discussed how ICT could be used in future as a digital coordinator, to keep track of contact information, referrals and appointments and provide accessible and updated information. The significant others were seen as playing an important role in the coordination of rehabilitation since they supported the patients emotionally and practically. For example, they reminded the patients about appointments and supported them in understanding and remembering information and instructions. Using ICT could therefore potentially ease the burden for significant others.

Another way of including the patients and their significant others in their rehabilitation was to use ICT to involve them in the process of choosing physical aids and adaptations for their use. One of the occupational therapists who had tried this explained: "I show them (on the mobile phone) what it looks like ... so that they get to see the aid before I deliver it at their home, because it's a total waste if I order something and then they say: No, I won't use this!"

Even though most of the professionals lacked access to smartphones and secure ways of communicating online, they were mainly positive to such a method of sharing information and considered it to be a useful way of communicating. On the one hand, the professionals expressed their desire to use ICT in order to enable patients to take control of their rehabilitation process while, on the other hand, they expressed difficulties such as a lack of accessible and understandable information, or a lack of ICT.

Collaborating from a distance

The professionals stated that they felt that resources to meet all the patients' needs were sparse, both at the acute stroke care units and within primary care, and that ICT could be a useful and effective tool for collaborating from a distance. The professionals stressed that ICT should be considered to be a supplement and not a replacement for normal rehabilitation and that it could have several benefits if used carefully.

Some of the professionals used computer software for home training for the patients. They described this as increasing independence, as well as intensity level and motivation in the rehabilitation process. However, a prerequisite was that patients were able to download applications and software on their own devices. Moreover, they had to be able to pay for this themselves. One of the physiotherapists said: "I think if you work a lot with home training you would get closer to the patients in a way ... to be able to go in and check whether they are exercising and maybe receive an alert if they have any problems ... "

The professionals discussed the possibilities of using ICT to enhance communication and follow up the progress of rehabilitation from a distance, for example, through videoconferencing. These solutions could save time and money through less travel, both for professionals and for patients. One of the professionals commented: "Very often they (the patients) might just have one question. Then they waste perhaps one or one and a half hours just getting here and then going back ... It feels like it would be easier if we could communicate in some other way!" The main obstacles to communicating through ICT were a lack of secure methods for transferring personal data, and the reimbursement system. The rehabilitation teams were only reimbursed for a follow up if they met patients faceto-face.

Being able to share the progress of the rehabilitation and communicate from a distance were considered to generate a sense of closeness and be motivating for both patients and professionals. Regarding the future development of ICT within rehabilitation, the professionals stated that ICT solutions must be easy to use by the patients, regardless of their reduced abilities and should be meaningful to use for patients as well as for professionals.

Having transparency in the documentation

The professionals' current use of documentation was mainly limited to medical records that were also often used to communicate with other professionals within the team or on other units. There was a desire to collaborate more closely with patients and colleagues using ICT.

The professionals stated that they used ICT mainly in their offices for administration purposes, searching for information and for contacting other professionals. The use of ICT together with patients was limited, since only a few of the professionals had access to smartphones or laptops. Making assessments, setting goals and planning rehabilitation were stated as being essential parts of the rehabilitation process, and particularly important when the rehabilitation periods are short. The professionals stated that assessments, goals and the rehabilitation plan were documented manually on paper together with the patients. They were then transferred to digital medical records which were not easily accessible to the patients. The professionals lacked access to suitable ICT-supported assessment tools that could enable them to document the assessment directly on a tablet that could facilitate the performance and administration of such assessments. Even though the medical records were open to patients upon request, they were not easily accessible by patients or their significant others.

Collaboration with professionals at other units was regarded as being important for a smooth transition for the patients. Currently, the primary method of communication is through documentation in the medical records. However, because this was one-way communication, there was no guarantee that the information had been read and understood by the recipient. One of the professionals commented: "I try to document what I have done quite thoroughly... in the hope that the person who takes over doesn't have to do it all over again."

Several professionals wanted more collaboration between the units and also wanted to be able to talk to other professionals when handing over patients. This could benefit both patients and professionals and support the professionals to develop within their professional role through feedback on their work. A number of professionals attempted to phone their colleagues, but it was not always easy to find the time and the opportunity. One of the professionals also described another area in which ICT could be useful in creating transparency between different stakeholders: "Maybe have some kind of network through a mobile application... between the county council and community care... have increased collaboration in order to provide the best possible care."

Transparent documentation that could enable communication and collaboration between all stakeholders, such as other team-members, colleagues at other units as well as the patients and their significant others, was desired but was described as challenging in the current system.

Supporting patients' use of ICT

The professionals stated that the patients' ability to use ICT was often affected by the stroke to a greater or lesser extent, while the need to use ICT in everyday life also increased.

The professionals stated that there was a need for them to assess the patients' ability and need to use ICT in their everyday lives, including rehabilitation after stroke, and then offer them support. However, no guidelines existed for when, how and by whom these assessments should be performed. The occupational therapists sometimes assessed the patients' ability to use their mobile phone, tablet or computer after a stroke as part of their assessment of the patient's ability to perform activities of daily living (ADL). One of the occupational therapists stated: "If there is a mobile phone on the patient's bedside table this is a perfect way of assessing them... by checking how they manage their technology."

One of the professionals stated how support was offered to enable patients to use ICT as they had done previously: "To try to find a way that makes it work... being able to continue using your mobile phone, computer and tablet and anything you could have used before you became ill." In addition to the impact of a stroke, the professionals' felt that other factors influenced the use of ICT in everyday life such as insecurity, previous experience, interest and access to ICT devices and/or software.

Discussion

The main results of this study highlight the possibilities for professionals to use ICT solutions in rehabilitation after stroke in order to enhance the participation of patients and their significant others throughout the rehabilitation process. ICT could be used by professionals to create opportunities for communication and sharing rehabilitation goals and plans with their patients.

In order to ensure that the patients' rehabilitation needs are met, the rehabilitation must be flexible in terms of whom, where and for how long rehabilitation is being provided [5]. In the current study, the professionals within primary care stated that a lot of resources and time are spent traveling to visit patients and that the patients used their limited strength, effort and time traveling to the outpatient rehabilitation center. Using ICT as a supplement to standard rehabilitation could reduce travel and costs [12,13]. The professionals stated that using ICT would be a valuable complement to face-to-face meetings, which is also the conclusion of a recent review [23]. However, it is important not to lose or reduce faceto-face contact resulting from increased use of ICT, especially at the initial stage when building a relationship with the patient [23,30,31]. In this study, the reimbursement system within primary care was described as being an obstacle for the development and use of ICT. This is likely to change as the demand for effective and secure solutions increases. The organizational context has also been highlighted by Brouns and colleagues [31]. When implementing a new ICT-based intervention, it is important to ensure that the new intervention is compatible with the current care process and that sufficient time is allocated [31]. Additionally, usability and accessibility have been described as requirements for developed ICT interventions [32].

There is a need to develop and implement personcentred interventions in order to meet the growing demand for person-centred rehabilitation as well as increased participation and sense of control on the part of patients and their significant others [7,33]. Even though the health care professionals in this study did not specifically mention having a personcentred approach they described that they aimed to work closely with their patients and to include the patients and their significant others in the rehabilitation process. Some of the key components of personcentred care are shared goal-setting, as well as shared information and decision-making [7]. Setting goals was described in this study as challenging by the professionals within both acute and primary care, and in a previous study, the patients described a lower degree of participation in goal-setting compared to what the professionals stated [34]. This highlights the importance of acknowledging that person-centeredness not only involves inclusion but also enabling patients to feel in control of their situation.

Strategies for increasing digitalization in healthcare provision have been developed globally [35] with the goal of enhancing patient participation in the community, disease management and positive changes in health behavior [10,35]. Our results show that ICT could be used as a tool for sharing rehabilitation goals and plans, thereby increasing the patient's participation in the rehabilitation process and creating a sense of control. Patients, particularly younger patients and patients of the future, will probably expect healthcare services to be flexible and digitalized. Additionally, digitalization of healthcare is needed in order for the society to manage the challenges of the future with an aging population, lack of healthcare staff and increased demands for accessibility [10]. Our previous study that explored the use of ICT among people after a stroke showed that ICT was used in everyday life, for example to feel safe, staying connected with friends and family and managing daily life [20]. Using a web platform for documentation that is accessible to everyone could enable professionals to make goals and plans more transparent for all stakeholders. Also, patients would feel more in control of their rehabilitation process. In this way, ICT could assist the creation of a person-centred care relationship. However, the use of ICT in rehabilitation has to be based on the needs and ability of patients,



recognizing that they might experience difficulties in handling ICT tools due to their impairments and activity limitations [15–17,31].

However, further research is necessary in order to develop and evaluate ICT-based interventions that could facilitate person-centeredness and increase participation in everyday life for people during their rehabilitation after stroke. It is important to work in close collaboration with future users, especially patients and their significant others, in order to identify ICT solutions and evaluate whether such solutions are usable and effective. It is also important to examine in detail the potential strengths and limitations of ICT usage, particularly in regard to the patients' cognitive impairment and economic inequality, which could potentially exclude certain people.

Methodological considerations

The use of both individual and focus group interviews in this study could be questioned but is considered to be a strength. In grounded theory, data collection is a flexible process and can be shaped and reshaped in order to increase knowledge [26]. In this study, the different types of interviews complemented each other by providing both individual experiences and the common experiences of using ICT in rehabilitation after stroke. The discussions and interaction between participants in the focus groups generated in-depth data, which saturated the categories that had emerged from the individual interviews [27].

In this study we included professionals representing all phases of the rehabilitation process after stroke, from acute care to primary care rehabilitation in the individual interviews. The two focus groups were formed with the aim of having a large variation in professions and different workplaces i.e. primary care teams in order to enhance the discussions [27,28]. Though, since the majority of participants worked in primary care the results may be more applicable to primary care and further research on the acute phase is needed. Data on the professionals' age, gender and work experience were not collected, which could be regarded as a limitation. Nevertheless, in future studies we will develop and evaluate a multidisciplinary ICT-based intervention for rehabilitation after stroke. Thus, the inclusion of participants with different professions was crucial. One limitation of the focus groups was that they only represented primary care teams and the views of people in acute rehabilitation were only present in the individual interviews. Additionally, no medical social workers were available for the focus groups at the time and there is a risk that their perspective was lost in the group discussions.

Conclusions

The results of this study contribute to an understanding of how ICT could be used among healthcare professionals in order to enhance patients' participation in the rehabilitation process after stroke. The professionals stated that using ICT could increase sharing between themselves as professionals and their patients and could improve patient participation in the rehabilitation process. ICT could also make rehabilitation after stroke more accessible and enable more people to receive rehabilitation at home.

Ethical approval

Ethical approval was obtained from the Regional Ethics Committee in Stockholm (2013/1808-31/5).

Disclosure statement

The authors report no conflict of interest.

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