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The use of eHealth in rehabilitation after stroke

Wentink, M.M.

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Author: Wentink, M.M.

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Summary & general discussion



SUMMARY

Aims of this thesis

eHealth is increasingly used in rehabilitation (eRehabilitation), yet evaluations of its effectiveness, the process of delivery and the perceptions of patients, their caregivers and health care providers are relatively scarce. This thesis aimed to:

- I. Evaluate the outcome and process of an eHealth intervention for cognitive stroke rehabilitation.
- II. Explore the (readiness for) use of eHealth among patients in rehabilitation.
- III. Investigate the requirements of patients, informal caregivers, health professionals, teachers and students regarding the use of eHealth interventions in stroke rehabilitation.

Main findings

The outcome and process of an eHealth intervention for cognitive stroke rehabilitation were addressed in Chapters 2 and 3.

Chapter 2 concerned a Randomized Controlled Trial (RCT) to evaluate the effect of an online serious brain training programme on multiple aspects of cognitive functioning, quality of life (QoL) and self-efficacy in comparison to a control intervention in stroke patients with self-perceived cognitive impairments. 110 stroke patients with self-perceived cognitive impairment 12–36 months after stroke were randomly allocated to the intervention (n=53) or control group (n=57). The intervention consisted of an 8-week brain training programme (Lumosity Inc.[®]). The control group received general information about the brain weekly. Assessments consisted of a set of neuropsychological tests and questionnaires on cognitive functioning, QoL and self-efficacy. After 8 and 16 weeks, no significant effect of the intervention was found on cognitive functioning, QoL or self-efficacy as compared to the control condition, except for small, yet statistically significant, effects on working memory and speed (mixed model analysis).

In **Chapter 3** the adherence of patients with the above mentioned 8-week brain training programme (intended use a minimum of 600 minutes of playtime) was described, with a focus on the role of health professionals' supervision. This study was part of the RCT described in Chapter 2 and used data from patients in the original intervention group (n=53) and the patients in the control group who accepted the offer to use the brain training programme after the initial trial period (n=52). Patients in the original intervention group

received supervision eight times during the training period (group 1), whereas patients in the original control group were only supervised twice (group 2). It was found that patients experienced several difficulties with tasks and conditions required to participate in the brain training (e.g. not able to cope with flashing screens, etc.). Only 24 out of the 105 patients (23%) were able to complete the intended dose of 600 minutes brain training over a period of 8 weeks, with the median playtime being 424 minutes (27-2162). The median playtime was significantly higher in group 1 (562 minutes, range 63-1264) than in group 2 (193 minutes, range 27-2162) ($p < 0.001$, Mann Whitney U). A possible explanation could be that excitement for the study waned for patients in group 2 who had to wait 16 weeks after the randomisation, whilst patients in group 1 started the training straight away after inclusion. Nevertheless, the findings may indicate that the frequency of the interaction with a supervisor can increase stroke patients' adherence with a brain training programme at home.

Given the suboptimal use of the brain training programme in Chapters 2 and 3, a descriptive study in **Chapter 4** explored the (readiness for) use of information and communication technology (ICT) devices (e.g. personal computer (PC), laptop, tablet, smartphone) among patients who were or had been admitted for rehabilitation. It also aimed to investigate patients' preferences to incorporate this technology in their rehabilitation process. For this study a cross-sectional design with a self-developed online questionnaire was used. The questionnaire comprised 61 questions about current possession and use of ICT devices, desired usage of ICT devices in the rehabilitation process in the future and socio-demographics and disease characteristics. Open answers, multiple choice and a 4-point Likert scale (1-4; totally disagree-totally agree) were used to examine current possession and user preferences. 190 out of 714 invited patients admitted for inpatient and/or outpatient rehabilitation and registered with an e-mail address, completed the questionnaire. 94 (49%) were women and 96 (51%) were men. The mean age of the participants was 49 (SD16) years. 149 out of 190 patients (78%) used one or more devices every day of the week. The most frequently used devices were: PC/laptop (93%), smartphone (57%) and tablet (47%). Most of the patients were willing to incorporate ICT devices in their rehabilitation process. The most frequently mentioned potential purposes for use in rehabilitation included: having insight in the medical health record, communication with peers and scheduled appointments with health professionals.

Chapter 4 provided insight in current and desired use of ICT devices in rehabilitation in general, but the perspectives of intended users regarding eRehabilitation after stroke are not yet explored. Therefore, requirements for use of stroke eRehabilitation were investigated and prioritized in chapters 5 and 6. **Chapter 5** describes the requirements for the accessibility, usability and content of comprehensive eRehabilitation after stroke as perceived by

patients with stroke, their informal caregivers and health professionals, as identified by a qualitative (focus group) study. In total, eight focus groups were conducted to identify user requirements; six with patients/caregivers and two with health care professionals involved in stroke rehabilitation (rehabilitation physicians, physiotherapists, occupational therapists, psychologists, team coordinators). Direct content analysis was used to identify the user requirements concerning three predefined categories: accessibility, usability and content. In total, 45 requirements emerged from the focus groups. It was concluded that the majority of requirements of patients, informal caregivers and health professionals concerned content (25 requirements), followed by usability (12 requirements) and accessibility (8 requirements). Moreover, requirements between stroke patients/informal caregivers and health care professionals differed on several aspects. For instance, a requirement of health professionals was that eRehabilitation programmes can be accessed by the computer in the rehabilitation center, whereas patients and caregivers preferred to use a smartphone or tablet.

Chapter 6 provides an overview of the most important requirements for comprehensive eRehabilitation after stroke according to larger groups of patients with stroke, their informal caregivers and health professionals (physicians, psychologists and physical therapists), as based on a quantitative (survey) study. In order to determine the importance of requirements, a questionnaire with a 4-point Likert scale (1-4; unimportant-important) was developed with statements regarding accessibility, usability and content of comprehensive eRehabilitation after stroke. 125 patients, 43 informal caregivers and 105 health professionals completed the survey. The most important requirements as perceived by the majority of all stakeholder groups were: applicability of eRehabilitation to possessed ICT-devices (e.g. tablet, smartphone, computer in rehabilitation center), support with usage (i.e. instruction videos, menu with frequently asked questions), physical exercises, general information about stroke, insight in the rehabilitation process (i.e. feedback about training results, final reports) and setting and evaluation of goals. Notable differences were also found between the stakeholder groups, for instance exercises for cognitive functioning were important for patients and informal caregivers, whilst this was a less important requirement for health professionals.

Except for matching eHealth interventions with the requirements of its users, successful adoption in stroke rehabilitation also depends on how well health professionals are prepared to use eHealth in daily practice. This readiness starts with educating health professionals to work competently and confidently with eHealth.

Chapter 7 describes the barriers and facilitators for eHealth education as perceived by teachers and students involved in the education of exercise/physical therapists. A qualitative study including six focus groups was conducted: two with teachers (n=11) and four with students (n=24), all selected from two universities of applied sciences in the Netherlands. Reported barriers and facilitators were identified, grouped and classified according to the levels of a generally accepted framework for implementation (innovation, individual teacher, individual student, social context, organizational context and political and economic factors). More barriers than facilitators were perceived for the uptake of eHealth education in the curriculum, by both educators and students. Most barriers and facilitators were identified on the level of the Innovation (eHealth, e.g. unclear concept) (n=26), followed by the Individual teacher (e.g. capabilities on how to use eHealth) (n=22) and the Organizational context (e.g. didactic materials) (n=20). Starting points for developing implementation strategies of eHealth (education) in the curriculum, for both teachers and students, can be found in reducing the barriers (e.g. limited knowledge of eHealth, lack of skills in critically appraising eHealth) and by using the facilitators (e.g. shared sense of importance of implementing eHealth in education, passionate teachers, didactic materials).

DISCUSSION

Focus of this thesis

This thesis focused on the evaluation of an eHealth intervention for cognitive stroke rehabilitation and the perspectives of different stakeholders on the uptake of eRehabilitation in general.

The studies included in this thesis showed that there was no overall effect of an online brain training programme on cognitive functioning of patients with stroke. Only performances on cognitive function tests that were similar to the games included in the intervention improved, no near transfer effect was found. Moreover, usage of the training was suboptimal and not all of the patients were able to complete it. In order to improve daily activities of stroke patients, computer tasks need to be closely related to the impaired task itself. Thus, computer-based cognitive rehabilitation (CBCR) needs to be tailored and adapted to each patient's individual profile. It would appear important to support stroke patients with CBCR training, since training is not well used by all patients. It is possible patients benefit more when they learn how to use strategies in their training and when motivated by clinicians.

However, regarding patients' ICT readiness, wishes and requirements it was also found that a relatively large amount of patients in rehabilitation wish to incorporate ICT in their rehabilitation treatment and that patients with a stroke have specific requirements regarding the accessibility, usability and content of eRehabilitation. The requirements of patients were not entirely similar to those of informal caregivers and health professionals, indicating that all perspectives of all stakeholders should be taken into account. In addition, developing tailored implementation strategies to implement eHealth in the bachelor curriculum of health professionals, based on the identified barriers and facilitators in this thesis is highly relevant to make sure that future health professionals are able to work with eHealth.

Given the abovementioned findings, this Discussion focuses on conditions that can facilitate the effect and uptake of eRehabilitation, with emphasis on rehabilitation of patients after stroke.

Part I. Evaluation of an eRehabilitation programme after stroke: outcome, process and study design.

Evidence for the effectiveness of cognitive eRehabilitation after stroke

Our finding (chapter 2 and 3) is in line with the suggesting that the evidence for the effectiveness of cognitive eRehabilitation in stroke is scanty [1-6].

A recent systematic review by Laver et al. concluded that the effect of cognitive

eRehabilitation through virtual reality on cognitive functioning in stroke patients is still unclear because of a lack of trials [2]. A recently performed RCT also found that a brain training programme, which was comparable to the training used in our study, did not improve cognitive functions, subjective cognitive functioning or quality of life in patients in the chronic phase after stroke compared to a control group (waiting list) [7]. The literature is however conflicting, as some studies have also found positive effects in patients with stroke or other acquired brain injury after brain training [8-17]. It should be noted though that effects were mostly seen for tasks (outcomes) similar to tasks in the training process (i.e. near transfer effect), rather than tasks that are dissimilar to the training (i.e. far transfer effects) [15-21]. In other words, outcomes in terms of tasks that are similar to the training are less likely to contribute to improvements in daily living than outcomes that are directly linked to activities done in daily life [6]. It is possible that cognitive eRehabilitation interventions in which the tasks are closely related to the cognitive tasks in daily life, are more effective to stimulate cognitive functioning after stroke than playing games. This is supported by a RCT of Faria et al. (2016). In this study the potential benefits of virtual reality based cognitive rehabilitation after stroke through simulated activities of daily living were compared to conventional therapy only [22]. The intervention involved a virtual simulation of a city where memory, attention, visuo-spatial abilities and executive functions tasks were integrated in the performance of several daily routines. A between groups analysis showed significantly greater improvements in global cognitive functioning, attention and executive functions in patients with stroke when comparing virtual reality to conventional therapy.

Except for the scarcity of trials on the effectiveness of stroke eRehabilitation, according to the previously mentioned systematic reviews the methodology and reporting is poor in many cases, hampering the interpretation of their findings [2;23-28].

The process of cognitive eRehabilitation programme after stroke

The RCT described in this thesis showed that only 24 out of 105 patients (23%) were able to complete the desired total number of 600 minutes of brain training over a period of 8 weeks. This is in line with other studies that concluded that intensive (eHealth)-exercise regimes after stroke are difficult to perform for stroke patients [29-32].

During the execution of the trial, patients experienced several difficulties with tasks and conditions required to participate in the brain training (e.g. no possession of the required operating system to run games on their computer, incompetency with technology, not able to cope with flashing screens, etc.). These barriers might have contributed to the relatively low usage. Other barriers were identified by Pugliese et al. for mobile tablet-based care in patients with stroke (e.g. complexity of therapy instructions, fine-motor requirements, and unreliability of internet or cellular connections) [33].

To allow successful uptake of eRehabilitation it is recommended to identify methods that

can minimize the barriers for the use of eRehabilitation and support maximize adherence of patients with stroke [33]. One of these methods, explored in this thesis, was the delivery of supervision during the eRehabilitation intervention. Two intensities of supervision offered by a health professional were compared, showing that more frequent supervision (weekly) resulted in significantly higher adherence levels than low frequent (4-weekly) supervision. This is in line with a review by Kelders et al. (2012), concluding that the frequency of interaction with a counselor was a significant predictor for adherence with web-based health interventions in different patient groups [34]. Therefore, regular interaction with a supervisor is important to increase stroke patients' adherence with eRehabilitation interventions and supports the importance of offering eHealth by means of a blended care strategy.

Study strategies to evaluate a cognitive eRehabilitation programme after stroke

Although effects of eRehabilitation interventions are often evaluated in conventionally designed clinical trials, as was done in the RCT presented in this thesis, these designs are not always appropriate to evaluate effects of eHealth [35-38]. For example, an RCT does not always represent daily health care practice because of its sometimes very strict inclusion and exclusion criteria [38]. Consequently, when the effectiveness of eHealth has been established in a "laboratory setting", the results may not be replicated in a different context, where e.g. patients with less digital skills or cognitive impairments are offered the intervention.

Another drawback of traditional research designs is that their time cycle is much longer than the speed at which eHealth develops and evolves. This can make (parts of) the innovation under study already outdated by the time the results of the RCT are published [39]. Moreover, 'early adopters' among patients and health professionals may use an eHealth innovation before the evidence is available [38], decreasing the contrast between intervention and control conditions.

All of the abovementioned aspects have implications for the design of future eRehabilitation research. First, alternative research designs than the traditional RCT are recommended in order to provide information about how an eHealth intervention works in health care practice and to make experiences of users more visible. The following (research) strategies can be considered for research in eRehabilitation:

- 1) Multiple evaluations and use of clinically meaningful outcome measures that are highly sensitive and quickly responsive to the effects being evaluated [39];
- 2) Using alternative resources to generate information, e.g. digital self-measurements, social media, online databases or personal health files, big data analysis [36;40];
- 3) Qualitative research into the experiences of patients; and
- 4) Action research. Action research, often led by a group of professionals as part of

a community of practice, is initiated to solve an immediate problem identified by professionals [41]. The goal is to investigate and solve the problem, for instance by developing guidelines, strategies and knowledge in order to improve the communities' work practices. This is done by active participation of the community of professionals itself (e.g. teachers, students, researchers, patients, health care professionals). After investigation of the problem, the group makes decisions, observes and keeps note of the consequences of changing the particular situation. So, the group participates in a change situation, whilst research is conducted simultaneously, alongside the iterative process of adapting, testing and evaluating the innovation.

To conclude with, it should be noted that the development, evaluation and implementation of stroke eRehabilitation interventions and associated research must be executed in collaboration with all relevant stakeholders to make eRehabilitation relevant and feasible for the intended users in health care [42;43]. An example of such a collaboration is a so called "Living Lab", where various stakeholders (e.g. knowledge institutions, health care organizations, practitioners, patients, financiers, innovators, established companies, startups, researchers, etc.) work together to develop, evaluate and implement eHealth. In a medical specialist rehabilitation center, Basalt rehabilitation, such a Living Lab, the SmartLab, is instituted. Here, a stepwise procedure is used to test innovations in rehabilitation for their potential added value and usability (www.medicaldeltalivinglab.nl; (<http://www.basaltrevalidatie.nl/onderzoek-innovatie/smartlab/>)). Subsequent steps involve research to systematically evaluate the effectiveness, experiences and costs, and implementation when appropriate.

Part II. Readiness and requirements for eRehabilitation after stroke: implications for the uptake, health care practice and education.

Incorporating perspectives of stakeholders in the development of stroke eRehabilitation

This thesis includes a number of studies aiming to identify the readiness and requirements for stroke eRehabilitation among stakeholders involved in stroke care. A survey study found that the possession and usage of ICT devices was relatively high among patients in rehabilitation and that most patients wished to use those devices during the rehabilitation process. Moreover, a focus group study showed that stroke patients, informal caregivers and health professionals had very specific requirements for stroke eRehabilitation, e.g. doing physical exercises, information about stroke and outcomes of rehabilitation and scheduling appointments with health professionals. These findings suggest that preferably, eHealth services should be developed where diverse purposes (e.g. telecommunication, training facilities, information, agenda, etc.) are combined in one digital platform to allow easy

access and use. Partly based on the outcomes of this qualitative study a comprehensive eRehabilitation platform for stroke was built and is currently evaluated in the Fit After Stroke 'Fast@Home' project (www.fastathome.org).

Moreover, our focus group study showed that eRehabilitation training facilities and feedback should both be adapted to patients' preferences and capabilities (tailored care) [44-50]. Offering support with daily use of an eRehabilitation programme (i.e. direct assistance, a helpdesk, videos with instructions and/or a menu with frequently asked questions) was considered a crucial element as well. These findings may imply that to develop stroke eRehabilitation programmes that match with the needs of the intended users, it is essential that eRehabilitation programmes are designed in co-creation with all relevant stakeholders ('co-design'). Requirements of patients, informal caregivers and health professionals should be incorporated in each step of the design process ('user-centered design'). This is especially important since this thesis showed that different types of stakeholders have different requirements to optimize usage of eRehabilitation. The aforementioned community of practice is a good method to establish active participation of all relevant stakeholders and thereby enhances co-creation and user-centered design in eRehabilitation.

The uptake of eRehabilitation in stroke care

The impact of a stroke varies widely among individuals with the optimal treatment depending on abilities, preferences and goals of both the patient and his or her caregiver(s) [51]. Health professionals can play a central role in this patient-centered delivery of eRehabilitation (e.g. adjustment of training facilities according to progression, feedback and motivation). They are able to link the patient to effective eRehabilitation interventions and can provide guidance with using a new eHealth service. It is recommended to further implement living labs, Communities of Practice, involvement of end-users (patient, caregiver, professional, students, designers, researchers, etc.) and co-create in ideation, testing, implementation, evaluation and upscaling.

In a qualitative study aiming to identify user requirements for stroke eRehabilitation by means of focus groups, the participating healthcare providers (rehabilitation physicians, physiotherapists, occupational therapists, psychologists, team coordinators and speech therapist) also acknowledged the importance of their role in the uptake of eRehabilitation in stroke care. Health professionals are often not aware of the opportunities of eHealth and poorly informed about available eHealth interventions [37]. It is often unclear to health practitioners how eRehabilitation can be effectively used for patients [52]. If evidence from research is available, it may not be suitable to directly support health practitioners in making clinical decisions [37;38]. Virtual reality, for instance, has emerged as a therapeutic tool facilitating motor learning for balance and gait rehabilitation in stroke patients [2]. The evidence, however, has not yet resulted in protocols or standardized guidelines and/

or a consensus regarding optimal intervention programmes (e.g. dosage and tasks) [52]. Furthermore, it is complex to integrate effective eHealth interventions in existing work processes.

Therefore, health professionals need to be supported with protocols and guidelines that provide insight which type of stroke eRehabilitation works for whom [37;53]. Moreover, an overview of applicable eHealth interventions in stroke rehabilitation should be developed based on different resources, such as evidence, experiences of users and patient consumer organizations and professional organizations [37]. Therefore, the above mentioned SmartLab is linked with the National eHealth Living Lab (NeLL), an eHealth community (patients, consumers, professionals, scientists, students, organisations) aiming to create the best eHealth solutions by sharing knowledge, contacts and experiences with each other (<https://nell.eu>).

Furthermore, this thesis showed that applicable eHealth needs to be integrated into working routines. A major challenge is realizing an integrated digital infrastructure, with patients, caregivers and healthcare providers connected in a safe, dynamic and efficient system.

eHealth in health professionals' education

Future health professionals should be able to competently and confidently work with eHealth [54;55]. However, education in eHealth is currently underrepresented in the curricula of health professions' education (e.g. dietetics, nursing, occupational therapy, physiotherapy, psychology or social work) [56-59]. In this thesis a focus group study among teachers and bachelor physical and exercise therapy students was conducted to identify barriers and facilitators for the uptake of eHealth education in the curriculum. Better integration of eHealth in the curriculum was considered important by both students and teachers who participated in the focus groups and they demonstrated their willingness to use eHealth. Nevertheless, in line with other studies in the field, their understanding of eHealth was limited [60]. Moreover, they expressed a lack of skills for critically appraising eHealth and the absence of a clear rationale for teaching eHealth. To enhance implementation in the curriculum of health care education clinical reasoning' will be the driver of the toolkit eHealth that is currently developed, based on our findings and in collaboration between three Universities of Applied Sciences.

A facilitator for the uptake of eHealth education identified in the focus groups was the optimal use of communities of practices. As described previously, in a community of practice, a mixed group (teachers, students, researchers and/or the work field) shares a passion and constantly innovates, in this case eHealth, by interacting regularly in a process of action research with all stakeholders [61]. Participation in such a community of practice benefits both teachers and students in their teaching and learning about eHealth [62]. In addition,

literature suggests that real-life experimentation of eHealth innovations in a realistic context with active user involvement (LivingLabs) are stimulating learning environments [63]. Other identified facilitators, which can be used in strategies for implementation, are the shared sense of importance of eHealth education, passionate teachers, didactic materials, collaboration with ICT professionals, direct accessibility to materials (lab with technology and eHealth), (scheduled) time for teachers to prepare lessons, special interest groups of teachers taking the lead and a national benchmark for the quality of eHealth.

In general, it is advised that eHealth education should be integrated in basic courses so that future healthcare professionals are already familiar with it, but also in postgraduate education to facilitate current use in daily practice [37].

Conclusion

In this thesis conditions that can facilitate the effect and uptake of eRehabilitation were described, with emphasis on stroke patients. The use of eRehabilitation after stroke is promising, but adoption of eRehabilitation in stroke care falls behind and their evidence regarding its effectiveness is scanty. More research is needed using appropriate study designs for evaluation of the outcomes and processes of eHealth. Moreover, development should be done in co-creation based on user requirements in order to increase the uptake in stroke care. To minimize barriers with usage, both patients and health professionals, should be supported in using eHealth and eHealth (education) needs to be integrated in the curriculum of (allied) health professions of universities for applied sciences.

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