

Human-centred research for fine motor control rehabilitation after stroke in the Netherlands

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<p>Abstract</p> <p>Stroke disables people globally every day. The rehabilitation process focuses mainly on the big muscle groups and re-learning walking. This is why the upper extremity and fine motor control rehabilitation after a stroke is usually left without significant focus. The dexterity rehabilitation after a stroke is lacking an unambiguous method and the guidelines for stroke rehabilitation present multiple recommendations.</p> <p>SilverFit is a Dutch wellness technology company, whose focus is to motivate people in rehabilitation and maintain their activity by gamification. The thesis was a part of an international product development project for finding a solution for fine motor control rehabilitation after a stroke. Thesis work focused on an iterative project trying to solve the most effective way for rehabilitating fine motor control after a stroke based on the most recent evidence-based studies and understanding the requirements and problems of the users. The human-centred research was conducted using a Design Thinking -process with methods of online ethnography, interviews and observation.</p> <p>The results from the evidence-based research and the human-centred research were compared through a theme analysis. The thesis showed that the most problematic thing in fine motor control rehabilitation after a stroke is the lack of knowledge, motivation and time, which together cause feelings of insecurity in the therapists and the stroke survivors.</p> <p>The recommendation for solving the current situation is to create a technological solution, which is always accessible for the stroke survivor, supports the decisions of the therapists based on the most recent evidence-based studies, gives supportive feedback during the therapy and provides realistic results about the progress of the rehabilitation. The thesis provides the first stage of an iterative product development process.</p>		
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<p>Tiivistelmä</p> <p>Aivoverenkiertohäiriö vammauttaa ihmisiä maailmanlaajuisesti päivittäin. Kuntoutus aivoverenkiertohäiriön jälkeen aloitetaan yleensä isoista lihasryhmistä keskittyen kävelyn uudelleen opetteluun. Tästä syystä yläraajojen sekä hienomotoriikan kuntoutus jää taka-alalle. Hienomotoriikan kuntoutukseen aivoverenkiertohäiriön jälkeen ei ole olemassa yksiselitteistä metodia, ja siksi hoitosuosituksissa esitellään useita eri vaihtoehtoja.</p> <p>SilverFit on hollantilainen hyvinvointiteknologian yritys, jonka tavoitteena on motivoida kuntoutumista sekä toimintakyvyn ylläpitämistä pelillisin keinoin. Opinnäytetyö oli osa kansainvälistä tuotekehitysprojektia SilverFitin yhteistyökumppaneiden kanssa. Projektin tavoitteena on luoda pelillinen ratkaisu hienomotoriikan kuntoutukseen. Opinnäytetyön osuus projektissa oli aloittaa iteratiivinen tuotekehitysprojekti, eli selvittää tehokkain tapa kuntouttaa hienomotoriikkaa perustuen viimeisimpään tutkimustietoon sekä ymmärtää käyttäjien vaatimuksia ja ongelmia käyttäjakeskeisen tutkimuksen kautta. Käyttäjätutkimus toteutettiin Design Thinking -prosessin mukaisesti online-etnografian, haastatteluiden sekä havainnoinnin keinoin.</p> <p>Teoria- sekä käyttäjätutkimustuloksia verrattiin teema-analyysin avulla. Opinnäytetyö osoitti, että ongelmallisinta hienomotoriikan kuntoutuksessa on tiedon, motivaation sekä ajan puute, jotka yhdessä aiheuttavat sekä terapeuteissa että kuntoutujissa epävarmuutta.</p> <p>Suosituksena tilanteen ratkaisemiseksi olisi luoda teknologinen sovellus, joka olisi aina aivoverenkiertohäiriökuntoutujan saatavilla, tukisi terapeuttien hoitopäätöksiä ajankohtaisimman tutkimustiedon perusteella ja antaisi kannustavaa palautetta terapiatilanteessa sekä realistisia tuloksia kuntoutuksen etenemisestä. Opinnäytetyön tuloksia voidaan pitää iteratiivisen tuotekehitysprojektin ensimmäisenä vaiheena.</p>		
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1 Towards accessible rehabilitation

1.1 The research questions of the thesis

Stroke disables 9 million people every year worldwide (Stroke 2016). From those 9 million *stroke survivors*, almost 4 million people will have permanent upper extremity impairment (Lawrence, Coshall, Dundas, Stewart, Rudd, Howard & Wolfe 2001). Stroke survivors are the largest group in rehabilitation centres. About two-thirds of all the stroke survivors will be functionally independent after a year from the accident. The rest of them will retain some level of dependency in ADL –actions. (O’Sullivan & Schmitz 2007, 706.)

The aim of the study was to determine an effective way to rehabilitate fine motor control after a stroke and understand why it is not met in the facilities where the rehabilitation takes place. The result was a recommendation for the requirements for the design process. There are three phases; evidence-based research, human-centred research and the analysis between the results of these two research phases (figure 1). The results will be presented at the end of each phase. This final thesis is part of a larger cooperation project between the employer of this thesis, SilverFit, and its cooperation partners.

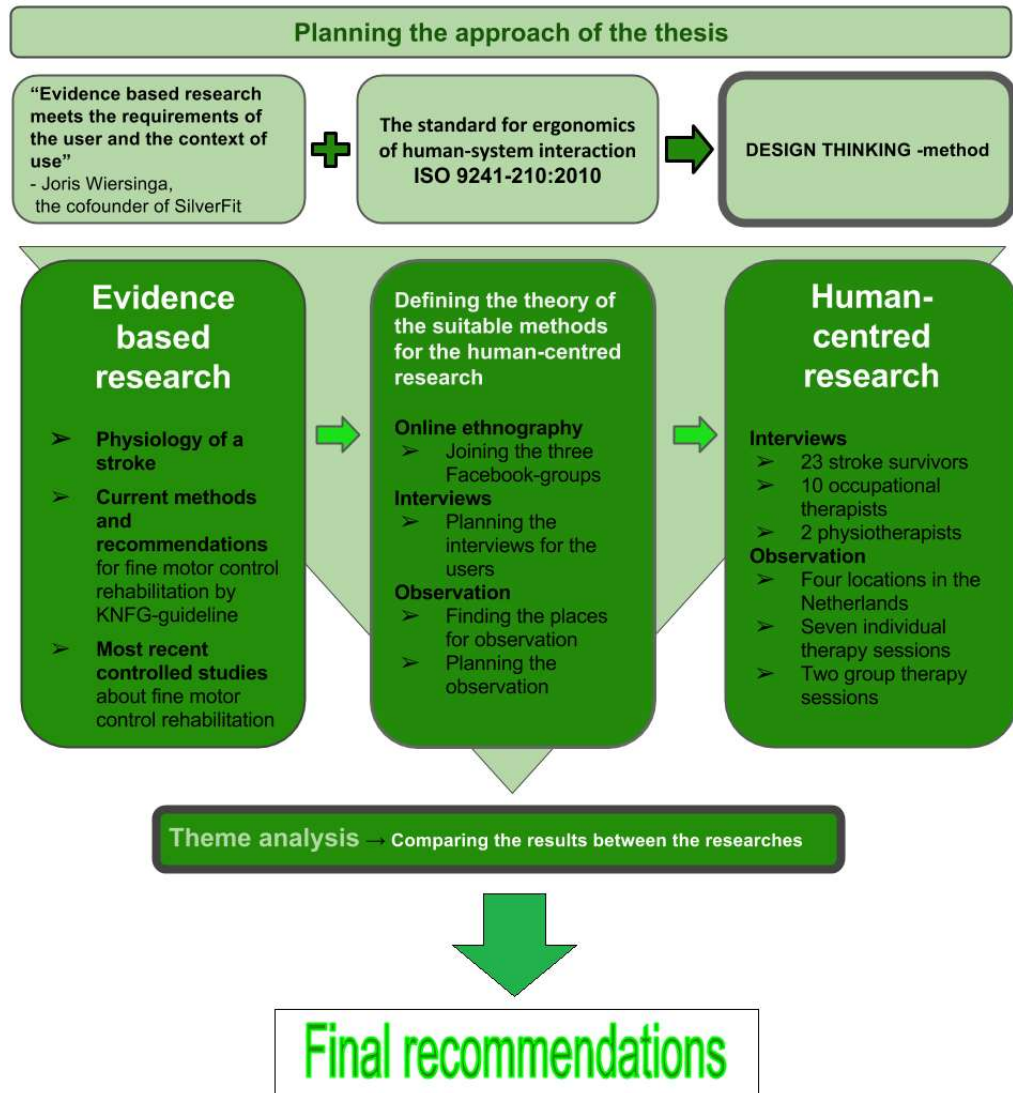


Figure 1. The approach of the final thesis

1.2 SilverFit

SilverFit is a Dutch company founded in 2008 by Joris Wiersinga and Maaike Dekkers-Duijts. The mission of SilverFit is to make the process of rehabilitation fun through technology and gamification. Today, the company’s multi-professional team works very closely with the users and environments for rehabilitation. Their goal is to provide gerontechnology devices which improve the quality of life. (SilverFit 2015.) SilverFit has a total of 20 employees including programmers, graphic designers, game

developers, software engineers, and part-time working therapists (We are SilverFit 2015). SilverFit is actively involved with interns and graduating students from different fields (Wiersinga 2015).

1.3 Design thinking as a method

The structure of this final thesis follows the idea and thought process of SilverFit's research principles. Based on a presentation by SilverFit's co-founder, Joris Wiersinga, a successful product design is fun, useful and reliable for the client. He emphasized that it is important to find the problems that the users are facing instead of trying to come up with solutions right away. Finding out the problems in the field will be combined with the evidence and the scientific results to offer the most recent solutions for this subject. (Wiersinga 2015.)

A successful and usable product is based on the user's needs and goals. The standard for *Ergonomics of human-system interaction – Part 210: Human-centred design for interactive systems* emphasizes an iterative process throughout the product design (figure 2). The iterative process will ensure a product that is suitable for the user group and for the context of use. (ISO 9241 – 210:2010, 2010, 20.) ISO 9241 – 210:2010 standard uses the word *human* instead of a *user* to emphasize the importance of taking all the stakeholders into consideration and not only the users of the design. The terms are often used as synonyms. (ibid., 15.)

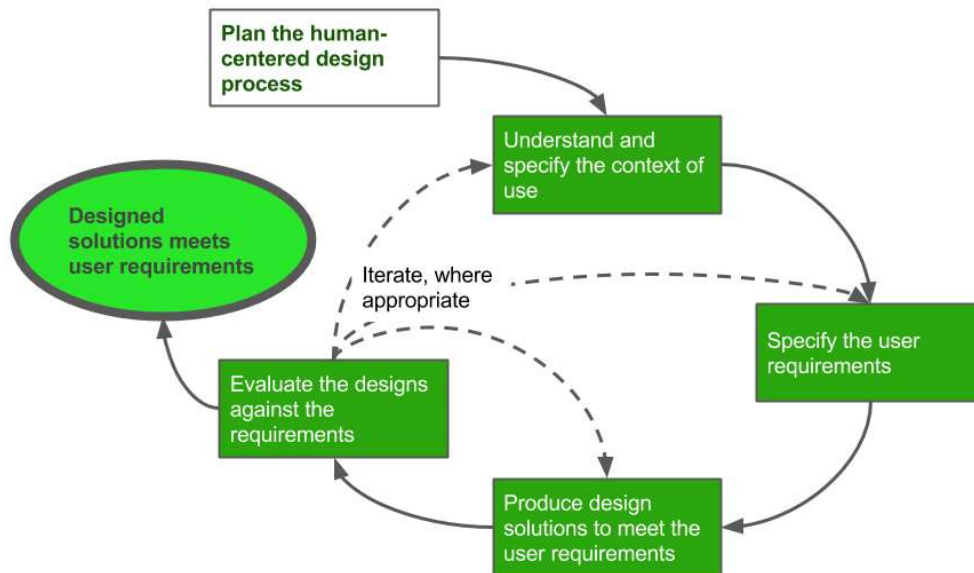


Figure 2. The human-centred design process is iterative (ISO 9241 – 210:2010, 2010, 29)

Design thinking process agrees with the idea of SilverFit. Design thinking focuses thoroughly on the user's goals (Birckhead 2013). This thesis will provide the first three steps of the process; understanding, observing and defining (figure 3), which are the first two steps in the human-centred design process.

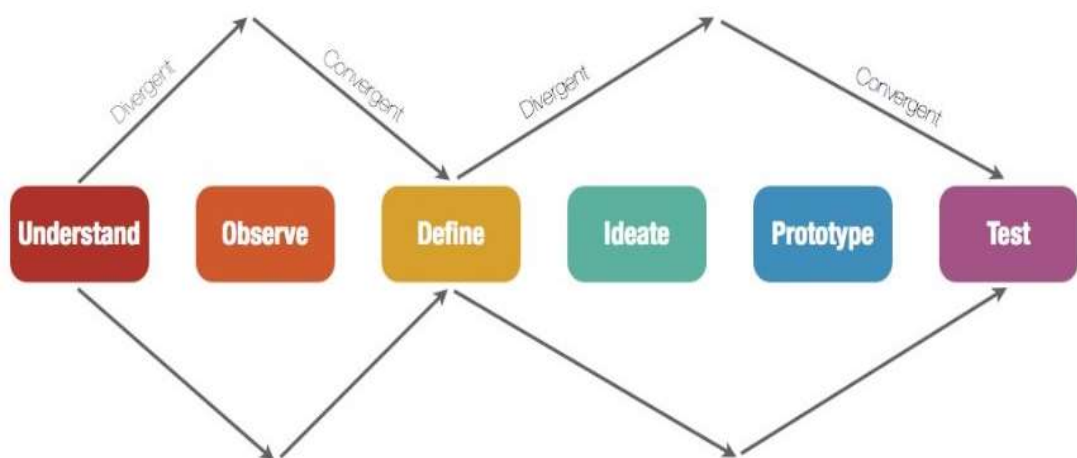


Figure 3. Design thinking process (Birckhead 2013).

1.3.1 Evidence-based research

The first step of the process was to *understand* the theoretical framework. The evidence-based research was made systematically through an online course (Asiantuntijan tiedonhankinta) (attachment 1) at JAMK University of Applied Sciences. A significant source of information also was SilverFit's own data base (SilverHippo) and library, which includes a plethora of material and recent studies in all the fields that this company is interested in, including stroke.

1.3.2 Human-centred research

The next two steps *observe* and *define* were executed through human-centred research. Clear, detailed knowledge of the user's problems, organization and the goals will offer a better result in the design (Cooper, Reimann, Cronin & Noessel 2014, 31). The techniques for the human-centred research were chosen based on the recommendation of the books *About Face: The Essentials of Interaction Design, Fourth Edition* (Cooper et al. 2014, 42) and *Palvelumuotoilu* (Tuulaniemi 2013, 65). The human-centred research included user interviews, observation and online ethnography. The results were qualitative, because it is recommended to collect behavioral and organizational knowledge with qualitative techniques (Cooper et al. 2014, 31).

1.3.3 Analysis - theory vs practice

Conclusions of evidence-based research and empirical studies were made to answer the research questions and to further define the problems in the field. *Theme analysis* was chosen for the method for evaluating the qualitative results. It suits analysing a practical problem very well (Eskola & Suoranta 1998, 25 section 4), because it compares tightly the results from evidence-based and empirical research (ibid., 23 section 4). The final recommendations are based on the analysis.

1.4 Abbreviations and the glossary

Abbreviations

ADL	Activities for Daily Living
OT	Occupational Therapist
CIMT	Constraint-Induced Movement Therapy
CVA	Cerebrovascular Accident
UE	Upper Extremity, from the shoulder to the fingertips

Glossary

Fine motor control	Control of small muscles of the hand
Dexterity	Precise, detailed movement of the hand
Hand	Wrist, palm and fingers
Stroke	Brain injury, that causes a variety of impairments
Online ethnography	A method for human-centred research executed on the internet
Facebook	A popular social media
Stroke survivor	A person who survived from CVA
Client	Stroke survivor in a hospital or rehabilitation centre environment
Occupational therapist	The main health care professional working with a stroke survivor to rehabilitate fine motor control and ADL-functions
Physiotherapist	A health care professional specialized maintaining movement
User	A person who is involved with the context of the study
Used pronouns	Them, themselves (instead of she/he, herself/himself)

2 Stroke as a global issue

Globally the most common reason for long-term disability is dementia, and the close runner-up is a stroke (Stroke 2016). There are 15 million people worldwide who suffer a stroke every year. This means over 40 000 CVAs every day. 40 % of the victims die and 33 % of the *stroke survivors* are left with a permanent disability. (Stroke 2016.) From those disabilities, around 77 % is upper extremity weakness (Lawrence et al. 2001). Stroke survivors are the largest group in rehabilitation centres. About two-thirds of all the stroke survivors will be functionally independent after a year from the accident. The rest of them will retain some level of dependency in ADL – actions. (O’Sullivan & Schmitz 2007, 706.)

A stroke is a blood clot (ischemic stroke) or a blood leakage in the brain (hemorrhagic stroke). All strokes belong under the term *cerebrovascular accident (CVA)*. Based on the location (anterior cerebral artery syndrome, middle cerebral artery syndrome, and so forth) and the severity of the damage (transient ischemic attack, minor stroke, major stroke, deteriorating stroke, young stroke) together with the etiology category (thrombosis, embolus or hemorrhage), a stroke causes many different neurological dysfunctions. The impairments concern cognitive, sensory, language, motor, and perceptual functions. The loss of motor activity is divided into hemiplegia (paralysis) and hemiparesis (weakness) and it occurs on the opposite side of the brain damage. The term *hemiplegia* is used to describe the general motor problem variety after CVA. The time window for reliable prognostics for the recovery is three weeks after the stroke. (O’Sullivan & Schmitz 2007, 705–706.)

3 Principles of fine motor control rehabilitation

There is a large variety of guidelines and theories that have proven to be effective in rehabilitation after a stroke and the investigation is still ongoing. In the Netherlands there are three guidelines; *KNGF guideline*, *Ergotherapie richtlijn CVA* and *Revalidatie na een beroerte*. Fine motor control rehabilitation in the Netherlands follows the principles defined in these guidelines and recommendations. This study focuses mainly on investigating the KNGF –guideline as it is published in English.

Relearning motor control is based on the brain's capacity for recovery. The brain is able to reorganize tasks and adapt to a new situation. (O'Sullivan & Schmitz 2007, 746.) There are categories for the phases of a stroke based on the time passed after the stroke (table 1) (Veerbeek, van Wegen, van Peppen, Hendriks, Rietberg, van der Wees, Heijblom, Goos, Hanssen, Harmeling-van der We, de Jong, Kamphuis, Noom, van der Schaft, Smeets, Vluggen, Vijsma, Vollmar & Kwakkel 2014, 3). Each phase of recovery has a different meaning from the rehabilitation point of view, but the principles stays the same throughout the process (figure 4).

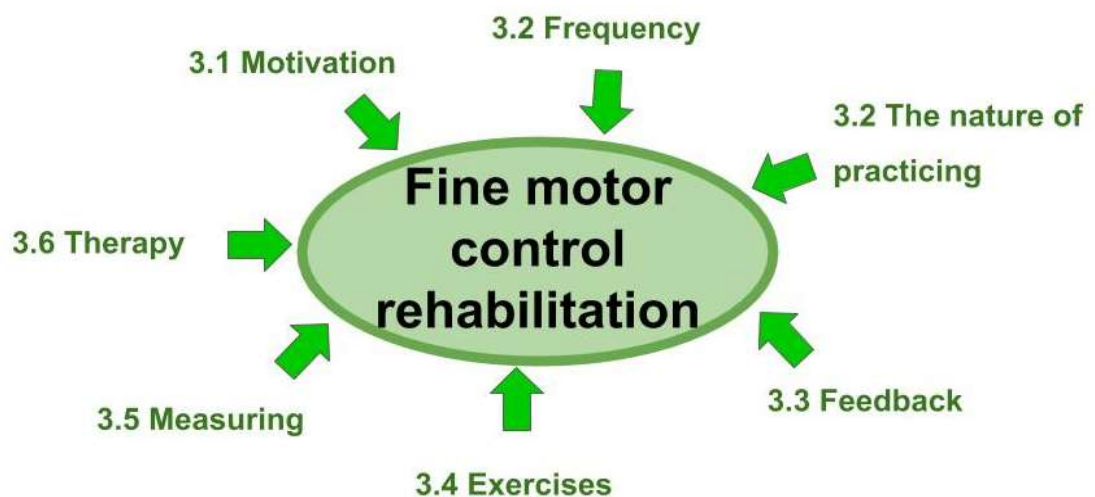


Figure 4. Principles for fine motor control rehabilitation

Table 1. A stroke is categorized into four phases based on the time passed after the stroke

Phase	Timeline	Focus
Hyperacute/acute	0 - 24 h	Diagnostics and secondary damage prevention
Early phase	24 h - 3 months	Restoring functions
Late phase	3 - 6 months	Limitations prevention and maintaining functions
Chronic phase	6 months - physical therapy goals are achieved	Learning to cope with limitations

The first two weeks after the stroke are the most critical for determining the fine motor control recovery. Functional recovery is most active in the first two months (Veerbeek et al. 2014, 22) but there is a possibility for improving the fine motor control in all phases (ibid., 19).

3.1 Motivation

Motivation for rehabilitation process is necessary. It is a successful combination of the other elements listed in figure 4. Without the client's full commitment, the results of the recovery are not adequate (O'Sullivan & Schmitz 2007, 746). Positive feedback, information about the goal and individual coaching are the key characters to maintain the motivation of the client (Veerbeek et al. 2014, 13). Reliable information about the prognosis helps the stroke survivor to commit to the rehabilitation program (Maclean, Pound, Wolfe & Rudd 2000).

3.2 Frequency and the nature of practicing

The rehabilitation and therapy for fine motor control starts as soon as possible after the stroke (McHugh Pendleton & Schultz-Krohn 2013, 599). Rehabilitation should take place every day, several times per day by a physical therapist or another therapist with sufficient qualifications for the rehabilitation of stroke survivors. The intensity and duration of the therapy is established individually in consultation with the client, the care providers, the client's neurologist and the doctor. The amount of therapy has no *ceiling effect*, which means that based on the client's condition, they can practice as much they are able to. The clients should be provided with every opportunity to exercise during the off-therapy hours either independently or with the help of a caregiver. (Veerbeek et al. 2014, 11.) A relatively high dose of repetitive task practice has been shown to improve fine motor control (Pollock, Farmer, Brady, Langhorne, Mead, Mehrholz and van Wijck 2014).

3.3 Feedback

The therapy should start and end with a positive note. Positive experiences increase the client's self-confidence and results in long-term use and commitment to the method. (O'Sullivan & Schmitz 2007, 746.) The feedback from the progress should be verbal and nonverbal while the practice (Veerbeek et al. 2014, 13).

Verbal mediation strategy

Explaining aloud what the next function and the content of the practice is going to be before doing it.

Auditory feedback

Verbal commands for the tasks should be clear and short. Timing is important; the command should not come too early nor too late. The tone of voice should be soft, thus offering reassurance and encouragement for smooth movement. When the motor task needs to be performed with the best effort, the tone should be louder.

Visual feedback

The therapist's position can be a cue for the client. Visual cues assist in initiation and coordination of movement.

Tactile system

The tactile system has temporal and spatial abilities. It is more important for the client to feel the movement patterns compared to coordination and balance. Therapists can give tactile cues by gentle touch, stretching and providing resistant during the therapy.

(McHugh Pendleton & Schultz-Krohn 2013, 808.)

Sonification

Sonification is an auditory feedback system without words and language. It works like a radar; the auditive frequency or the sound changes with movement. (Brückner, Schmitz, Scholz, Effenberg, Altenmüller & Blume 2014.) Sonification can be an alternative cueing solution for clients with aphasia (the impairment of speaking and understanding (Aivoverenkiertohäiriöihin liittyvää sanastoa 2012)).

3.4 Exercises

In the lack of controlled studies, the theoretical model for the most effective way of rehabilitation stroke survivors has not been determined. What has been proved though is that task-oriented learning has been the most effective way to relearn motor skills. The rehabilitation program has to be customised with every individual to maintain the difficulty level suitable. The program has to have frequent, sufficient repetition with periods of rest and practice. The frequency should be increased when there is progress. Complex motor tasks (for example dressing up) should be divided into individual tasks and then combining the practice into a complete function. (Veerbeek et al. 2014, 13.)

The activities for rehabilitating fine motor control have to be meaningful and important to the client. They should include objects with different weight, shape and size. Using the stopwatch for time measurement can serve variation for the level of difficulty. The exercises should include a sufficient amount of grasping, reaching and manipulation. (O'Sullivan & Schmitz 2007, 746.)

3.5 Measuring the progress

The practice itself is a measuring tool for the therapists to evaluate the skills of their client. Physical limitations can be assessed through observation while the client is performing tasks in realistic environments. This reveals the interaction and the shortcomings in the client's activity. (McHugh Pendleton & Schultz-Krohn 2013, 49.)

In addition, there are several ways to evaluate upper extremity control and recovery (figure 5). The recommendations vary a lot between the location and the profession (occupational therapists versus physiotherapists). What they all have in common, is

the emphasis for the client's self-evaluation. (O'Sullivan & Schmitz 2007, 746.) Self-evaluation is not enough alone, because the clients may deny the presence or extent of their disability (ibid., 1151). It is recommended to have instruments for measuring the rehabilitation process for the objective assessment of the progress and impairments. They give information about the limitations of activities, body functions, restrictions and impediments. The therapists use these tools for diagnostics and hypothesis reconstruction for conclusions. (Veerbeek et al. 2014, 15–16.)

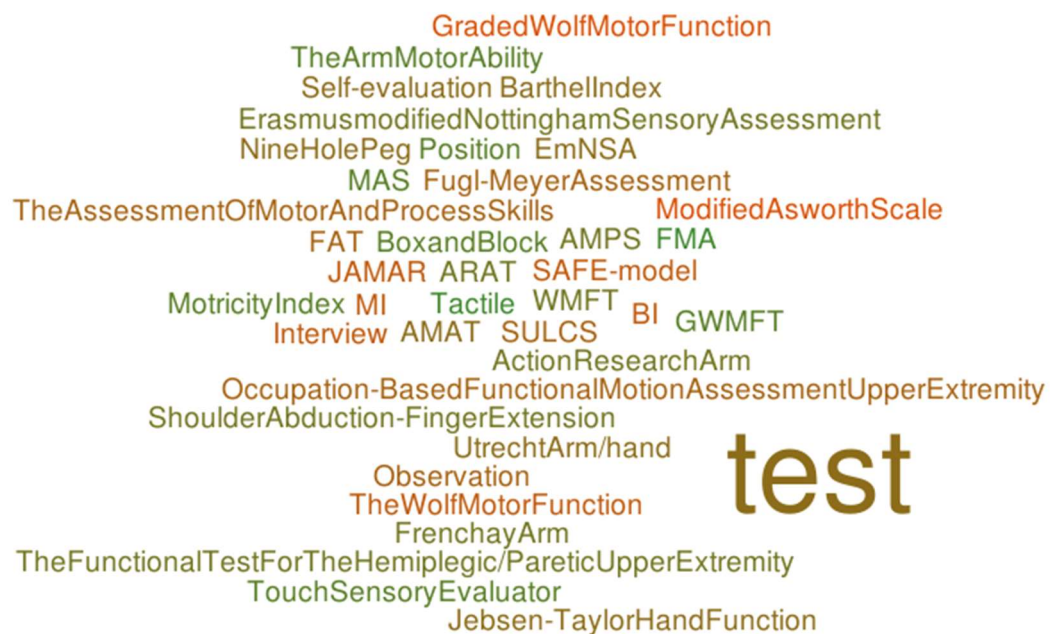


Figure 5. A word cloud to visualize the amount and variety of the measuring tools

3.6 The therapy session

Fine motor control therapy follows a certain structure (figure 6). The therapist assists the client to relearn the desired task with the goals that the client has set for their recovery. The task is presented to the client and then they try it themselves. If there

are many different tasks in one function, they are presented in the right order, for example making coffee is divided into smaller, separate tasks. The therapist demonstrates the task and gives clear, simple, verbal instructions without overloading the client. The learning starts with the healthy side and then with the affected side. (O'Sullivan & Schmitz 2007, 746.) Unilateral practicing with the affected side has been proven more effective than bilateral training (Pollock et al. 2014). Mental practice of the movement (visualisation of the tasks) can help some clients with cognition. Self-evaluation is an important part of the rehabilitation process. (O'Sullivan & Schmitz 2007, 746.) The rehabilitation and the relearning process should be conducted in an environment familiar to the client (Veerbeek et al. 2014, 11).

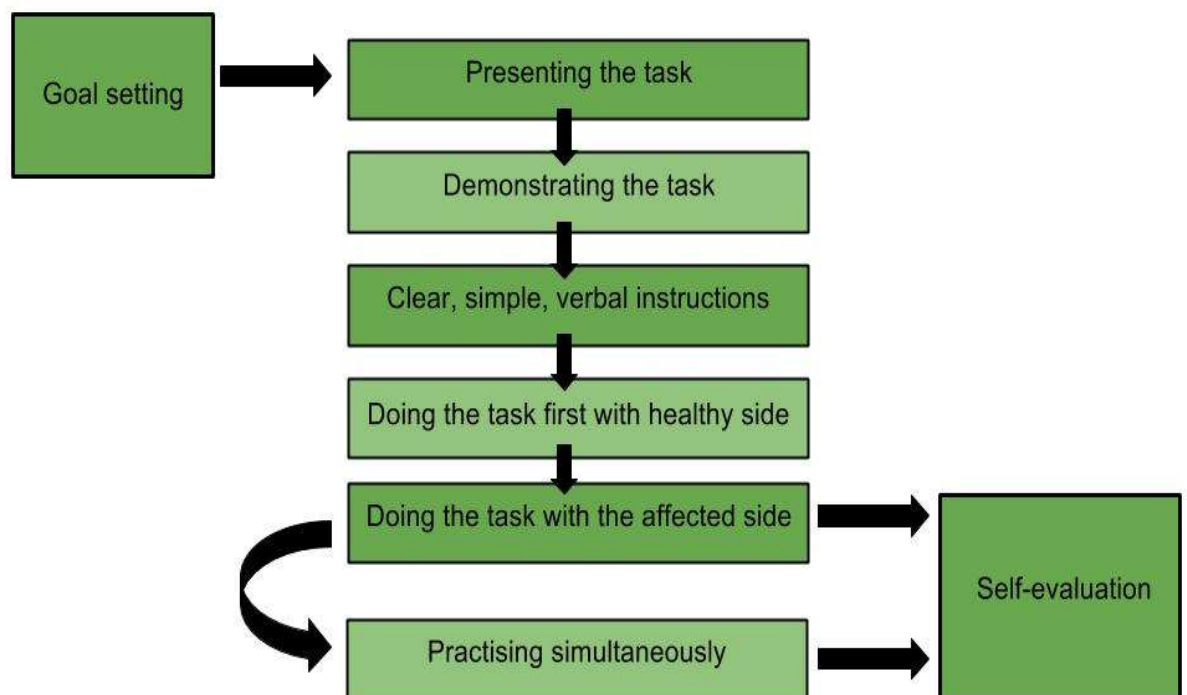


Figure 6. Chart for the therapy process for a motor control rehabilitation

4 Recommended methods

KNGF-guideline describes the currently suggested methods for upper extremity rehabilitation in the Netherlands (Veerbeek et al. 2014, 37–44). Table 2 compares all the methods that are recommended by KNGF. The recommendation is based on scientific research. The methods with a lack of controlled studies were left out from the table. The methods pointed out in the table were searched from the Cochrane database to find the most recent reviews. Cochrane is a global network of health care related professionals whose goal is to provide high-quality evidence-based research results (About us 2016).

Every method is rated based on the research question *What is an effective way to rehabilitate fine motor control after a stroke?* Some of the methods support the fine motor control rehabilitation only indirectly by easing the pain or the position of the arm, shoulder and hand. This is why despite the headline *Interventions to improve dexterity*, only the methods with active fine motor control relearning were selected in the *Fine motor skills*-category. The column *Active* is marked when the method requires volitional movement of the client. *Effectiveness* of the method is proved by scientific research. From these methods, *(Modified) Constraint-Induced Movement Therapy and immobilization* and *Virtual reality training of the paretic arm and hand* met the wanted features.

Table 2. Upper extremity rehabilitation methods for dexterity (Veerbeek et al. 2014, 37–44)

Interventions to improve dexterity	Fine motor skills	Effective	Active
Bilateral arm training			x
(Modified) Constraint-Induced Movement Therapy and immobilization	X	X	X
Robot-assisted training of the paretic arm		x	x
Virtual reality training of the paretic arm and hand	X	X	X
Electrostimulation of the paretic arm and hand	x	x	
Training muscle strength in the paretic arm and hand			x
Interventions to improve the somatosensory functions of the paretic arm and hand		x	
Circuit class training for the paretic arm	x	x	

4.1 (m)CIMT and immobilization

CIMT or mCIMT ((modified) Constraint-Induced Movement Therapy) is a therapy form where the non-affected hand is immobilized. After this, the training includes a large number of repeats with the affected hand. The client is trained intensively for

several weeks only with the affected hand. This method is also described with the term *forced use*. The clients with motor impairments in their upper extremity tend to do everything with the non-affected side, even though the paretic upper extremity would have the potential to do the functions. The meaning of this method is to prevent the *learned non-use* of the paretic arm. (Veerbeek et al. 2014, 39.)

The original CIMT is the most intensive form with immobilizing the non-affected arm for 90 % of the waking hours. Training with task-oriented repetitive is performed every day for six hours and only using the affected arm. The training lasts 2-3 weeks. Immobilization is performed with a mitten or a sling, although the mitten is safer to use (for example in the case of falling). The modified versions of CIMT include several stages with less time for training. The training should be started with a lower intensity and gradually increase the level towards more intense training. (ibid., 39–40.)

Cochrane review on CIMT

The Cochrane study shows conflicting results for CIMT and mCIMT. The study released in October 2015 differs from a previous meta-analysis made by the Cochrane team. The earlier study suggested that CIMT is beyond effective compared to the traditional methods. The newer research shows that the ability to use the affected arm improved, but did not have an effect for ADL -functions, such dressing up, eating and toileting. The long-term effects of CIMT are still being discussed. (Corbetta, Sirtori, Castellini, Moja & Gatti 2015.)

4.2 Virtual reality training

Virtual reality training involves computer based technology, which gives the client an opportunity to move in a virtual environment. The virtual reality can be *immersive* or *non-immersive*. The immersive virtual reality involves 3D-glasses for creating an illusion of being actually in another environment. The non-immersive method means

showing the virtual environment from a screen or a monitor. The client receives feedback on their performance. The favorable elements of virtual reality methods are challenge, repetition, context-specificity and the enjoyment of the exercise. (Veerbeek et al. 2014, 30–31.) The recommendation is to train 30 minutes and five days a week for two weeks (ibid., 42).

Cochrane review on virtual reality

Laver, George, Thomas, Deutsch and Crotty (2015) compared virtual reality systems to no rehabilitation and an alternative rehabilitation method for upper extremity function and activity to determine the efficiency of virtual reality methods. They found that interactive systems, gaming and virtual reality may be beneficial for the recovery of ADL -functions when it is used to increase the overall therapy time. More controlled studies are needed to determine the long-term benefits and evidence for grip strength and global motor function. The more detailed beneficial features of virtual reality are still unclear. (Laver, George, Thomas, Deutsch & Crotty 2015.)

The studies gave favorable results for virtual reality for upper extremity rehabilitation. Also, Laver et al. (2015) found a slight improvement in the recovery of ADL -functions with virtual reality methods compared to the conventional therapy. Nevertheless, the review was executed with small amount of studies (37 trials, 1019 participants) and therefore, the results should be carefully interpreted. (ibid.)

4.3 Other favorable methods by controlled studies

Pollock et al. (2014) made a data-collection analysis of the methods used for improving upper extremity after a stroke. The comparison was between interventions with no treatment, usual care or alternative methods. The primary focus was upper limb function and secondary focus on motor impairment and ADL –performance. (Pollock et al. 2014.)

The evidence stays insufficient despite the controlled review of Pollock et al. (2014). Based on the reviewed 1840 records to make conclusions on the most effective intervention for upper extremity rehabilitation, Pollock et al. (2014) found moderate-equality beneficial evidence for the following methods:

- CIMT
- Mental practice
- Mirror therapy
- Interventions for sensory impairment
- Virtual reality

The authors emphasize that the moderate-equal results are not fully comparable and future research is essential. There is also a need for controlled studies for these following methods:

- Repetitive transcranial magnetic stimulation (rTMS)
- Transcranial direct current stimulation (tDCS)
- Hands-on therapy
- Music therapy
- Pharmacological interventions
- Interventions for sensory impairment
- Biofeedback
- Bobath Therapy
- Electrical stimulation
- Reach-to-grasp exercise
- Repetitive task training
- Strength training
- Stretching and positioning

(ibid.)

5 Conclusions on the evidence-based research

The main focus of the literature and theory research was to understand the field of fine motor control rehabilitation and to get theory based answers for the research problem of the thesis.

The most effective way to rehabilitate fine motor control after a stroke is to give therapy at least three times per day in an environment which is meaningful for the client by a professional who has the education for rehabilitation. Every client should have individually customized rehabilitation program based on their personal goals and the level of their skills. Feedback and self-evaluation are the keys for building motivation for a sufficient amount of repetition. Repetition is the key for relearning fine motor control.

The challenge behind determining the most efficient method to rehabilitate fine motor control is the amount of compared features. To get reliable data from the studies, the same methods should be used with the same kind of CVA type and the progress should be measured with the most reliable measuring tools. Finding the target audience with an adequate amount with these requirements is a major mission. Also, the environments should be comparable.

Because of the lack of controlled studies, there is no evidence to tell which rehabilitation method suits each phase and each level of CVA. However, the most recent guideline in the Netherlands, KNGF, recommends CIMT and Virtual Reality as methods. Based on the most recent Cochrane studies, CIMT does not reduce disability in ADL -functions. The Cochrane studies show some careful favorable evidence towards *virtual reality, mental practice, mirror therapy, interventions for sensory impairment and relatively high dose of repetitive task practice*, which all need more investigation.

What comes to the objective measuring tools, there is no clear answer. The rehabilitation progress should contain self-evaluation of the client, but the unambiguous measuring tools for objective data are not determined, and vary by the profession.

6 Human-centred research

The human-centred research phase included an online ethnography, user interviews and observation. The main wanted outcome was qualitative data on the user/users with information about the environments of the users. The goal of the human-centred research is to recognize the user's environment, patterns, motivations and goals (desired, specific outcomes) (Cooper et al. 2014, 24). Human-centred approach is used to design highly usable systems and products, which has a huge positive impact for social and economical benefits (ISO 9241 – 210:2010, 2010, 17). Keeping the product development process iterative (figure 7), the uncertain features can be eliminated in an early phase. Iteration minimizes the risk of not meeting the user requirements (ibid., 21).

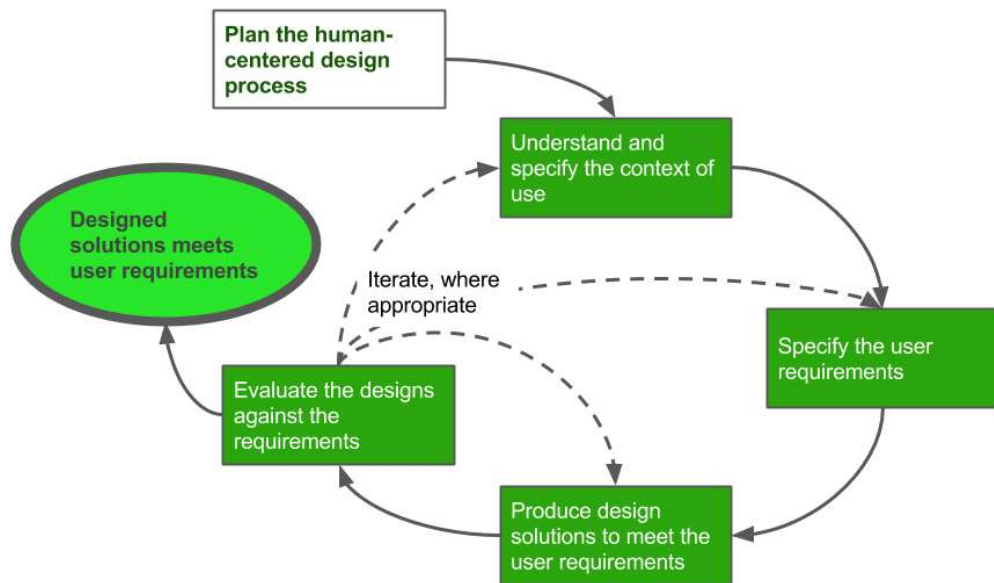


Figure 7. Human-centred design process with iterative structure (ISO 9241 – 210:2010, 2010, 29)

Understanding the goals of the user is more important than listing the tasks they are currently performing. Tasks can change relatively fast, but goals are driven by inner motivation. Capturing the inner motivation of the users will more likely provide long-term-use. Understanding the goals also provides an asset in competition. Tasks are easier to define, but finding the user’s inner motivation and goals will provide more usable product. (Cooper et al. 2014, 44–45.)

6.1 Defining the end-users

End-users are all of the people who are using the solution or the device. After recognizing the users, their characteristics are listed. This list can include information about the users’ knowledge, skills, experiences, education, training, physical qualities, habits, preferences and capabilities. (ISO 9241–210, 2010, 31.) Defining the us-

ers before the field study is important for forming a *hypothesis* on the people that are about to be observed (Cooper et al. 2014, 46).

6.1.1 Stroke survivor

CVA may cause all or part of the following impairments:

- **Visual issues:** neglect, agnosia and difficulty processing visual cues
- **Emotional issues:** lability, apathy, irritability, low frustration levels, depression, impulsiveness, anxiety about poor performance and difficulty for expressing positive emotions
- **Behavioral issues:** impulsive or slow and cautious style
- **Cognitive issues:** confusion, short attention span, loss of memory and executive functions, lack of abstract reasoning, difficulties in following a pattern and synthesizing information, difficulties in problem-solving (confusement or disorganization), inability to self-correction, stiffness of thought, difficulty planning and sequencing movements
- **Motor issues:** hemiparesis, hemiplegia, difficulty sustaining a movement, pain, tremor, apraxia, hemisensory loss, alterations in tone and abnormal synergy patterns
- **Memory impairments**
- **Language and speech issues:** aphasia, difficulty processing verbal cues and commands
- **Difficulty with processing delays**
- **Difficulties with naming colours**

(O’Sullivan & Schmitz 2007, 710, 720–721, 725.)

The effects on upper extremity

The complications after stroke for upper extremity are loss of voluntary movement, immobility, edema, pain, limitations in shoulder movements (flexion, abduction and external rotation), contractures, elbow, wrist and finger extensors, and forearm pro-

nators. Disuse of the upper extremity can cause atrophy and muscle weakness. (O'Sullivan & Schmitz 2007, 725–726.)

6.1.2 Occupational therapist

From all the professionals the stroke survivor encounters, occupational therapist is the one who focuses on fine motor control rehabilitation. The occupational therapist supports the client's engagement towards meaningful life that affects health, wellbeing and life satisfaction (McHugh Pendleton & Schultz-Krohn 2013, 5). The term *occupation* is highly related with *activity*. Occupations are viewed as activities in which the client engages, gives meaning to their life and what they look forward to be engaged with (goals). Occupational therapists are focusing on main eight categories to improve their client's quality of life; ADL-functions (person's own body care), rest and sleep, work, leisure, social participation, activities associated with play (entertainment, enjoyment, amusement or diversion), education and instrumental activities of daily living (home and community related; more complex interactions than ADL). (ibid., 6-7.)

6.2 Online ethnography

The online ethnography is a research done through internet. The method is one of the most significant and natural approach for investigating different virtual forums and groups, even though it is not commonly used yet. Its aim is to increase understanding towards the user. It can be executed with passive or active methods; the researcher only observes the conversation or directs it towards the wanted direction. It is ethical to introduce the role of the researcher and the meaning when joining the groups or creating one. (Tuulaniemi 2013, 67-68.) Online ethnography was chosen one of the methods because of the popularity of the social media and an opportunity to reach as many stroke survivors as possible without a language barrier from all over the globe.

By the advice of Finnish foundation for CVA (Aivoliitto ry), Facebook turned out to be a forum for the purpose of online ethnography. Through a Finnish Facebook-group, two other international groups were discovered. The participation in the groups for research purposes was ensured from the group admins before joining the group and starting the observation.

The discussion was followed in two international and one Finnish Facebook-groups (Stroke Survivors, The stroke exercise and rehabilitation group and Aivoverenkiertohäiriöt (AVH)) (table 3) from September 2015 until the beginning of January 2016. They provide a forum for reaching other people, getting peer-support and sharing their story. The stroke survivors shared links to their blogs and videos, which also provided useful information.

Table 3. The activity of groups for the online ethnography (amount of members 13.1.2016)

Name of the Facebook-group	Members	Amount of members	Activity (posts/day)
Stroke Survivors	International	3532	more than 100
The stroke exercise and rehabilitation group	International	2093	7
Aivoverenkiertohäiriöt (AVH)	Finnish	217	2

6.2.1 Passive and active observation

The conversation and activity in the groups were mostly observed by passive methods. The posts about fine motor control was the main focus, but the overall comments and conversation was also followed. To create conversation about the goals of recovery between the members of the groups, three polls were presented. Two polls were posted on a wall of the biggest group (Stroke Survivors - 3449 members at the time of the poll). One poll was performed in the Finnish group. The results were gathered based on the comments and the “likes” of the comments. For example, if one comment had three “likes”, the total amount of answers was 4. The results of the polls are presented later in this thesis.

The poll questions:

- *What is your main goal in your recovery?*
- *What is your main goal in arm/hand recovery?*
- *Mikä on päätavoitteesi kuntoutuksessa aivoverenkiertohäiriön jälkeen?*

6.2.2 Results from online ethnography

The Facebook-groups are *safe-spaces* for the stroke survivors to switch experiences. They feel strongly that “healthy” people do not understand them and that causes feelings of frustration and anger. The biggest cause of frustration is that disability is not always visible. The stroke survivors get a lot of comments concerning their “normal appearance” but “strange and changed behavior” from their family and friends, which creates misunderstandings. The members of the group support each other by positive comments, understanding and sharing their similar experiences.

The stroke survivors are not filtering their posts; all negative and positive information is shared. Some of them suffer from depression and feel that they have finally found a forum to share their story through the Facebook-groups. They have found more understanding from people in the groups (which they have never met) instead of their loved ones.

One of the biggest changes in their lives is that they cannot filter the information and stimulations around them. This is why they avoid going to public places or events. When they are having a conversation with someone, they might just say “STOP!” all of a sudden, because the amount of new information gets overwhelming.

They have strange sensations in their affected arm and hand. Some of them have no feeling at all and some have highly sensitive fingertips, that even the smallest touch creates pain. Also, the sensations of hot and cold are different; some things that used to be warm now feels burning hot and cool objects freezing cold.

The stroke survivors are lacking of knowledge. They are asking from the other stroke survivors of information for the period of recovery, methods for rehabilitation and even prognosis for their own diagnosis. They are also desperate with their recovery, which makes them exposed to hoaxes. They are warning each other about the scams. Another observation was about their way to celebrate their “birthday” based on the day of the CVA and congratulate each other. They also define their *age* based on the time past after the CVA.

Rehabilitation is not consistent because of the memory impairment. They simply forget to rehabilitate their upper extremity. When they do rehabilitate their fine motor control, they are using all the things they can find from their home; handling coins, macaronis, buttons and candy. The stroke survivors use stopwatch to test themselves. Taking time is also an objective measuring tool for the progress.

6.3 User Interviews

Interview is an easy and quick way to gather big amount of data. The interview includes usually filming, photographing or audio recording. Considerable things in in-

interviews are reliability of the results and anonymity of the interviewee. Interview can be structured or unstructured. (Anttila 1998.)

Interview, as any method, has also risks and downsides. The method requires certain qualities from the researcher; personal input, cooperation, well-aimed questions and empathy. Sometimes the interviewee does not want to talk about the things that are interesting from the researcher's point of view. Also communication, lingual and understanding problems are possible. (Anttila 1998.) Reading between the lines is one of the most important things. Interviewers has to be careful not to implement their own assumptions, attitudes or interpretation to the answers. (Cooper et al. 2014, 74–75.)

Nine out of twelve interviews for the therapists were executed in the interviewee's own environment, which adds the possibility of revealing the important details and behavioral activities (Cooper et al. 2014, 74). The interview has to be well planned with the following principles:

- Executed in the environment of the user
- Fixed questions should be avoided
- The researcher is *an apprentice*
- Use of both open- and close-ended questions to direct the discussion
- Focus in goals instead of tasks
- Avoid making the user as the designer
- Technology talk is not relative
- Encourage storytelling
- Ask show-and-tell questions
- Avoid leading questions

(Cooper et al. 2014, 81.)

6.3.1 Interviews for the stroke survivors

The stroke survivors were reached through the online ethnography to understand the stroke recovery process from the user's point of view. The topic of the research was introduced in all of the three Facebook-groups and asked from volunteers. In total of 55 people "liked" or commented the post. The interview (attachment 2) was sent for all of them with a Facebook-message. 23 stroke survivors from ten different ethnicities participated.

6.3.2 Interviews for the therapists

Because the health care staff has a big role in rehabilitation process, it was necessary to get information about their perspective. To understand the nature of the work of occupational therapists and physiotherapists, in total of nine occupational therapists, two physiotherapists and one occupational therapist student were interviewed. The participants were Finnish and Dutch. Three of the interviewees works in a hospital setting and eight in a rehabilitation centre.

The face-to-face interviews were loosely structured by the principles mentioned above. The time varied between 15 minutes and 4 hours. Six of the interviews were made in between of the observation. The interviews for the Finnish therapists working in a stroke recovery ward (attachment 3) were conducted via email.

6.3.3 Results from the interviews

Stroke survivors

The interview for the stroke survivors was about their recovery process so far, the methods they have used for rehabilitating fine motor control (attachment 4), their enjoyment in life (attachment 5) and their main goal in recovery. The goals are presented later in this thesis. Some of the stroke survivors did not answer all the questions of the interview.

All of the 23 stroke survivors had a different process of rehabilitation and recovery. The locations were the same (hospital, rehabilitation centre and then home) but the times spent in these locations varied a lot. The most significant difference was the time when the fine motor control rehabilitation started. One of the 23 answered that they received fine motor control rehabilitation the next day after stroke and four of them have never even started. The rehabilitation methods varied from CIMT-course to independent learning.

The therapists

During the interview it became very clear that all the therapists enjoy the most working with their clients. The group and individual therapy methods are based on the client's individual goals determined by an interview, observation and tests. However, in a hospital environment, setting individual goals is not as important as defining the level of the CVA. If the client is unable to communicate or express themselves in the beginning, the goals are set with the health care staff and the family members. In a hospital, it is common to use objects from the current environment, such as opening and closing a roll-on deodorant. The most long-term location after the hospital care is a rehabilitation centre (3-16 weeks post stroke)

The stroke survivor has to fulfill these criteria before the fine motor control rehabilitation can begin:

- Sufficient cognitive skills
- Volitional movement of the hand
- Freedom from pain
- Motivation for rehabilitation (without motivation the therapy is useless)

One therapist felt challenging in their work to distract the client attention of the performance, if the client is very insecure of their skills. The performance might improve when the client is not so focused on their impairments. Also, the fine motor control

in acute phase is disturbed with other examinations, therapies and family member's visits, which postpones the guided therapy even to the next day.

All the interviewees were frustrated with the current technology, mainly with the patient file system. The therapists are working a lot with pen and paper, for example when making the tests for the clients. Afterwards, the results are reported to the patient file system, twice. The report for the nurses is simpler, and more concrete and detailed description is for the doctors.

What makes all twelve interviewees feel powerless, is the lack of knowledge among the family members and health care staff (nurses). They wish they would have more time to educate people that are involved with the client. Information would increase understanding towards the importance of rehabilitating the fine motor control and so they would become committed for the recovery process. Seven out of twelve therapists were struggling with the feeling of inadequance because of the lack of time, resources or outdated knowledge. They are motivated to learn new methods and theories about fine motor control rehabilitation, but only three of them has the opportunity for more advanced studies.

The tests are part of the diagnostics and evaluation of the process. The occupational therapist's input is one part of the multi professional cooperation when the next step of the client's rehabilitation process is discussed (for example transfer to the next location: rehabilitation centre or home). One therapist explained that their opinions are sometimes only based on "gut-feeling", because there are no consistent "proof" about the functional skills of the client. Sometimes the gut-feeling is hard to explain without concrete measuring results, which makes it hard to convince the doctors that the client is or is not ready for example to transfer to the next location. The answers from the interviews were gathered into one table (attachment 6). The tests used in all five locations (A-E) are presented in the table 4.

Table 4. In total of 12 different tests by the five different locations (A-E).

Location	SULCS	9HPT	JAMAR	UAT	Drawing	FAT	Tactile	Position	TTSE	MI	EmNSA	MAS
A												
B												
C												
D												
E												
In total	4	3	2	2	1	1	1	1	1	1	1	1

The explanations for the tests: SULCS: Stroke Upper Limb Capacity Scale, 9HPT: Nine Hole Peg Test, JAMAR: Hand dynamometer, UAT: Utrecht Arm/Hand Test, Drawing: Drawing a picture (also for defining cognition), FAT: Frenchay Arm Test, Tactile: TactileTest, Position: PositionTest, TTSE: Touch Test Sensory Evaluator, MI: Motricity Index, EmNSA: Erasmus modified Nottingham Sensory Assessment, MAS: Modified Asworth Scale.

The contradictory answers considered using creativity in work. Five out of twelve therapists said that it is challenging to come up with new rehabilitation methods, when one therapist mentioned creativity one of the things they enjoy. There was also difference between the Finnish and Dutch therapists' answers about when the fine motor control rehabilitation is started; with or without doctor's referral. Although, all of the interviewees agreed, that the rehabilitation is started as soon as possible. Four out of the twelve therapists had a different idea about how often and how much the fine motor control should be practiced. These differences were also between the colleagues in the same location.

6.4 Observation

The observations are focused on the human behavior and interaction. It is both verbal and nonverbal. The observations can be recorded by notes, photographs, audio recording or taking a video. The observation can be structured or free observation and the role of the observer can change during the process. (Jyväskylän yliopisto 2016.) Observation gives more genuine information about the behavioral patterns than an interview, because people are not aware all of their actions (Cooper et al. 2014, 43).

By using Facebook, Google and the contacts of SilverFit, in total of 35 possible locations of occupational therapy was found. All of these locations were reached by an email, a phone call or a voicemail in addition to introduce the subject and asked for an opportunity for observation. Out of the 35 locations, five facilities agreed. From these five locations, four of them included observing the actual fine motor control therapy session.

The observation followed a process by David Travis (2010). The method includes five stages: creating a focus question, recording the session, taking photographs, taking detailed notes and making a summary immediately after the observation. (Travis 2010.) From the method only the voice recording was excluded. The voice recording was not allowed in the locations. When going to the observation, the therapists were sometimes unsure about the researcher's role in the situation, but after explaining they were okay with the matter. Notes and remarks were made by hand during the observation. The disturbances which affected on the therapy session were also listed. All of the sessions included the researcher's presence as a disturbance. Pictures of the locations and the therapy room were taken after the sessions to understand and describe the environment where the rehabilitation takes place. The method in each location was free observation.

6.4.1 Observing fine motor control therapy

The observation included seven individual and two group therapy sessions. The focus of the observation was on the interaction between the client and the therapist. The attention was aimed to the way the therapist gives instructions and feedback, and how much the client needs more information about the task. The challenge with the observation was to keep up with the situation and to write everything down, for example all the tasks performed (attachment 7). Because motivation is the key for repetition, and so the key for recovery, the atmosphere and the feedback had a lot of attention during the therapy sessions.

6.4.2 Results from the observation

These results of the observations are a summary from four different locations. The data is based on the field notes. Different locations had different ways to act, so not all therapists acted the same way. The aim was to find problems and differences with the theory research. The approach for the observation was phenomenological, which suggest that one individual act is an example from a common procedure. This kind of approach also focus simplifying the observed target without prejudice or attitudes. (Eskola & Suoranta 1998, 5 section 4.)

Individual therapy

In a hospital setting, the occupational therapist used 6-9 minutes for transferring data from the patient file (the computer) to a paper note for the therapy for each client. The individual therapy session lasted 30 minutes. The guided individual therapy included 2-6 different tasks highly related to ADL-functions, but also games and repetition needed tasks (attachment 7). Sometimes the therapists asked from the client which things they would like to practice, but other times the exercises were pre-chosen by the therapist. In some cases, only the affected hand was trained. The therapists gathered information about the functional skills and the overall condition

of the client by interviewing, asking self-evaluation and observing. The client told a lot of their concerns, progress, plans and thoughts to the therapist.

Group therapy

From the two group sessions observed, the other lasted 60 minutes. It contained one shared goal (making pasta salade together) that included multiple tasks. During the group therapy, there was a major difference between the levels of the skills of the clients. The atmosphere was supportive and each participant got the amount of help from the therapist that they needed, even though they had to wait their turn for a while (the group session had five participants and three therapists). After the therapy, there was a discussion led by the therapist of how they have exercised independently their hand since last group therapy (during the past week).

In another location, the group therapy included individual tasks without a shared goal. The group therapy was basically individual therapy done together with other stroke survivors around one big table, like “workshops”. The five participants were in the situation for different amount of times between 15 to 60 minutes.

Feedback

The client needed a lot of guidance and support from the therapist. The feedback depended sometimes on the client’s skills; if the client could perform the given task, the feedback was positive and the atmosphere was supportive. In other cases the feedback was either neutral or negative. The clients got exhausted by trying hard to work with the affected hand. They easily gave up and continued the task with the healthy side. The therapist said during the session comments for the client such as “you are tired” and “I can see you are tired”. One of the therapists manipulated the given tasks by “finishing” them after the client tried it first themselves. The client was not aware of their own skills or progress and some of them were saying “I can’t do it” a lot during the sessions. Also, there was a negative and frustrated attitude towards long-term clients, because of the lack of positive rehabilitation results.

Tests

Four individual therapy out of seven included testing. The Nine Hole Peg -test and drawing a picture was both done once out of the four sessions, the SULCS was performed three times out of four. In one out of the four therapy sessions, that included testing, both SULCS and the Nine Hole Peg -test were performed for the same client.

Disturbances during the therapy

- The therapist's phone was ringing
- Someone opened the door without any warning
- The therapists were talking to each other during the therapy
- The clothes of the client were too tight and caused pain
- Different kind of medicinal devices restricted the movement (the RR-meter, the SpO2-meter, EKG-pads, the IV-cannula and the patient monitor)
- The RR-meter started to measure the blood pressure (this happened 6 times during one session)
- An examination of the patient interrupted the therapy session
- The patient monitor was beeping
- The door was open to the hallway and people were passing by
- Noises from other rooms; the client asked about them
- Magazines and other objects on the table took the client's attention away from the task of rehabilitation
- Family members were in the room
- There was not enough space for the client to function because of the clutter on the therapy table
- The client had no pants and they tried to pull the shirt down during therapy
- The phone of the client was ringing
- Someone entered the room
- Observation situation; unfamiliar person (the observer) was in the room

6.5 Defining the context of use

One major part of human-centred design is determining the context of use. This should be stated in the user requirements to understand the conditions of the user and specify the design (ISO 9241–210, 2010, 31). Context of use is an essential input for the design process (ibid., 21). This considers the technical environment with hardware, software and materials. The context of use also contains physical, social and cultural aspects. From the physical features, thermal conditions, lighting, spatial layout and furniture should be measured. The cultural and social features include work practice, attitudes and organizational structure. (ibid., 31.) Context of use reveals needs, problems and constraints that usually would be overlooked (ibid., 29).

Even though home-environment is also one of the contexts-of-use, it was excluded because of the focus on the interaction between a stroke survivor and a therapist.

6.5.1 Hospital environment

The hospital setting was determined by a brainstorming session online through a Facebook-conversation between eight Finnish nurses and one institutional cleaner. The participants are former colleagues of mine who are currently working in a hospital environment. After introducing the subject and the purpose of the brainstorm, they were asked to list things that might be in a hospital room. These brainstorming results were translated into English and then categorized because of the large amount of the answers. The categories are people, medicinal devices, client's personal belongings, things that you might find from the hospital bed and from the night table and furniture (figure 8). The list of the words is in attachment 8.

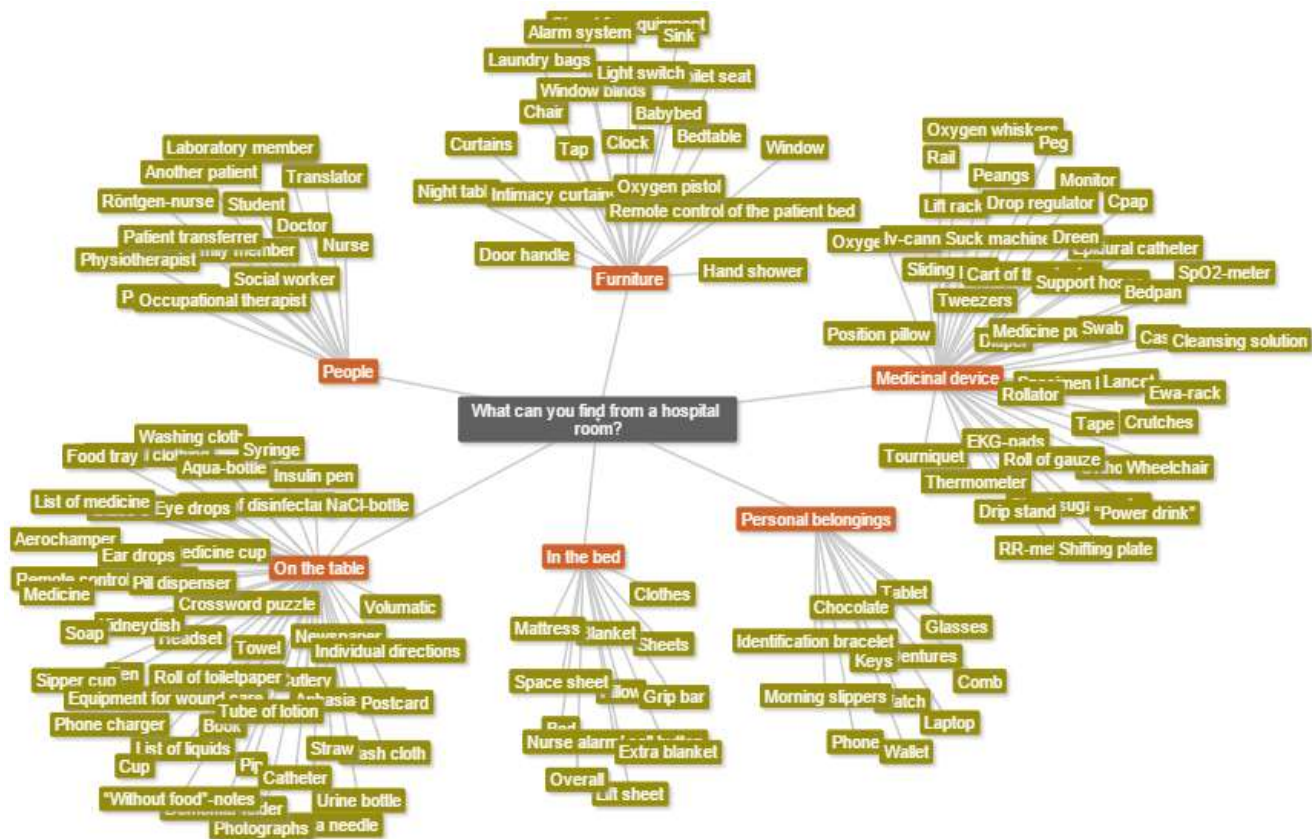


Figure 8. Results from the brainstorming-session - What can you find from a hospital room?

6.5.2 The rehabilitation centre

The rehabilitation centre environment is defined by the pictures taken during the observation visits. The main focus of the pictures were the tables, because the rehabilitation took place in front of a table. I total of five tables for individual therapy was photographed. From these tables four were unorganized and full with unrelated objects (figures 9-10) from the fine motor control therapy's point of view. One of the five was very small (figure 11). The table for group session was unorganized, but at least all the objects were related to the therapy session (figure 12). All the photos respects the anonymity of the location, the clients and the participated therapists.



Figure 9. A therapy table from occupational therapy room



Figure 10. The therapy table can be this small



Figure 11. The table in client's room right after fine motor control therapy.



Figure 12. A table after group therapy session

6.5.3 Results of the context-of-use

The hospital and the rehabilitation centre can be highly unorganized environments; physically and schedule wise. The hospital and rehabilitation centre have their own schedule for the day, which is rhythmmed by doctor's visits, therapy sessions, visiting hours and mealtimes. Sometimes there are delays and unexpected changes caused by the changed state of the client or other not assumed event such as a fire alarm, flood, resuscitation, a sick leave of the therapist, threat of violence or arrival of a new client (attachment 6). The changes might leave the client unable to receive guided rehabilitation.

The hospital rooms are filled with different objects. There is no extra space on the levels (nightstand, chair, table, window ledge, etc.) because of all of the space is used for medicinal and health care purposes. The tables for the rehabilitation session are different sizes and include a lot of non-related objects from the therapy's point of view. Both environments, hospital and rehabilitation center, have a high focus on hygienic aspects. Thus, all the used materials, that has a contact with a user, are individual (single-use) or capable of disinfection.

7 Conclusion of the human-centred research

The main focus of human-centred research was to understand the goals of the users driven by their inner motivation. However, the interaction and the relationship between the stroke survivor and the therapist revealed problems in the field, of which recognizing was incredibly important.

The therapists have a limited time with one client per day. Sometimes the guided therapy is postponed multiple times because of other therapies and examinations, fatigue or the motivation of the client, or a changing situation. The execution of the therapy relies on the impossible schedule of the therapist in the changing environment. Therapy sessions are executed when and if the therapist has the time. This is why the emphasis in the training upper extremity and fine motor control is on the individual training during off-therapy times.

The stroke survivor as a user has to fulfil the following criteria before starting fine motor control rehabilitation:

- Sufficient cognitive skills
- Volitional movement of the hand
- Freedom from pain
- Motivation for rehabilitation (without motivation the therapy is useless)

The environments for individual training are the hospital, a rehabilitation centre and the home. The individual training is performed while sitting in a wheelchair or in front of a desk, lying in a hospital bed or standing. The reporting is a huge part of the therapists work, but it was the most frustrating task for the occupational therapists and physiotherapists.

The stroke survivors will not get consistent feedback with encouragement from the therapists. They are unaware of their skills and performance. This is why the self-evaluation cannot be the only measuring tool. Facebook is a social and safe place for the stroke survivors. Seeing friends or going to social events is not an option anymore because of the bombard of the unfiltered information. They are interested of their recovery, because they rehabilitate themselves and use for example stopwatch to measure their process.

7.1 The goals of a Stroke Survivor

The main goal for each stroke survivor is to rehabilitate back to the state before the stroke, which means independency. More detailed goals for the recovery were determined by online ethnography including three polls and an interview for 23 stroke survivor volunteers. The 156 answers were categorized as hobby, ADL, and family-related answers (figures 13–15). The results of these polls can be used as an inspiration when designing a solution for the fine motor control rehabilitation of stroke survivors.

Hobby-related answers

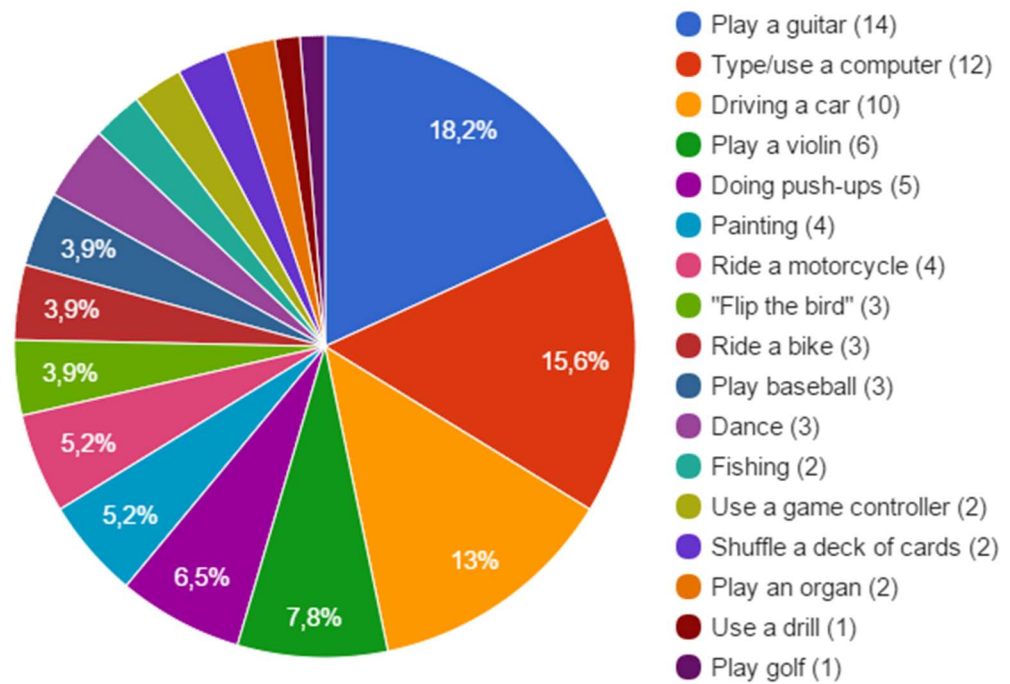


Figure 13. 50 % of the 156 answers were hobby-related (the amount of answers is in brackets)

ADL-related answers

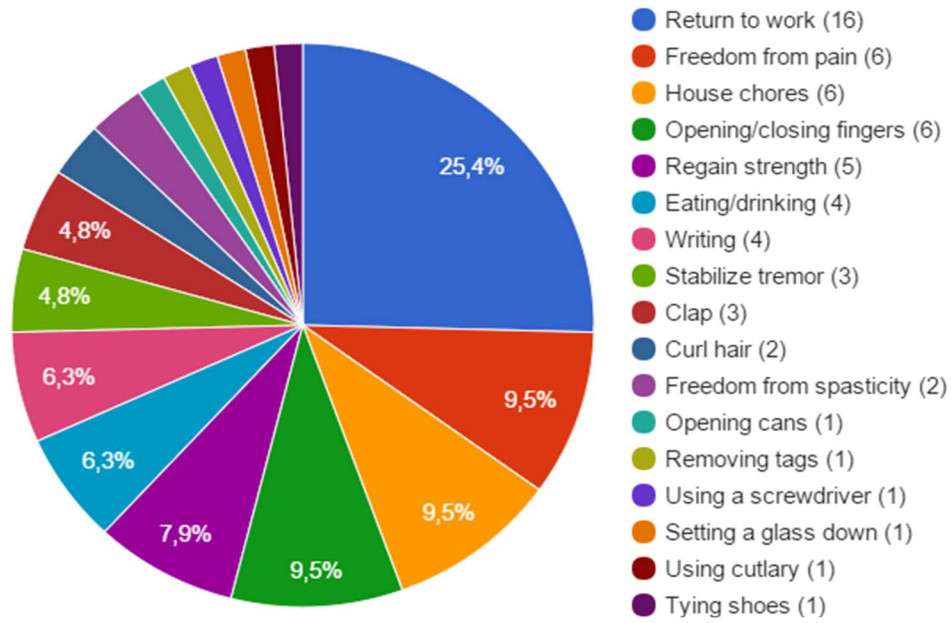


Figure 14. 40 % of the 156 answers were ADL-related (the amount of answers is in-brackets)

Family-related answers

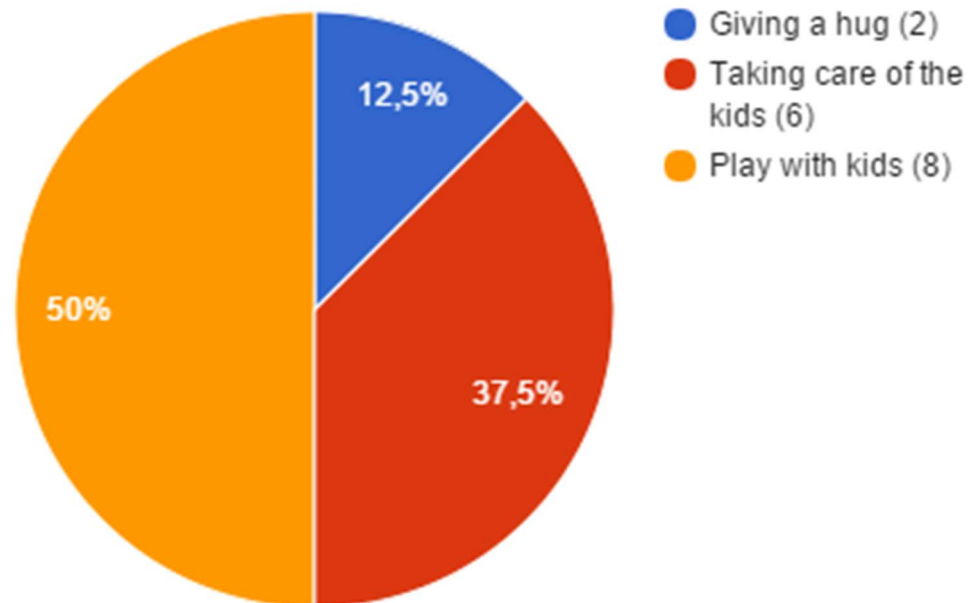


Figure 15. 10 % of the 156 answers were family-related (the amount of answers is in-brackets)

7.2 The goals of an Occupational Therapist

The main goal of an occupational therapist is to succeed in the work that they enjoy. The goal is to rehabilitate the stroke survivor's function to the level that they can go back home safely. There is also a very powerful need to see the progress in the recovery process, to a point where they manipulate the client's results of performance. The most important feedback for the therapist on their work is to see their clients' successful rehabilitation. The challenge is to find time for all the clients and balance between the changing situations.

8 Theme analysis - theory vs practice

The analysis is categorized by themes that are important for the research questions. The analysis is based on a phenomenological assumption that an individual case is an example of the general situation (Eskola & Suoranta 1998, 5 section 4). Theme analysis requires a thorough investigation of the theory and empirical research. Every theme related subject is compared against the results of the research. (ibid., 23 section 4.) Theme analysis suits analysing a practical problem very well (ibid., 25 section 4). Qualitative results are so full of information, that it is hard to decide which things are important to the subject. The risk of qualitative analysis is a statistical approach, which means using words such as "some" and "few" instead of numbers. (ibid., 26 section 4.) Qualitative results and the analysis is only an interpretation of the researcher. The results are exposed to many different interpretation; first when gathering the data, secondly in analysing the results, thirdly when writing the report and finally reading the report. (ibid., 3 section 4.) This analysis focuses defining the problems of the users and the context of use.

8.1 The stroke survivor

The stroke survivor is in a strange, new situation after the stroke. Their whole life has changed all of a sudden. They have lost their independence and self-determination. Also, their personality has changed. They cannot function as they used to and communication is difficult or impossible. In addition, they are in a new environment that is confusing and strange (hospital). This completely life-changing condition brings feelings of helplessness, fear, confusion, depression, anxiety, loneliness, apathy, exhaustion, sorrow and frustration in addition to the physiological disfunctions.

Interaction with the therapist

The experiences with the health care professionals are disappointing which makes the stroke survivors not to trust them. This develops even more negative feelings and hopelessness towards the rehabilitation. The social interaction with the therapist makes a huge impact on the motivation towards rehabilitation. During the therapy it is important to get positive feedback from the therapist. The better their performance is the more positive feedback they should receive. When exercising with non-ADL -related objects, motivation is based on pleasing the therapist and not the stroke survivor's individual goals.

Goals

There were 37 different functional goals for the upper extremity in 156 answers. Even though "friends and family" was the most common answer for enjoyment in life (11 answers out of 23), 50 % from the individual goals for upper extremity were related to hobbies. The main goal for every stroke survivor is to function the same way than before the stroke again, but the more specific goals are highly individual.

8.2 The therapists

All twelve therapists interviewed enjoy working with their clients. Social interaction is the most important thing in their work. The observation revealed more information; the client's skills affect the therapist's enthusiasm towards their work.

Therapy

The guidelines and the theory emphasise the subjectiveness during the therapy. Because it is so important for the therapist to see their client's positive progress, they struggle to maintain realistic results. They manipulate the given tasks by "finishing" them after the clients themselves have tried first. The feedback always has to be supportive towards the client according to the guidelines. During the session one therapist made the client comments for the client such as "you are tired" and "I can see you are tired". Even though the comments might have been a gesture of empathy, from the stroke survivor's point of view, they are hard to argue with when they are coming from *a reliable* professional. There is a period of time after the stroke when the rehabilitation is most effective, but there can be improvement even after many years. Despite this fact, there are negative and frustrated attitudes towards long-term clients, because the lack of positive rehabilitation results.

Difficulties

In the interviews with the therapists, eight out of twelve mentioned the difficult cooperation with the other health care professionals, because of communication problems. Writing the reports was annoying for nine therapists and four of them mentioned the frustrating feeling, when nurses do not read their reports. This might cause the feeling of unimportance, which reduces the motivation. All of the administration and reporting tasks are also away from working with the client.

Tools

The motivation and welfare in the workplace is also dependent on reliable working tools. The guidelines (KNGF, Ergotherapie richtlijn CVA and Revalidatie na een beroerte) give information and suggestion for the tools of rehabilitation. These recommended tools cannot be found in the field or there is no information on how to use them. Three out of twelve therapists said that they are unsure about the effectiveness of their work and that their knowledge is outdated.

Goals

A therapist is motivated by their success in work; successful cooperation with the health care professionals, family members and with the stroke survivors. Their main goal is to rehabilitate the stroke survivor into a stage where they can function in their own home environment safely. Even a more profound goal is to help people. Cooperative clients bring satisfaction and joy to the therapist. Seeing the progress of their clients is the most important feedback in their jobs. Providing the feeling of success in their work is a work welfare issue.

8.3 Exercises

An individual therapy session lasts 30 minutes and a group therapy session 60 minutes. The therapist has a limited time with one client per day, even though guidelines recommend giving guided therapy multiple times per day. The therapy sessions do not follow the recommended path in practice.

Tasks

The tasks for fine motor control rehabilitation are meaningful for the client when they are practicing with the therapist. The therapists give verbal cues to the client, but the visual cues are not consistent during the therapy and there is very little use

of tactile cues. Individual practicing is based on copies of certain exercises. Out of 33 different tasks shown in the copies, only 10 matched the goals of the stroke survivors. The exercises for the individual training should be meaningful for the client. Despite this fact, individual instructions are basic, boring and most likely not related to ADL -functions.

Methods

The observed therapists used conventional methods instead of alternative, recommended interventions. The use of these interventions are unclear for the therapists. For example, four of the therapists told that mirror therapy is used only when nothing else helps, and the attitudes towards the method were vague. Mirror therapy equipment was found in two out of five locations. CIMT or (m)CIMT is not used in the five locations that were observed and only one stroke survivor mentioned that as a rehabilitation method. Also, use of virtual reality was never mentioned in any of the interviews or came up during the observation.

8.4 Rehabilitation process

Based on the stroke survivor interviews, all of them had a different process of rehabilitation and recovery. The locations were the same (hospital, rehabilitation centre and then home) but the times spent in these locations varied a lot. The most significant difference was the time when the rehabilitation started. One answered that they received fine motor control rehabilitation the next day after the stroke and four had never even started. Rehabilitation methods varied from CIMT -course to independent learning.

One reason for this variation is the level and type of CVA, which seems to be very individual. Also, the years of the stroke varied with 40 years. This can be one of the reasons for different rehabilitation processes, because the guidelines and recom-

mendations have changed during the years. Although, even when comparing the rehabilitation processes in the last five years, there are differences, but at least the therapy started at some point (attachment 4).

8.5 The guidelines

It was not possible to make a full comparison between different guidelines used, because only KNGF -guideline is published in English. KNGF-guideline is aimed at physiotherapists and Ergotherapierichtlijn CVA -guideline for occupational therapists. The Revalidatie na een beroerte -guideline was used by an occupational therapists, but it is unclear, to whom it is aimed at.

Reliability

The guidelines are published in different years which makes the evidence-based methods old in some of them. This reduces the reliability of the guideline and might contribute to the fact that therapists have many assumptions and opinions about the rehabilitation methods and the overall process. Printed guidelines are impossible to keep up to date because of the ongoing studies on their effectiveness. A very good example about this was CIMT and (m)CIMT method, that was strongly recommended in KNGF -guideline (published in 2014) but the most recent Cochrane-reviews (published in 2015) were not so favorable towards that method anymore.

8.6 Measuring tools

There are huge differences in the measuring tool recommendations between these three guidelines. Only ARAT (Action Research Arm Test) is recommended in all of the three guidelines. The most used test in the field, SULCS (Stroke Upper Limb Capacity

Scale), is recommended only in one of the guidelines. In total eight measuring tools that are recommended are not used at all. On the other hand, there are five measuring tools that the therapists use, but which are not mentioned in these guidelines. One occupational therapist following the Hartstichting -guideline even performed SULCS, which is not included in that particular guideline. All twelve therapists are using the stroke survivor's self-evaluation as a measuring tool in addition to observation during therapy sessions.

Table 5 compares these measuring tools in the three guidelines (KNGF (Veerbeek et al. 2014, 23) Ergotherapie richtlijn CVA (Steultjens, Cup, Zajec & Van Hees 2013, 34–47) and Revalidatie na een beroerte (Commissie CVA-Revalidatie 2001, 53)).

Table 5. All measuring tools for fine motor control by the three guidelines

	Guideline (release year)		
Test	KNGF (2014)	ErgotherapieCVA (2013)	Hartstichting (2001)
SULCS			
9HPT			
UAT			
FAT			
MI			
EmNSA			
MAS			
ARAT			

		Guideline (release year)	
Test	KNGF (2014)	ErgotherapieCVA (2013)	Hatrstichting (2001)
Abilihand			
MAL			
BI			
FMA			
SSS			
BF-MS			
Thumb			

The explanations for the tests: SULCS: Stroke Upper Limb Capacity Scale, 9HPT: Nine Hole Peg Test, UAT: Utrecht Arm/Hand Test, FAT: Frenchay Arm Test, MI: Motricity Index, EmNSA: Erasmus modified Nottingham Sensory Assessment, MAS: Modified Asworth Scale, ARAT: Action Research Arm Test, Abilihand, MAL: Motor Activity Log, BI: Barthel Index, FMA: Fugl-Meyer Assessment, SSS: Scandinavian Stroke Scale, BF-MS: Brunnstrom Fugl-Meijer score and Thumb: Thumb finding test

8.7 Context-of-use

Therapy should be performed in a meaningful environment without any distractions. This recommendation is very challenging to follow in the hospitals and rehabilitation centres. Health care staff and therapists are used to a cluttered environment (figure 16). Therapy always starts with organizing the environment. Because one of the effects of a stroke is a short attention span, the objects on the table distract the stroke survivor's focus from the tasks. Also, during the observation for the individual practice, eight out of the 17 distractions were caused by the environment.

Distractions caused by the environment during the therapy:

- The RR-meter started to measure the blood pressure (this happened 6 times during one session)
- Different kind of medicinal devices restricted the movement (the RR-meter, the SpO2-meter, EKG-pads, the IV-cannula and the patient monitor)
- The patient monitor was beeping
- Magazines and other objects on the table took the client's attention away from the task of rehabilitation
- There was not enough space for the client to function because of the clutter on the therapy table
- The phone of the client was ringing
- An examination of the patient interrupted the therapy session



Figure 16. Stroke survivor's room in rehabilitation center after fine motor control session.

9 Final recommendations

These final recommendations focus on solving the challenges in the field of rehabilitation the fine motor control from the users' perspective. These can be solved with a technological solution (in an order of importance):

- Individualism and independence
- Non-visual impairments of the stroke survivor
- Outdated information and knowledge
- Lack of motivation
- Inconsistent or negative feedback
- Lack of measuring tools
- Challenging environment
- The importance of peer support
- The patient file system

Individualism and independence

Independent exercising is the most significant part of the recovery process. Although the guidelines emphasize its importance, it is missing or not done properly because of the recourses and attitudes of the health care staff and the stroke survivors. The instructions for the independent training are not meaningful or the devices and training objects are out of reach. To keep the stroke survivor motivated, the tasks and therapies should be involved with their individual goals. Because there is a different goal for each stroke survivor, it is a huge task to provide the suitable method for everyone. The motivation comes from the information of the progress. A measuring tool for fine motor control movement activity should be universal but still gives individual information personally.

User oriented approach rehabilitation would enforce the feeling of independence and self-determination, which brings the sensation of control. The recovery training

device should be accessible for the stroke survivor wherever they are (lying on a bed, sitting in a wheelchair or in a chair) and all day long. An accessible training device would ensure the rehabilitation for fine motor control in the environment of challenging time management and when the therapist is not available. Technology can give many types of exercises and save time for the occupational therapists to plan the therapy sessions. In addition, technology is always available, because it has no “working hours”.

A strong recommendation is to find a solution in wearable technology. It is easy to put on by any health care member, family member or even the stroke survivor themselves. When practicing ADL -functions for the fine motor control, the hand should be as bare as possible for realistic situations.

Non-visual impairments of the stroke survivor

Despite the fact that fine motor control rehabilitation is a physical disfunction, it is accompanied by multiple non-visible impairments. The brain is damaged because of the stroke, so it cannot filter the relevant information for each situation. This is why the stroke survivor is bombarded with too much stimuli and information. It is very tiring and creates feelings of anxiousness. The solution should include *a panic button* which stops the therapy whenever the stroke survivor wants. This also creates feeling of self-determination, which is highly important for the recovery. It should also include different cues so that each individual could be guided with the most suitable way. Stroke also impairs memory functions. The technological solution could *remind* about the therapy at least three times per day. There is no maximum limit for training fine motor control, but it should be done three times per day. The device should also take *high-contrast design* into consideration as the stroke survivors usually have visual impairments as well.

Outdated information and knowledge

The most recent and reliable information should always be available for the therapists and the stroke survivors automatically. The tasks and therapies, which the technological interface provides, should follow the recent results of highly controlled studies and be automatically updated.

Lack of motivation

Motivation is the key to repetition, and repetition is the key to recovery. To keep the motivation high, the stroke survivors should get reliable and realistic information for their progress with encouraging feedback.

Inconsistent or negative feedback

Luckily, any technological device can be programmed onto a positive note. Technology never gets tired or frustrated, which means excluding the possibility of *not getting along* with the therapist. The solution can also give the therapist direct positive feedback on their work including the indirect feedback they get from the positive progress of their client.

Lack of measuring tools

The device itself should measure the progress and show the results to the stroke survivor and the health care professionals through different interfaces. The most affective measuring method could be researched through evidence-based research and programmed to the interface. Clear figures and even the smallest progress would increase the stroke survivor's motivation and help the health care professionals evaluate when it would be safe for the client to return home or be transferred to the next health care facility.

Challenging environment

The hospital and rehabilitation centre are very challenging environments. It brings requirements for the materials; everything has to be single-use or possible to disinfect. The environment is also cluttered and filled with objects that are needed for the treatment, but in the way of therapy. The guidelines recommends that the environment should be stimuli-free while training. *Virtual reality –glasses or even a helmet* would isolate the extra-stimuli for the training. Some things in the environment could be replaced with *smart technology*, so the objects in the environment would not increase. The solution should take advantage of those objects that already exists in the client's personal rooms. This would reduce the use of space and utilize the objects in the client's environment for practicing. Integration is part of the solution, which means invisibility, accessibility and low threshold for using.

The importance of peer support

Social media is an important channel for the stroke survivors. They are already sharing their stories and progress on Facebook. Social media is the only social interaction for some stroke survivors. The device could offer a sharing option for the most common social media. This would also bring more visibility for the product which would increase the interest and the amount of customers.

The patient file system

The data from the technological solution should be transferred into the patient file system automatically. The therapists can add their observations and thoughts, but the system would give an unambiguous and realistic figures about the activity of the stroke survivor using vocabulary that the health care professionals understand.

10 Suggestions for the following steps

For a successful solution the following steps in Design thinking process are *ideate*, *prototype* and *test*. Before starting ideating, the empirical study should be continued until it does not give any more new information. It would be very important to follow the user for multiple days to understand the daily rhythm in the context of use (hospital and rehabilitation centre). This would also improve the understanding of the environment. Also, it would be very important to contact the locations and interviewees and discuss the results and analysis.

The purpose of ideating is to create as many ideas as possible, because a great amount of ideas increases the possibility of creating an innovation. The key elements of a creating process is to consciously focus on excluding the solutions that are common and have an open mind without criticism. Even though a creative process can be conducted almost in any environment and with any group of people, knowledge and professionalism in the field is advised. Creative process is an individual or a group effort. (Matilainen 2015.)

The principles for the creative process:

- Take your ideas to your customer/employer unfinished
- Have multiple choices and do not push any of them
- Avoid yes/no options
- Listen to the opinion of the customer/employer and learn from the comments
- List the pros and cons equally and realistically
- Be clear and visual
- Have a positive attitude towards the negative comments and encourage to finding solutions to the problems
- Avoid *fancy* words and not related details

- Tell about the existing solutions and the experiences related to them
- Also give credit to others

(Matilainen 2015.)

After a thorough research of context of use and ideating, creating user personas based on real-life is suggested. The concepts from ideating are tested with the user personas using RealityMaps. Only after using the RealityMap -testing in theoretical situations, can the final concept be defined.

When the concept has been selected and defined, it should be tested. Using simulations, models, scenarios, mock-up models and other prototypes, the designers get a better understanding of the interaction between the user and the device. The feedback from the users by observation and interviews gives new insights and deeper perspective for the interaction. The feedback should also be collected following the use of the program (log files), performance data, field reports and defect reports. (ISO 9241–210, 2010, 29.)

From the alternative methods for rehabilitating fine motor control, at least CIMT and (m)CIMT, mirror therapy and virtual therapy should be investigated. Virtual reality platform could be used with the principles of mirror therapy. Using virtual reality for stroke survivors creates a few ethical questions. Is it ethically correct to offer this so called “alternative reality” for the user who is in a state where they cannot express themselves? The virtual reality environment makes the user feel that they are in a *real world* -situation and it can be confronting. However, if there is a scientific proof that imagination is actually correcting the brain damage and helps the brain cells to recover, the use of virtual reality would be a benefit.

The therapists’ attitudes towards technology are positive. One of the therapists was hoping to work with an iPad, in one location they were already using tablets for individual practice for off-therapy and in one location they were using E-LINK, which is a

rehabilitation and measuring tool with features of gamification (Biometrics Ltd, 2015).

11 Discussion

The aim of the study was to determine the most effective methods for fine motor control rehabilitation and understand the users in their environments and the problems they face every day. SilverFit asked for recommendations on what they should take into consideration when designing a solution for the users' problems in the field of fine motor control rehabilitation. The result was a firm guess on the methods that could be used for fine motor control rehabilitation, but the human-centred research provided strong understanding on the users' requirements and goals with the challenging context of use.

The successful parts for this thesis came from the human-centred research process. Interviewing and observing the users provided a huge amount of information about the problems and frustrations that the users face every day. On the other hand, the original goals for this thesis were not reached because of the lack of time and insufficient project planning. The amount of research was underestimated in the beginning. This thesis provides more understanding towards the stroke survivors and the occupational therapists, but the evidence-based research results for the best rehabilitation method should be investigated more thoroughly.

The language issues also affect to the results of this thesis. Insufficient Dutch language skills of the author and the lack of medicinal and scientific vocabulary in English set some limitations to this study. The language barrier with the time restrictions affected the observation as well. The plan was to do free observation at first based

on the theoretical hypothesis, and afterwards structured observation. Still, the free observation gave a lot of information. The language barrier also excluded face-to-face interviews with the stroke survivors in the Netherlands. The results of the interviews are from the Facebook users who could participate in English, but might have different goals and answers than the stroke survivors who do not use Facebook. Facebook users are interested in social media and sharing and getting information from others. The stroke survivors reached through online ethnography were a group that is familiar with computer and social media. This is why they represent just one type of stroke survivors - familiar with computer technology.

The decision to use Facebook was well thought, because it defies the idea of anonymity. Even though it brought a few unexpected situations, it was the most accessible way reaching the stroke survivors. Approaching the stroke survivors required planning and *new tries* as the first questionnaires generated some confused answers at first. The answers for the interview questions were sometimes incoherent, filled with typing errors or even lacking an answer to a certain question. Most of the stroke survivors were happy to tell about their lives and explain more when asked for details. Some of them answered with a long letters and descriptions of their lives, but also apologized the length of their answers. "This became a long letter now that someone is really interested in my life", some people added in their answer.

11.1 Reliability of the results

I gathered a great amount of information on the theory about the research methods for human-centred research, but this was the first time I actually fulfilled them in practice. The lack of experience from the research methods affects the reliability of the results. The evidence-based research was fulfilled systematically and thoroughly, but the answer to the most effective way for rehabilitating fine motor control is not yet provided by the controlled studies or meta-analyses. It needs more investigating.

Even though the stroke survivors reached in worldwide, they are in a group which is familiar with computers and social media. On the other hand, a stroke influences the same way despite your ethnicity or geographical position. It seems that the locations in the rehabilitation process (from hospital to rehabilitation centre to home) are the same for all the interviewed stroke survivors. The recommendation of creating accessible and integrated technology for fine motor control rehabilitation is an approachable and possible solution anywhere around the world, because the rehabilitation process should emphasize individualism.

As mentioned in chapter 10 *Suggestions for the following steps*, the analysis of the interviews should be confirmed from the interviewees. Also, the context of use should be determined as precise as possible with measurements. Confirming the results from the observation can provide confusing reactions from the occupational therapists' side, because they are not aware of their actions. On the other hand, the information could provide a reflective information of their own behaviour in the therapy situation. Also, observation should be continued to gain a more thorough understanding of the interaction between the stroke survivor and the health care professionals. Confirming the analysis results should have been part of this thesis, because I am the only one, who holds the information of the identity of the participants.

The results of this thesis can be used for *the first round* of the iterative product development process. The users and the context of use should be determined precisely until it does not give any more new information. Even though the participants of the human-centred research stayed anonymous, the methods and the questions can be used in further investigation as they are described precisely. Despite the fact that the research was done in the Netherlands with the Dutch guidelines, the results can be applied to other contexts. The struggle with rehabilitating fine motor control after stroke is the same all over the world.

11.2 Financial benefits of the study

Finding the requirements from the users and the context of use in the beginning of the design process saves a lot of financial resources. Changes in the design are easier and financially less painful to do in the early phase. This is why it is highly essential to continue the discussion with the user throughout the whole development process. When taking the other indirect expenses into account, for example making usability changes in final product without human-centred research, the expenses of the whole process might double because of delays in production, or even redesigning the whole product from the scratch. The most important aspect of expenses is the one considering the image of the company. In the field of wellness technology, reputation is the most valuable merchandise. The value of a successful user experience received from an accessible, usable, and user-oriented product cannot be measured in money.

11.3 Self-evaluation

This project was the greatest challenge I have had during my education. I worked with high enthusiasm throughout the whole process. Human-centred research is the reason I started to study wellness technology and now I finally got to do it. I feel privileged that I found a project that I really enjoyed and felt motivated to do. From the beginning it was very important for me to create all of the content for this thesis myself. With the exception of the figures about *Design Thinking –process* and the iterative process from *the standard for ergonomics of human-system interaction*, I have created all of the tables, figures, and attachments myself.

The Design Thinking –process is familiar for me from my education, but I had to find suitable methods for the execution. I was really happy to get experience from observation as a method. During the interviews and the observations I could empathise with the users' struggle. Even though the language barrier between me and the ther-

apists turned out to be surprisingly big, I could really relate to the problems and issues in their work mainly because of my background as a practical nurse. In some points the emphasizing influenced also to my focus. I got distracted for quite a while because I wanted to find a solution for the therapists in one point so hard. Luckily, I got back on track with the help of my thesis instructor, Matti Siistonen, and my supervisor from SilverFit, Marjolein Smit.

In the beginning, there was a discussion whether the time is enough for the project like this. I was optimistic with my enthusiasm to start the process so I did not understand the amount of work that this field requires. My schedule with the timing was extended from the original plan. Even then, I did not have the time to reach all the original goals. This caused the biggest personal disappointment of the whole project, which was not having enough time for the creative process for the product development. I find creativity one of my strongest points and my original plan was to make a thorough and structured brainstorming sessions with the other interns of SilverFit and create working concepts from those results.

Even though the brainstorming and the concept creating did not fit into this thesis, it has been at the background all the time. I started thinking the ideas already in July 2015 when I heard the subject of this research. The more I got information from observing and listening to the therapists, the more I got new ideas. The most experimental technological solutions appeared on my Facebook-wall, since I follow Facebook-groups related to the newest technological innovations. Finding the new innovations encouraged me for the important phase of product development, *dreaming*. The evidence-based study also gave me new ideas when I got to know the current rehabilitation methods. The cofounder of SilverFit, Joris Wiersinga, helped me occasionally with the ideating by sharing new technologies through email and during face-to-face meetings.

The hardest part of the thesis was the evidence-based research. I used materials which were suggested for me from SilverFit and I also had the *Asiantuntijan tiedonhankinta* –course (5 ECTS) from JAMK University of Applied Sciences to support the research. Also, I struggled with the writing. Starting writing my thesis earlier would have revealed the shortcomings and the progress. Fortunately, when I got into the writing, it turned out to be exciting and motivating.

I hope my results are used in the product development in the future. It would have been exciting to see what kind of outcomes the brainstorming brings and what kind of new inputs other people could have brought to this project. I hope my thesis provides inspiration and useful information for SilverFit for the design process.

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Attachments

Attachment 1. Systematic evidence-based research

The keywords for the evidence-based research were defined after free mind mapping by these following glossary databases (for Finnish and English synonyms):

Finto Asiasanasto- ja ontologiapalvelu (suomi, ruotsi, englanti)

YSA Yleinen suomalainen asiasanasto

YSO Yleinen suomalainen ontologia, myös englanninkielisiä termejä

MOT-sanakirjasto

Finmesh Lääketieteen ja terveystieteen asiasanasto, jossa termejä voi etsiä suomeksi tai englanniksi

Terminologian tietokannat Terveysportin lääketieteen termit, sanakirjat ja sanastot (myös suomalaiset luokitukset, lyhenteet sekä MeSH)

Finnish keywords: aivoverenkiertohäiriö, AVH, aivohalvaus, aivoinfarkti, hienomotoriikka, kuntoutus, toimintaterapia, fysioterapia ja näppäryys

English keywords: stroke, CVA, fine motor control, fine motor skills, fine motor control, dexterity, occupational therapy, physiotherapy, stroke rehabilitation, upper extremity rehabilitation methods and neuroplasticity

Finnish databases:

Janet, Theseus, Melinda, Terveysportti, Kuntoutusportti, THL-toimia, STM:n julkaisuarhasto, Arto, Käypä hoito, Medic, Aleks, Tilastokeskus, THL tilasto and Elektra (Doria)

International databases:

Cochrane, SFS-standards, Eurostat, Ebsco: Academic Search Elite, Ebsco: Cinahl with full text, DOAJ, BioMed Central Open Access Free, PQDT Open, PEDro and PubMed

Other search tools and methods:

Google, SilverHippo, SilverFit's own library and interviews

Search phrases were usually cut by *-mark or left *unfinished* to include as much results as possible.

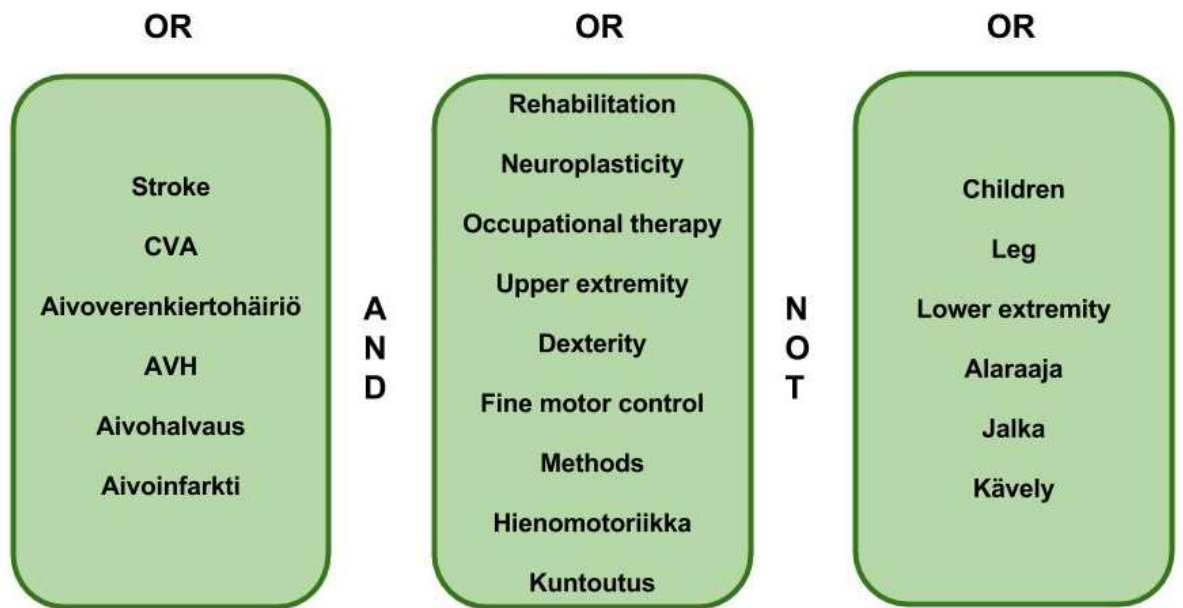


Figure above. The keywords were combined with a Booleans AND or OR or NOT.

Attachment 2. Questionnaire sent to the stroke survivor volunteers for the online ethnography interview

Hello (name of the volunteer)!

I am also a member of (the name of the group) -Facebook group. I posted on the wall if someone would like to participate the study for my final thesis. I sent these questions to everyone who liked or commented that post. The subject of my thesis is upper extremity rehabilitation after stroke.

Thank you for the opportunity to interview you!

If you feel that some questions are too personal, you don't need to answer those. I want to emphasize that the conversation and interview is completely confidential between you and me. Also, the information that I will use for my study cannot be related to any individual or institution.

I am also interested about you and your life. This is why some questions might not be related to the rehabilitation or stroke.

1. What is your official diagnosis and how old were you when you had the stroke?
2. How old are you?
3. What is your nationality?
4. How did your life proceed after the stroke? (Environments, timelines, when did the rehabilitation start.. etc)
5. In which point did you start to rehabilitate your fine motor control?
6. What kind of therapy methods have you used for rehabilitating your fine motor control with a health care professional?
7. Have you rehabilitated your fine motor skills independently? How?
8. What things do you enjoy in life?
9. What makes a good day?
10. Is there some things that you would like to do, but because of the stroke you cannot do?
11. What is your main goal in recovery?

Your answers are very valuable for me. Thank you again for your participation!

Kind regards,
Krista Kivihalme

P.s. If you want to answer via email, my address is [krista.kivihalme\(at\)gmail.com](mailto:krista.kivihalme(at)gmail.com)

Attachment 3. Email interview for the Finnish therapists working in a stroke ward

Hei!

Keskustelimme alustavasti sähköpostihaastattelusta Facebookin kautta. Alla on kysymyksiä koskien työtäsi. Olen erityisesti kiinnostunut hienomotoriikan kuntoutuksesta, mutta toki kuntoutuksen kokonaisuuden hahmottaminen on tärkeää tutkimuksessani. Olen kiinnostunut työstäsi, sillä kun suunnitellaan apuvälineistöä tai kuntoutusvälineistöä, kuulut yhteen käyttäjäryhmään. Kysymyksiä käsitellään anonyymisti, eli vastausten perusteella on mahdotonta määrittellä vastaajan identiteettiä.

1. Mikä on tarkka ammattinimikkeesi?
2. Mitä teet ensimmäiseksi kun tulet töihin?
3. Mikä tekee työpäivästä hyvän?
4. Mikä olisi ennalta odottamaton tapahtuma työpäivässäsi? Eli sellainen tapahtuma, johon tulee olla varautunut, mutta jota harvemmin tapahtuu.
5. Mistä tykkäät työssäsi?
6. Mistä et tykkää?
7. Mikä on helppoa?
8. Mikä on vaikeaa?
9. Mitkä asiat auttavat sinua tekemään päätöksiä työssäsi?
10. Onko työssäsi asioita ja tehtäviä, joiden tekemistä välttelet tai lykkäät?
11. Mitkä tapahtumat ovat mielestäsi ajanhukkaa työssäsi?
12. Kuinka järjestätte yksilöllisen kuntoutusohjelman aivoinfarktin jälkeen?
13. Missä vaiheessa hienomotoriikan kuntoutus on tehokkainta?
14. Toteutuuko hienomotoriikan kuntoutussuunnitelman mukaan? Jos ei, miksi ei? Mitkä seikat vaikuttavat hienomotoriikan kuntoutuksen toteuttamiseen "kirjan mukaan"?
15. Mitä mittareita käytätte hienomotoriikan mittaamiseen?

Toivon, että vastaat kyselyyni lokakuun 2015 loppuun mennessä. Kiitos vielä erittäin paljon osallistumisestasi projektiin! Vastauksesi ovat arvokkaita.

Ystävällisin terveisin,

Krista Kivihalme

Attachment 4. Summary of the interviews of the stroke survivors: upper extremity rehabilitation started and methods (sorted by the year)

Participant	Year of CVA	UE rehabilitation started	Methods
Caucasian	2015	The next day	Knitting, colouring
Caucasian	2015	In one week	Stacking coins
American	2015	After one month	SaeboFlex
British	2015	After five months	Writing, position training
Dutch	2015	After 11 months	Intensive hand rehabilitation course
American	2014	After four months	Cutlery use, TheraPutty
American	2014	After six months	Theraband
Filipino	2014	After three weeks	TheraPutty, E-Stim
Hispanic	2013	In one week	Coin handling
American	2013	(time not specified)	(not specified)
British	2012	After four weeks	Exercises from YouTube
Finnish	2010	After six months	Own exercises
Belgian	2009	After two weeks	(not specified)
Finnish	2008	After over six months	CIMT-intensive course
Afroamerican	2008	Never	-
Finnish	2006	Never	-
British	2006	After six months	Saebo Stretch splint
Scottish	2005	After three months	Using iPad
British	2005	Never	-
American	2004	After two weeks	TheraPutty, moving small items
American	2004	Never	-
American	1975	After 27 years	Exercises with occupational therapist, hand spring squeeze
British	not specified	After two weeks	(not specified)

Attachment 5. Summary of the interviews of the stroke survivors: enjoyment in life (sorted by ethnicity)

Participant	Age when CVA	Enjoyment in life
Afroamerican	58	(not specified)
American	53	Going to church, family
American	0	Soccer, reading, public speaking, exercising
American	48	Concerts, friends, swimming, hiking,
American	73	Fishing, hunting
American	45	(not specified)
American	46	Music
American	50	Travelling, biking, reading, dancing, friends
Belgian	40	Nature, photographing, friends, food, movies, laughing
British	29	(not specified)
British	52	Family, friends, grandkids, word games
British	43	Friends
British	44	Family
Caucasian	42	Swimming, camping, reading, knitting, puzzles
Caucasian	62	Reading, tv, Facebook, cooking, AngryBirds, cleaning
Dutch	60	Sports, running, family
English	63	Family
Filipino	42	Running, cooking, baking, reading, traveling
Finnish	57	Focusing on what is left
Finnish	33	Travelling, gym, dog
Finnish	49	Reading-club, making food, summer cottage, family
Hispanic	56	Family
Scottish	47	(not specified)

Attachment 6. Interview for the occupational therapists and physiotherapists (quantitative text analysis)

Interviewees in total:

9 occupational therapists

2 physiotherapists

1 occupational therapist student

What is easy in your job?	Amount of answers
Interaction with patients	5
Interaction with family members	1
Interaction with the health care staff	1
Therapy sessions	6
Coordination meetings	1

What do enjoy in your job?	Amount of answers
The diversity, every day is different	2
Successful cooperation with the client	10
Successful cooperation with the family members	4
Successful cooperation with the health care staff	5
Ability to use imagination and creativity	1
Helping people	7
Long-term customers (seeing the progress)	1
Good atmosphere at work	1
Multi professional work environment	1
The rehabilitation with the neurological patients	4
Learning everyday something new	1
Abilities to get advanced special studies	1

What things do you find hard, frustrating or difficult?	Amount of answers
Evaluate the progress	1
The cooperation with the nurses	5
Feeling for not being enough	7
The lack of recourses in the hospital	6
The lack of recourses at home (the work at the hospital goes waste if it is not continued after the hospital period)	1
Trying to come up with variety of exercises	5
Administration tasks	3
Outdated knowledge of this field	3
Finding motivating activities	4
Lack of time	1
Lack of objective "proof" of patient's independent performance	1

What things you don't like in your job?	Amount of answers
Patient file system (reporting)	9
The fact that the health care staff don't read the reports	2
Extra tasks that are not related to working with the client	1
Too much different kind of meetings in the hospital	1

Which guidelines do you use in your work?	Amount of answers
Käypä Hoito -suositukset	2
Ergotherapierichtlijn CVA	6
Hartstichting revalidatie na een beroerte	3
KNGF guideline	1

What would be an unexpected event in your workday?	Amount of answers
Resuscitation	2
Threat of violence	2
Fire	2
Water damage (flood)	2
Colleague's sick leave in the middle of the day	2

What does occupational therapy include?	Amount of answers
Emphasizing meaningful and important things for the patient	2
Focus on ADL-functions	2
Practicing those skills that the patient has done before stroke	2
Realistic goal-setting with the patient and family members	1
Realistic rehabilitation situations based on the goals	1
Focusing upper extremity	3
Defining the level of the stroke, help with diagnostics	1

What is the most effective way to rehabilitate UE after stroke?	Amount of answers
Starting the rehabilitation right away	4
First practicing bigger movements and later more detailed	2
The patient might need manual support for preventing the dispositioning of the muscles and joints	2
Patient's independent practicing	3
ADL-functions	3
Exercised every day, three times a day 10 to 20 minutes	4
Six weeks after stroke	1

What things should be taken into consideration when rehabilitating UE after stroke?	Amount of answers
Neglect	2
Focus issues	2
Cognition issues	2
The affected side's dominance	2
The patient's own motivation and interests	8
There can be positive progress after many years	2
It is never too late to help the upper extremity functions forward	1
There has to be volitional movement in the arm	3
The main goal for all the clients is to return home	2

Why the upper extremity rehabilitation is not fulfilled "by the book"?	Amount of answers
The lack of commitment for the goals	2
The lack of cooperation (with the health care professionals or family members)	2
Patient does not fulfill the requirements for starting the rehabilitation	2
Patient is not motivated	3

Which measuring tools do you use for evaluating the progress? (tests are excluded)	Amount of answers
Client's self-evaluation	4
Observation (which includes the following:)	6
- Buttoning a shirt	2
- Taking medication from a pill dispenser	2
- Writing their own name	2
- Opening a milk can	2
- Use of practical tools	1

If there were unlimited recourses, how would you do your work?	Amount of answers
More different kind of materials and methods, so there would be variety between the rehabilitation sessions	3
More group activity for different levels of clients	3
A huge rehabilitation centre that would provide different activities to everyone, but also relaxation methods	3
Different kind of workshops would motivate and inspire the clients	3
Focus on only doing what we enjoy in work	3
Working with the most professional staff	3
Multi professional expertise	3
Highly educated people	3
The most updated facts to back-up the work	3
More ADL-related exercises	2
Working with an ipad	2
More time for the patients	1
More cooperation with the family members and health care professionals	3
Game for rehabilitating UE	1

What are the requirements for UE rehabilitation?
Client is motivated
Practices independently every day
Volitional movement in the arm
No restrictions from pain
Sufficient cognitive skills
Meaningful practice
Integrated to the day schedule easily

Describe the rehabilitation process after stroke.

Hospital environment	Rehabilitation centre
<ul style="list-style-type: none"> • Nurses take care of “position treatment”, swallow-evaluation and organizing the patient’s room • The doctor talks with the nurses and therapists about starting the rehabilitation • Therapy starts after a referral from the doctor • Therapy starts immediately, without doctor’s referral • Meeting the patient for the first time for evaluating the “starting point” • The goal setting with the patient (if they are able to express themselves) • The goal setting with the family members and the staff (if the patient cannot express themselves) • The goals are written down and are updated daily • Physiotherapy takes place 3-5 times per week depending of the amount of the patients in the ward and performance of the patient • Occupational therapy takes place 1-3 times per week • Occupational therapy takes place 6 times per week • The rehabilitation should be taken into consideration 24 h per day • Occupational therapists have their own clients • Every week there is a cooperation meeting with all of the members related to the rehabilitation process (a doctor, a physiotherapist, a social worker, an occupational therapist and a nurse) • There are meetings for the family members and the patients 	<ul style="list-style-type: none"> • Interview with the client: <ul style="list-style-type: none"> ○ What they want to do and what are their goals? ○ What did they used to do before the stroke? ○ The goal is to know the client well. • Observation: <ul style="list-style-type: none"> ○ What the client can do? ○ How they do it? ○ This observation is executed in a home-like environment. ○ The observation concerns making breakfast, going to the toilet, grooming, brushing teeth and other ADL-functions • Tests: <ul style="list-style-type: none"> ○ There are five tests in total, they are executed in a certain order ○ Occupational therapists have their own clients

Attachment 7. Tasks during the guided fine motor control therapy session

Group sessions

- Making lunch together around a big table. Each client was cutting cucumber, paprika, cherry tomatoes and sundried tomatoes, opening two different sizes of cans, dosing pasta from a bigger dish to another with a ladle. The tasks were switched so everyone can do everything.
- Playing ConnectFour

Individual sessions

- Staking cylinders
- Buttoning a shirt
- Drawing a given picture
- Drawing a clock
- Lifting fingers from the table while pawn is flat without lifting the wrist
- Draughts-token handling
- Beanbag reaching
- TheraPutty
- Playing ConnectFour
- Using Senseo (making coffee with Senseo)
- Peeling a fruit with a knife
- Going to the bathroom
- Squeezing a wet towel
- Cleaning a table with a towel
- Handling a tube of hand lotion
- Opening a peanut butter jar
- Opening a toothpaste jar
- Opening a 0,5 litre bottle
- Opening a yoghurt pot
- Placing pegs to holes on a soft surface

Attachment 8. What can you find from a hospital room?

Categorized lists from the brainstorming session results.

PEOPLE	IN THE BED	PERSONAL BELONGINGS
Social worker	Pillow	Phone
Psychologist	Sheets	Watch
Occupational therapist	Blanket	Glasses
Student	Mattress	Dentures
Family member	Bed	Comb
Doctor	Nurse alarm/ call button	Identification bracelet
Nurse	Grip bar	Keys
Physiotherapist	Clothes	Wallet
Translator	Extra blanket	Laptop
Cleaner	Space sheet	Tablet
Patient transferrer	Lift sheet	Chocolate
Röntgen-nurse	Overall	Morning slippers
Laboratory member		
Another patient		

ON THE TABLE	MEDICINAL DEVICES	FURNITURE
Wash cloth	RR-meter/cuff	Curtains
Urine bottle	SpO2-meter	Chair
Towel	Thermometer	Table
Bottle of disinfectant	Blood sugar meter	Night table
Cutlery	Drip stand	Closet for equipment
Pip	Tourniquet	Tap
Straw	Diaper	Sink
List of liquids	Sliding plate	Toilet seat
Remote control of the tv	Lift rack	Window
Newspaper	Rail	Window blinds
Phone charger	Oxygen whiskers	Bedtable
Headset	Oxygen mask	Intimacy curtains

ON THE TABLE	MEDICINAL DEVICES	FURNITURE
Pen	Monitor	Clock
Crossword puzzle	Cpap	Door handle
Hospital clothing	Drop regulator	Hand shower
Book	Medicine pump	Remote control of the patient bed
Glass of water	Epidural catheter	Oxygen pistol
Food tray	Peg	Laundry bags
Sipper cup	Iv-cannula	Alarm system
Washing cloth	Suck machine	Babybed
Kidneydish	EKG-pads	Light switch
Soap	Dreen	
Medicine	Position pillow	
Medicine cup	Tweezers	
Pill dispenser	Peangs	
Volumatic	Tape	
Aerochamper	Cart of the doctor	
Eye drops	Specimen bottle	
List of medicine	Lancet	
Ear drops	Support hoses	
Insulin pen	Orthoses	
Aqua-bottle	Cast	
NaCl-bottle	Crutches	
Equipment for wound care	Wheelchair	
Syringe	Ewa-rack	
Cover of a needle	Shifting plate	
Aphasia-folder	"Power drink"	
Photographs	Rollator	
Postcard	Bedpan	
Dementia-folder	Swab	
Individual directions	Roll of gauze	
"Without food"-notes	Cleansing solution	
Tube of lotion		
Roll of toiletpaper		
Catheter		
Cup		