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TESTING AND VALIDATING “TAKING CHARGE AFTER STROKE“ SESSION IN ESTONIA

Master’s thesis

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SESSIOONI „*TAKING CHARGE AFTER STROKE*“ TESTIMINE JA VALIDEERIMINE EESTIS

Magistritöö

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MD, PhD

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Author’s declaration of originality

I hereby certify that I am the sole author of this thesis. All the used materials, references to the literature and the work of others have been referred to. This thesis has not been presented for examination anywhere else.

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Abstract

Background: stroke is common, sudden and devastating disease that causes neurological disability and in some cases death. In Estonia, there are more than 3500 strokes annually. Recent data supports that person-centred, self-management interventions can reduce dependence after stroke. Based on person-centredness program Taking Charge after Stroke was introduced in New Zealand. TaCAS is validated and stroke specific intervention with individuals interview sessions. *Aim:* the aim of this thesis is to test the feasibility of TaCAS and validate it in Estonia. *Methods:* a qualitative validation study was conducted, where TaCAS session was tested on Estonian stroke patients in acute treatment setting in West Tallinn Central Hospital stroke unit. The inclusion criteria were adult persons, who were in West Tallinn Central Hospital stroke unit with ischemic or haemorrhagic stroke, were able to give informed consent and were willing to participate. The exclusion criteria were inability to provide informed consent and being in the stroke unit intensive care unit. From the middle of January 2020 additional exclusion criteria was added – not being able to communicate in Estonian or English. After TaCAS session a short semi-structured interview was conducted to get patients feedback on TaCAS. *Results:* in total 39 patients were assessed for eligibility. 8 patients were unwilling to participate, 3 patients were unable to consent, and 9 patients were not able to communicate in Estonian or English. TaCAS interview was tested on 19 patients. Conclusion: TaCAS interview session is feasible in Estonia and in acute treatment setting. The mean time of conducting the session was 33 minutes. However, to make the session more comprehendible for acute stroke patients, suggestions are made. Moreover, the facilitator of TaCAS does not need medical education, but previous experience in working with stroke patients is beneficial.

The thesis is in English and is 73 pages long, consists of 6 chapters, 2 figures, 3 tables.

Annotatsioon

Sessiooni „*Taking Charge after Stroke*“ testimine ja valideerimine Eestis

Taust: insult on sagedasti esinev ja järsult algav haigus, mis põhjustab neuroloogilist puuet ja ka surma. Eestis haigestub insulti ühel aastal üle 3500 inimese. Värskeimad andmed kinnitavad, et sekkumised, mis lähtuvad patsiendikesksest ja enese juhtimise ideest võivad vähendada vajadust kõrvalisele abile. Patsiendikeskse lähenemise põhimõttel on Uus-Meremaal loodud programm *Taking Charge after Stroke* (TaCAS), mis on valideeritud ja insuldikeskne individuaalsete intervjuusessioonidega sekkumine. *Eesmärk:* töö eesmärk on testida TaCAS sessiooni teostatavust ning see valideerida Eestis. *Metoodika:* teostati kvalitatiivne valideerimisuuring, kus TaCAS’e sessiooni testiti Eesti insuldipatsientide peal akuutses ravietapis Lääne-Tallinna Keskhaigla insuldikeskuses. Uuringusse kaasamise kriteerium oli täiskasvanud inimene, kes oli Lääne-Tallinna Keskhaigla insuldikeskuses insuldi tõttu ja oli võimeline andma informeeritud nõusolekut. Uuringust kõrvalejätmise kriteerium oli patsiendi võimetus anda informeeritud nõusolekut ning viibimine insuldikeskuse intensiivravipalatis. 2020 aasta jaanuaris lisati uus kriteerium – suutmatus suhelda eesti või inglise keeles. Peale TaCAS’e sessiooni viidi ka läbi lühike poolstruktureeritud intervjuu, et saada patsiendi poolset tagasisidet. *Tulemused:* uuringusse kaasati 39 patsienti, kellest 8 ei soovinud uuringus osaleda, 3 ei olnud suutelised andma informeeritud nõusolekut ja 9 ei olnud võimelised suhtlema eesti või inglise keeles. TaCAS’e intervjuu viidi läbi 19 patsiendiga. *Järeldused:* TaCAS intervjuu on teostatav Eestis üldiselt ja ka akuutses ravietapis, kuid töös on antud soovitusi, kuidas teha TaCAS paremini teostatavaks akuutravis. TaCAS’e sessioon võttis keskmiselt aega 33 minutit. Intervjuu läbiviijal ei ole vaja meditsiinilist haridust, kuid eelnev töökogemus insuldipatsientidega on kasulik.

Lõputöö on kirjutatud inglise keeles ning sisaldab teksti 73 leheküljel, 6 peatükki, 2 joonist ja 3 tabelit.

List of abbreviations

ADL	Activities of daily living
CDSMP	Chronic Disease Self-Management Program
CI	Confidence interval
CSI	Carer Strain Index
ICD-10	The International Statistical Classification of Diseases and Related Health Problems 10th Revision
MCS	Mental Component Summary
NIHSS	The National Institutes of Health Stroke Scale
PCS	Physical Component Summary
RCT	Randomized controlled trial
SF-16	Short Form 36
SM	Self-management
SMI	Self-management intervention
TaCAS	The Taking Charge After Stroke
WHO	The World Health Organization

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1 Introduction

Stroke is one of the leading causes of death and disability worldwide. Stroke is sudden and acute event, but the consequences are long-term. Stroke can result in disabilities concerning person's motor, sensory, speech and cognitive functions [1], [2]. These functional disorders not only affect the persons everyday life and quality of their life, but are also a major burden on relatives and the healthcare and social care system [2]. In Estonia, there are more than 3500 strokes each year [3]. About 40% of stroke patients die within the first year. About 30% remain dependent on others for basic activities of daily living (ADL), but about half of the stroke patients recover fully or are mostly independent in ADL [3]-[5].

Nowadays, more and more emphasis is put on patient-centred approaches in medicine. In Estonia, the public health development plan 2020-2030 pays great attention to the personalized approach to healthcare, to the needs and expectations of patients and their families in maintaining, improving and managing health [6]. Moreover, patient-centredness is considered to be a very important part of stroke rehabilitation. Research has presented that stroke patients value the opportunity to direct their own recovery process [7].

Self-management interventions are designed to help the patient to take an active part in managing their health by teaching the patient problem solving skills, utilization of existing resources and goal setting [8]. In 2011 in New Zealand, stroke specific self-management intervention called Taking Charge after Stroke (TaCAS) was introduced. TaCAS is based on patient-centredness and self-directed rehabilitation idea and it demonstrated significant improvements in health-related quality of life and independence [9]–[11].

The thesis consists of six chapters. The first chapter introduces the topic of this thesis. The second chapter gives an overview about stroke in general, self-management and its interventions and introduces TaCAS. Chapter three describes the thesis' methodology and methods and chapter four presents the results. The fifth chapter discusses the results of the study and makes further suggestions in correlation with previous literature. The final chapter presents the conclusions of the study.

2 Background

2.1 Background of the disease

The World Health Organization (WHO) defines stroke as a “rapidly developing clinical 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].

2.1.1 Subtypes of stroke

Stroke occurs when the blood supply to the brain is disrupted. The pathological background of stroke can be ischemic or haemorrhagic [13].

In case of an ischemic stroke, the blood circulation is obstructed in the cerebral blood vessels by a blockage. The blockage can be caused for example by thrombosis or embolism that results in the lack of oxygen (ischemia) in all or part of the territory of the occluded vessel. Thrombotic stroke is due to blood clot or atherosclerotic obstruction that forms in the arteries of the brain. Embolic stroke is caused by a blood clot, air bubble, fat globules or atherosclerotic obstruction that is formed in other parts of the arterial system, for example in the heart valves, and travels through the arterial bloodstream to the brain [13], [14].

Furthermore, haemorrhagic stroke is caused by a non-traumatic rupture of a cerebral vessel which leads to bleeding into the brain tissue. Haemorrhagic stroke is divided into intracerebral haemorrhage and subarachnoid haemorrhage, based on the location of the bleeding. While cerebral infraction could have multiple other causes, they can be ignored for epidemiological purposes as they are relatively rare [13], [14].

2.1.2 Symptoms and neurological signs of stroke

The exact symptoms of stroke depend on the location and the extent of the brain tissue affected. The neurological symptoms can include acute onset of muscle paralysis or weakness and sensory deficit, numbness that usually affects only one side of the body. Furthermore, it includes problems with muscle coordination (ataxia) and balance, speech disturbance (aphasia, dysarthria), swallowing disturbance (dysphagia), cognitive impairment and memory loss. In addition to the neurological symptoms more general symptoms to the brain damage may occur, like headache, nausea, impaired consciousness and epileptic seizures that are mainly associated with haemorrhagic stroke [15]–[17].

2.1.3 Classification in ICD-10

In the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) stroke is classified under chapter IX, diseases of the circulatory system (I00-I99) in section cerebrovascular diseases (I60-I69), where strokes are categorised based on the pathology and the location in the brain. The code for ischemic stroke in ICD-10 is I63. The code for intracerebral haemorrhagic stroke is I61 and for subarachnoid haemorrhagic stroke I60 [18].

2.1.4 Epidemiology of stroke

Based on the epidemiological studies done in Estonia, the incidence of first ever stroke is 188 to 250 per 100 000 people. 74% of the stokes were ischemic [19], [20]. In 2016, 5659 primary diagnosed cerebrovascular diseases were diagnosed in Estonia (ICD-10 I60-I69) [21]. Based on Estonian Health Insurance Fund’s statistics, 3218 patients with ischemic stroke (I63.0-I63.9) and 411 with haemorrhagic stroke (I61.0-I61.9) were diagnosed in 2016. 30-day mortality in Estonia is relatively high – 708/3629 (20%) died after stroke during the first 30 days in 2016 [3] compared to the best practices in the world – that is 10% [22]. Moreover, during the first year, 0,8% of the ischemic stroke patients suffer from recurrent stroke [23].

2.1.5 The severity of stroke

About half of the stroke patients recover fully or are independent in ADL and 30% of stroke patients need more or less assistance in ADL. Furthermore, about 40% of patients die within the first year and 20% within first month after a stroke [3]–[5].

In case of acute ischemic stroke recanalization therapies like intravenous thrombolysis or thrombectomy are used to restore blood flow in the occluded vessel. Thrombolysis is a procedure where recanalization of the vessel is achieved with a thrombolytic medication, alteplase. Thrombolysis is generally performed only within 4,5 hours after stroke onset. Thrombectomy is a procedure where thrombus is removed mechanically within 6-12 hours after symptom onset. The recanalization procedures improve patient’s prognosis and reduce disability [24], [25].

To assess the initial severity of the impairments and patient's prognosis after stroke The National Institutes of Health Stroke Scale (NIHSS) is widely used. It is a well-validated scale where patient's ability to answer questions and perform different activities are measured with 11 components. The first assessment is performed when the patient is hospitalized in the acute stroke unit. It is repeated after recanalization procedure, 24 hours later and again when the patient is discharged from acute care. Disability measured by NIHSS is scored with 0 as normal and 42 as maximum. The NIHSS score at admission and specifically at discharge predicts hospital disposition. [26], [27].]The values are shown in Table 1.

Table 1. The predictions on hospital disposition based on NIHSS [27].

Score	Stroke severity
≤ 5	Are discharged home and to ambulatory rehabilitation
6-13	Need inpatient rehabilitation
≥ 14	Need long-term care

A bit simpler scale is The Modified Rankin Scale. This ordinal scale has 6 categories where zero means that the patient has no symptoms, five means severe disability and six marks that the patient is dead [28].

2.1.6 Risk factors of stroke

The risk factors of stroke are hypertension, atrial fibrillation, high blood cholesterol, tobacco use, unhealthy diet, high alcohol consumption, physical inactivity, diabetes and advancing age. For example, embolic stroke can be due to atrial fibrillation when the normal rhythm of the heart is disrupted and allows the formulation of clots in the heart. Moreover, spontaneous intracerebral haemorrhages are mainly related to chronic hypertension [13], [14].

Pathogenetically, stroke is never the primary disease itself, but rather a complication of more widespread vascular disease. Thus, it is important to assess and properly diagnose the risk factors of the stroke to reduce the risk of stroke reoccurring [29].

2.2 Self-management interventions

Taking into account epidemiologic data about stroke it is obvious that a high number of stroke survivors face more or less significant disability after stroke. In today’s world, due to the fact that more and more people are living with chronic diseases and long-term conditions, the health care systems throughout the world are facing the challenge of how to adjust and respond to the burden. For this reason, policy makers and researchers have suggested that health care systems should besides prevention also prioritize new ways of rehabilitation, so the patients could live as fully and independently as possible. To achieve that, improving patient’s self-management (SM) skills have been presented as one possible solution. However, in order to achieve this, it is important to ensure that the interventions during treatment pathways take into account the wishes and preferences patients including the stroke survivors [30], [31].

Furthermore, qualitative research has demonstrated that patients after stroke and with many other chronic conditions have very important role in directing their own recovery process [7]. The main idea is that the more the patients feel that they are “in charge” of the situation, the better is their quality of life [9]. However, it has been indicated that considering patient’s view and personal goals are problematic [32], [33]. Moreover, based on a study published in 2019 in the United Kingdom, poststroke patients pinpointed many unmet needs related to information and educational aspects on stroke, problems with support and access to rehabilitation. The authors believed that patient-led approach combined with stroke education and SM during the treatment pathway would be beneficial [34].

2.2.1 Self-management (SM) and self-management interventions (SMI)

The term self-management has been in use since 1960s when it was first used in the context of paediatric asthma program. At that point, SM indicated simply that the patient takes an active role in managing and treating their condition. However, no specific concept and definition of SM was given. For a long time, the term was used widely, but mostly in educational programs for chronic disease [8]. In 2004, the US Institute of Medicine proposed a definition: “SM means the tasks that individuals must undertake to live well with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management, and emotional management of their conditions.” [35] Another important aspect in the SM context is that decisions related to individual’s health are made together with the individual. Medical specialists ensure that the treatment process is based on the patient’s wishes as much as possible and thereby laying the foundation for the patient to practice SM skills [32].

In addition, after 25 years of experience in this field Lorig and Holman [8] came up with the concept that SM is based on five core skills: problem solving, decision making, resource utilisation, creating a partnership with health care provider and taking action. SMI is based on patient perceived problems, they need to define the problems and the patients are taught basic problem-solving skills. Therefore, patients are taught basic problem-solving skills. Next, it is necessary to find possible solutions, implement them and evaluate the results. Secondly, since a patient who has a chronic illness has to make decisions constantly depending on the change of their condition. It is important that the patient has enough and appropriate information about health, risk factors, symptoms and treatment to make informed decisions.

Furthermore, the third core skill is the ability to find and utilise resources but also support. Fourth skill is to create a partnership with the health care specialists in order to be an active party in making informed choices during the treatment rather than being a passive recipient of health care. The final core skill is to take charge in order to implement the solutions. Therefore, coping with the situation, making a short-term action plan and setting goals are an important part of SMI. An important mediator between acquiring these five SM core skills and establishing SM behaviours is self-efficacy (Figure 1.), which is simply put an individual’s belief in their own ability to carry out a specific task or behaviour [8], [36].

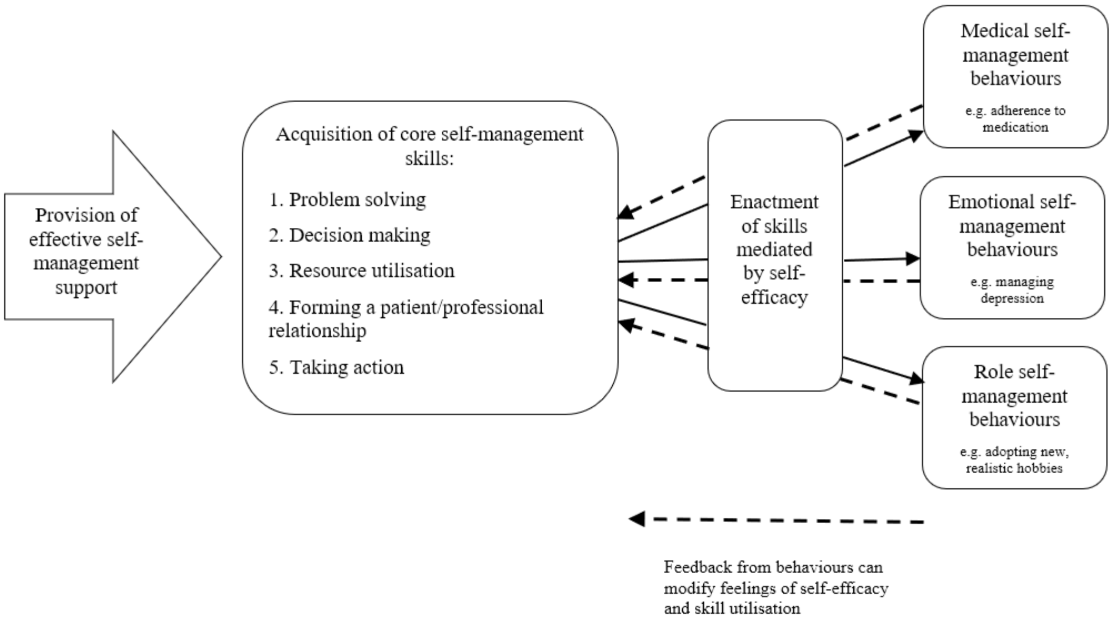

Figure 1. The process of adoption of self-management behaviours [36].

2.2.2 SMI methods post-stroke

SMI should concentrate on patient’s perceived needs and the ability to adapt to lifestyle changes due to disabilities in the context of stroke. It should also support goal setting and focus on the individual’s ability to manage their medical tasks, treatment and prevent complications. Lastly, it should help to manage psychosocial aspects after stroke [36], [37].

Methods of SMI could be very different. For example, the delivery of the intervention could be based on a group discussion, like Chronic Disease Self-Management Program (CDSMP) or individual session, for instance TaCAS or mixed [8], [9], [38]. Moreover, the programs could be generic or disease specific and could differ also in the context of by whom the intervention is conducted by - a medical specialist or a lay person [39].

In chronic diseases like diabetes, asthma and chronic obstructive pulmonary disease SMI have shown to be beneficial, for example by improving quality of life, self-efficacy and reducing health care utilisation [40]–[42]. In the context of stroke, SMI have been studied less than with other long-term conditions as for many years, stroke was not classified as a chronic disease and rather thought of as a one-off event [43]. Parke with colleagues [36] also pointed out that SM terminology is not used very often in the context of stroke.

However, new evidence is emerging that support SMI following stroke. Studies have presented positive patient outcomes, like improvement in health-related quality of life, improvement in mental health, reduced dependence and improved activities of daily life, reduced strain experienced by carers, improved occupational performance and satisfaction and positive effect on self-efficacy, like health-related self-efficacy and self-efficacy of communicating with physicians [9]–[11], [38], [44]–[46].

On the other hand, there is still no consensus on **what type of** SMI is most appropriate and optimal for patients following stroke as the wide range of different methods of delivery and different targeted outcomes make comparisons across studies difficult [17], [11], [39], [47], [48]. Jones and colleagues [43] pointed out that the capability and needs are very individual after stroke. Therefore, individual and stroke specific approach may be most suitable. Hirsche and colleagues [49] used a generic CDSMP in their study on patients with different neurological diseases. They pointed out that some stroke patients expressed that they would have appreciated more stroke specific information. Despite this, patients were quite satisfied with the program. Additionally, the authors also mentioned that in the context of stroke, it could be difficult to conduct group session as participants may be with a limited attention span and in a wide range of ages.

2.2.3 When to implement SMI after stroke

Furthermore, there are still questions about **when** in the treatment pathway, in acute, subacute, rehabilitation, nursing home or home, the interventions should be introduced [43], [48]. Mäkelä with fellow researchers [50] and Messina with colleagues [38] mentioned in their study that to their knowledge, there are hardly any studies made on SMI and acute or early post-acute treatment phase. Almost all studies completed on stroke SM have started with the intervention at home. [17], [47], [51]. However, Jones with colleagues [52] emphasised the importance of starting from the beginning of stroke pathway to prioritise each patient's preferences, needs and personal aims in order to assure that these are addressed in the following treatment plans.

As stroke patients are very different, there is a question of whether one intervention is suitable for everyone. Also, in addition, some stroke patients might be unable to take on responsibility for their rehabilitation process immediately after stroke or not at all, due to issues with cognition and/or communication. Moreover, stroke is sudden and adjusting to the new situation may take longer time [43], [48]. Regardless of the limitations SM has been mentioned in national guidelines of stroke in the UK, USA and Canada as a method that should be implemented during the treatment pathway [53]–[55].

2.3 Taking Charge After Stroke

2.3.1 TaCAS session

Based on a self-determination theory, patient centred approach and self-directed rehabilitation idea TaCAS was created in 2011 in New Zealand. According to the authors experience most of the patients in New Zealand and in the UK did not pursue SM strategies after stroke. They created a new SMI method - designed to promote self-directed rehabilitation specifically for stoke patients. The new method was based on the earlier theoretical work and comprehensive qualitative work with stroke patients [9].

TaCAS session is around a 40-minute-long interview that involves conducting a thorough analysis of the stroke patient’s own expectations, fears, future plans, aims, risk factors after the stroke without forcing upon the opinions of the medical professionals. The session itself consists of two main parts that is preceded by baseline assessments, like Modified Rankin score, Barthel index, risk factors etc. The session is constructed in a way that the patient and their family can identify the problems and personally set goals for solutions (i.e. self-directed rehabilitation) [9], [11]. The main aim is to succeed the participant to take the responsibility for their own recovery and use the resources that they already have or in some cases to try to develop the resources [56]. More precise description of the session is given in chapter in Appendix 1 – TaCAS session description.

2.3.2 Previous studies made on TaCAS

In 2011, the first randomized controlled trial was published where TaCAS was tested on community level. The participants where Maori and Pacific New Zealanders as previous studies had presented worse outcomes after stroke for them when compared to New Zealand Europeans. The study included participants that were over 15 years old, had a stroke, were form Maori or Pacific New Zealanders ethnicity and their discharge to the community was realistic. No other exclusions were made. The participants were recruited **between 6 to 12 weeks after stroke** [9].

172 participants were randomized into four groups. The first group was demonstrated an 80-minute professionally produced DVD where 4 stroke patients and their families talked about their recovery, highlighting potential positive outcomes and encouraging people to contribute actively to the recovery. The second group received TaCAS session delivered by a trained facilitator. The facilitator had at least 5 days of training before the study. Furthermore, ongoing training was received throughout the interviewing process. The third group received both DVD and TaCAS session, and the fourth group (control group) received written stroke educational materials. All patients received treatment and rehabilitation based on a standard practice [9].

The primary outcome was self-rated health-related quality of life after 12 months. Health-related quality of life was measured with Physical (PCS) and Mental Component Summary Score (MCS) of the Short Form 36 (SF-36). SF-36 with scores over 50 show better than average and lower than 50 poorer than average quality of life. Secondary outcome measures were Frenchay Activities Index, Carer Strain Index (CSI), Barthel Index and modified Rankin score. All the outcomes were assessed after 12 months. TaCAS session showed effect on PCS of 6.0 with 95% confidence interval (CI) 2.0 to 10.0, the DVD intervention showed 0.9 with 95% CI of -3.1 to 4.9. Also, TaCAS group had a better CSI score. Therefore, TaCAS intervention provided after stroke showed clinically significant improvements on health-related quality of life and reduced dependence and strain on carers [9]. The detailed results of TaCAS 2012 RCT are shown in Appendix 2 - Main and secondary results after 12 months in TaCAS study 2012.

Results of a new randomized controlled trial were presented in 2019. In this study, 400 patients **within 16 weeks** of acute stroke were recruited. The exclusion criteria were inability to give informed consent and patients who were unlikely to survive beyond 12 months. Also, Maori and Pacific stroke patients were excluded. The participants were divided into three groups: the first group had one TaCAS session, the second group had two TaCAS sessions 6 weeks apart and the third was a control group. The sessions were conducted by trained facilitators who were either a nurse, physiotherapist or occupational therapist. All patients received treatment and rehabilitation based on a standard practice that was not influenced by the study [10], [11].

The primary outcome was self-rated health-related quality of life measured with the PCS score at 12 months after stroke comparing both TaCAS intervention groups to control group. The results of the study demonstrated that at 12 months following stroke, patients in both intervention groups had significantly higher health-related quality of life. They had 2.9 points better PCS score than control and the difference stayed statistically significant when adjusted for pre-specified baseline variables. There was also a dose effect for each extra Take Charge session received, the PCS score increased by 1.9 points per session [10], [11].

3 Methodology and methods

3.1 Aim of the study

The aim of this master’s thesis is to test the feasibility of TaCAS and validate it in Estonia. To achieve the aim, three research objectives are established:

- Analyse the feasibility of TaCAS interview in Estonia.
- Adjust the TaCAS method for Estonian stroke patients in acute treatment setting.
- Evaluate what kind of competency or training the interviewer needs to ensure the proper use of TaCAS.

The following research questions will be answered:

- Can TaCAS interview be used in Estonia?
- Is TaCAS feasible in acute care?
- What is the response from stroke patients in Estonia to TaCAS interview?
- What factors determine the optimal time for conducting TaCAS?
- What kind of competency or training does the facilitator of TaCAS need?

The hypotheses are:

- TaCAS interview is usable in Estonia and the results can be used as a basis for planning further treatment pathways for stroke patients.
- Introduction of TaCAS in the acute care enables early involvement of stroke patients in their care
- TaCAS may be conducted by a facilitator who has competence necessary to interact with stroke patients through basic training, without the need for medical education.

3.2 Overview of the study design

This is a qualitative validation study of Taking Charge after Stroke interview session in stroke acute care.

3.2.1 TaCAS translation

The translation process of the TaCAS booklet to Estonian and Russian and the manual to Estonian was instituted from the original version of the booklet and manual in English. The translation was done by Wiedemann Translations by licenced translators. The translation was based on forward- and back-translation method. Overview of TaCAS translation process is shown in Appendix 3 – TaCAS translation process. TaCAS authors approved the use of TaCAS in Estonia. The approval is shown in Appendix 4 – Approval from TaCAS authors.

3.2.2 Recruitment and participants

The study took place in West Tallinn Central Hospital stroke unit. Recruitment began in December 2019 and ended in May 2020. All patients with stroke diagnosis both ischemic (I63) and haemorrhagic (I60-I61) in the stroke unit who were not in an intensive care unit were assessed for eligibility. Before recruiting the participant, the facilitator got information about the patient's name and room number from the stroke unit's nursing manager. Then, the stroke unit's medical nurse introduced the facilitator to the patient. After that, the facilitator presented the subject, purpose and relevance of the study, facilitator's information and information that the study is voluntary and will not affect the patient's treatment. Patients could ask for additional questions about the study. If the facilitator determined that the patient was able to give informed consent and the patient agreed to participate consent form was handed out for the patient to read through and sign. If the patient was not able to read it by themselves, the facilitator read it out loud.

The participants were not selected. All participants were recruited from the stroke unit during random working days, mostly Mondays and Wednesdays. The recruitment was done by the thesis author from December 2019 to March 2020 and continued by stroke unit's social worker in April 2020 as the hospital was in quarantine due to coronavirus pandemic.

The inclusion criteria were adult persons, who were in West Tallinn Central Hospital stroke unit with ischemic (I63) or haemorrhagic (I60-I61) stroke, were able to give informed consent and willing to participate. The exclusion criteria were inability to provide informed consent and being in the stroke unit intensive care room. From January 22nd 2020 additional exclusion criteria of not being able to communicate in Estonian or English was added. The ability to understand the study and therefore to give an informed consent was determined by the facilitator. All the participants received standard care.

3.2.3 Training before interviewing

Both TaCAS session facilitators, the thesis author and the social worker, had an independent training based on the TaCAS manual [56] before conducting the sessions. Furthermore, every page of the booklet was completed by the facilitators to get an experience of what it is like to be a participant. Also, a rehearsal session was done. Before the social worker started with recruitment a discussion via telephone was done with the thesis author to resolve any issues that might occur. Furthermore, the author had a one-hour long training with neurologist on the topic of stroke, problems patients following stroke might have and about speech and cognitive disorders. The author of the thesis has a physiotherapist education. Both the author and the stroke unit's social worker have had a previous work experience with stroke patients in an acute treatment. Taking this into consideration thorough training about stroke was not needed.

3.3 Data collection

3.3.1 Data collection: TaCAS interview session procedure

TaCAS interview session was conducted by the thesis author or stroke unit's social worker. During 3 sessions a research assistant was also present. With patients from the stroke unit who met the inclusion criteria and agreed to participate in the study the TaCAS interview session was conducted. To adjust the method for Estonian acute treatment extensive baseline assessment was not conducted. Instead, medical data collected through standard care was used. The main emphasis was put on the interview session itself.

The session was conducted based on the manual and TaCAS booklet was used in every session. TaCAS booklet is presented in Appendix 5 - TaCAS booklet. The session was carried out in the stroke unit in a private room, if possible. If due to the health reasons the participant was not able to sit in a chair or in a wheelchair, the session was performed in the patient’s room, visually separated with curtains. The facilitator assisted with writing in the booklet if the participant was unable to write.

During the session, participant’s ability to collaborate, the degree of information gathered from the interview and the time spent for the session was evaluated. If the facilitator noticed that the patient is getting tired or the ability to collaborate declined, the facilitator asked the participant if they wanted to end the session. The facilitator informed the participant that if they feel they want to skip some section or return to a previous section later then it is entirely appropriate. Also, if the participant was not able to suggest any answer, the page could be left empty.

Qualitative data collected through conducting TaCAS interview session was documented in the booklet used during the session and in a free-form study diary during and immediately after the session, where the facilitator documented her thoughts and observations on feasibility and time spent on conducting TaCAS. Furthermore, suggestions on what kind of competency or training the interviewer needs to ensure the proper use of TaCAS was documented. Audio-recordings of the interviews were not used as ethics committee approval was only obtained for written documenting.

3.3.2 Data collection: semi-structured interview procedure

After the TaCAS session, opinion of the participants and response to the session were collected in the form of semi-structured qualitative interviews by the thesis author or the social worker. The interview consisted of 10 questions which are presented below in Table 2. Interview questions conducted after TaCAS. Answers to short semi-structured interview were documented in the study diary during the interview with keywords.

Table 2. Interview questions conducted after TaCAS.

- Please describe what your overall impression of TaCAS interview session was?
- Were the questions clear and understandable?
- Were there any important questions that were missing?
- Could you please describe whether the interview session reflected your wishes and needs?
- What was the best, most important part of the interview session?
- What was the worst, meaningless part of the interview session?
- What would you think of your rehabilitation plan being based on this interview session?
- How could this interview session be improved?
- If and what kind of additional information would you need to make answering to TaCAS questions easier?
- How much effort did it take to answer the questions?

3.3.3 Time spent for the interview procedure

Using documented information from 10 TaCAS interviews the estimated time spent for the total procedure and different parts of the procedure are shown in Table 3. Time spent for the interview procedure.

Table 3. Time spent for the interview procedure.

Part of procedure	Time range	Mean time
Whole procedure	36 to 81 min	56 min
Introduction & consent	7 to 25 min	12 min
TaCAS session	**20 to 45 min**	**33 min**
Interview after TaCAS session	8 to 15 min	11 min

3.3.4 Data collection: data from hospital medical record

Additionally, subsequent data from the participant’s medical record was gathered by the head of the Neurology clinic: socio-demographic characteristics, like age, sex, language, place of residence. As well as, clinical data, like stroke type, hospitalisation date, NIHSS score and if available then assessment of cognitive condition by psychologist and assessment of speech by speech therapist. Also, data of participant’s further referral (home, rehabilitation, nursing care) was collected.

3.4 Data analysis

3.4.1 Data analysis from TaCAS interview and semi-structured interview

To analyse the TaCAS interview and semi-structured interview conducted after TaCAS, thematic analysis were used by the author of the thesis. Analyzing process was based on 6 phases that were introduced by Braun and Clark [57]. More detailed overview of thematic analysis used is presented in Appendix 6 – Thematic analysis. In the analysis of TaCAS interview session and the short semi-structured interview conducted after TaCAS, the main themes, similarities and differences were brought out together with quotes from the participants.

3.4.2 Data analysis: quantitative data from medical record

Socio-demographic and clinical characteristics of the participants were presented using mean and range of the characteristics were possible. When data was not numeric, listing of data was used to summarise it.

3.5 Ethical considerations

Ethics approval for this study was obtained prior to recruitment by the Research Ethics Committee of National Institute of Health Development in 28th November 2019, (approval number 127). All participants were provided with verbal and written information about the aims and procedures of the study. The study was voluntary. In order to participate, all the participants had to also sign an informed consent form that is shown in Appendix 7 – Informed consent form. No one consented on behalf of participants. All patients who participated in the study received standard care.

The author of the thesis did not get access to the medical records due to ethical and data protection reasons. All the data and documents collected during the research was pseudonymised – the participant was assigned a unique code so they could not be identified. The key to the code was located in a locker at Clinical Trial room at West-

Tallinn Central Hospital, where only the head of the Neurology clinic and thesis author had access to.

4 Results

39 patients were assessed for eligibility, 8 patients were unwilling to participate, 3 patients were unable to consent, and 9 patients were not able to communicate in Estonian or English. TaCAS session was tested on 19 participants. 11 sessions were conducted by the thesis author, 8 by stroke unit social worker.

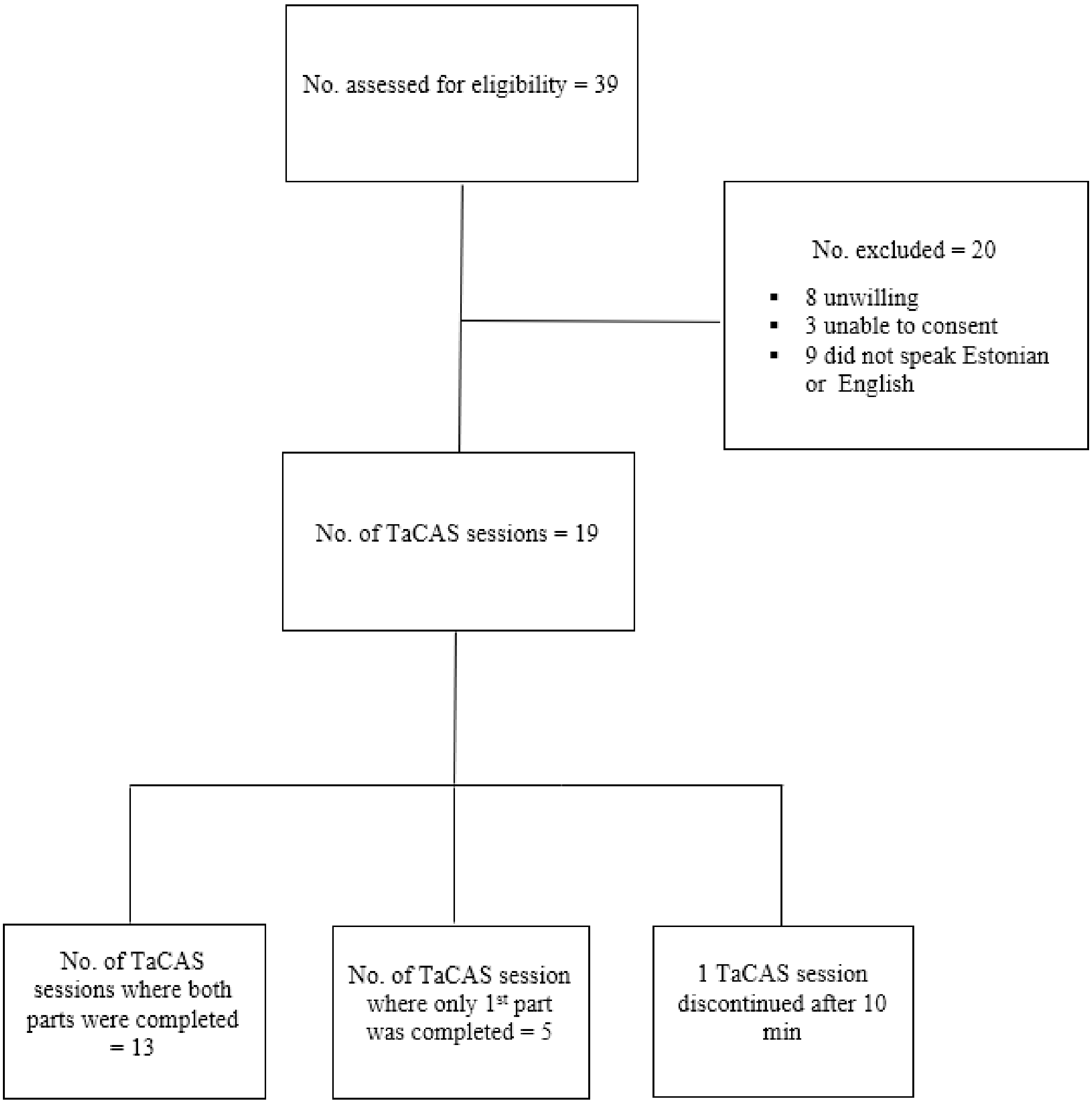

Figure 2. Study flowchart.

4.1 Baseline characteristics

4.1.1 Socio-demographic characteristics

TaCAS session was tested on 19 participants, eleven (58%) females and eight (42%) males. The participants' range of age was from 46 to 91 years, the average age of the participants was 74 years. Seventeen participants were over 65 years, two were under 50 years. 13 participants were from Tallinn, where six participants where from North-Tallinn district, two participants form Kristiine district, three from Haabersti district, one from Nõmme district and one from Mustamäe district. Four participants were from Harju county and lastly, one from Hiiumaa and one from Lääne-Virumaa county. Furthermore, 17 participants spoke in Estonian, two spoke in Russian (two Russian speaking participants were recruited before January 22nd 2020 when change in exclusion criteria was made). The socio-demographic characteristics are shown in table form in Appendix 8.1 – Participants socio-demographic characteristics.

4.1.2 Clinical characteristics

Moreover, the most common type of stroke was ischemic, with 17 of the participants. Two of the participants had haemorrhagic stroke. Eight participants had received thrombolysis. Participants' severity of stroke was mild to moderate with NIHSS ranging from 1 to 9 points. The mean NIHSS of the participants was 4 points. Three participants had records of a mild dysarthria, one had additionally severe aphasia and one mild aphasia. One participant had a mild cognitive disability. For one participant no data of cognitive condition and speech disabilities. The participants clinical characteristics are shown in table form in Appendix 8.2 – Participants clinical characteristics.

4.1.3 Timing of TaCAS session

The timing of TaCAS session after hospitalisation ranged from 1 day to 7 days, the mean number of days after hospitalisation was 3 days. Those participants' timing of the session whose facilitator was the thesis author was higher, the mean was 4 days. Those participants' timing of the session whose facilitator was the social worker was smaller, the mean was 2 days.

4.2 Main results

4.2.1 Findings from conducting TaCAS session

TaCAS session was tested on 19 participants. 13 participants were able to participate fully in the session. With 5 participants only the first part was conducted. With one participant, the session was discontinued after 10 minutes as the investigator noticed that the patient was getting tired and the ability to collaborate declined.

The following section presents findings that emerged from conducting TaCAS session. The first section of TaCAS session begun with participants talking how they feel and what has been affected due to stroke. Many pointed out feeling weak, dizzy or not feeling well and even feeling sick. Some participants said they feel tired and both physically and emotionally unstable. Moreover, difficulty of walking and having problems with balance was pointed out many times. Furthermore, having problems with hand and fingers, like holding something and having issues with writing was also mentioned. In addition, having trouble expressing oneself and having difficulty to concentrate was also noted in some cases. One participant emphasised the impact stroke had on her life: "*I can't do handicraft anymore and it is difficult to talk. We had to cancel bigger travel plans. I can't ski or ride a bicycle with my husband anymore. I have poor balance, so I need help."*

Furthermore, in the "Who I really am?" circle on the right of the page 2, the participants answered very differently. Some answered with many words from different aspects, like *"Grandmother, great-grandmother, gardener, happy, energetic, warm, lovely and gentle, I jump from one activity to another. I am in a hurry all the time*". Others used only one or two words to describe themselves, for example: *"Friend".* However, the most used words were related with family, for example grandmother or mother. Two participants chose to skip this part.

Moving to TaCAS booklet page 3, where the participant wrote down their overall wishes and goals, common theme was hope of being independent. Many participants wished they could manage living without needing assistance from others. Some participants said they want to be the same person as they were before and to continue with the same activities they did before stroke. Like having a social life, going to theatre or small things, for instance going to the balcony every day for a one hour. *"I want to be healthy, so I could continue with going to different societies, and have a social life."*

What is more, one wish that was mentioned many times was related to health not getting any worse and wanting to recover.

In addition, the fears part on the booklet page 3 showed that most of participants have fears related to managing their situation, health and future. One participant emphasised, *"I have lots of questions in my head. Like how am I going to manage? How am I going to move on from this point? Why am I like that, that I try so hard to think why this happened to me? I am usually an optimist, I know I can do it, but I'm afraid of the future a bit."*

Many participants mentioned fear of not being able to manage on their own with their everyday life and being a burden for others. One participant expressed her fear of being the one that needs help now as it's unusual for her. "*I'm afraid of being the one who needs help. It is scary for me to admit that I might need help, because I have been the helper my whole life. The roles are now changing, and I don't like it. .... I'm afraid of going to the nursing home, and I don't want to go there."* Fear that health could worsen was also mentioned a couple of times. Additionally, few participants said that at the moment they are not afraid of anything. Some participants chose to leave this question unanswered as they could not think of anything at that moment.

The next page concentrated on participant's best day. As expected, answers were very different, but similarity was that most of the participants would like to continue with their life as it was before. Another similarity was that most of the participants would enjoy their day with their family or friends. One participant described *"The best day would be exactly like my day was before being admitted to the hospital. In the morning, I would wake up with my husband and make the bed together. I would drink a good cup of coffee that my son-in-law has prepared, read newsletter, and spend one hour in the balcony. Then I would eat lunch, watch "The Bold and the Beautiful" from the TV and at 9 o'clock would watch the news and then go to bed."*

On that note, some participants would have spent their best day alone, to focus more on themselves. *"I would be calmly on my own, go to the water pool to train and focus on myself".* For one participant the perfect day would involve moving up and down the stairs without any problem. She said, "*… we would walk around the city and if I arrive home I could walk easily up and down the stairs.*" This part of the session anticipated participants to draw their best day. However, most of the participants did not want to draw. They preferred describing it.

The second section of TaCAS concentrated on goal setting and finding ways on how to accomplish them. This section was divided into seven topics: physical things, communication, emotional issues, information needs, financial issues, supportive network and secondary prevention. The TaCAS manual suggests for the participant to choose one topic. If the participant wishes, then it is possible to continue with the topic preferred next. Some participants selected 3 topics, some chose 2 and some 1. The most answered topics were physical things and secondary prevention. Information needs, communication and supportive network was also chosen a few times. Emotional and financial issues were not chosen by any of the participants. For five participants the second section was a bit difficult to comprehend at that moment. After introducing the goal setting and gathering thoughts on the selected topic, the participant and facilitator together decided to end the session. What seemed to be the most common theme in the goal setting part was its complexity to participants.

The most popular subject was physical things. One participant set a goal *“I want to be independent in my everyday life”.* For more specific objectives she stated firstly, to be independent by the end of January 2020. Secondly, to be able to carry firewood inside to heat up the fireplace by the end of January 2020 and lastly, also by the end of January 2020 to be able to shovel snow and start knitting. Regarding ways on how to achieve the goals, the participant proposed three ideas. To start with, believing in myself and really wanting to get better. Next, *“I think to adjust to the situation, like to carry smaller amounts of firewood inside at one time, if I don’t have the strength to carry the full basket”*. Lastly, she proposed to do the exercises that the physiotherapist has advised.

On the subject of secondary prevention, which was second most popular topic, one participant set a goal to control her blood pressure, be more physically active and control nutrition better. More specific objectives were to take medicine as prescribed by the doctor to control blood pressure, to continue with exercises to be more active and to eat more plant-based food, but no specific time frame was put to the aims. When talking about ways on how to achieve those goals, the participant was a bit clueless and sad as she had already done most of those things, but still had a stroke. *“I have tried to do all those things, but I still had a stroke. ... Maybe I could try to think more about what I* *buy from the grocery store and buy more vegetables and fruits".* Another participant stated that her problems concerning risk factors are her blood pressure, nutrition and physical activity. She said she should control her blood pressure and have a diary, to eat more liquid foods and to continue going to a group training as she did before.

4.2.2 Participants response to TaCAS session

With 10 participants short semi-structured interview was conducted after TaCAS session. To start with, participants overall impression of the session was positive. *"The impression is positive. It is nice that someone cares what I think."* Many participants emphasised that it was beneficial to talk with somebody in a calm setting, gather their thoughts about their situation and express their point of view in context of expectations, hopes and aims. *"It is a very good initiative. It was helpful to discuss my situation in a calm setting."* Furthermore, all participants agreed that questions in TaCAS booklet were clear and easy to understand, no confusion was mentioned. More than half of the participants stated that in their opinion the session gave a good overview of their wishes and needs and could be a base for patient's rehabilitation plan. Three participants could not take a stand on that matter.

When it was asked, what the best and most important part of the interview session was, there were multiple answers. Many participants emphasized the best day visualization on page 4. *"It's a question that I didn't expect. Nobody has never asked me something like that. But I think it makes you see, that right now all you want is to return to your daily life. At least that's what I feel."* Some participants felt the most important part was when the overall hopes and aims were asked on page 3. Some participants pointed out physical aspects in the goal setting section. One mentioned three following topics in the goal setting section: emotional issues, support network and most importantly information needs. Three participants did not nominate a specific component. The question of the worst and meaningless part of the session was quite in unison. Most participants did not take a stand and did not give an answer, however some participants said that the goal setting part was a bit difficult to comprehend. *"I wouldn't say that it's the worst or meaningless part, but for me, it needed a lot of effort."*

In addition, some participants had a suggestion on how to improve the session. First, suggestion was that the first section could be made more specific, but clear examples were not given. Secondly, question about patient's point of view on what could be improved in the health care facility should be included, so the feedback from patients would be available.

Moreover, half of the participants felt that they needed some additional information to make answering easier. The most needed information was about further possibilities of recovery, treatment and rehabilitation options. *"I would like to know what happens next? What are my options?"* Some participants also described their confusion about rehabilitation, they wanted to know what patients do there. Some participants felt they needed information about stroke itself and how the risk factors affect it. Few participants found it difficult to answer. Two participants did not need any additional information. On the topic of additional burdens on the participants, some of the participants felt that the session did not require much effort from them, some of the participants answered that it needed a bit of effort. However, many participants felt that in order to answer and actively participate quite a lot of effort was needed.

4.2.3 Participants wishes on the treatment pathway and their further referral

Based on the information gathered during the interview session, it was possible to identify participants preferences on the treatment pathway. 12 participants wished to continue treatment in inpatient rehabilitation facility. Seven participants wanted to return home, three of those would have preferred ambulatory rehabilitation or home-based rehabilitation. From the stroke unit, 11 participants were referred to inpatient rehabilitation, two to nursing care facility and three to home, one of whom was referred to ambulatory rehabilitation.

For five patients, their treatment pathway was not in accordance with their wishes. One participant wished to go home as she lived with her family and had a supportive system but was referred to a nursing care facility. Another participant preferred home together with ambulatory or home-based rehabilitation but was directed to inpatient rehabilitation. Moreover, one participant was referred to inpatient rehabilitation although he wished to go home. One participant was sent home, but they would have preferred inpatient rehabilitation. Lastly, one participant expressed wishes to continue treatment in rehabilitation but was referred to nursing care.

5 Discussion

Stroke is a common and serious disease with frequently long-term consequences. In order to reduce the burden for healthcare system and achieve better quality of life for stroke patients implementation of SMI have been suggested [30], [31]. TaCAS is a stroke specific method and has several advantages over other tested methods.

TaCAS as an SMI method emphasises the importance on listening patient’s needs, wishes and implementing these into stroke pathway by self-directed rehabilitation [11]. TaCAS intervention showed significantly improved the results of patient’s quality of life implemented in subacute treatment phase [9]–[11]. However, it is considered important to start early with SM in order to plan the treatment journey based on patient’s preferences [50], [52].

5.1 TaCAS interview session as a method

TaCAS was chosen as a method because literature overview showed no better alternative. TaCAS is validated - it showed clinically significant improvement in health-related quality of life in subacute treatment phase [9]–[11]. It is free to use, stroke specific, person-centred and less time-consuming than alternatives [9]. Jones with colleagues [43] pointed out that considering stroke patient’s different needs, individual session could be the most appropriate approach since attention span could be limited and in a group session the range of ages can be wide. Also, as TaCAS is designed for stroke patients, it reflects topics and information that are specific to stroke. This was a problem that was indicated by stroke patients participating in a generic SM program study [49].

TaCAS is feasible in Estonia. From 19 conducted sessions, 13 participants were able to complete in both sections of the session, 5 participants completed only the first section of the session. With one participant, the session was discontinued after 10 minutes as the investigator noticed that the patient was getting tired and the ability to collaborate declined. The mean time of conducting TaCAS session was 33 minutes. It is important from practical point of view that the time spent on extra services, like TaCAS, should be in the time frame feasible for stroke management practice.

According to our experience, the most practical section of the session proved to be the patient’s best day (booklet p 4). In this part of the session all participants had to describe what their best day is like. This discussion revealed participants´ wishes with honest analysis of their situation. The general impression of this section indicated that most of the patients just wanted to continue with activities similar to what they did before. This part also helped the patient to think about what makes them themselves. What seems important to point out is that no participant described their best day at nursing care facility.

What seemed the most difficult part of TaCAS session, both for the facilitator and the participant, was the goal setting section. Likewise, the same feedback was gathered during TaCAS RCT in 2019, where the facilitators mentioned that the goal setting was the most difficult section. It was a new approach for most of the participants and it took a lot of time and explanation [11]. The thesis author noticed, the participants had trouble understanding what they could do for themselves to support the achievement of their goal or in what direction they should start working. Most of the participants were able to set a general goal, for example being independent in everyday life or trying to prevent recurrent stroke by managing the risk factors.

However, thinking of a more specific goal appeared to be challenging for some, for example, what kind of risk factors participants need to manage and in what activities they want to be independent: for instance, walking to the shop or getting dressed independently. What appeared to be even more difficult was setting the timeframe. Some participants mentioned that they do not know when it would be realistic to achieve the goal and quite a few participants answered that they want to achieve something right now not knowing if it is rational. Moreover, it occurred that some participants did not have background knowledge before the interview session about what stroke exactly is and what the risk factors are. In that case, the goal setting was confusing.

On the other hand, as Fu [58] acknowledges in her interview in 2019 in European Stroke Organisation Conference that even if the participant could not come up with a goal or a solution and wanted to leave the page blank, they were perfectly satisfied with that, as the aim of this section is to give the person the permission, possibility and power to think and analyse things.

5.1.1 Time spent for conducting TaCAS

The mean time of conducting TaCAS session in this study was 33 minutes. In TaCAS study in 2019 [11] the mean time of the session was estimated 38 minutes. Although the difference is small the thesis author supposes it could be due to the differences in study designs (acute vs subacute) as patients in subacute setting could have more context to analyse and assess.

Moreover, in this study there was a considerable difference in time spent for conducting the sessions. The duration ranged from 20 to 45 minutes. The differences could have been due to multiple reasons. To start with, the severity of stroke and caused disabilities varied remarkably, meaning that if the participant had for example aphasia or dysarthria and communicating was difficult, then time needed for analysing, finding right words and discussing was also longer. Furthermore, what could have also influenced the duration of the session was how tired the participant felt and how long their attention span was. Another reason could simply have been how good connection was achieved with the participant, how comfortable they felt in the situation, how much they wanted to open up and talk about personal things. Additionally, participant’s nature could have an effect as some people are more talkative and some are more reserved. The thesis author noticed that if the participant was waiting for their family member to come and visit them, as the interviews took place during visiting hours, they were more in a hurry to complete the session.

5.1.2 Testing TaCAS in acute treatment phase

Fu explained in her doctoral thesis [11] that they chose a home-based setting for the sessions in RCT in 2019 because they felt it was important to give people time after stroke so they could get used to the new situation and experience their own challenges in their daily life. Due to that reason, they did not consider TaCAS suitable for a hospital setting. In their study, the time of the first session varied from 4 days to 18 weeks post stroke.

The acute phase is considered the most intense period for the stroke patient. It may even be chaotic with all the medical care, therapeutic interventions and more importantly the personal challenges [1]. But on the other hand, it is necessary to give the power to the stroke patient from the very start. Jones with colleagues [43] emphasized that if key elements of SM are not introduced in the acute treatment then both the stroke patient and medical specialist could have become used to more of a specialist-patient relationship. Therefore, it is important to ask about patients hopes and wishes in the beginning of the treatment, so when the patient's pathway is planned, patient's viewpoint can be taken into account. As a result, patient is not just a passive treatment receiver, put rather plays an active part by directing their treatment pathway. This aspect has been considered important by stroke patients and also by SM specialists [7], [52].

Some difficulties for participants were related to the novelty of the situation. The mean time when the interviews were conducted was three days poststroke and even less for interviews conducted by social worker. Still, 13 participants of 19 were able to participate fully in the session during such an early stage in the treatment pathway. Although, with 6 patients the complete session was not completed the first part of the session gave a good overview of patient's expectations. The fact is even more remarkable as in this study, we had unselected population. In both of the TaCAS RCTs [9], [11] the study population was preselected. In the study made in 2012, only those patients were included whose discharge into community was realistic. In the 2019 study, patients who were unlikely to survive beyond 12 months were excluded.

The second facilitator, stroke unit social worker pointed out that participants who had been only one day in the hospital seemed to struggle more with the session. The same problem emerged with some of the thesis authors' sessions, but on the other hand there were also some sessions that were quite successful even on the first day after hospitalization. Taking all that under consideration, it seems that as patients are very different, early involvement of patients is important but individual specificity should be taken into account.

5.1.3 Participant's response and feedback on TaCAS session

The overall feedback to the session was positive. Many participants mentioned after the TaCAS interview that they felt the session was a good way to think things over. The session made them analyse the situation and think what they can do themselves. Some also pointed out that after the interview they could pinpoint their problematic aspects more clearly, for example needing more information on rehabilitation. The common theme was that participants enjoyed the visualization task about their best day, while the most difficult part was goal setting. Based on participant's feedback and the authors experience of delivering the session, further implementation suggestions are made in chapter 5.2.

5.1.4 Participants wishes on the treatment pathway and their further referral

By comparing information gathered during the interview sessions on participants' preferences on the treatment journey and where they were referred to from the stroke unit, it appeared that for five participants there was a conflict between their wishes and reality. Previous qualitative research has presented many reasons why patient-centredness could be difficult to apply. The reasons could be lack of time to listen to patient's aims and wishes, bed shortage in healthcare facility or putting patient safety first [33], [59]. The aim of the study was not to analyse the reasons for the described discrepancies between the hopes and reality for further referrals after stroke unit. However, even with a small number of participants it seems to be characteristic of the current situation today.

In her doctoral thesis Fu [11] also recognises problems with needs and hopes of participants and reality: "The Take Charge session cannot fix all of these problems. … It is not a quick fix that can force a clinician to suddenly become more interested in a patient's needs. However, what the TaCAS study has done is produce a signal. That when we practise with empathy, when we allow the environment to support autonomy … and when we provide a person with the tools to Take Charge of their own recovery, their quality of life improves."

5.1.5 Competency of and training for the TaCAS session facilitator

Harwood with colleagues [9] stated that the content of TaCAS session could be found similar to a stroke liaison worker's or a stroke coordinator's work. They emphasized that the major difference is that the session's facilitator is trained not to ask guiding questions, but rather listen and let the participant review opportunities to take charge. This means that, during TaCAS interview, the participant should be in the centre of the session, where the facilitator assists with reflecting participant's own thoughts but does not solve the problem or take the leading role [56].

In 2019 TaCAS study, the facilitators were either a nurse, occupational therapist or physiotherapist. They received at least 8 hours of training. The main idea of the training was the same, facilitator is there to listen and reflect not to offer suggestions. The facilitators were also asked to complete the booklet themselves to put them in the participant’s position [11]. Likewise, this was also done by the facilitators in this study. In the 2012 study, the training was longer, minimum of 5 days and continuing training was received during the study [9].

The ability to actively listen and not provide ideas is very important in order for the session to be successful. To assist this, TaCAS manual has been prepared by the authors of the session. The manual gives an overview of the aim of every page and also provides specific examples on how to help the participant but not to answer for them [56]. According to thesis author’s experience, in order to assist the training process in the future, it would be a good idea to create demonstration video on how to conduct the session. The same suggestion was presented in TaCAS 2019 study [11].

Furthermore, experience with TaCAS is also important. The thesis author started to feel comfortable with the process after about eight sessions. The study conducted in 2012 [9] came to the same conclusion stating that the session facilitators felt confident and comfortable with the concept of the session after about ten sessions [11].

Moreover, most SMI are guided by health professionals, but there are also SMI that are conducted by a lay leader, like CDSMP [1]. In our study, one facilitator was physiotherapist, and another was social worker. According to our experience medical education is not necessary but previous experience with stroke patients is important. Also, knowledge about stroke treatment journey is critical for further practical discussions. In addition, if the sessions take place in acute hospital setting, experience with hospital setting would be beneficial.

Fu [11] found that in the future, the most suitable person to deliver TaCAS session would probably be community stroke advisor as the stroke advisors are less affected by the pressures of the public hospital system. It was pointed out that facilitators who had a clinical rehabilitation background had a difficulty not to return to their specialist-patient mindset. The thesis author who has a background in physiotherapy felt the same, however with more practice it was possible to leave the specialist’s mindset in the background and concentrate on patient’s own wishes.

In the future in Estonia TaCAS session could be delivered by a stroke coordinator, who has a background in social work. However, with more work on the patient centred mindset, person with a background in physiotherapy, occupational therapy or speech therapy are also suitable facilitator.

5.2 Conclusions and suggestions for further implementation

TaCAS interview session is feasible in Estonia and conducting the sessions in acute stroke setting is also feasible. However, some adjustments are proposed. If the session is conducted in a stroke unit then it should be delivered after three days of hospitalisation, not earlier. Also, shorter TaCAS session would be suitable for some patients. Specifically, the first three pages of TaCAS (booklet p 2-4) may be used. This short version still gives a good overview of what is important for the patient. The session in the stroke unit should be used more as a tool to direct patient’s treatment pathway according to the patient’s wishes and to set a solid base to exercise SM in the future.

The second session would be more for taking charge of the situation by specifically assessing the risk factors and ADL, and also setting goals and finding solutions to problems. The study result on TaCAS published in 2019 also showed a dose effect on each additional session [10], [11]. Therefore, the next session could be a couple of weeks after the patient has been discharged home or to the next facility to give time for the patient and their family to recover and get used to life after stroke TaCAS 2019 study [11].

The next recommendation is to conduct the session both individually with the patient and also with their family. The first session’s aim would be hearing the patient’s own expectations, hopes, wishes and fears and not being influenced by someone else’s opinions and wishes. During the session, some participants had difficulty with speech, they also needed time to gather their thoughts and find suitable words. For that reason, it was crucial to give them time and create a friendly environment. It could be that if the session involves more people then the participant’s thoughts could get lost. The family members should be involved from the second session. It is absolutely necessary to hear the family’s point of view on the situation before making final decisions on the treatment pathway. The author suggests that family’s opinion could be asked after the patient’s wishes have been identified.

5.3 Limitations

Study participation was voluntary and did not influence the management of participants. Therefore, there were quite a number of patients who chose not to participate. This was not surprising for the thesis author. The reasons of not participating were different. Quite a few patients declined because they had visitors at that moment as the recruitment and interviewing took place during visiting hours. Some felt too tired after a long day to join in an hour-long interview. Furthermore, a few patients mentioned that the situation is too new for them and they do not feel comfortable yet to discuss it. In addition, one patient felt embarrassed and uncomfortable due to problems with speech. These reasons lead to the aspect that if TaCAS session would be part of a routine clinical practice in stroke unit to gather information about patient's expectations and wishes, then some of these problems could be minimised. Moreover, if TaCAS would be a routine practice, then problems that had arisen from conducting it during visiting hours would not be an issue. Based on the discussion with the declined patients the author of the thesis assumes that most of them would possibly have been suitable for the interview.

Moreover, another weakness of the study was an unpredicted change in methods due to coronavirus pandemic. The interviews were conducted by the thesis author from December 2019 to March 2020 and continued by stroke unit's social worker in April and May 2020 as the hospital went into quarantine. With two different facilitators there could have been a problem of ensuring that the session was delivered uniformly.

Likewise, the same weakness was discussed in TaCAS study 2019 [11]. They offered three possible ways how to ensure consistency between sessions. Firstly, letting the main facilitator observe the sessions and give feedback. Secondly, filming the main facilitator's sessions to create a study material for others. Lastly, to film each facilitator conducting the session to provide feedback. However, none of those solutions were applied due to difficulties of coordinating the main facilitator between study sites and due to ethical reasons of filming participants in their home. The consistency was ensured by the training process – facilitators were trained by the same person and used materials were the same. However, it was stated that overall, giving the facilitators more freedom on how to establish the relationship with the patient and conduct the session had probably a positive impact [11]. In this study, the facilitators trained independently with the manual. Taking that into consideration, it could also be taken as a strength of TaCAS intervention. It shows that it is possible to grasp the session by individual learning with the help of the manual and booklet.

Another limitation of the study is that for the most part, Russian speaking patients were excluded. The exclusion criteria was added in the mid-January after study assistant who helped conducting TaCAS for Russian speaking patients left the study due to personal reasons. The thesis author felt her Russian language is not fluent enough to conduct the sessions by herself. Although this decision created 9 more patients who could not participate in the study, the thesis author does not consider this as a major limitation. Since TaCAS booklet is already translated to Russian and the study showed its feasibility with Estonian speaking patients, the thesis author suggests there is no reason why it would not be feasible in the close future with Russian patients.

5.4 Future research

To start with, there is no consensus on the best approach of SMI as comparisons between studies have proven to be challenging, so further research is very important. [11], [17], [39], [47], [48].

For future research, it would be recommended to test TaCAS session in the acute treatment phase in large-scale randomized controlled trial taking adjustments of TaCAS session and suggestions from this qualitative study as a basis. The author suggests that the RCT could have four groups: first group would receive TaCAS in acute phase, second group would receive TaCAS both in an acute setting and after being home for a couple of weeks, third group would only receive TaCAS at home and fourth group would be a control group. The measures should be the same as they were in both TaCAS RCTs [9], [11] to make the studies comparable.

Moreover, West-Tallinn Central Hospital is starting to integrate this interview session into stroke standard practice. Also, The North Estonia Medical Centre has shown interest.

However, further research is also required to identify how TaCAS could be more accessible for patients with communication problems like severe aphasia or dysarthria to make sure that as many patients as possible can express their wishes and expectations in order to direct their treatment pathway. For further research, it would be suggested to test TaCAS session via telemedicine as it could be more convenient, time saving and also probably more cost-effective. Furthermore, additional research would be recommended to adjust and test TaCAS session for other chronic disease patients, for example patients with chronic heart diseases, diabetes or chronic obstructive pulmonary disease.

6 Conclusions

The aim of this thesis was to test the feasibility of TaCAS and validate it in Estonia.

Firstly, the results of this thesis demonstrate that TaCAS interview session is feasible in Estonia. Based on the TaCAS interview sessions conducted in this study, TaCAS intervention proved to be a useful and valuable tool in gathering information about stroke patient's own expectations and wishes in stroke acute care in Estonia. TaCAS enables the patients to be involved in their own care from early on and plan further treatment pathways for them.

Secondly, conducting TaCAS sessions in acute stroke setting is feasible.

Thirdly, Estonian stroke patients had a positive impression of the session. Many participants felt the session was a good way to analyse their situation and pinpoint their problematic aspects more clearly.

Fourthly, the mean time of conducting TaCAS session was 33 minutes in this study.

The ability to actively listen and not provide ideas is critical for the session to be successful. Medical education is not necessary but previous experience with stroke patients is important. In our study both physiotherapist and social worker with experience in stroke were able to conduct TaCAS.

In addition, following recommendations are proposed. Firstly, the session should be delivered not earlier than three days after hospitalisation. Second, shorter version of the session (booklet 2-4 p) may be the option for the first interview in acute setting. Secondly, the conduction of the second session after couple of weeks is recommended. During the second session assessment of the risk factors and ADL and setting goals with finding solutions to problems together with the patient's family would be more successful.

Acknowledgments

I would like to express my sincere gratitude to my supervisor Katrin Gross-Paju, for her continuous guidance and support throughout the thesis process.

Furthermore, I would like to thank Helin Pevkur from The Stroke Project of West Tallinn Central Hospital for helping with the administrative side of the study. Additionally, I would like to thank the participants of the study and the team of West Tallinn Central Hospital stroke unit.

Last but not least, special thanks go to people close to me for their continuous understanding, encouragement and support.

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Appendix 1 – TaCAS session description

TaCAS interview session consists of two main sections, that are called “looking at the big picture” and “breaking it down into do-able pieces”.

The “looking at the big picture” step consists of three pages (booklet p 2-4). The aim is to firstly look and analyse the bigger picture of the person’s life, to get an overview what is important for the person. “In this step, questions like: ‘Who am I?’, ‘Who are the important people in my life?’, ‘What do I want to be doing with my life in 6 months’ time, in 12 months’ time, and beyond that?’ are asked.” These questions allow the person to think and define who they are as a person, where they want to be, what their hopes, expectations and overall goals are [9], [11], [56].

On the first page of the first section (booklet p 2) two circles are shown. Between the circles is an arrow, that illustrates one circle changing to another. On the left circle it is written “My stroke”. The participant is asked to write everything that they feel is affected due to stroke. It could be their emotions, activities they cannot do, etc. In the “Who I really am?” circle on the right, the participant is asked to write down all the things they feel describe them. It could be adjectives, professions or word related to family, like mother, sister etc. Moreover, the second page (booklet p 3) is where the participant can write down their hopes, goals and wishes for the next twelve months and also their main fears, as sometimes acknowledging fears and saying out loud what one’s afraid of can help with understanding their real hopes and wishes. Next, the third page (booklet p 4) concentrates on what participant’s best day would look like. To illustrate the page, some drawings are made of people doing different activities. The participant is asked to visualise their best day and then draw it on the page. If the participant does not want to draw, they can simply visualise it and write down some keywords or ask the interviewer to do it [9], [56].

Furthermore, the second part of TaCAS (booklet p 5-12) concentrates on goal setting and on how to make the hopes and goals happen by breaking them down into do-able steps and really take charge of the situation. The second part is divided into seven topics: physical things, communication, emotional issues, information needs, financial issues, supportive network and secondary prevention. For each topic, there is a possibility to set goals with time frames. The person is guided to think what smaller steps are necessary to achieve the goal itself, what activities could help to make the step happen and how long could it take to get there. The person should focus on what they can do for themselves, different rehabilitation services are just a helpful part of the plan. As that kind of analysis needs person’s full attention, then it is advised to concentrate on only one topic during one session that the person can choose (for example physical). If the person wishes to continue, then it is necessary to make sure that they have enough energy to do so [9], [56].

Appendix 2 – Main and secondary results after 12 months in TaCAS study 2012.

Variable	DVD	TaCAS	DVD & TCS	Control	Main effect DVD		Main effect TaCAS	
	Mean (SD)				Estimate	P-value	Estimate	P-value
PCS (n=117)	39.5 (12.0)	44.8 (10.4)	42.8 (10.4)	35.9 (10.1)	0.9 (-3.1 to 4.9)	0.67	6.0 (2.0 to 10.0)	0.004
MCS (n=117)	53.7 (5.7)	52.7 (9.3)	52.6 (9.2)	50.3 (10.1)	1.6 (-1.5 to 4.8)	0.31	0.6 (-2.6 to 3.7)	0.72
FAI (n=132)	23.1 (12.7)	27.3 (12.8)	25.4 (9.8)	24.2 (10.2)	-1.5 (-5.5 to 2.5)	0.36	2.7 (-1.4 to 6.7)	0.19
CSI (n=95)	4.5 (3.8)	2.8 (3.2)	3.1 (2.9)	4.4 (3.2)	0.18 (-1.2 to 1.5)	0.57	-1.5 (-2.8 to -0.1)	0.03
BI (n=132)	16.9 (4.8)	17.9 (4.3)	18.7 (3.1)	18.0 (3.3)	Kruskal-Wallis P=0.31 for difference between treatment arms			
	N/N (%)							
mRS>2 (n=139)	16/38 (42.1)	11/38 (29.0)	5/32 (15.6)	12/31 (38.7)	0.79 (0.38 to 1.64)	0.52	0.42 (0.20 to 0.89)	0.02

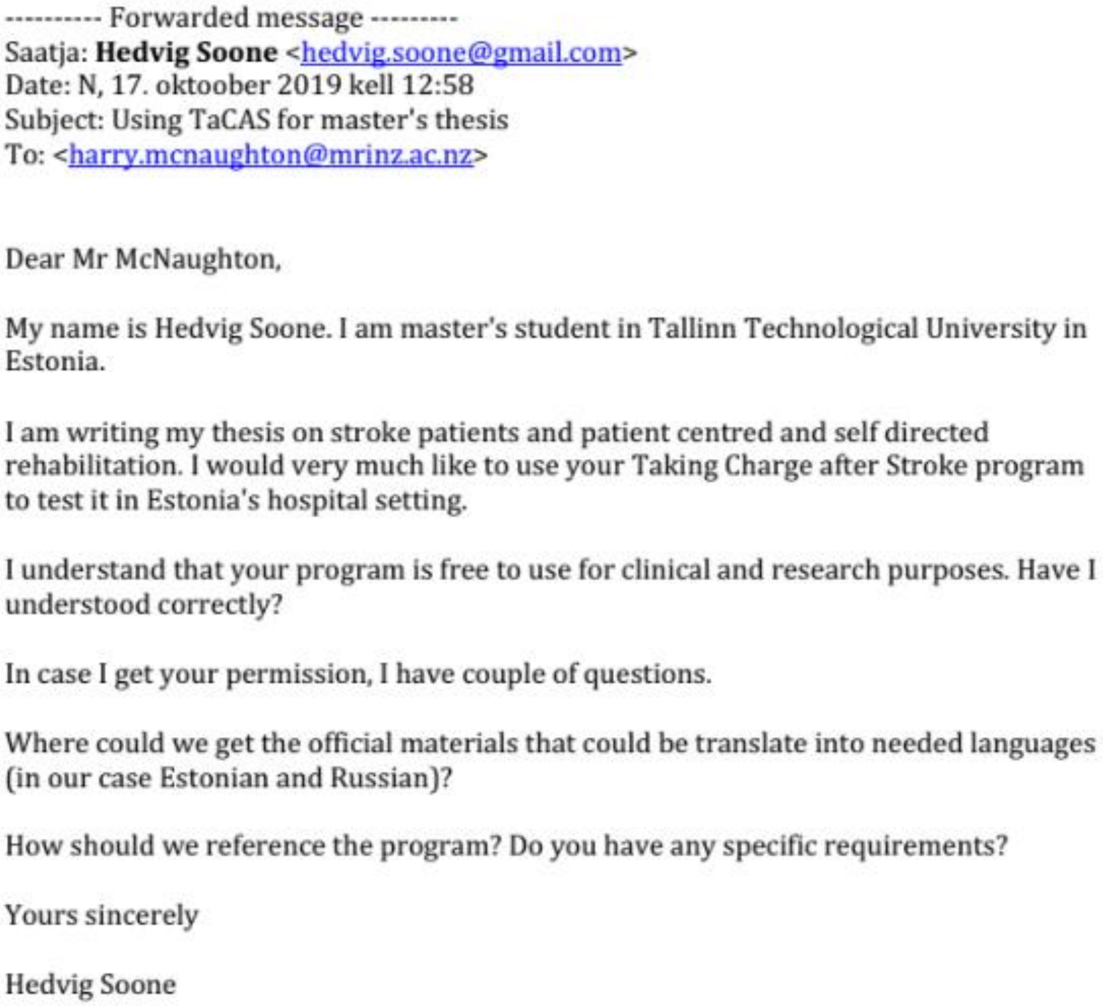
DVD, DVD-based intervention; TaCAS, Taking Charge after Stroke Session; PCS, Physical Component Summary; MCS, Mental Component Summary; FAI, Frenchay Activities Index; CSI, Caregiver Strain Index; BI, Barthel Index; mRS, modified Rankin Score.

Source: [9].

Appendix 3 – TaCAS translation process

Firstly, the booklet was translated by one translator from English to Estonian, English to Russian and the manual from English to Estonian. Secondly, a panel of native speakers were consulted, and suggested adjustments were made. Lastly, the booklet was retranslated by another translator who had no knowledge of the material from Estonian back to English, from Russian back to English and the manual from Estonian to English to control the quality of the translation. The emphasis was on conceptual equivalence rather than linguistics. After that necessary adjustments were done. Also, minor adjustments were suggested by the thesis author after conducting interviews.

Appendix 4 – Approval from TaCAS author



---------- Forwarded message ---------
Saatja: **Hedvig Soone** <hedvig.soone@gmail.com>
Date: N, 17. oktoober 2019 kell 12:58
Subject: Using TaCAS for master's thesis
To: <harry.mcnaughton@mrinz.ac.nz>

Dear Mr McNaughton,

My name is Hedvig Soone. I am master's student in Tallinn Technological University in Estonia.

I am writing my thesis on stroke patients and patient centred and self directed rehabilitation. I would very much like to use your Taking Charge after Stroke program to test it in Estonia's hospital setting.

I understand that your program is free to use for clinical and research purposes. Have I understood correctly?

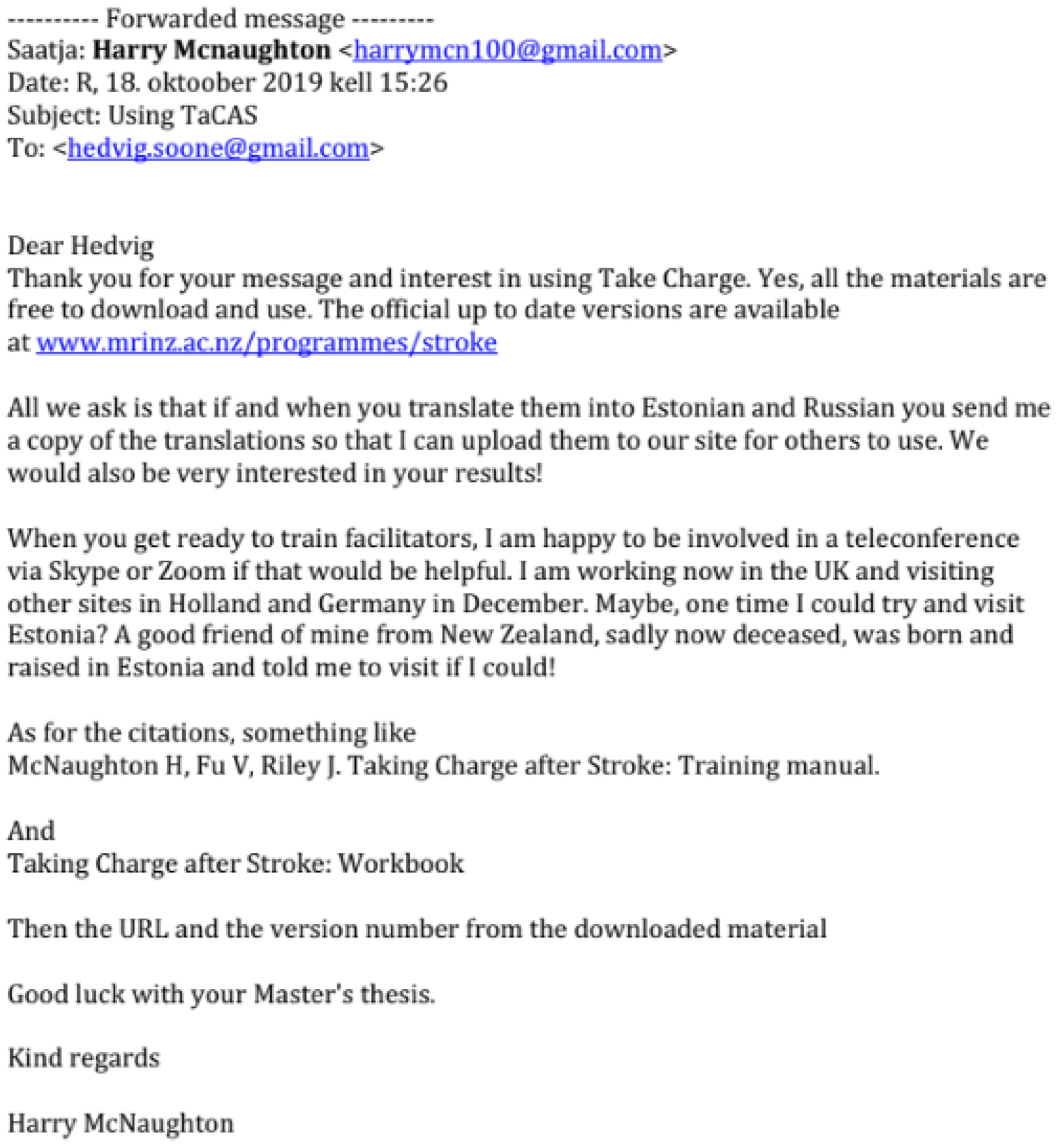
In case I get your permission, I have couple of questions.

Where could we get the official materials that could be translate into needed languages (in our case Estonian and Russian)?

How should we reference the program? Do you have any specific requirements?

Yours sincerely

Hedvig Soone



---------- Forwarded message ---------
Saatja: **Harry Mcnaughton** <harrymcn100@gmail.com>
Date: R, 18. oktoober 2019 kell 15:26
Subject: Using TaCAS
To: <hedvig.soone@gmail.com>

Dear Hedvig
Thank you for your message and interest in using Take Charge. Yes, all the materials are free to download and use. The official up to date versions are available at www.mrinz.ac.nz/programmes/stroke

All we ask is that if and when you translate them into Estonian and Russian you send me a copy of the translations so that I can upload them to our site for others to use. We would also be very interested in your results!

When you get ready to train facilitators, I am happy to be involved in a teleconference via Skype or Zoom if that would be helpful. I am working now in the UK and visiting other sites in Holland and Germany in December. Maybe, one time I could try and visit Estonia? A good friend of mine from New Zealand, sadly now deceased, was born and raised in Estonia and told me to visit if I could!

As for the citations, something like
McNaughton H, Fu V, Riley J. Taking Charge after Stroke: Training manual.

And
Taking Charge after Stroke: Workbook

Then the URL and the version number from the downloaded material

Good luck with your Master's thesis.

Kind regards

Harry McNaughton

Appendix 5 – TaCAS booklet

Insuldijärgne taastusravi (TaCAS)

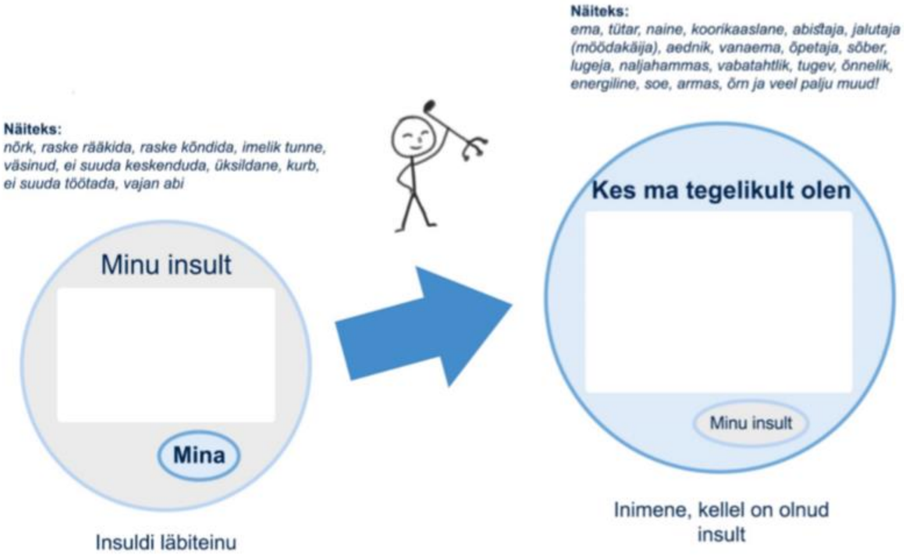
Õpperaamat

MEDICAL RESEARCH
INSTITUTE
OF NEW ZEALAND

Autorid: Harry McNaughton, Vivian Fu, Judith Riley. Kui teil tekib küsimusi, võtke palun ühendust e-posti aadressil harry.mcnaughton@mrinz.ac.nz
Vabaks kasutamiseks (koos kõigi sobivate modifikatsioonidega) kliinilisel ja uuringu eesmärgil. Palun viidake allikale.

Insuldijärgse taastusravi õpperaamat Taking Charge v6.0 (15/5/19) 1

Insuldijärgne taastusravi



Näiteks:
ema, tütar, naine, koorikaaslane, abistaja, jalutaja (möödakäija), aednik, vanaema, õpetaja, sõber, lugeja, naljahammas, vabatahtlik, tugev, õnnelik, energiline, soe, armas, õrn ja veel palju muud!

Näiteks:
nõrk, raske rääkida, raske kõndida, imelik tunne, väsinud, ei suuda keskenduda, üksildane, kurb, ei suuda töötada, vajan abi

Minu insult

Mina

Insuldi läbiteinu

Kes ma tegelikult olen

Minu insult

Inimene, kellel on olnud insult

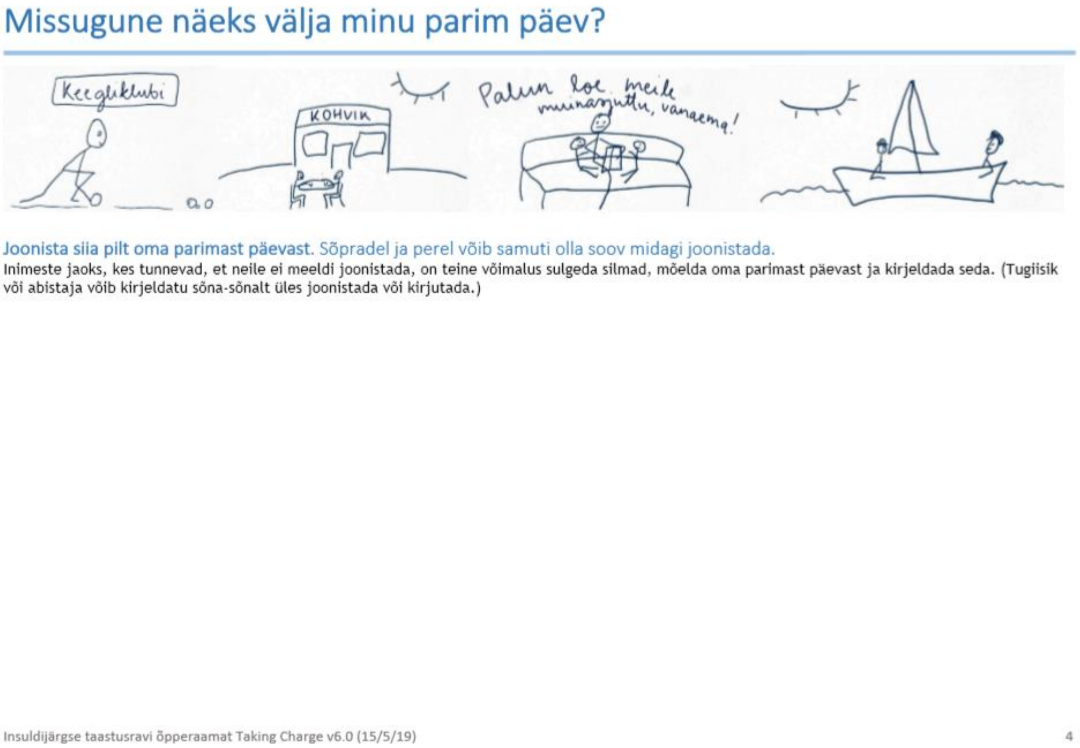
Taastumine pärast insulti

Üldised lootused, eesmärgid ja soovid järgmiseks 12 kuuks

1.
2.
3.
4.

Peamised hirmud

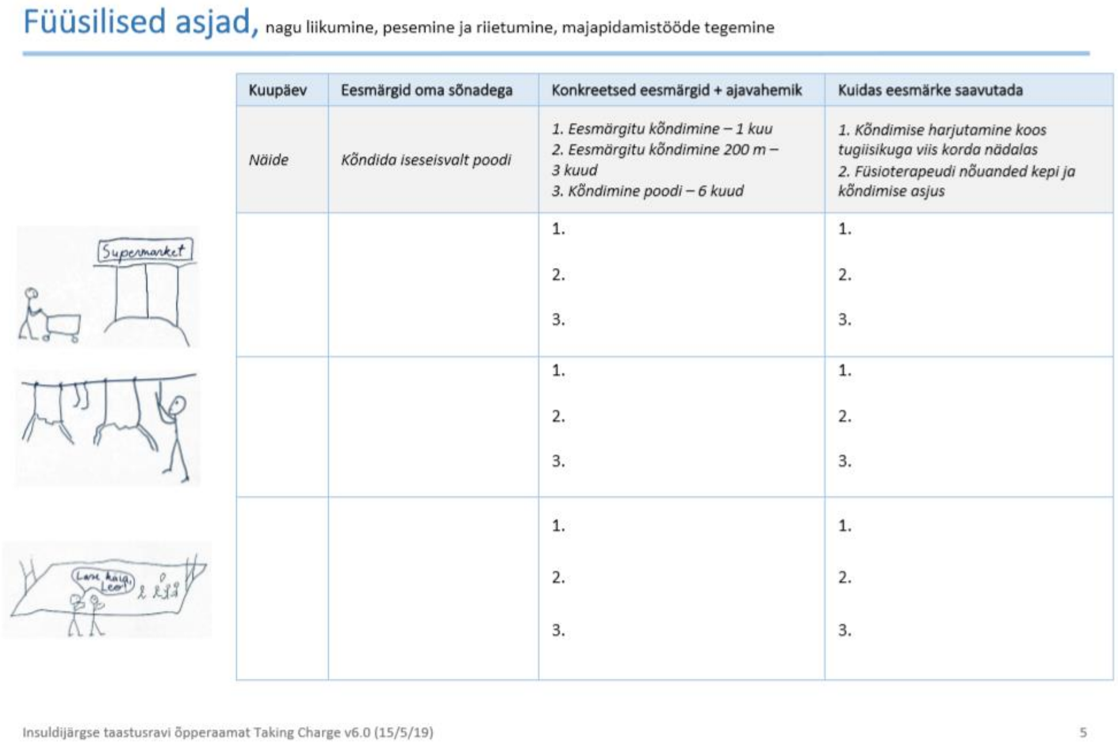
1.
2.
3.



Missugune näeks välja minu parim päev?

Joonista siia pilt oma parimast päevast. Sõpradel ja perel võib samuti olla soov midagi joonistada.
Inimeste jaoks, kes tunnevad, et neile ei meeldi joonistada, on teine võimalus sulgeda silmad, mõelda oma parimast päevast ja kirjeldada seda. (Tugiisik või abistaja võib kirjeldatu sõna-sõnalt üles joonistada või kirjutada.)

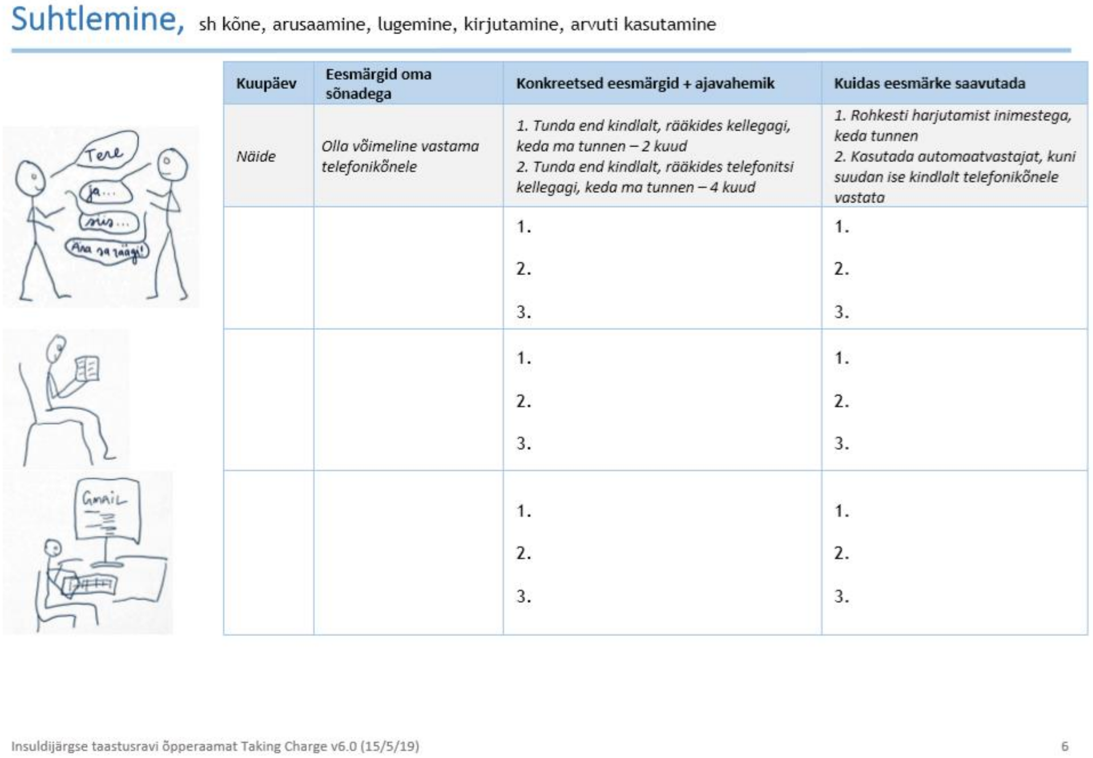
Insuldijärgse taastusravi õpperaamat Taking Charge v6.0 (15/5/19) 4



Füüsilised asjad, nagu liikumine, pesemine ja riietumine, majapidamistööde tegemine

Kuupäev	Eesmärgid oma sõnadega	Konkreetsed eesmärgid + ajavahemik	Kuidas eesmärke saavutada
Näide	*Kõndida iseseisvalt poodi*	*1. Eesmärgitu kõndimine – 1 kuu* *2. Eesmärgitu kõndimine 200 m – 3 kuud* *3. Kõndimine poodi – 6 kuud*	*1. Kõndimise harjutamine koos tugiisikuga viis korda nädalas* *2. Füsioterapeudi nõuanded kepi ja kõndimise asjus*
		1. 2. 3.	1. 2. 3.
		1. 2. 3.	1. 2. 3.
		1. 2. 3.	1. 2. 3.

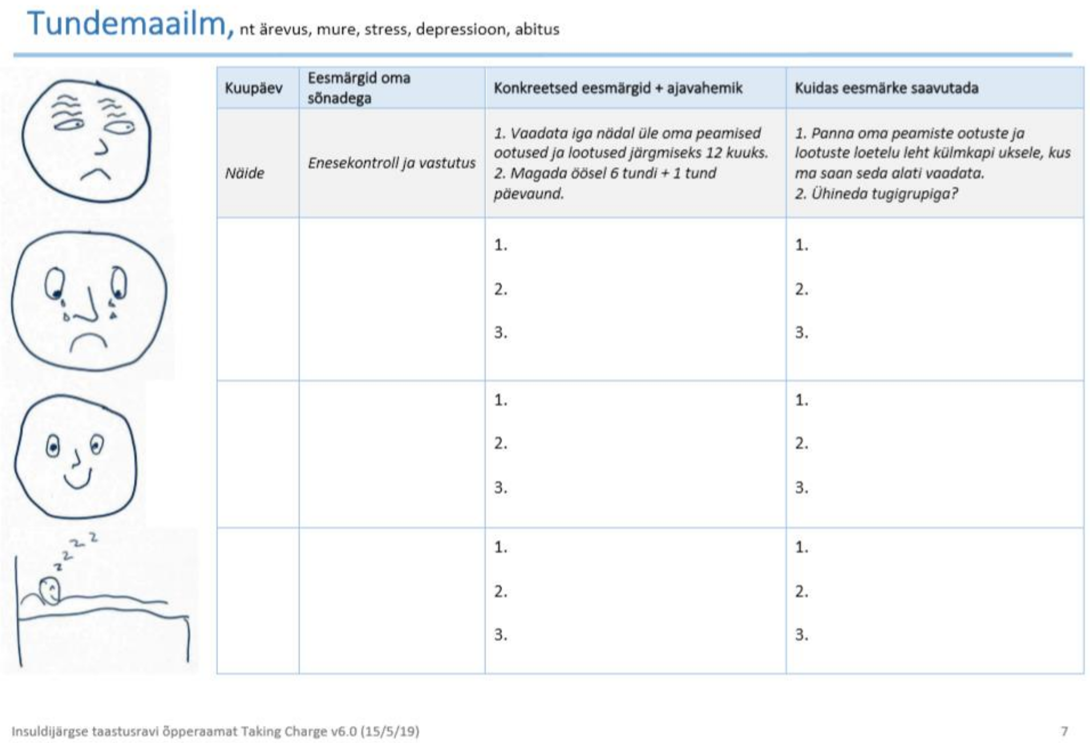
Insuldijärgse taastusravi õpperaamat Taking Charge v6.0 (15/5/19) 5



Suhtlemine, sh kõne, arusaamine, lugemine, kirjutamine, arvuti kasutamine

Kuupäev	Eesmärgid oma sõnadega	Konkreetsed eesmärgid + ajavahemik	Kuidas eesmärke saavutada
Näide	*Olla võimeline vastama telefonikõnele*	*1. Tunda end kindlalt, rääkides kellegagi, keda ma tunnen – 2 kuud* *2. Tunda end kindlalt, rääkides telefonitsi kellegagi, keda ma tunnen – 4 kuud*	*1. Rohkesti harjutamist inimestega, keda tunnen* *2. Kasutada automaatvastajat, kuni suudan ise kindlalt telefonikõnele vastata*
		1. 2. 3.	1. 2. 3.
		1. 2. 3.	1. 2. 3.
		1. 2. 3.	1. 2. 3.

Insuldijärgse taastusravi õpperaamat Taking Charge v6.0 (15/5/19) 6

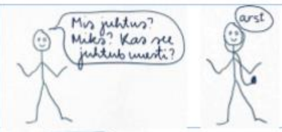


Tundemaailm, nt ärevus, mure, stress, depressioon, abitus

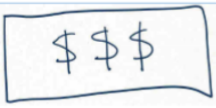
Kuupäev	Eesmärgid oma sõnadega	Konkreetsed eesmärgid + ajavahemik	Kuidas eesmärke saavutada
Näide	*Enesekontroll ja vastutus*	*1. Vaadata iga nädal üle oma peamised ootused ja lootused järgmiseks 12 kuuks.* *2. Magada öösel 6 tundi + 1 tund päevaund.*	*1. Panna oma peamiste ootuste ja lootuste loetelu leht külmkapi uksele, kus ma saan seda alati vaadata.* *2. Ühineda tugigrupiga?*
		1. 2. 3.	1. 2. 3.
		1. 2. 3.	1. 2. 3.
		1. 2. 3.	1. 2. 3.

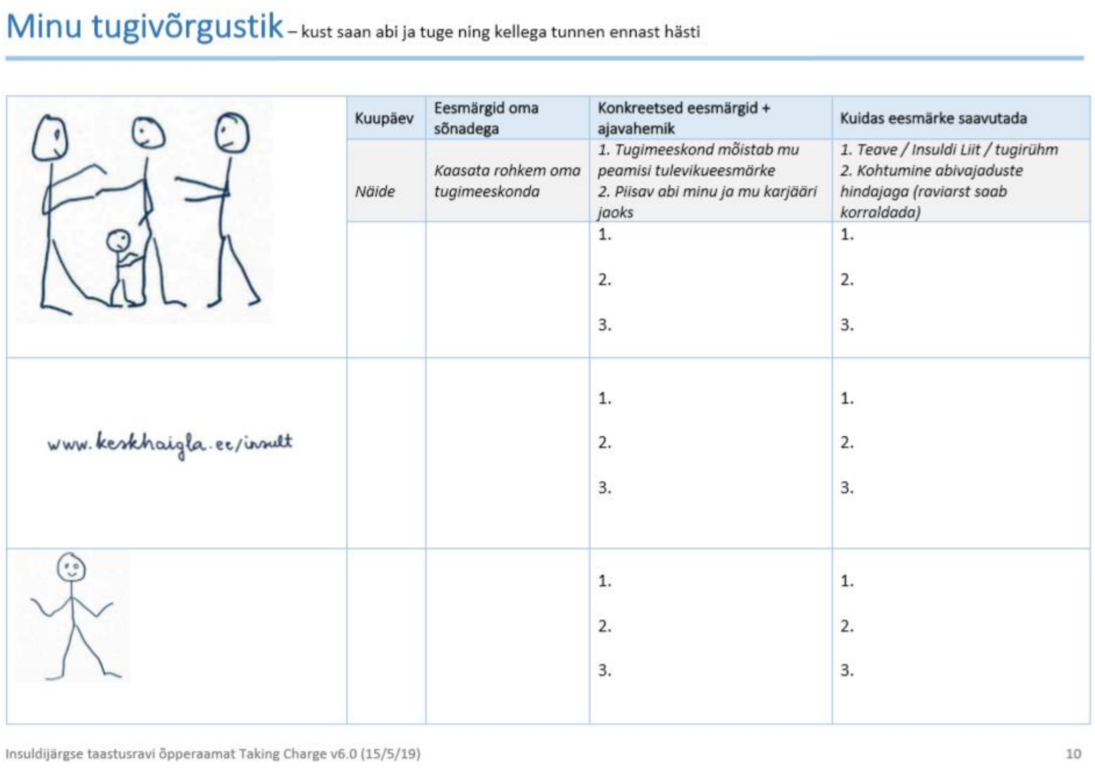
Insuldijärgse taastusravi õpperaamat Taking Charge v6.0 (15/5/19) 7

Teabevajadus

	Kuupäev	Eesmärgid oma sõnadega	Konkreetsed eesmärgid + ajavahemik	Kuidas eesmärke saavutada
	*Näide*	*Mõista, mis ja mispärast juhtus*	*1. Mõista, mis on insult* *2. Mõista, miks insult aset leidis.* *3. Saada aru taastusravist*	*1. Rääkida teiste inimestega, sh Insuldi Liiduga, arstiga, uurida teavet internetist (www.keskhaigla.ee/insult)*
			1. 2. 3.	1. 2. 3.
			1. 2. 3.	1. 2. 3.
www.keskhaigla.ee/insult			1. 2. 3.	1. 2. 3.

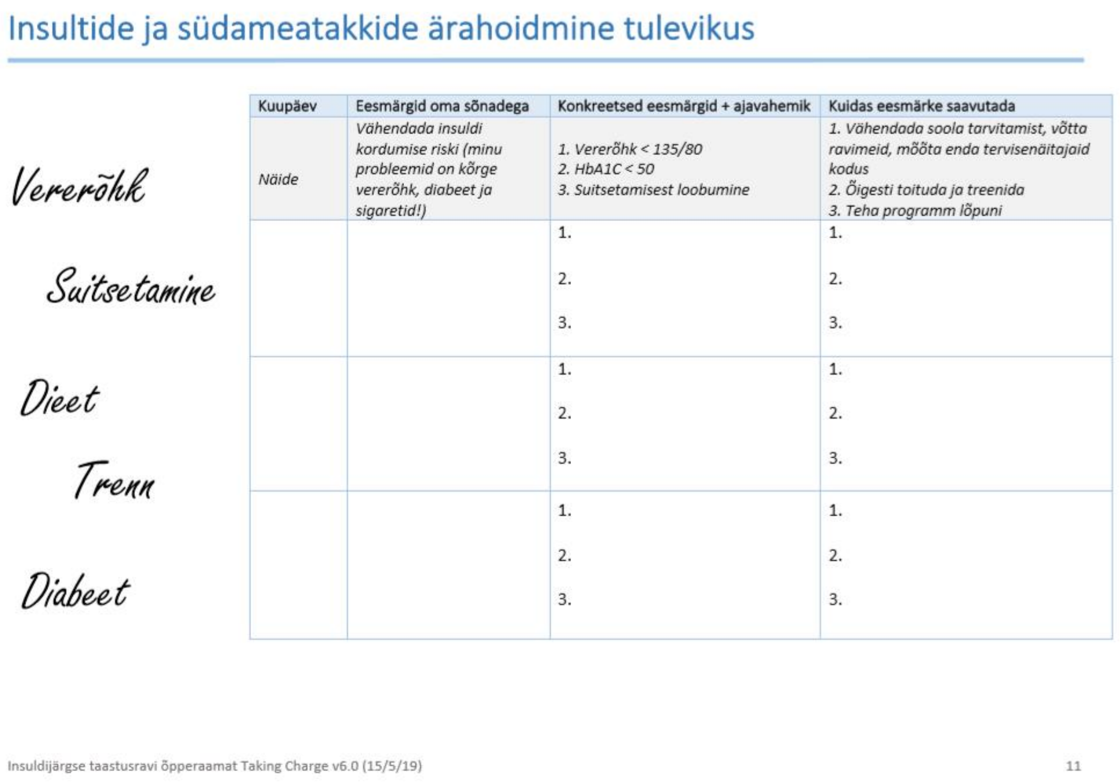
Rahaasjad, nt arvete maksmine, tööle naasmine, eelarve kasutamine, saadaval olevate toetusvõimaluste teadmine

	Kuupäev	Eesmärgid oma sõnadega	Konkreetsed eesmärgid + ajavahemik	Kuidas eesmärke saavutada
	*Näide*	*Vähendada sõidu-/reisikulusid*	*1. Puudega inimese autokleebis* *2. Taksotšekid ja muud tugiteenused* *3. Olla teadlik oma kodukoha toest*	*1. Raviarst* *2. Insuldi Liit, kohalikud teenuseosutajad* *3. Oma kodukoha teenused*
			1. 2. 3.	1. 2. 3.
			1. 2. 3.	1. 2. 3.
			1. 2. 3.	1. 2. 3.



Minu tugivõrgustik – kust saan abi ja tuge ning kellega tunnen ennast hästi

	Kuupäev	Eesmärgid oma sõnadega	Konkreetsed eesmärgid + ajavahemik	Kuidas eesmärke saavutada
	Näide	*Kaasata rohkem oma tugimeeskonda*	*1. Tugimeeskond mõistab mu peamisi tulevikueesmärke* *2. Piisav abi minu ja mu karjääri jaoks*	*1. Teave / Insuldi Liit / tugirühm* *2. Kohtumine abivajaduste hindajaga (raviarst saab korraldada)*
			1. 2. 3.	1. 2. 3.
www.keskhaigla.ee/insult			1. 2. 3.	1. 2. 3.
			1. 2. 3.	1. 2. 3.



Insultide ja südameatakkide ärahoidmine tulevikus

Vererõhk

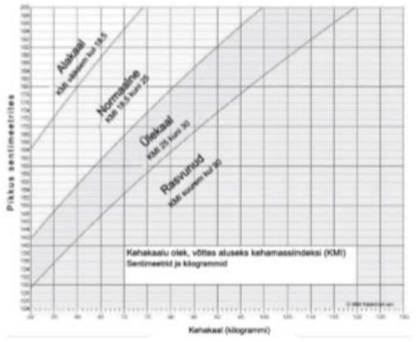
Suitsetamine

Dieet

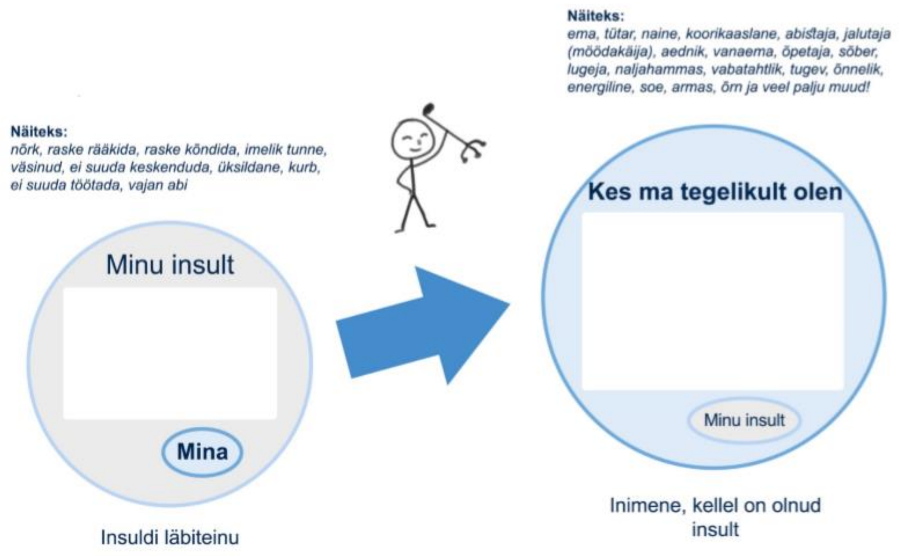
Trenn

Diabeet

Kuupäev	Eesmärgid oma sõnadega	Konkreetsed eesmärgid + ajavahemik	Kuidas eesmärke saavutada
Näide	*Vähendada insuldi kordumise riski (minu probleemid on kõrge vererõhk, diabeet ja sigaretid!)*	*1. Vererõhk < 135/80* *2. HbA1C < 50* *3. Suitsetamisest loobumine*	*1. Vähendada soola tarvitamist, võtta ravimeid, mõõta enda tervisenäitajaid kodus* *2. Õigesti toituda ja treenida* *3. Teha programm lõpuni*
		1. 2. 3.	1. 2. 3.
		1. 2. 3.	1. 2. 3.
		1. 2. 3.	1. 2. 3.



Insuldijärgne taastusravi



Näiteks:
nõrk, raske rääkida, raske kõndida, imelik tunne, väsinud, ei suuda keskenduda, üksildane, kurb, ei suuda töötada, vajan abi

Minu insult

Mina

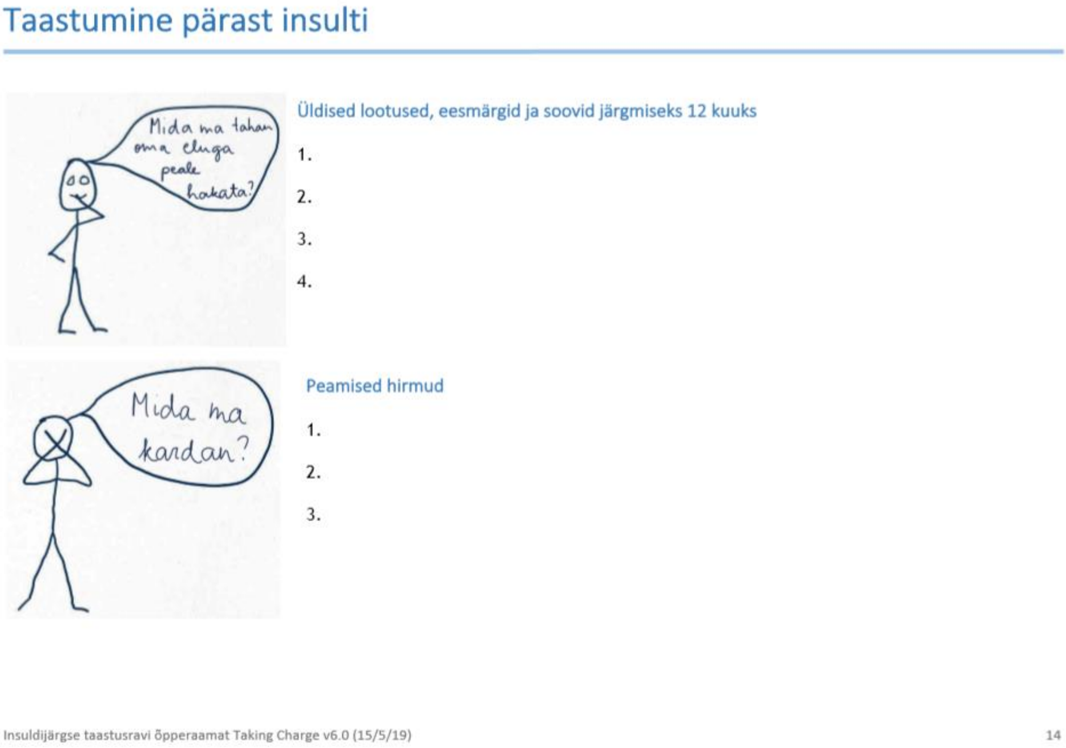
Insuldi läbiteinu

Näiteks:
ema, tütar, naine, koorikaaslane, abistaja, jalutaja (möödakäija), aednik, vanaema, õpetaja, sõber, lugeja, naljahammas, vabatahtlik, tugev, õnnelik, energiline, soe, armas, õrn ja veel palju muud!

Kes ma tegelikult olen

Minu insult

Inimene, kellel on olnud insult



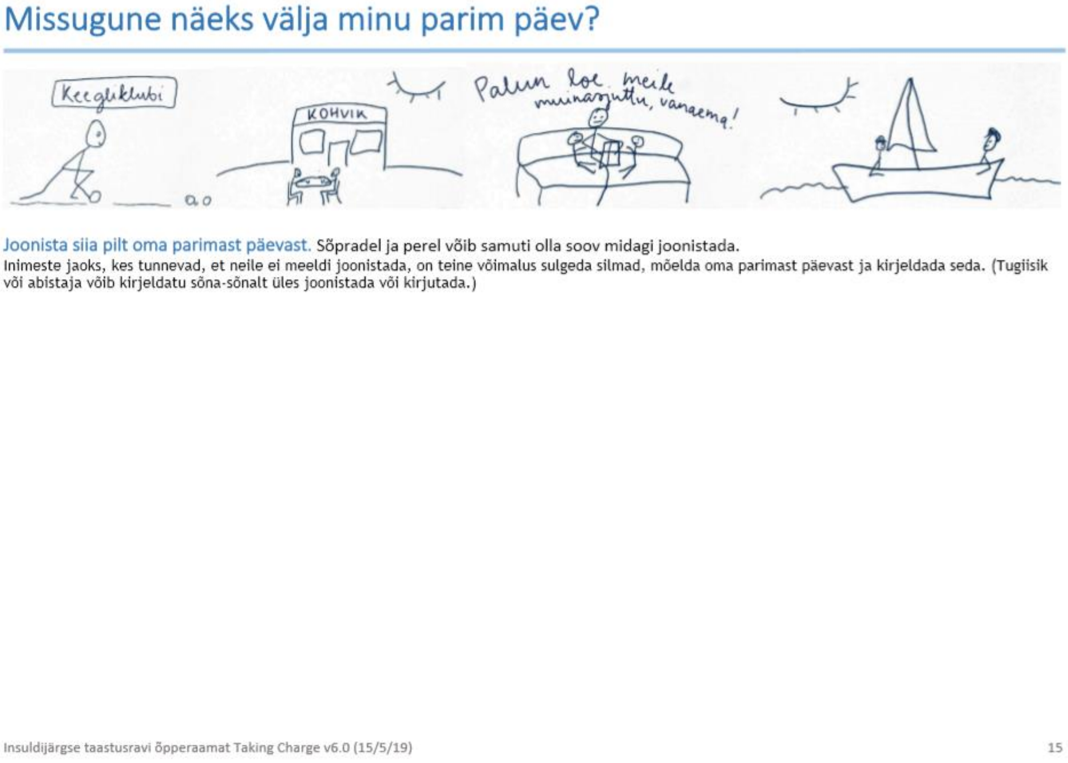
Taastumine pärast insulti

Üldised lootused, eesmärgid ja soovid järgmiseks 12 kuuks

1.
2.
3.
4.

Peamised hirmud

1.
2.
3.



Missugune näeks välja minu parim päev?

Joonista siia pilt oma parimast päevast. Sõpradel ja perel võib samuti olla soov midagi joonistada.

Inimeste jaoks, kes tunnevad, et neile ei meeldi joonistada, on teine võimalus sulgeda silmad, mõelda oma parimast päevast ja kirjeldada seda. (Tugiisik või abistaja võib kirjeldatu sõna-sõnalt üles joonistada või kirjutada.)

Source: [61].

Appendix 6 – Thematic analysis

Braun and Clark [57] stated that thematic analysis is a flexible and useful tool. It can provide detailed and complex account of data. The aim of thematic analysis is to identify and analyse the themes and patterns within the data. Thematic analysis helps to present experiences, meanings and reality of the subjects on a selected topic. In addition to the research objectives and questions, attention is also paid on what is important for the participants, like interviewees. This kind of analysis is useful with under-researched topics.

The first step was to get familiar with the data, then initial memos and notes were written in order to generate initial descriptive codes. In thematic analysis open coding is used. The most important keywords and sentences were highlighted and then given codes [60]. After that, patterns were identified, and the codes were collated into potential themes to start reviewing them. The aim of reviewing is to check if the themes are accurate representations of the data. If needed, then changes are made. After this step, final list of themes should be available. Next, the themes are defined and named by analyzing the specifics of each theme. The last step is to write the final report [57].

Appendix 7 – Informed consent form

INFORMEERITUD NÕUSOLEKU VORM

TaCAS´e küsimustiku valideerimine ja

koduteenuste vajaduse hindamine

Lugupeetud patsient!

Palume Teid osalema jälgimisuuringus, mille eesmärgiks on hinnata TaCAS´e (Take charge of Stroke) küsimustiku ostarbekust ja kasutamist tavalises kliinilises praktikas insuldi diagnoosiga inimestel. Uuringus analüüsitakse teaduslikel eesmärkidel Uus-Meremaal välja töötatud küsimustiku kasutamise võimalust Eestis. Antud uuringut korraldab Lääne-Tallinna Keskhaigla Eesti Haigekassa arendusprojekti raames.

Küsimustiku eesmärgiks on koguda andmeid Teie ootuste ja lootuste ning vajaduste kohta pärast insulti, sealhulgas kodupõhiste teenuste vajaduste kohta. Tulevikus saab rakendada küsimustikku individuaalse taastusraviplaani välja töötamisel.

Uuringu raames kogutakse Teie sotsiodemograafilisi andmeid (vanus, sugu) ja insuldiga seotud andmeid haigusloo alusel. Insuldiga seotud haigusloo andmeid dokumenteerib uuringu jaoks kliiniku juhataja, Katrin Gross-Paju, kes on selle uuringu vastutav uurija. Kliiniku juhatajal, Katrin Gross-Pajul, on ligipääs Teie haigusloole ka tavapraktikas. Uuringus osalevad teised uurijad Teie haiguslugu ei näe. Haigusloo andmetest kasutatakse informatsiooni Teie insuldi raskuse – neuroloogilise puude (insuldi hindamiskaala NIHHS alusel) ja kõnehäire kohta ning neuropsühholoogilise hindamise tulemusi (kui olete läbinud neuropsühholoogilise hindamise).

Uuringu raamides küsitleb Teid kvalifitseeritud uurija varem insuldi uuringutes kasutatud küsimustiku TaCAS alusel. Intervjuu kestab umbes 60-80 minutit ja viiakse läbi privaatsetes tingimustes insuldikeskuses. Pärast küsimustele vastamist tehakse Teiega lühike intervjuu, umbes 15-20 minutit, kus palume Teil anda hinnangu eelnevalt teostatud küsimustiku kvaliteedile ja koduteenuste vajadustele. Kui Te olete nõus, siis korratakse sama küsimustikku ja intervjuud 1-2-3 kuu jooksul Teie kodus, või mõnes muus Teile sobivas kohas, Teile sobival ajal.

Kas Te olete nõus korduvalt küsimustikule vastama? Palun märkige ära õige vastus.
Olen nõus Ei ole nõus

Uuringus osalemise kasu/kahju

Patsientidele on uuring kasulik, sest uuringusse kaasamisega toimub uuritava ootuste ning vajaduste analüüs, mida uuritav ise saab oma edasise rehabilitatsiooni plaani koostamisel edastada rehabilitatsioonimeeskonnale. Kahju ei kaasne, sest tavaravisse ei sekkuta.

Konfidentsiaalsus ja andmekaitse

Käesolev uuring viiakse läbi rahvusvaheliste Hea Kliinilise Tava kohaselt. Teie osalemine uuringus ja identiteet on konfidentsiaalsed ning kolmandatele pooltele Teie isikut tuvastavaid uuringudokumente ei avalikustata. Teie andmeid säilitatakse pseudonümiseerituna (ainult uuringukoodiga identifitseeritult, mitte koos isikuandmetega) uuringu andmebaasis, mille valdajaks on uuringukeskus, milleks on Lääne-Tallinna Keskhaigla. Ainult uuringupersonalil on juurdepääs Teie isikustatud andmetele (piiratud ainult osalejate identifitseerimise nimekirjaga), mida hoitakse uuringukeskuses lukustatud kapis. Teie haigusloole on juurdepääs vaid kliiniku juhatajal. Uuringuandmeid säilitatakse turvaliselt Lääne-Tallinna Keskhaigla uuringukeskuses ainult autoriseeritud juurdepääsuga ruumis ja digitaliseeritud andmeid haigla serveris 25 aastat. Vastava perioodi möödumisel dokumendid hävitatakse ja digitaliseeritud andmed kustutakse lõplikult.

Uuringuandmeid kasutatakse magistritööde teadusprojekti raames, kusjuures andmeid avaldatakse vaid üldistatult, nimesid ei avalikustata.

Kontakt andmekaitse kohta:

Isikuandmete töötlemisega seonduvate küsimustega võib pöörduda Lääne-Tallinna Keskhaigla andmekaitsespetsialisti poole:

Andmekaitse spetsialist: Heino Põhjala Telefon: 650 7245
E-post: andmekaitse@keskhaigla.ee
Aadress: Paldiski mnt 68, 10617 Tallinn.

Mina kinnitan, et olen läbi lugenud ja aru saanud ülalnimetatud uuringu infolehest. Mulle on selgitatud uuringu eesmärke ja ma olen neist aru saanud, mul on olnud võimalus seda teavet kaaluda, esitada küsimusi ja nendele küsimustele on rahuldavalt vastatud. Ma mõistan, et minu osalemine on vabatahtlik ning et mul on õigus katkestada oma osalemine ükskõik millal, põhjust esitamata, kusjuures kuni katkestamiseni kogutud andmed säilitatakse anonüümselt. Olen nõus oma isikuandmete töötlemisega infolehes kirjeldatud viisil.

Minu keeldumine uuringus osalemisest ei mõjuta minu ravi ega seaduslikke õigusi. Küsimuste korral võin pöörduda dr. Katrin Gross-Paju poole (Lääne-Tallinna Keskhaigla, Paldiski mnt 68, Tallinn, tel 6507 397).

Käesolevaga kinnitan, et nõustun ülalnimetatud uuringus osalema.

Patsiendi nimi (trükitähtedega)	allkiri	Kuupäev

Uuringut tutvustanud uurija (trükitähtedega)	allkiri	Kuupäev

Uuringu arsti, vastutava uurija nimi (trükitähtedega)	allkiri	Kuupäev

Appendix 8 – Participants' characteristics

Appendix 8.1 – Participants' socio-demographic characteristics

Characteristics	Mean (Range) or Number (%)
Age (years)	74 (46 to 91)
<65	2 (..%)
≥65	17 (..%)
Gender	
Male	8 (42%)
Female	11 (58%)
Place of residence	
Tallinn	13 (69%)
Harju County	4 (21%)
Hiiumaa	1 (5%)
Lääne-Virumaa	1 (5%)
Language	
Estonian	17 (89%)
Russian	2 (11%)

Appendix 8.2 – Participants' clinical characteristics

Characteristics	Mean (Range) or Number (%)
Type of stroke	
Ischemic	17 (89%)
Hemorrhagic	2 (11%)
Thrombolysis	
Yes	8 (42%)
No	11 (58%)
NIHSS	4 (1 to 9)
Dysarthria	3 (16%)
Aphasia	2 (11%)
Cognitive disability	1 (5%)