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A SELF-MANAGEMENT PACKAGE FOR STROKE PATIENTS WITH CHRONIC PAIN

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Stroke is a third leading cause of death in Finland (Soinila, Kaste & Somer 2006, 271). The damages of stroke are individual and can have an effect on person's physical, mental and social capacity in many ways. Post stroke patients might develop chronic pain due to the possible permanent changes of the neural pathways after stroke.

Physiotherapy has a big role in stroke rehabilitation. The aim of physical management is to achieve patient's functional capacity and independence as much as possible and therefore minimize complications. Stroke rehabilitation is involved in all stages: acute, sub-acute and long-term phase to return patient's mobility. Home rehabilitation offers experiences of safety, independence and capability due to learning how to cope with daily activities.

The aim of the thesis was to make a self-management package for stroke patients with chronic pain for the use of Laitilan Terveyskoti. The objective was to make a clear datafile including information of chronic pain among stroke patients to help them to manage with it at home and to understand chronic pain. The package was done through a literature review and by interviewing a stroke patient's relation.

CONTENTS

1 INTRODUCTION

In our country altogether 25 000 people have a stroke annually, of which approximately 18 000 are ischemic and 1 800 are hemorrhagic. About 4 500 of the cases lead to death and approximately 2 500 of those having ischemic stroke will relapse in a year. (Website of Aivoliitto 2017.)

The need and duration of rehabilitation after stroke is individual and varies a lot. Approximately 40 % of stroke patients need a long-term rehabilitation. It has been found that rehabilitation started in the early phase leads to the best results. Rehabilitation is performed by a multidisciplinary team. (Website of Aivoliitto 2017.) Physiotherapy is a significant part of rehabilitation. A physiotherapist investigates the person's functional capacity and locomotion. The examination is guided by International Classification of Functioning, Disability and Health (ICF) which is used between different professionals in health sector. (Website of Suomen Fysioterapeutit 2017.) After three months approximately 50-70 % of the stroke patients have recovered independent in their daily activities, 15-30 % have permanent disabilities and 20 % need institutional care (Website of Aivoliitto 2017).

Home rehabilitation has been shown to offer positive effects in coping with daily activities. In addition to that it increases active participation of individuals and helps them in returning to work and social life. (Reunanen 2017, 72.) For this reason, the aim of the thesis project is to help stroke patients with chronic pain to understand the pain and give tools to them for pain management at home.

2 THE AIM AND OBJECTIVE OF THE THESIS

The aim of the thesis is to make a self-management package for stroke patients with chronic pain for the use of Laitilan Terveyskoti. The objective is to make a clear data-file including information of chronic pain among stroke patients to help them to understand chronic pain and how to cope with it at home.

3 STROKE

Stroke is a cerebrovascular accident which occurs when oxygen supply to the brain fails. Stroke is classified into two main categories: ischemic and hemorrhagic stroke. (Gillen & Burkhardt 2004, 2.) An ischemic stroke is the most common stroke, and is caused by a blocked blood vessel which leads to obstructed blood supply to the brain tissue. Lack of blood supply and oxygen causes a necrosis in that area of the brain where the vessel is blocked. (Website of Aivoliitto 2017.) An ischemic stroke can be caused by a thrombosis where a contraction of the artery wall leads to local obstruction, or by an embolism which means a clot originated from elsewhere of the body producing a blockage to the brain artery (Salmenperä, Tuli & Virta 2002, 27). In a transient ischemic attack (TIA) the symptoms are similar to ischemic stroke but last only minutes or hours. Therefore TIA is sometimes called a mini-stroke. (Stokes & Stack 2012, 10.) The risk of an ischemic stroke increases after having a TIA (Website of Aivoliitto 2017).

A hemorrhagic stroke occurs when a blood vessel is ruptured and causes a blood leakage to the brain. In an intracerebral hemorrhagic stroke the bleeding occurs directly in the brain tissue, whereas an intracranial hemorrhage is a result of leakage somewhere between the skull and the brain. (Stokes & Stack 2012, 10-11.) In a subarachnoidal hemorrhage the bleeding appears in the space under the arachnoid membrane (Salmenperä et al. 2002, 28).

The most important risk factor is elevated blood pressure which contributes the formation of an ischemic or hemorrhagic stroke. Smoking, obesity, lack of physical activity and plentiful use of alcohol are also increasing the risk of stroke. As a matter of fact, the risk is from three to five times higher among smokers. The risk is also increased if there are multiple risk factors effecting simultaneously. (Salmenperä et al. 2002, 32-33.)

Applying hospital care fast and initiating the treatment immediately are essential for patient's care and recovery. The acute care should focus to the units where are enough specialists and a possibility to examine and begin a patient treatment quickly 24 hours

a day. (Salmenperä et al. 2002, 29.) Majority of acute stroke cases can be recognized by the symptoms of facial weakness, unilateral limb weakness and troubles in speech. The FAST (face, arm, speech) test can be used as a screening tool for acute stroke patients, although in some cases there might occur some other symptoms and therefore a stroke cannot be defined with the FAST test. (Royal College of Physicians 2016, 34.)

Subacute stage covers the period from three to six months post stroke. Evaluation of patient's need for physical, cognitive and psychosocial rehabilitation is done in one week after the stroke if possible. Rehabilitation plan is composed in cooperation with the patient, his or her relation, the caring department and multidisciplinary team. Multidisciplinary team consists of a doctor, a nurse, a physiotherapist, an occupational therapist, a speech therapist, a neuropsychologist and a social worker. If necessary, occupational health care, Kela and insurance companies can be involved in estimating patient's ability to work. (Website of Käypä hoito 2017)

4 EFFECTS OF STROKE ACCORDING TO ICF

International Classification of Functioning, Disability and Health (ICF) represents functional capacity and limitations in function as a multidimensional, interactive and dynamic condition which consists of the synergy of health, individual and environment. ICF gives a possibility to describe functional capacity as an integrated phenomenon, and hereby to use it as a common language among different professions. Furthermore, it serves an opportunity to follow the changes in functional capacity of a person. ICF describes functional capacity in the perspectives of body structures and functions, activities and participation. ICF Core Sets consist of descriptions that are suitable in certain situations or conditions. The Core Sets include a minimum amount of the descriptions that are needed to get a perception of person's functional capacity as a result of a certain disease. (Website of Terveyden ja hyvinvoinnin laitos 2017.)

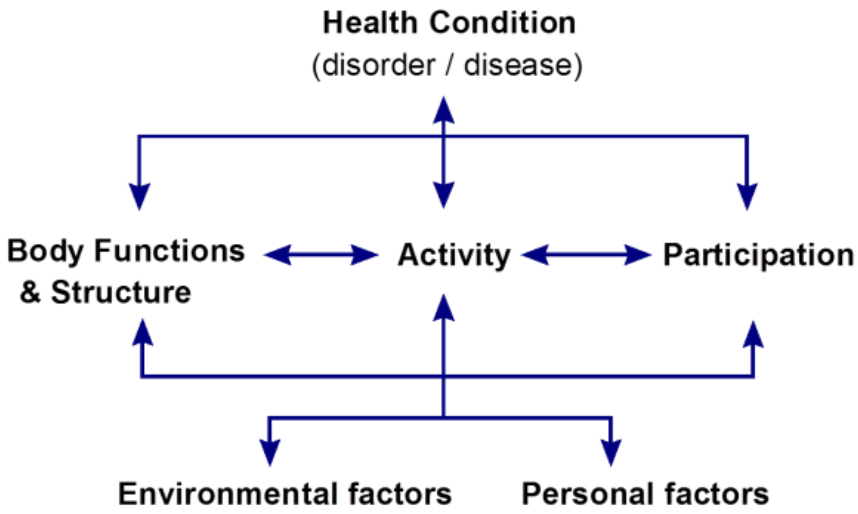

Figure 1 – ICF framework in rehabilitation. (Website of Physiopedia 2017.)

4.1 Body functions and structure

Body functions and structures describe the physical and psychological functions of body systems or body's anatomical parts (Website of Terveyden ja hyvinvoinnin laitos 2017). Usually a stroke leads to long-term or permanent disturbances in functional capacity and the impact to patients' quality of life is massive (Salmenperä et al. 2002, 28). The effects of stroke are individual and depend on the size of the affected area and in which part of the brain it occurs. Most commonly stroke leads to partial paralysis (hemiparesis) or total paralysis (hemiplegia) of one side of the body. (Soinila, Kaste & Somer 2006, 272.) The symptoms manifest usually on the opposite side of the damaged brain area because the neural pathways travel mainly to the opposite side of the body (Salmenperä et al. 2002, 34).

Other post stroke symptoms related to functional capacity are weakness one side or both sides of the body, excessive activation of healthy side of the body, increased or decreased muscle tone, disturbances in sensation, speech impairment, visual disturbance, swallowing disorders. Also memory and coordination problems, vertigo, impairment of perception, neglect (inability to notice or react to stimuli on the contrary side of the damage) and apraxia. (Salmenperä et al. 2002, 34, 37, 38.) Apraxia means trouble in performing volitional movements and it usually leads to problems with activities of daily living. Apraxia is commonly related with left cerebral hemisphere damage,

and it should be observed with standardized tools to determine person's capability. (Royal College of Physicians 2016, 60-61.)

4.2 Activity and participation

Activity and participation include the important areas in life, such as learning, communication, locomotion, domesticity and interpersonal relations (Website of Terveyden ja hyvinvoinnin laitos 2017). Cognitive impairments occur commonly in the early post-stroke stage and are related to long hospital stay and decreased independence after stroke. Disturbance in alertness is common after a stroke and may occur particularly between the first days and weeks post stroke. The effects may be specific and seen for example in focusing or sustaining attention, or they can be more general and cause usual slowness. Difficulties with problem solving, planning and organizing are also common consequences of stroke. (Royal College of Physicians 2016, 60.) Also agnosia (trouble in recognizing objects), difficulty of learning new things, and problems in orientation and attentiveness might occur after stroke (Salmenperä et al. 2002, 38).

4.3 Environmental and personal factors

Environmental factors consist of the external factors that effect on the person positively or negatively, and can be seen on the individual's activities, participation, body functions or structure (Website of ICF e-learning 2017). The environmental factors include products and technologies, natural environment, changes in environment, support and relations, attitudes, services, management and politics. Personal factors are for example age, gender, lifestyle, education and profession. (Website of Terveyden ja hyvinvoinnin laitos 2017.)

5 STROKE REHABILITATION

Rehabilitation is planned and diverse, usually persistent functioning which aims to improve person's functional capacity, self-management, wellbeing, employment and ability to participate. The client or patient should be actively participating in the rehabilitation process. (Website of Suomen Fysioterapeutit 2017.) Usually stroke patients need many kinds of rehabilitation due to the diverse symptoms after stroke (Soinila et al. 2006, 327). Rehabilitation can be arranged in institutes that are specialized in rehabilitation, outpatient clinics or health-care centers. A rehabilitation period can be organized in a rehabilitation department if the patient is not able to manage daily activities at home. (Salmenperä et al. 2002, 31.)

Physiotherapy has a big role in stroke rehabilitation. A physiotherapist examines the person, his/her functional capacity and mobility both extensively and in detail. (Website of Suomen Fysioterapeutit 2017.) Stroke rehabilitation is involved in acute, subacute and long-term phase. During the whole rehabilitation period the purpose is to encourage the patient to participate actively. (Stokes & Stack 2012, 15.)

It is necessary to clarify that the patient is medically stable before initiating physiotherapy. At the early stage the focus is on controlling mobility, skin care and normal respiration. A physiotherapist needs to assess patient's ability to control movements and the need of help in mobility and transfers, and investigate whether the patient is able to follow commands. In the later stage many assessments have been already done and the emphasis is on restoring patient's functional capacity as much as possible with active participation of the patient. The baseline of patient's functional ability should be determined to be able to measure the effectiveness of physiotherapy. (Stokes & Stack 2012, 16.) It is important that the patient does not compensate the paralyzed side of the body with the healthy one (Soinila et al. 2006, 328).

After the intensive rehabilitation period the emphasis is in maintaining the achieved functional capacity (Soinila et al. 2006, 329). In this stage the rehabilitation should also focus on helping the patient to adapt into the new situation, role and identity. Discharging from the hospital to home or a care home and finishing the physiotherapy

program are the two most challenging and critical points for stroke patients, whereupon it can cause stress and confusion for them. (Stokes & Stack 2012, 17.)

5.1 Post stroke therapeutic exercise

It is known that people learn to perform actions by practicing themselves. In addition, it is essential to have a possibility to make mistakes as well. In an early post stroke phase patients have problems to perform movements and daily activities. To relearn to perform them, they have to practice repetitively. Repetitive practicing is important to increase muscle strength and coordination and to develop the skill. Repetitions facilitate the muscle activation and improve the performance. As patients' strength and control improve they can pay more attention to the goal because less focus is needed on performing the task. (Carr & Shepherd 2003, 14-15, 23.)

Rehabilitation can be organized also in a group, for example as a circuit class. Circuit training can be planned in a way that the participants are working in pairs. Practicing together with someone can improve stroke patient's motivation. Also observing another person and helping each other have beneficial effects. Different tasks and exercises in circuit training increase persons' alertness and eagerness. It has been found that patients' problem-solving skills may benefit from giving them some control in the practice situations. (Carr & Shepherd 2003, 10, 13.)

It has been studied that both task-oriented exercise therapy and cognitive exercise therapy have notable improvement in upper limb function, quality of life and activities of daily living in chronic stroke patients. In fact, the study of Lee et al. showed that after eight weeks of training for five times per week and sixty minutes each time, cognitive exercise therapy was considerably more effective on upper limb function and quality of life in chronic stroke patients. (Lee, Bae, Jeon & Kim 2015, 2787, 2789.)

5.1.1 Balance

Balance disturbances, especially putting weight over the base of support, are needed in activities of daily living and are very critical parts in motor control. For this reason

balance training may play a key role in stroke rehabilitation. Balance involves the ability to adapt movements to internal and external changes. Intensive strengthening exercises of the lower limb muscles have to be included in rehabilitation if they are too weak to support, shift, and balance the body mass. (Carr & Shepherd 2003, 35, 37, 48.)

According to the study of Park & Kim closed kinetic chain exercises are improving stroke patients' balance and lower extremity muscle activation more than open kinetic chain exercises, although both had significant improvement on them. EMG-biofeedback system was used with both kinetic chain exercises because it has been found to be useful in rehabilitation of musculoskeletal and neurological diseases by reducing pain and increasing muscle strength. The effects of EMG-biofeedback intervention on dynamic balance has been studied by Tsaih et al. and on muscle activation by Dogan-Asla et al. and both of them showed significant improvements. (Park & Kim 2017, 1390-1392.)

Standing up and sitting down are important abilities to manage independently. Standing up requires balance, lower limb muscle strength and bigger range of motion of the knee than walking. Inability to stand up may lead to decreases in muscle strength and physical condition. It is essential to train standing up and sitting down to increase mobility and independence. Loading the paretic limb during standing up or sitting down can improve person's performance in other daily activities. (Carr & Shepherd 2003, 129, 145-146.)

5.1.2 Body weight supported treadmill training

Stroke can have a big effect on gait ability and the recovery of it depends on the severity of lower extremity paresis after stroke. Multiple cortical areas of brain are needed in controlling gait. Stroke patients usually have reorganized cortical areas which leads to different disturbances in gait. The studies have proven that control of the proximal lower extremity is important in increasing speed and performance of gait after stroke. (Mao et al. 2015, 1-2.)

Body weight supported treadmill training is used in stroke patients to restore gait and it has been shown to be more effective in increasing gait speed and improving balance than conventional physiotherapy in many studies. The study of Mao et al. investigated the effects of body weight supported treadmill training on balance, gait recovery and motor function of lower extremity in subacute stroke patients. After a three weeks training period body weight supported treadmill training as well as conventional over-ground gait training improved balance and lower extremity function without notable difference between the methods, indicating that both of the training techniques could be used in rehabilitation of subacute stroke patients. (Mao et al. 2015, 1-2, 4.)

Based on the results of the study, body weight supported treadmill training was remarkably more effective on cadence and speed of gait than conventional training. In addition, the results showed that treadmill training with supported body weight improved hip extension. These findings lead to the conclusion that body weight supported treadmill training can improve the quality of gait in subacute stroke patients. (Mao et al. 2015, 1, 4, 7.)

Middleton et al. studied the effects of an intensive therapy period of body weight supported treadmill training on gait, balance and mobility compared to overground gait training in chronic stroke patients. The results indicated that after 10 days of intensive training there were no remarkable differences between the effects of treadmill training with supported body weight and overground gait training. However, the study showed that both of them had moderate effects on gait, balance and mobility. (Middleton et al. 2014, 462, 467, 468.)

5.1.3 Mirror therapy

Mirror therapy has been used in many studies and it has been proven to be effective within six months after stroke. Mirror therapy is a method where the person sees his/her unaffected extremity's reflection in the mirror, which gives visual feedback to the person. This facilitates the primary somatosensory cortex to provoke movement of the affected side. Mirror therapy bases on the mirror neuron system. (Yeldan, Huseyinsinoglu, Akinci, Tarakci, Baybas & Ozdincler 2015, 3519.)

The studies of Altschuler et al. and Yavuzer et al. indicate that the mirror therapy has more beneficial effects on upper extremity's functional recovery comparing to the conventional therapy. A study by Lim et al. was performed to see the effects of mirror therapy containing functional tasks in subacute stroke patients. The results of this study showed that after four weeks mirror therapy had significant improvements on upper extremity function and activities of daily living. (Lim, Lee, Yoo, Yun & Hwang 2016, 629-635.)

However, Yeldan et al. studied the effects of very early mirror therapy on the upper extremity function in acute stroke patients. The subjects were divided into two groups: mirror therapy group and neurodevelopmental treatment group. The results indicated that mirror therapy performed very early does not improve the function of upper extremity in acute stroke patients. In addition to that Yeldan et al. found out that neurodevelopmental treatment does not have beneficial effects on upper limb function in the very early phase. (Yeldan et al. 2015, 3519, 3523.)

5.1.4 Constraint-induced movement therapy

Constraint-induced movement therapy is a method used for recovery of upper extremity function in post stroke patients who have a possibility to recover. It has been drawn attention over 15 years and has been seen as an effective technique in rehabilitation of upper extremity. It means a forced use of the hemiparetic arm instead of the healthy arm in exercises and daily activities. The earlier Cochrane review performed in 2009 showed positive effects of constraint-induced movement therapy on motor function of upper extremity in post stroke patients. A new study was executed in 2010 to update the results and to compensate the deficiencies. The results of the updated study indicate that constraint-induced movement therapy is ineffectual in terms of disability but has moderate effects on upper extremity function. (Corbetta, Sirtori, Moja & Gatti 2010, 537-542.)

6 PAIN

Feeling pain is essential because it can warn us about a damage in our body which already exists or is going to occur. There are sensors in the nerve cells that respond to different kinds of stimuli, all around the nervous system. (Butler & Moseley 2013, 8, 30.) Experiencing pain due to a tissue damage is called nociceptive pain and it can be separated into four categories: transduction, transmission, modulation and perception. In transduction the energy (chemical, mechanical or thermal) of the stimuli causing tissue damage leads to the activation of nociceptors. The second phase is called transmission, where the peripheral sensory nerves forward the impulses to the brain through the spinal cord. Modulation means modifying pain in the nervous system. The last phase is perception which means a subjective response to pain. During that pathway the signal activates systems that are building up the nociception and also systems that are decreasing it. The balance between these two systems determines how intensively the pain is experienced. (Kalso & Vainio 2002, 50, 88, 96.)

Experiencing pain is typically unpleasant. In addition to pain itself, the unpleasantness of pain consists of the immediate will of getting rid of it, avoiding the cause of pain, counteracting pain, denying it or coping with it. These reactions can be hard to separate from the actual pain and they can be more harrowing than the original pain perception. This kind of instant pain experience is related to our own evaluation of its effects on our body and state of mind. (Kalso & Vainio 2002, 93.)

6.1 Chronic pain

Acute and chronic pain are separated from each other by the duration of the pain. Pain is considered to be chronic when it lasts more than 3 months or when pain is experienced for a longer time than the expected time of tissue healing takes. (Kalso & Vainio 2002, 87.) In contrast to acute pain, chronic pain does not protect the body from damages. Actually in chronic pain the brain itself can provoke sensation of pain, without any effects of outer factors. (Ojala 2015, 16, 18.)

An intense, long-term pain shapes the function of the central nervous system. Continuous pain sensation leads for example to contraction of functional content of the grey matter in the areas which are used in pain processing. Also new neural nets are appearing to the brain which is increasing the development of chronic pain. Most of the changes in the central nervous system can recover by removing the tissue damage totally. However, for some patients, removing the factor causing pain does not effect in the recovery of brain function anymore. In chronic pain treatment the concentration is usually in decreasing pain, as well as blocking and managing ramifications such as insomnia, anxiety, depression and cognitive disorders. (Expert Group on Management of Chronic Pain and Cancer Pain 2017, 10.)

6.2 Post stroke pain

A stroke can cause permanent changes to the neural pathway leading nerve cells to react to stimuli more sensitively. This kind of pain is called neuropathic pain or central post stroke pain. (Royal College of Physicians 2016, 79; Kalso & Vainio 2002, 97.) There can be a long period of time between the pathological process and the beginning of pain. Also the nature of pain can change in the long run. A normal touch can be very painful for the patient as a result of neuropathic pain. Usually after a stroke the pain develops to the paralyzed side of the body but it can also be localized for example either in upper or lower limb. Post stroke pain is typically continuing, harrowing, aching and burning, and also most commonly sensation of temperature is decreased as well. Early neuropathic pain treatment in the acute phase may prevent the formation of chronic pain. The longer the pain lasts the more new synaptic connections root to the central nervous system which makes the pain reduction harder. Increasing and activating patient's survival management and attitude is important. (Kalso & Vainio 2002, 98, 262.)

Approximately 70% of post stroke patients have shoulder pain at some point (Forsbom, Kärki, Leppänen & Sairanen 2001, 37). Shoulder pain after stroke can be related to spasticity or subluxation of the joint (Royal College of Physicians 2016, 81). Shoulder pain disturbs and delays rehabilitation significantly. If every movement increases shoulder pain and the pain occurs even when being still the person may become

unwilling to do any actions. Independent functional ability decreases if for example showering and dressing are increasing pain. The pain might also disrupt focusing and learning. It is important to clarify the factor which is causing pain to prevent its exacerbation. (Forsbom et al. 2001, 37.) Careful positioning of the affected arm and supporting the weight of it are decreasing the risk of shoulder pain. Manigandan et al. (2014) showed that the evidence of electrical stimulation of the long head of biceps in shoulder subluxation is inadequate. Singh and Fitzgerald (2010) found out that local injections of botulinum toxin had some positive effects in decreasing pain and improving shoulder function. In addition, there is slight evidence that shoulder strapping prevents shoulder subluxation. (Royal College of Physicians 2016, 81.)

7 MOTIVATION AND SELF-EFFICACY

Experiences and understanding of self-efficacy play the key roles in person's agency. Self-efficacy effects on person's adaptation and attitudes to changes in life. It determines person's ability, effort and tolerance in challenging situations. Understanding of self-efficacy is guiding the person to relate either optimistically or pessimistically to challenges. Person's own opinion of self-efficacy is essential in regulation of motivation because they effect on the choices a person makes in life, the challenges a person takes and the amount and duration a person is able to tolerate. (Reunanen 2017, 20.)

Understanding of self-efficacy can be increased during the rehabilitation period by producing experiences of success. Also observing and modelling other patients' performing some tasks or actions which require effort is strengthening the understanding of self-efficacy. Thirdly, encouragement of close relatives, peers or professionals is also improving the understanding of self-efficacy by making the person to receive tasks that feel almost impossible. Also monitoring and interpreting the internal feedback from the tasks may increase the person's understanding of self-efficacy. The effects of self-efficacy in rehabilitation of stroke patients has been studied by Jones and Riatzi (2011). They found that self-efficacy was related to quality of life, depression, management of daily activities and also more or less physical functional ability of stroke patients. (Reunanen 2017, 22, 25.)

Volz et al. (2016) studied the effects of self-efficacy on depression six months post stroke. The scholars found out that depressive symptoms in the early post stroke phase often led to post stroke depression later. Also decreased self-efficacy was noticed to be related to depression. The researchers state that dissatisfaction and negative experiences during rehabilitation can decrease self-efficacy and increase depressiveness. In the study they also manifested that post stroke social support prevented later post stroke depression. (Volz, Möbus, Letsch & Werheid 2016, 253-254.)

Person's agency and self-efficacy are closely related to coping. Factors related to personal resources, health and environment effect on disease controlling. Personal resources are for example those opinions of self-efficacy that effect on person's trust in his or her own role in rehabilitation. Health factors are for example the severity of disease and its consequences as well as threats of the future. Environmental factors are social connections and the possible obstacles of physical environment. (Reunanen 2017, 25.)

A person learns to cope in a new situation where he or she estimates the threats related to the disease and his or her own coping possibilities. The resources of control determine how the person adapts to a new situation, how the person gets motivated and retains opinions of self-efficacy which are improving the ability to cope and create a new identity after a severe disease. Furthermore, also those resources are needed which help to deal with feelings, to learn new things related to the disease and to control the changes related to social relations and roles. (Reunanen 2017, 26.)

It has been studied that during the recent years empowerment and self-efficacy have become more important in rehabilitation and self-management after stroke. According to Jones et al. (2013) physiotherapists should approach the stroke client in a way that enhances his or her ability to set goals, solve problems and make his or her own decisions. Post stroke rehabilitation requires determined, ascending and long-term training which makes the client's confidence in his or her own potentials and self-efficacy essential. (Reunanen 2017, 34-35.)

The interview of stroke patient's relation showed that in her opinion motivation and attitude play the key role after stroke. She emphasized the importance of keeping up the hope and not giving up, and that it should always be kept on both the patient's and the relative's mind.

> "Alussa on tärkeää muistaa, että elämä ei lopu tähän, vaikka siltä saattaa tuntuakin." (=In the beginning it is important to keep in mind that life does not end here even though it can feel like it.)

> “Positiivisuus ja motivaatio, sekä valmius kuntoutukseen ovat todella tärkeitä. Jos ei ole motivaatiota, ei tule kehitystäkään.” (=Positivity and motivation as well as readiness for rehabilitation are essential. If there is no motivation, there will not be progression.)
>
> She adds: “Kuntoutuksessa on valtava määrä työtä, joten täytyy olla motivoitunut kuntoutumaan. Jatkuvuus on tärkeää kuntoutuksessa.” (=Rehabilitation requires a huge amount of work so motivation is needed. The continuity is important in rehabilitation.)
>
> “On myös tärkeää osata ja ymmärtää hakea apua, koska sitä ei tule kukaan tarjoamaan kotiin.” (=It is also important to be able and understand to seek help because nobody will come to your house and offer it.)

In the end of the interview she summarized that maintaining hope is overall the most important thing after stroke. (Stroke patient’s relation, personal communication on 6.10.2017.)

8 THESIS PROCESS

The thesis process started in December 2016 during my clinical practice in Laitilan Terveyskoti by roughly agreeing on the topic and cooperation for the thesis. After the topic was decided, the method of the thesis was discussed. It was determined to use an interview of one stroke client's relation of Laitilan Terveyskoti in the thesis. The client and the relative were both already familiar with me from the practice.

The thesis consists of a written part and a practical part which in this case is the self-management package for the use of Laitilan Terveyskoti. The method of the package was discussed with Laitilan Terveyskoti in the early phase of the thesis process and it was decided to be a clear datafile concerning stroke patients with chronic pain. Afterwards the form and content of the package was considered more precisely with a physiotherapist of Terveyskoti, leading to the result that it would be a PowerPoint presentation which they will print out in Terveyskoti and give for the suitable patients. During the thesis process quite many parts of the schedule changed and delayed from the original plan. The overall goal of the thesis process was to finish the thesis in November 2017. Here is the final thesis schedule.

Table 1 – Thesis schedule.

December 2016	Deciding the topic.
February 2017	Writing the agreements and presenting the thesis plan.
September 2017	Reading and writing theory.
October 2017	Reading and writing theory, performing the interview and starting the implementation of practical part.
November 2017	Finishing the practical part. Finishing and presenting the thesis.

9 THE PACKAGE FOR STROKE PATIENTS WITH CHRONIC PAIN

Rehabilitation should base on the client's participation and everyday life. Home rehabilitation helps to manage with activities of daily living and supports client's mood and participation. Rehabilitation professionals think that home rehabilitation allow the client to compare his or her earlier capability and self-efficacy which is encouraging to make his or her own decisions. Home rehabilitation has been shown to offer experiences of safety, independence and capability due to learning how to cope with daily activities. (Reunanen 2017, 35, 72.) The self-management package for stroke patients aims to help them to manage with chronic pain at home. The package is produced for Laitilan Terveyskoti.

Laitilan Terveyskoti offers a wide selection of wellness and rehabilitation services for people of all ages. The personnel consists of a multiprofessional team and altogether there are approximately 70 employees. Terveyskoti offers diverse physiotherapy, occupational therapy and psychotherapy. In addition, it enables institutional care periods and housing services. Physiotherapy services cover many different areas of expertise, such as gerontology, musculoskeletal physiotherapy, adult and pediatric neurology, occupational physiotherapy, sports physiotherapy, lymphatic therapy and incontinence therapy. (Website of Terveyskoti 2017.)

9.1 Interview

After the theory part was completed, the interview of a stroke client's relation was carried out. The telephone interview was performed by using several open-ended questions and a lot of natural conversation. The questions of the interview were:

1) Which things are important to include to the self-management package in your opinion?
2) How big should the role of patients' relations or close ones be in the package?
3) What do you think about including some instructions/exercises to the package?
4) What is the most important thing for the package?

The purpose of these questions was to evoke conversation about the certain topic and hear the interviewee's opinion and experience on those things. The aim of the interview was to find out what would be important to include to the self-management package from the relation's point of view. The interview started by explaining the idea of the self-management package and the aim of it to the interviewee. After that the interview continued by asking one question at a time, having time for discussion about the topic and letting the interviewee tell her opinion in her own words.

For the first question she answered that at least general information about stroke and importance of patient's own motivation and attitude towards rehabilitation would be important to include to the package. About the relations and close ones her opinion was that they could be included to the package as well because also they have to be motivated in the rehabilitation process and they need to encourage the patient. She thinks that physiotherapy has a very big role in stroke rehabilitation and due to her experience it has had massive effects on the patient's functional ability. Because of that she said that it would be a good idea to add some instructions for patients to control and decrease chronic pain. She also stated that the continuity in rehabilitation is important which makes it beneficial for the patient to be able to do some exercises at home. From her point of view the most important thing is to remember that there is always hope. Due to the practical experience of stroke and chronic pain she had a lot of good points and knowledge. The main words that she clearly emphasized during the whole interview were hope, attitude and motivation.

9.2 PowerPoint presentation

The instructions of a physiotherapist in Laitilan Terveyskoti for the stroke patients' self-management package were that it should be compact and consist of essential information about stroke and chronic pain, including instructions for stroke patients to decrease and manage with chronic pain. Her wish was that there would be an even number of the pages to make it easier to print for example two or four slides on the same page.

In order to achieve a clear self-management package for stroke patients, it was necessary to consider the target group all the time during the making of it. Factors that were taken into account in the self-management package were limitation of the information, structure of sentences, diction, word order, text font, font size, font color and color of background. These points were considered because some stroke patients might have for example visual disturbances, and problems with memory, perception and focusing. They might also have difficulties in learning new things.

To make the package easy to read, the aim was to summarize each subject of the package quite roughly and to form as simple and short sentences as possible. Pictures were applied to make it more pleasant to read and to draw reader's attention and interest. By utilizing dashes in the sentences the text became spacious which makes the sentences to stand out beneficially and also makes it easier to read. The pictures that are included are positive and associated with rehabilitation in order to motivate and encourage the reader.

In the beginning of the package there are general information about stroke classification and the effects of stroke, shortly explained. Second, the package explains rehabilitation, the role of physiotherapy in it and the importance of motivation in rehabilitation. The third, main subject of the package is chronic pain. It contains definition of chronic pain, the relation of stroke in chronic pain and information about chronic shoulder pain. In the end of the package there are tools given for stroke patients to understand, control and decrease chronic pain to manage with it at home. The aim of the tools are to introduce easy and understandable ways to control pain and make it easy for the patients to implement them. The PowerPoint slides are presented in Appendix 1.

The package was sent to the physiotherapist in Laitilan Terveyskoti to get feedback from her and to be able to make possible changes on time if needed. She said that the information in the package is clear and it nicely emphasizes the physical rehabilitation aspect. About the pain management instructions she stated that they are easy for the patients to understand and implement. Based on the feedback few little changes were made: one word was changed because it was not the best possible diction and sounded

unfamiliar to her, and a picture of Lokomat therapy was added to the rehabilitation slide.

10 DISCUSSION

A stroke can cause permanent changes to the neural pathway leading to chronic pain. Also many of the post stroke patients have shoulder pain at some point. Self-efficacy and motivation have a big role in self-management of chronic pain. In the chronic pain cases, in addition to returning patients' functional capacity physiotherapy also focuses on chronic pain treatment which aims to decrease pain and prevent other distractions, such as insomnia and depressive symptoms. There are many different ways to treat chronic pain in physiotherapy but the aspect I was having in this thesis project was: how do post stroke patients treat and manage with chronic pain at home? Based on this question I wanted to give pain management tools that are easy to implement for post stroke patients to be able to decrease and control chronic pain at home environment. By understanding and controlling chronic pain as well as learning to cope with it in everyday life post stroke patients can affect their own health and life.

Although the thesis topic was not related to ICF, it was included to the thesis by introducing the effects of stroke by making use of ICF. ICF framework is published by WHO and it aims to use a neutral and mutual language which takes many health factors into account. Introduction of ICF has proceeded quite slowly in Finland and the use of it is still pretty minor. A challenge in introducing ICF is that changing a custom requires time and patience.

The original plan was to interview a stroke patient himself in addition to his relation to receive both perspectives to the thesis project but it came out that it was too challenging for the patient to answer to the interview questions. Of course including the stroke patient's own point of view would have been advantageous but also the relation's aspect is beneficial for the thesis. The interview was performed via phone due to the distance between me and the interviewee. It would have been helpful to send the

questions to her beforehand so that she could have thought about them for a longer time and more extensively. She might have more some important facts and experiences concerning the questions which did not come to her mind during the telephone interview.

During the making of self-management package the challenge was to produce a PowerPoint presentation suitable for the target group. Thinking of the diverse cognitive effects stroke might have on patients it is quite difficult to think a common and suitable conclusion for post stroke patients in general. This also made the limitation of information in the package challenging since the aim was to make it compact but still include a lot of essential information about stroke and chronic pain. In my own opinion and based on the feedback of the physiotherapist in Terveyskoti the package manages to give post stroke patients with chronic pain an understanding of the importance of rehabilitation, self-efficacy and motivation. Moreover, it offers crucial information about chronic pain, ways to control it and gives an understanding how controlling it at home affects beneficially their everyday life.

The thesis project could have contained a follow-up observation. It would have been interesting to see through the observations whether the package was helpful for stroke patients in controlling chronic pain at home. This would have made it possible for me to modify the package based on the patients' feedback. For future studies, the follow-up observation concerning the self-management package and its effects on stroke patients with chronic pain could be carried out.

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APPENDIX 1

SISÄLLYSLUETTELO

1. MIKÄ ON AIVOVERENKIERTOHÄIRIÖ?

- Aivoverenkiertohäiriö voi olla tilapäinen tai se voi aiheuttaa pysyviä vaurioita.
- Erilaisia aivoverenkiertohäiriöitä:
  - **Aivoinfarkti =** Tukkeuma verisuonessa estää verenkierron aivoihin.
  - **Aivoverenvuoto =** Verisuoni repeää, jolloin veri pääsee vuotamaan aivoihin.
  - **TIA =** Mini-aivohalvaus, jonka oireet kestävät alle 24 tuntia. Usein oireet saattavat kestää alle tunnin.

2. AIVOVERENKIERTOHÄIRIÖN VAIKUTUKSET

- Aivoverenkiertohäiriön vaikutukset ovat yksilöllisiä.
- Yleisimpiä oireita ovat:
  - halvaus toisella puolella vartaloa
  - lihasheikkous toisella puolella vartaloa
  - tuntohäiriö toisella puolella vartaloa
  - hahmotushäiriöt
  - nielun ja suun toimintahäiriöt.

3. KUNTOUTUS

- Koska aivoverenkiertohäiriön jälkeiset oireet vaihtelevat ja ovat erilaisia, yleensä kuntoutujat saavat monipuolista kuntoutusta.
- Fysioterapia on tärkeä osa kuntoutusta. Fysioterapian tehtävät ovat:
  - parantaa kuntoutujan toimintakykyä ja liikkumista mahdollisimman paljon
  - estää mahdollisia sivuoireita
  - kannustaa kuntoutujaa osallistumaan aktiivisesti kuntoutukseen.
- Myöhemmässä vaiheessa fysioterapiassa pyritään ylläpitämään kuntoutujan toimintakykyä.
- On todettu, että kotikuntoutus lisää kuntoutujan aktiivista osallistumista kuntoutukseen ja auttaa kuntoutujaa selviytymään arkielämässä.

4. KUNTOUTUJAN MOTIVAATIO

- Kuntoutujana **on erittäin tärkeää, että uskot itseesi ja omiin kykyihisi.** Tämä auttaa sinua:
  - **motivoitumaan** paremmin kuntoutusta kohtaan, eli kuntoutumisen halu kasvaa
  - **selviytymään** hankalissa tilanteissa ja haasteissa
  - **pysymään positiivisena** ja välttämään masennusta
  - **pärjäämään** paremmin arjen askareissa

- Usko itseen ja omiin kykyihin parantaa kuntoutujan elämänlaatua. Muista, että **toivoa ei saa koskaan menettää!**

5. KROONINEN KIPU

- **Krooninen kipu = pitkäaikainen kipu**
- **Aivoverenkiertohäiriö voi aiheuttaa pysyviä vaurioita hermoratoihin, jolloin kipu tuntuu tavallista herkemmin.** Joskus kipua voi syntyä myös tuntemattomasta syystä.
- Aivoverenkiertohäiriön jälkeen kipu tuntuu yleensä halvaantuneella puolella, mutta voi tuntua muuallakin kehossa.
- Kipu voi aiheuttaa tuntomuutoksia. Esimerkiksi normaali kosketus voi tuntua hyvin kivuliaalta.
- Kipu on usein jatkuvaa, repivää, polttavaa tai särkevää. Myös lämpötunto voi heikentyä.
- Fysioterapiassa pyritään hallitsemaan ja vähentämään kroonista kipua.

6. KIVULIAS OLKAPÄÄ

- Aivoverenkiertohäiriön jälkeen on hyvin yleistä, että olkapää kipeytyy. Tämä saattaa johtua:
  - heikentyneestä lihasjänteydestä
  - lisääntyneestä lihasjänteydestä
  - lievästä sijoiltaanmenosta.

- **Kivun hoitaminen ja ennaltaehkäisy on tärkeää**, koska kivulias olkapää voi vaikeuttaa kuntoutumista ja itsenäistä toimintakykyä.
- Käden pitäminen oikeassa asennossa ja käden painon tukeminen vähentävät olkapääkivun riskiä.

7. KROONISEEN KIPUUN SOPEUTUMINEN JA SEN HALLINTA

- **Krooniseen kipuun sopeutuminen** on helpompaa, kun:
  - hyväksyt muuttuneen elämäntilanteesi
  - asennoidut elämään myönteisesti ja toiveikkaasti
  - luotat omiin kykyihisi
  - sinulla on runsaasti voimavaroja.

- **Kroonisen kivun hallinta** auttaa sinua:
  - jaksamaan ja selviytymään kivun kanssa
  - vaikuttamaan omaan terveyteen ja elämään.

8. KEINOJA KIVUN HALLINTAAN

- On monia tapoja hallita kroonista kipua, kuten esimerkiksi:
  - rentoutuminen
  - ajatusten suuntaaminen muualle
  - levon ja rasituksen sopiva tasapainottaminen
  - kivun hyväksyminen ja rauhallinen suhtautuminen kipuun
  - iloa tuottavien asioiden tekeminen
  - liikunta
  - kylmä tai kuuma
  - realististen tavoitteiden asettaminen ja keinojen löytäminen niiden saavuttamiseksi.

- Erilaisten hallintakeinojen yhdistäminen on yleensä parempi kuin yhden hoitomuodon käyttö.

9. SOSIAALISET TUKIVERKOSTOT KIVUN HALLINTAKEINONA

- **Sosiaaliset tukiverkostot kuntoutujan ympärillä ovat hyvin tärkeitä kivun kroonistuessa**, koska kuntoutujan voimavarat saattavat olla heikot jatkuvan kivun vuoksi.
- Sosiaaliset tukiverkostot estävät kuntoutujan eristäytymistä. **Kuntoutuja saa tukiverkostolta tukea ja ymmärrystä**, jotka auttavat sopeutumaan krooniseen kipuun.
- Kuntoutujan tukiverkosto muodostuu perheestä, suvusta ja ystävistä. Tämän lisäksi myös työyhteisö, sekä vapaa-ajan harrastuksista muodostuneet ihmissuhteet kuuluvat tukiverkostoon.
- Kuntoutuja voi myös hakeutua ryhmään, josta hän saa vertaistukea. **Ryhmätoiminta vähentää yksinäisyyttä, lisää sosiaalisia taitoja ja antaa toivoa kivun kanssa selviytymiseen.** Ryhmässä voi jakaa omia kokemuksiaan ja saada tukea vertaisryhmältä.

10. KIPUPÄIVÄKIRJA KIVUN HALLINTAKEINONA

- **Kipupäiväkirja on yksi keino löytää kipua pahentavat ja helpottavat asiat.** Päiväkirjan avulla voit huomata, miten kivun voimakkuus vaihtelee eri tilanteissa ja vuorokaudenajoissa.
- Kipupäiväkirjan pitäminen auttaa saamaan huomion pois kivusta.
- Kipupäiväkirjaan voi merkitä:
  - kivun voimakkuuden säännöllisin väliajoin, esimerkiksi 4-6 kertaa päivässä asteikolla 0-10. (0=ei kipua, 10=sietämätön kipu)
  - kivun sijainnin ja keston
  - päivittäiset toiminnot
  - tuntemuksia ja mielialaa
  - asioita, jotka lisäävät tai vähentävät kipua

11. RENTOUTUMINEN KIVUN HALLINTAKEINONA

- Rentoutuminen on hyvä kivunhallinnan keino. Rentoutumisella on monia hyviä vaikutuksia, kuten:
  - ahdistuneisuuden vähentäminen
  - lihasjännityksen vähentäminen
  - stressin ja kivun vähentäminen
  - hallinnan tunteen lisääntyminen

- Rentoutumiseen käytetään erilaisia tekniikoita, kuten **hengitys- ja mielikuvaharjoituksia.**
- **Hengitysharjoitusten** vaikutusta voidaan tehostaa syvään hengittämällä. Lisäksi harjoituksiin voi lisätä musiikkia tai lihasrentoutuksia. Kun opit oikean hengitystekniikan, voit tehdä harjoituksia itsenäisesti kotona.
- **Mielikuvaharjoituksilla** voidaan syventää rentoutusta ja voittaa kipuongelmat esimerkiksi luomalla itselle mielikuvituksessa miellyttävä ympäristö, jossa kipu unohtuu.

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