

# The role of nurses in the long-term rehabilitative process of stroke patients.

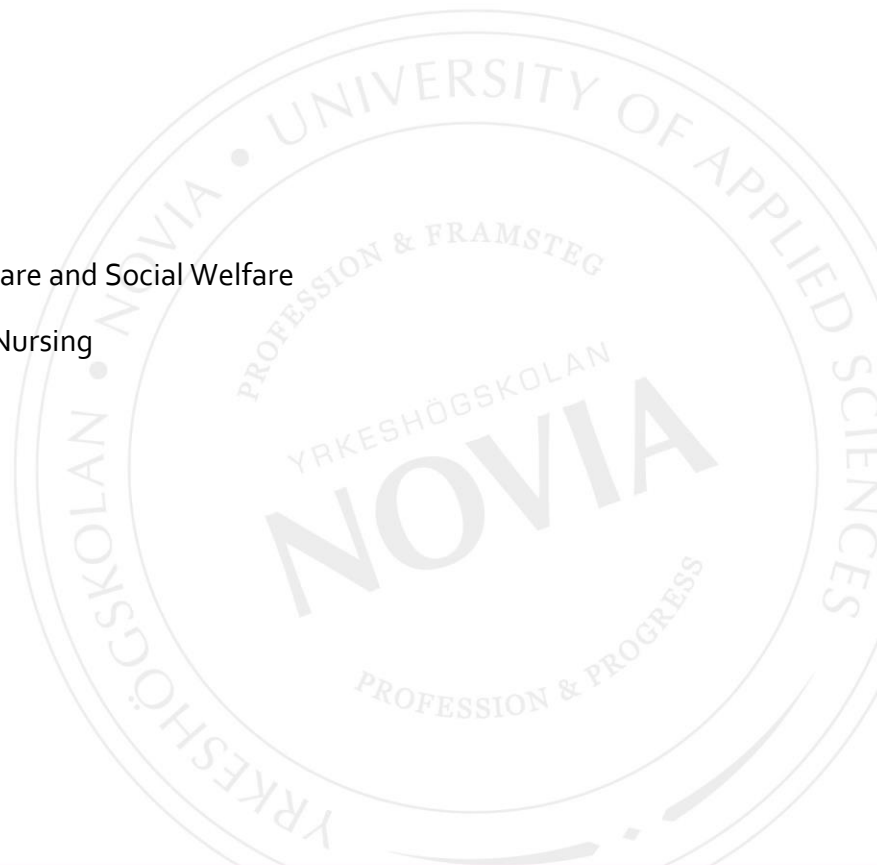
A scoping review inspired study

Joakim Bengs

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Author: Joakim Bengs

Degree Programme: Nursing, Vaasa

Supervisor: Maj-Helen Nyback

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**Abstract**

The individual that has suffered from a stroke, has a long rehabilitation process in front of them. The role of various specialists included in the rehabilitation process are well defined in literature, while nurses are known to be included in this process, the actual role of nurses has not been clearly defined. The aim of this thesis was to determine the role of nurses in the long-term rehabilitation of stroke patients.

The study is done with the use of a qualitative literature review, with scoping review as inspiration.

In the background, knowledge about stroke, it's risk factors, preventive measures and rehabilitative process that is essential for the understanding of the results are explained; it was also important to be mirror the background with the results to be able to clearly define similarities and differences between the texts.

The texts used for the study are scientific articles that are relevant to the topic.

The results found show a clear role of the nurse in the long-term rehabilitation process; primarily the care of the physical, emotional, familiar and socioeconomic status.

Challenges in the results showed that the nurses experienced a lack time as the biggest barrier for giving good care.

When the results were mirrored with the nursing theories, clear signs of influence from the theories were also noted in the texts.

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Language: English

Key words: Nursing, Stroke, Rehabilitation

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## 1 Introduction

One of the main reasons for me to research and write about this topic is because it is close to me and my personal experiences: a relative of the family passed away due to complications caused by stroke. When visiting the relative in the hospital I was fascinated by the nurses working in the ward, even though the relative was connected to life support and non-responsive, the nurses would still treat her as if she was responsive. The compassion and respect that they showed had a great impact on me as a person, which later would lead me to study and work in the nursing field.

When I was on clinical practice in the Hospital, including the emergency room and the bed wards, I had the opportunity to see some instances of stroke rehabilitation: from the acute setting in the emergency room, to the long-term rehabilitation process and increasing independence of a stroke patient. On clinical practice in the emergency room I witnessed a suspected stroke, and the response time of the personnel was quite adequately prepared, resulting in a quick diagnosis of a TIA, known also as a minor stroke: the quick diagnosis allowed the patient to get the right type of care in a timely manner, resulting in a better prognosis and recovery in the long run.

In the cardiac ward we will quite often have patients that have suffered from a stroke and are in the rehabilitation process or have gone through the rehabilitation process and are being increasingly independent. In these instances I would often see that the nurses would encourage the patients to do basic tasks by themselves, without assistance, or only assisting if they actually required it. These simple tasks included eating, taking care of showering/basic hygiene, intake of medicine, putting on/taking off clothes and similar actions. At first I thought this was cruel, seeing that these patients might not be able to do these tasks independently, but with time I could see that this improved these patients sense of independence, not feeling that they need to rely on a nurse or nurse practitioner to be able to accomplish basic tasks. I did not know it at the time, but this connects directly to Dorothea Orem's self-care theory, and Jean Watsons theory of human caring.

The desire to write and research about this topic formed from my experiences working in bed-wards and seeing the long-term rehabilitation process of patients that have suffered from stroke; realizing that nurses in general play a huge role in the rehabilitation process lead me to further research and write about their role in this

process. The subject of this thesis is very broad, with many articles and studies available, and more articles being constantly written since the socioeconomic burden of stroke is steadily increasing globally, especially in developing countries. Realizing this, lead me to narrow down my research and keep it restricted to more local occurrences (within the European union) , and a select few developing countries : For example, China due to the rise in population and quick development of the nation.

An article that I will use as an example of the increasing socioeconomic burdens of stroke is one from the World Health Organization, written by Johnson et al. (2016), which states that “Worldwide, cerebrovascular accidents (stroke) are the second leading cause of death and the third leading cause of disability. [...] Globally, 70% of strokes and 87% of both stroke-related deaths and disability-adjusted life years occur in low- and middle-income countries. Over the last four decades, the stroke incidence in low- and middle-income countries has more than doubled.”

It is astounding how much this one condition affects the world in such an impactful way, both locally and globally. This factor lead me to always stay interested in this topic. The final goal of this thesis will be to define the role of a nurse in the long term rehabilitation of the stroke patient, defining and researching along the way the limitations a patient can encounter regarding individuality and self-care. This will be further explored in the chapter “Aim and Research Question”.

## **2 Background**

All organs depend on a constant supply of energy to be able to function, this supply of energy being sugar and oxygen transported in the blood; when a part of the brain is deprived of this source of energy for an extended period, it loses its ability to function properly. (Caplan, 2006)

Before the rehabilitation methods and process for stroke patients can be described, stroke must be clearly defined: what it is caused by, its risk factors and the different types of stroke.

### 3 Stroke

Stroke is a term that is used for describing “brain injury caused by an abnormality in the blood supplied to a part of the brain” (Caplan, 2006). The word stroke deriving from the event of the patient being suddenly struck by blood vessel abnormality, with these abnormalities affecting brain function almost immediately (Caplan, 2006).

Even though it is hard to determine specifically how many stroke victims there are in a country, according to the United Kingdom’s Stroke Association (2018), *“There are more than 100,000 strokes in the UK every year. That is around one stroke every 5 minutes; Stroke is the 4<sup>th</sup> biggest killer in the UK, 3<sup>rd</sup> biggest in Northern Ireland and Wales”*.

In a smaller country like Finland, the number of stroke incidents is reduced, with an average of a little above 13,000 per year in 1991, 1999 and 2007 (Meretoja, 2011). But this does not take away from the severity of the situation of a person afflicted by a stroke: a stroke victim has lost some part of brain function, the severity of the case can always vary, but none the less it is a dehumanizing incident, affecting the very core of the individual and their quality of life (Caplan, 2006). Stroke is a very complicated disease and has different effects on individuals, with loss of function varying from permanent to temporary disabilities, depending on the type of stroke and how quick the patient is brought in for treatment. (Caplan, 2006)

Now that the definition of stroke is defined, the risk factors of stroke patients can now be explored, since a specific cause has yet to been found. (Sacco et al., 2013 p.2)

#### 3.1 Risk Factors

Risk factors can be both modifiable and unmodifiable, with the 5 largest modifiable risk factors being: High blood pressure, hyperlipidemia, diabetes mellitus, cigarette smoking, and atrial fibrillation (Hennerici et al., 2012 p.11); according to Hennerici et al. (2012), modifiable risk factors should be frequently monitored and treated when/if possible, this helps preventing stroke and eventual mortality, also increasing rehabilitation possibilities.

### **3.1.1 Modifiable Risk Factors**

When monitoring risk factors, healthcare professionals need to be able to treat and inform patients what these risk factors can lead to and should be able to go through these with patients in an order that states the severity of the situation (needing treatment as soon as possible). Often due to the underlying risk factors a patient can suffer from a myriad of other diseases, including cardiovascular diseases, these should be treated and monitored closely. (Hennerici et al., 2012 p.11)

### **3.1.2 High blood pressure (Hypertension)**

According to recent studies, hypertension is the most significant risk factor that leads to a stroke and to recurring strokes, so the correct diagnosing and treatment of hypertension should be the main initial focus in prevention. An analysis of treatment trials shows that an increase as low as 10-mmHg in systolic pressure leads to a small, but significant increase in risk of stroke, and a significant increase in mortality in case of a stroke. (Hennerici et al., 2012 p.13) When treating hypertension, it has been observed that a reduction of 5-6 mmHg in diastolic pressure leads to a maximal 40% reduction in stroke incidences. The reduction of blood pressure in general has been linked to an overall reduction of stroke cases but lowering the blood pressure too much can also lead to an increase in myocardial infarctions, thus it is recommended to not lower blood pressure too much. (Hennerici et al., 2012 p.13) Treatment of hypertension can be done with varying medicines and lifestyle changes, although the best method varies depending on the patient self; medical treatment such as alpha and beta-blockers, diuretics, calcium channel antagonists, angiotensin-converting enzyme inhibitors (ACE) and angiotensin receptor blockers (ARB) are all proven to be efficient in the reduction of blood pressure (Hennerici et al., 2012 p.13); though a recent study with non-CAD (Cardiovascular disease) patients has shown that calcium antagonists are the most effective in both treating hypertension and reducing risks for stroke, compared to beta-blockers that on the contrary seem to increase the risk for stroke. Beta-blockers are still recommended in treating a patient with CAD, but are not recommended as a first-hand treatment of high blood pressure. (Hennerici et al., 2012 p.14)



### 3.1.3 Atrial Fibrillation

Atrial Fibrillation goes hand in hand with hypertension and cardiovascular diseases: Atrial fibrillation is when a patient's heart-rhythm is fast and, in most cases, also irregular. (Medline Plus, 2019) In atrial fibrillation the electrical impulse is irregular, due to the sinoatrial node not being able to control the heart rhythm in an adequate manner. (Medline Plus, 2019) The most effective treatment for atrial fibrillation is with oral anticoagulation (Hennerici et al., 2012 p.11). The specific causes of AF are complex and multiple, both degenerative and genetic diseases play a huge role, but the most obvious and common circumstances that lead us to diagnosing AF are hypertension and heart failure. (Hennerici et al., 2012 p.20) Also, in many instances of myocardial infarction, AF is subsequently observed and diagnosed, leading to the observation that myocardial infarction, among other risk factors (alcohol consumption, psychological stress, thyrotoxicosis, obesity, mitral stenosis, sleep apnea, and metabolic system) are the cause of AF. Often atrial fibrillation can be asymptomatic, and is not recognized in a healthy patient until a serious incidence occurs and hospitalization is required (Hennerici et al., 2012 p.20). These need to be recognized, diagnosed and treated in a timely manner, also increasing the public awareness about asymptomatic AF, encouraging regular check-ups, even for the healthy patient. Asymptomatic AF has recently been getting a lot more attention, thus increasing the amount of undiagnosed AF being diagnosed and therefore treated. Since strokes caused by underlying AF have a tendency of being more grave, and having a greater risk for disability, the detection and treatment of AF plays a very important role in reduction of stroke and thus decreasing the burden that stroke and AF has on the general population. (Hennerici et al., 2012 p.20)

Treating AF can be quite straightforward, the use of per os anticoagulants has been studied and confirmed to reduce risks of stroke and alleviating symptoms of AF in general; the most effective oral anticoagulants that have been studied are vitamin-k antagonists, such as warfarin, the use of these medications in treating patients with AF has seen a significant reduction in ischaemic strokes and embolisms. (Hennerici et al., 2012 p.21) According to Hennerici et al (2012), this treatment is not used to its full potential, vitamin-k antagonists are particularly responsive to changes in diet, interactions with other medicines and liver functionality, when using these medications there is also a greater risk for internal bleedings, specifically in the elderly patient that might have cognitive impairments and greater fall risk. When treated with

oral anticoagulants, especially vitamin-k antagonists, it is recommended to take regular laboratory tests to see how fast ones blood coagulates, this result is called the International Normalized Ratio (INR) (University of Rochester, 2019), an optimal INR value for the elderly patient is 2.0 to 3.0, but staying within these values reduces significantly the pre-emptive effects of warfarin. Effective coordination with patients is essential, to allow for as many benefits as possible without increasing risk for internal bleedings. (Hennerici et al., 2012 p.21)

#### **3.1.4 Diabetes**

According to the World Health Organization (2019), diabetes mellitus is “a chronic metabolic disease characterized by elevated levels of blood glucose, which, over time, leads to serious damage to vital organs.” There are 2 types of diabetes mellitus: Type 1 is the chronic form, when the pancreas ceases to produce insulin, or produces such a small quantity that it has no impact on blood glucose; Type 2 is often caused because of lifestyle tendencies, the body has been exposed to so much glucose that the body has become resistant to the insulin produced by the body, or doesn't produce enough, thus needing additional insulin. (World Health Organization, 2019)

Diabetes in of itself is a huge burden on healthcare, but it is also linked to higher incidences of stroke, so treatment and more importantly management of this condition is of great importance, even though few studies show that there is no noteworthy decrease of stroke incidences when managing diabetes. (Hennerici et al., 2012 p.15)

The only completed research study that has been done about the effects of glucose control on the type 2 diabetic and its preventive efforts for stroke is the “United Kingdom Prospective Diabetes Study” (UKPDS), in this study it was discovered that even with constant glucose control using insulin, it resulted in a non-significant increase in risk for stroke relative to a non-intensive lifestyle change. (Hennerici et al., 2012 p.15). In a secondary study conducted with overweight type 2 diabetic patients using metformin to control their blood glucose there was a significant decrease in risk of stroke, relative to a non-intensive lifestyle change. (Hennerici et al., 2012 p.15)

## **3.2 Different types of stroke**

Now that the definition of stroke and its risk factors has been discussed, it can be further divided in a few subcategories: Ischemic stroke, haemorrhagic stroke, and transient ischemic attacks.

### **3.2.1 Transient Ischemic Attack (TIA)**

A transient ischemic attack (also known as a TIA) is when an area of the brain is temporarily deprived of blood flow, caused by a blockage, with symptoms lasting for less than 24 hours. This event has significantly less symptoms than a normal stroke, specifically symptoms of only the functions that the affected area of the brain pertains to. (Mätszch & Gottsäter, 2007 p. 45). Even though the effects of TIA's are less severe than ischemic strokes, the cause is the same, this can be a severe warning sign for future stroke events and should be taken seriously. (Mätszch & Gottsäter, 2007 p.45)

### **3.2.2 Ischemic Stroke**

Ischemic strokes are the most common types of strokes, they compromise most stroke cases; they are caused by a blockage of blood flow to a focal area of the brain, resulting in ischemia of that area. Sometimes the blockage does not cause significant damage to the area, thanks to collateral blood vessels that can supply blood to that area when a main artery cannot. (Mätszch & Gottsäter, 2007 p.45-46) When there is no collateral blood supply by other vessels, it results in an ischemic stroke minutes after the blockage occurs. (Mätszch & Gottsäter, 2007 p.46)

### **3.2.3 Haemorrhagic Stroke**

According to the National Institute of Health (2020), an embolism is when an artery is blocked by one (or many) clot/s. A haemorrhagic stroke is a cerebral ischemia that is solely caused by a clot that derives from the heart. (Mätszch & Gottsäter, 2007 p. 47)

## **4 Rehabilitative process**

Now that the definition, risk factors and different types of strokes have been discussed, the next topic is the rehabilitative process and the nurse's role in it.

## **4.1 Acute phase and treatment**

In the acute phase it is of the utmost importance that a patient that is suspected of suffering from a stroke is diagnosed as quickly as possible, this includes passing through any other healthcare facility that is not adequately prepared for a quick diagnosis, it is best if the patient is transported directly to the closest hospital; there shouldn't be any unnecessary waiting in the care chain. Preferably treatment should be started within 4 1/2 hours of the suspected stroke. (Jönsson, 2012 p. 46)

Once the patient has been diagnosed with the type of stroke that he/she has suffered from, treatment should be started, the main goal of the treatments is to limit the effects of the stroke, preventing any further damage to the affected cerebral area(s). (Jönsson, 2012 p. 50) There are different types of treatments that suit for different types of situations:

- a) Thrombolysis
- b) Thrombectomy
- c) Surgical procedures

### **4.1.1 Thrombolysis**

Thrombolysis is a treatment which goal is to dissolve fibrin that can be the cause of a blood clot, thus loosening up the clot and allowing for blood to circulate in the affected area again. There are great risks with this treatment, for example it can cause serious internal bleeding and sometimes the substance used to dissolve fibrin does not have the desired effect, thus not allowing blood to circulate in the affected area. Even though these risks are very serious, if this treatment is right for the patient it is usually quite effective, inducing almost instant positive effects on the patient's well-being. A negative aspect of this treatment is that it is only effective within the first 4,5 hours. (Jönsson, 2012 p. 50) Whenever this treatment is an option, a patients age, physical status and health status are taken into consideration and are the deciding factors if this treatment is adequate or not. (Jönsson, 2012 p.50)

### **4.1.2 Thrombectomy**

In the cases where a thrombolysis is not successful or not an option for treatment then the next best option is a thrombectomy. This is a procedure that can be done in an acute phase but requires advanced techniques and a highly trained medical professional. It is done through the insertion of a catheter that is then used to capture and aspirate the clot in question. This can only be done in certain hospitals, since not all hospitals have the required equipment or trained professionals. (Jönsson, 2012 p. 51)

### **4.1.3 Surgical procedures**

Surgical procedures in the acute phase are quite rare, and there aren't many patients that are able to go through them. But in the cases where it is possible, it has a significant effect on the prognosis of the patient. (Jönsson, 2012 p.51)

- When there is a bleeding in the cranial space around the brain, it is often caused by a ruptured aneurysm, where the capillaries are weak. This can be treated by "clamping" shut the aneurysm. (Jönsson, 2012 p.51)
- Bleedings and infarcts in the cerebellum (also called "little brain") are quite difficult to treat surgically, due to limited space; the bleeding can also cause swelling and pressure around vital parts of the brain, thus only pressure-relief surgeries can be performed if the option is available. (Jönsson, 2012 p.51)
- Bleedings or swellings in the front and middle part of the brain are easier to treat surgically, since there is space for the brain to expand: in life-threatening situations there is a possibility to surgically implant a drain for the bleeding or to lift a part of the skull-bone to relieve the pressure from a swelling. (Jönsson, 2012 p.51)

## **4.2 The Stroke Unit**

One of the most important "wards" that has a direct effect on the recovery of a patient that has suffered from stroke is the "stroke unit", where patients are put under observation, care and first-hand rehabilitation is initiated. Studies have shown that the care and rehabilitation that is started in stroke units increases chances of survival and decreases the amount of disabilities in the recovery process. (Jönsson, 2012 p.50)

According to the Helsinki University Hospital's (HUS, no date) stroke unit data, about 800 patients per year are taken into the unit; most of the patients come from the emergency room, but a part of the patients also come from the hospitals own wards.

A stroke unit can be mainly defined as:

- A specific ward that focuses on treating stroke patients. The ward's personnel include a multidisciplinary team that has special training within the treatment of stroke. (Jönsson, 2012 p.59)

The stroke unit is an identifiable ward in a hospital where the focus is on stroke patients, it encompasses healthcare professionals that have special training with stroke and its rehabilitation, these professionals usually undergo a yearly update of guidelines within stroke treatment and its rehabilitation. (Jönsson, 2012 p.59-60)

The multidisciplinary team includes doctors, nurses, practical nurses, physiotherapists and speech therapists, with also the availability to meet nutritionists and neuropsychiatrists. These professionals should also have regular meetings. (Jönsson, 2012 p.60) An important job that they also have is informing the patient and relatives about the patients situation and continued line of care, explaining the importance of rehabilitation. (Jönsson, 2012 p.60)

#### **4.2.1 Observational period (what needs monitoring?)**

During the observation period in the stroke unit, many aspects are monitored and regularly checked: Neurologic status and level of consciousness, inclination to time, place and person, respiratory frequency, blood pressure, pulse, electro cardiograms (filming of the patients heart-rhythm, monitoring disturbance in rhythms), blood tests (infection value, fats, cholesterol, general blood status etc.), regular measuring of blood sugar levels (specifically in the first few days, to be able to see the blood-sugar curve), temperature, blood saturation (amount of oxygen that is carried in the blood, expressed in percentage), assessment of fall risk, movement ability, communication ability as well as ability to swallow, measurement of intake of food and liquids, coupled with measurement of urination and excretion. (Jönsson, 2012 p.61)

The observation of blood pressure and blood sugar is of the upmost importance until it stabilizes either by itself or through medicinal interventions (blood pressure medicine, insulin), this is because the damage that has occurred to the brain tissue can

be worsened, especially if blood sugar levels are higher than normal. (Jönsson, 2012 p.61)

The observation and measurement of temperature is also very important, the brain is quite susceptible to rises in internal temperatures in the initial recovery period: if a temperature is measured above 37.5° centigrade, it is quickly corrected with antipyretic medicines (medicinal compounds that reduce internal temperature). A rise in internal temperature can also indicate infection (for example respiratory tract infection, urinary tract infection etc.), the cause of a rise in temperature needs to be investigated as soon as possible. (Jönsson, 2012 p.61)

Typically, also the observation of a patients need for resting is monitored, stroke patients are more prone to tiredness and require an adequate amount of rest. (Jönsson, 2012 p.61)

A patient's intake of nutrition is closely monitored, especially in the acute phase, because taste, appetite and one's ability to swallow are affected if the nervous system is damaged. Before a patient can start eating/drinking at the ward, a speech therapist will assess the ability to swallow and if any corrective measures need to be taken. An adequate intake of nutrition is essential for recovery and rehabilitation, a lacking diet will directly affect the patient's rehabilitation and its results, prolonging the rehabilitative process, this will be discussed in detail in the chapter pertaining to nutrition. (Jönsson, 2012 p. 62)

Monitoring of mouth hygiene is required during the initial observational period: this is done to assess if the patient requires any assistance, a plan is set up if assistance is required. (Jönsson, 2012 p.62)

A patient's excretion and urination ability is monitored the first few days, nerve damage to the parts that control these abilities can be affected after having suffered from a stroke (loss of feeling, paralysis), so it is vital to observe if these are functioning normally, for urination this is typically done with non-invasive ultrasounds of the bladder after urination (IE. A bladder-scan), which give a result in millilitres of approximately how much liquid is in the bladder, the results of these bladder-scans give the staff an indication if catheterization is necessary. Long-term indwelling catheters are avoided until they are necessary, these always have a risk of causing urinary tract infections. (Jönsson, 2012 p.62) When monitoring for constipation one of

the most effective way is to observe excretion frequency and amount/consistency during bathroom visits, the staff should also offer frequent bathroom breaks, since the affected patient might not have the own ability to visit the bathroom independently. (Jönsson, 2012 p.62-63)

Epileptic attacks can occur after a patient has suffered from stroke, if such an attack is observed the staff should note the time it begins and ends, as well as how the epileptic attack looks. If an epileptic attack occurs, antiepileptic medicines are started as a preventive measure. (Jönsson, 2012 p. 63)

A patient's sleep-rhythm is often disturbed when in the hospital ward, often due to the regular check-ups that are done as well as the general environment in the hospital. Sleep and rest should thus be monitored, and medication should be given in case of sleeplessness, but the caretaking professional should be the deciding factor that decides if medication is needed, because usually these medications affect the neurologic status of the patient. (Jönsson, 2012 p.63)

Assessment and monitoring of movement ability should be initiated and individualized as soon as possible, a quick start to mobilizing the patient leads to a quicker recovery, less complications and promotes brain plasticity. (Jönsson, 2012 p. 65)

### **4.3 Complications in the acute and observational phase**

Complications that are observed in the acute and observational period (also including the rehabilitative period) are mostly related to lack of mobility, typically deep vein thrombosis, pressure wounds (decubitus), and fractures caused by dizziness, inadequate balance and overall worse mobility which can lead to falls. (Jönsson, 2012 p.67)

Preventive measures are usually taken to avoid complications, these preventive measures include: pain assessment, fall-risk assessment, pressure-wound assessment and prophylactics, thromboprophylaxis (intervention with medication), supportive stockings to prevent swelling of the feet, nutritional intake assessment, swallowing assessment. Many patients also suffer from a general depressed mood in this phase, consideration of anti-depressive medications should be discussed. (Jönsson, 2012 p.67)



## **4.4 Mobility**

A mobility assessment is done at the stroke unit which results are used to assess how much assistance the patient is going to be requiring; these assessments are done multiple times by a physiotherapist, initially it is done the first day of arrival to the stroke unit if possible, then when the patient can start moving, and later with a few days in between each assessment, this is done to observe if the patient is becoming more independent. (Jönsson, 2012 p.73)

The physiotherapist will do an assessment of: the patients displacement ability (with how much ease/difficulty the patient moves for example from a bed to a chair), motor skills, muscle tone, balance and feeling when in movement. (Jönsson, 2012 p.73)

Regular nurses should also be able to do a simple mobility assessment.

### **4.4.1 Mobility after the acute phase**

Training mobility in the rehabilitative phase becomes more task-oriented and personalized, to be able to do tasks that are required on the personal level. This training is individualized and planned usually at the stroke unit, and is done by physiotherapists and ergo therapists. (Jönsson, 2012 p. 81)

The task-oriented rehabilitative process' focus is setting a relatively easily obtainable goal for the individual, for example walking up and down stairs: this goal allows for the training of strength in an individuals legs, and balance. (Jönsson, 2012 p. 81)

The intensity and type of training depends on how much the patient has been affected by stroke, some individuals may be able to do the training at home or at a health center, while others may need more intensive forms of training while staying in bed-wards or assisted living housing, in these cases the physiotherapist will come to the individual and also guide the personnel. (Jönsson, 2012 p. 81)

In cases where physical rehabilitation and training can be done in the home, the home rehabilitation team is involved, this team functions differently from municipality to municipality, but the general premise is to allow the training and rehabilitation to be done in the comfort of an individuals own home. (Jönsson, 2012 p.81)

In cases where more intensive physical rehabilitation is required but the patient is in relatively good shape to live at home, training is done at the rehabilitation clinic. The

process in the rehabilitation clinic is similarly structured to the process in the stroke unit, the difference is that the main focus is on rehabilitation and is done intensively, usually about 3 to 4 days a week for several weeks, even months, depending on the speed of recovery of the individual patient. In these cases the patient comes from home to the clinic. The personnel in the clinic is comprised of physiotherapists, occupational therapists, speech therapists, artistic curators and doctors, with the availability to consult neuropsychiatrists if necessary. (Jönsson, 2012 p. 81)

#### 4.4.2 International Classification of Functioning, Disability and Health (ICF)

The World Health Organizations International Classification of Functioning, Disability and Health (ICF) is a tool that is used in assessing the individual's specific training program and prerequisites. The classification gives a wholesome perspective of how the patient has been affected by a specific disease, in this case a stroke, and shows the impairments and individual needs of each patient, extending to the socio-economical, environmental and personal factors as well, since they have a direct effect on the recovery of the patient. (Jönsson, p. 74)

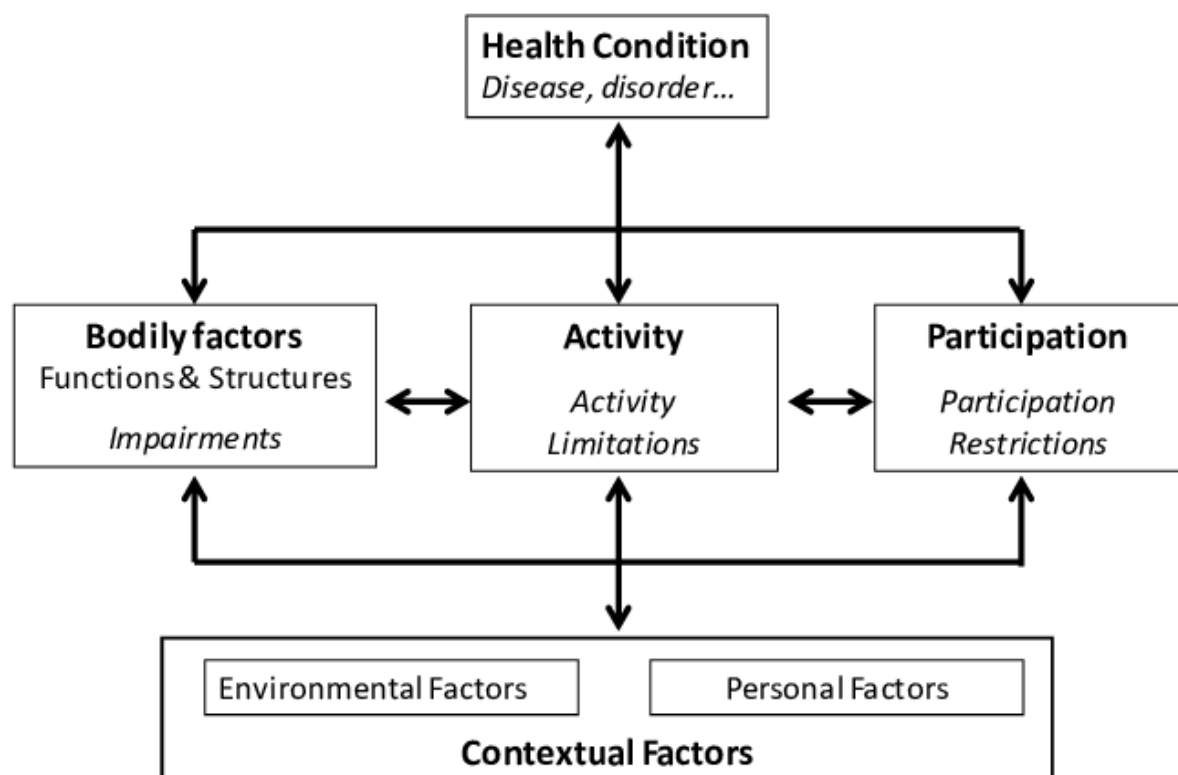


Figure 1. The international classification of functioning, disability and health. (Adolfsson, 2020)

Components	Domain	1 <sup>st</sup> Level Classification	2 <sup>nd</sup> Classification Level (if applicable)	Supporting Quotations (theoretical example)
<b>Impairments</b>	Body Function	Structures related to movement	Upper limb	"I can't use my right hand" "My right hands grip is okay, but it feels unsafe to use it"
			Lower limb	"I have difficulty moving my left leg" "My left leg still feels weaker"
<b>Activity Limitations</b>	Mobility	Walking and moving	Walking	"My right leg drags behind; I can't walk properly" "I only walk a short distance"
		Moving, transportation	Public transportation	"Using public transport is difficult with my impairments"
			Driving	"I can't drive anymore"
	Self-care	Hygiene		"I can't shower by my self, somebody always needs to help me"
		Dressing		"I can't put on a t-shirt properly, I can't get it over my head"
<b>Participation Restrictions</b>	Major life areas	Work and employment	Significant employment, self-worth	"I used to work a lot, now the days go by so slowly and I feel useless"
	Domestic life	Caring for household, assisting others	Assisting others	"I can't help around the house as much as I used to, I feel like a burden"
		Buying necessities	Goods and services	"I don't go the shop anymore, I feel uncomfortable"
	Interpersonal interactions and relationships	Particular interpersonal relationship	Informal relationships (acquaintances, friends)	"I don't see my friends that often anymore, they don't come and visit me and I don't want to ask them"
	Community, social and civic life	Recreation, leisure		"I went to a party and it felt difficult being there"
<b>Environmental Factors (Facilitators)</b>	Products, technology	Products and technology for assisting indoor and outdoor mobility/transportation		"I can't walk up the stairs anymore, I need to use the stair lift"
	Support, relationships	Family		"My kids are always here to help me when needed"
	Services, systems	Healthcare		"The physiotherapy helps but only to a certain degree"
<b>Environmental Factors (Barriers)</b>	Support, relationships	Family		"My spouse has been cold towards me ever since the incident, I feel like she resents me"

Table 1. Constructs according to the ICF (Rhoda, 2020)

Figure 1 by Adolfsson (2020) represents the ICF structure. Table 1 by Rhoda (2020) represents constructs according to the ICF in use for a hypothetical stroke patient.

## 4.5 Eating

An individual's ability to eat can be greatly affected after having suffered a stroke. Eating is a complex process, comprised of meal preparation, mealtime habits and mealtime situations; preparation includes grocery shopping and the actual cooking of food, habits include when a person eats and food preferences, situations revolves

around the actual moment of eating, interaction with others during mealtime and mealtime environment. (Jönsson, 2012 p. 85)

All aspects of having a meal are affected by age, sex, civil status, living situation, disease and general troubles (ex. Allergies, intolerance), as well as the type and quality of care received. (Jönsson, 2012 p. 85)

#### 4.5.1 Swallowing

One of the most important abilities that has to do with nutrition and eating that can be affected by stroke is the individual's ability to swallow, impairment with swallowing is called dysphagia. This needs to be assessed in the acute phase, since dysphagia is directly linked to pneumonia (caused by aspiration), malnutrition and extended periods of hospitalization. (Jönsson, 2012 p. 87)

The most common tool for assessing swallowing ability in the acute phase are dysphagia screening tools, there are several different types of these screening tools, figure 2 is an example of such.

Barnes-Jewish Hospital Stroke Center		The Center for Stroke and Cerebrovascular Disease	
<b>BJH STROKE DYSPHAGIA SCREEN</b>		BARNES JEWISH Hospital St. Louis	Washington University in St. Louis Physicians
Date: _____		NATIONAL LEADERS IN MEDICINE	
To be completed on all patients upon admission with diagnosis of stroke. If any of the following questions are answered with a yes, stop and refer to speech pathology.			
		<b>YES</b>	<b>NO</b>
1.	Is the Glasgow Coma Scale LESS than 13?	<input type="checkbox"/>	<input type="checkbox"/>
2.	Is there Facial Asymmetry/Weakness?	<input type="checkbox"/>	<input type="checkbox"/>
3.	Is there Tongue Asymmetry/Weakness?	<input type="checkbox"/>	<input type="checkbox"/>
4.	Is there Palatal Asymmetry/Weakness?	<input type="checkbox"/>	<input type="checkbox"/>
5.	Are there signs of aspiration during the 3 oz. water test?	<input type="checkbox"/>	<input type="checkbox"/>
<ul style="list-style-type: none"> <li>• If all findings for the first 4 questions are <b>NO</b>, proceed to the 3 oz. water test.</li> <li>• Administer 3 oz. of water for sequential drinks, note any throat clearing, cough, or change in vocal quality immediately after and 1 minute following the swallow. If clearing, coughing, or change in vocal quality is noted, refer to speech therapy.</li> <li>• If all of the answers to the above questions are <b>NO</b>, then start the patient on a regular diet.</li> </ul>			
_____ R.N. Signature			
Assessment methodology and form developed by Barnes-Jewish Hospital, Speech Pathology Services. ©2006, All Rights Reserved.			

Figure 2 The BJH Stroke Dysphagia Screen by Edmiaston et. Al (2013)

These screenings are done before anything via mouth is given to the patient, if the initial screenings result is a suspected dysphagia, the patient must be labelled as “nothing per os”, until a qualified speech therapist has done an evaluation of the patient. This evaluation must be done no more than 2 days later than the patients’ arrival to the hospital. (Jönsson, 2012 p. 90)

Every time the consistency needs to be changed; a new evaluation must be done, assessing the individual’s ability to swallow the new consistency. (Jönsson, 2012 p.90)

#### **4.5.2 Other eating impairments**

Other eating impairments include an individual’s energy and strength during mealtimes, or rather a persons reduced energy in connection with mealtime, this results in the individual stops eating because of being tired/without energy rather than because of being full, this has the strongest connection to malnutrition, since it causes a repeating cycle of being tired at mealtimes. (Jönsson, 2012 p. 94)

The reduced energy during mealtime is also observed to be the only eating impairment that doesn’t improve during hospitalization, which further causes malnutrition when the patient has been discharged. Malnutrition directly affects the patients ability to perform physical rehabilitative tasks, which in turn directly affects the prognosis and rehabilitations results; special interventions are required to correct the reduced energy of a patient, such as: smaller portions which are eaten more often, energy rich food and drinks. (Jönsson, 2012 p.95)

If the reduced energy is accompanied with a loss of weight, a nutritionist should be consulted. (Jönsson, 2012 p.95)

#### **4.5.3 Types of meal consistencies in relation to impairment.**

- Whole and divided: Whole and divided consistency at mealtimes are given to patients with none to very light eating impairments (patients with dry mouth, making it more difficult to swallow, need more sauce/liquid), these portions are normal consistency or at the most have to be cut up into smaller pieces. (Jönsson, 2012 p. 131)

- Rough paté: rough paté consistencies are ideal for patients with light eating impairments (motor problems, lethargy), this consistency is characterized by being airy, soft and coarse-grained texture, it should be easy to eat and cut with only the use of a fork. Examples of this type of consistency are coarse meat patties, cooked fish that is soft, coarse vegetable patties, well cooked vegetables, whole or puréed cooked potatoes and sauce. (Jönsson, 2012 p.131)
- Timbal: This consistency is ideal for patients that have biting and swallowing difficulties: the food holds together in a form but requires no further chewing. Works well for when the duration of a mealtime is extended. The consistency is distinguished by being soft, smooth and cohesive and having similarities with an omelette. Foods that have this type of consistency are meat or fish timbals, vegetable timbals or vegetable purée, mashed or pressed potatoes with sauce. To avoid any risk of aspiration the food should all be puréed as to create a homogenous consistency and is more porous than rough paté's. (Jönsson, 2012 p.131)
- Gelé/Gel-consistency: This consistency is most adequate for patients with severe swallowing difficulties, slow swallowing reflex and damaged oral cavity. It is soft and slippery, allowing it to be easily eaten, even with severe dysphagia. Examples of food that have this type of consistency are cold meat or fish jellies, vegetable purée or jelly, cold vegetable jelly, mashed potatoes, and vanilla-sauce consistency sauces. These consistencies usually melt in the mouth. For patients with difficult dysphagia, that receive nutrition mostly through enteral means, small "tasting" portions of gel-consistencies are the best option for boosting general morale, allowing the experience of taste and company during mealtime. (Jönsson, 2012 p. 131)
- Liquid: This consistency is best for patients that have damages in the throat or oesophagus. It is smooth and runny and falls off the spoon, cannot be eaten with a fork. Examples of this are enriched meat, fish and vegetable soups. (Jönsson, 2012 p.132)
- Thick (or viscous) liquid: these consistencies are also for patients with severe dysphagia, it is smooth, viscous and drops off the spoon but not completely. Sour-cream is the best way to envision this consistency. Foods that have this

type of consistency are thick meat, fish or vegetable soups. There should be no small pieces in the consistency, being completely smooth. These are also best for patients that have a paralysis in the throat (throat palsy). (Jönsson, 2012 p.132)

- **Thickeners:** Thickeners are used with liquid consistencies that are not viscous enough for the patient with dysphagia. (Jönsson, 2012 p. 132)
- **Energy rich food:** Energy rich food is administered to the patient that suffers of malnutrition or is suspected of being in the risk zone for malnutrition. (Jönsson, 2012 p. 133)
- **Enteral and Parenteral nutrition:** If a patient that has suffered from stroke does not have the ability to eat within the second, or latest third, day, then a gavage should be considered. A Nasogastric tube is put through the nose and reaches the stomach, is used in the initial phase to deliver medicines and nutrition, it is supposed to be in place for a relatively brief period. If the patient's inability to eat extends over two to three days then a percutaneous endoscopic gastrostomy (PEG) should be considered, which is a procedure where a tube is passed into a patient's stomach through the abdominal wall. Parenteral nutrition is administered through an intravenous port, these are liquids with added nutrition (proteins, electrolytes, carbohydrates, fats, minerals) and are only given to patients that cannot have nutrition administered enterally. (Jönsson, 2012 p.134)

#### **4.5.4 Eating exercises and supportive interventions**

Eating exercises should be started as soon as physically possible, in some cases the patient might have to completely learn how to eat again. These exercises are done by a trained speech therapist. (Jönsson, 2012 p. 134-135)

Supportive interventions aim to increase a patient's autonomy morale and stimulates the conservation of abilities that are connected with eating. These interventions can be small actions or inactions, but have a big significance: for example, verbal encouragement to eat by themselves, cutting up the pieces but letting the patient eat autonomously, guide the patient when eating, assisting with eating. (Jönsson, 2012 p. 135)

## **4.6 Bladder function**

40-70% of patients that are hospitalized due to stroke suffer from urine incontinence, 25% have a chronic leakage problem after hospitalization and about 15% still have bladder impairments one year after stroke onset. (Jönsson, 2012 p.173)

### **4.6.1 Bladder function in the rehabilitative phase**

Like other functions and abilities that have been affected by stroke, also bladder function can be trained back to an almost normal ability. The goal of the training is to come as close as possible to the function's ability before stroke onset, thus a very detailed survey of the patients urinary and defecatory function needs to be taken, this information is usually given by the patient's relatives and/or spouses. (Jönsson, 2012 p.177)

## **4.7 Communication impairments**

If a person that has suffered from stroke has impairments that affects the patient's cognitive function and emotions, this will result in a direct difficulty in communication. For example if an individual's memory has been severely affected, they may not remember previous conversations, or even previous days, thus causing communication to become incoherent, or in a patient where the stroke affected the visual area of the brain, they may not notice a objects and people on their right/left side (whichever side is affected). (Jönsson, 2012 p. 203)

### **4.7.1 Specific communication impairments**

Specific speech impairments that can arise after a stroke, other than the previously stated ones, can be aphasia/dysphasia, anarthria/dysarthria verbal apraxia/verbal dyspraxia. (Jönsson, 2012 p.204)

- Aphasia/Dysphasia: is an impairment that directly affects an individual's ability of comprehending and producing speech, writing and reading. (Jönsson, 2012 p. 204)



- Anarthria/Dysarthria: an impairment that affects the individual's speech muscles, making them weaker or losing control over them, resulting in slurred, slow speech. (Jönsson, 2012 p. 214)
- Verbal Apraxia/Verbal Dyspraxia: an impairment that affects the individuals speech sound, resulting in trouble saying some words consistently and correctly (Jönsson, 2012 p. 217)

#### **4.7.2 Speech therapists role**

As soon as a patient is in the right condition, and is suspected of having a communication impairment, a speech therapist should give an assessment of the type (or types) of impairment(s) and the level of impairment that the patient suffers from. (Jönsson, 2012 p. 218)

When a result is obtained, the speech therapist informs the patient, relatives and any personnel about the impairment, what difficulties arise with the impairment, a prognosis of the condition and how to make communication easier with the impaired patient. (Jönsson, 2012 p. 218-219)

## **5 Theoretical framework**

The nursing theories are used as a tool, and are Dorothea Orem's Theory of self-care, and Jean Watson's Theory of Human Caring, specifically Watson's theory of caring and non-caring, as well as the transpersonal caring relationship.

### **5.1 Theory of self-care**

When discussing and researching the care of stroke incidents, initially we tend to focus more on the acute incident: it is well known that to successfully care for stroke, we need to have relative quick access to high quality emergency care, and traditionally that has been the main focus. Recently the main focus has shifted more towards a process-oriented perspective of care, taking more into account a plan of care for the patient that has suffered of stroke: this involves the use of rehabilitation that should be initiated as soon as possible and should also be continued throughout the whole recovery process, through the use of communal rehabilitation care. (Jönsson, 2012 p. 28-29)

When researching long-term rehabilitative care, a topic that is often discussed is the patients perspective, and how we as nurses need to be able to view the patient for what they are and involve : humans beings and the use of their freedoms; for example when a patient that suffers from a disability caused by stroke decides to undertake the long rehabilitative process of taking part in daily activities and routines of life, it is necessary for nurses to get out of the ward so that they can observe the rehabilitation process from another perspective, since they are only used to the ward care process. (Orem et al., 2003 p. 98-99)

Once we realize that in the caring process we need to take heavily into account the patients perspective, we can connect the whole process to Dorothea Orem's Theory of Self-Care Deficit, specifically that functioning adults tend to care for themselves and their dependents. (Orem et al., 2003 p. 103) For example, brushing one's teeth is done voluntarily, thus it is an act of self-care, whether done deliberately or not. *"Self-care is action for self. It is action through which inputs are made to self or environment – inputs that contribute to the maintenance of human functioning, to the continuance of life, health and well-being."* (Orem et al., 2003 p. 103)

Self-care is a response to needs (or requirements) in human beings, these requirements can be both subjective and objective, they can also be divided into universal requirements and requirements that arise due to health conditions. Universal requirements are self-care needs that are routine and executed to be able to maintain normal human function (ex. Food intake, hygiene etc.). Requirements that arise due to health conditions are the type of needs that are necessary because of a human's reduced ability to care for one's self. For example, a patient that suffers from aphasia (language impairment) has a reduced ability to communicate, or to understand communication, the need to communicate in such a manner that the patient is understood is the self-care requirement. The action that is used to meet the requirement (speech therapy, letter board, or essentially any tool used to help with the impairment) is the actual fulfilment of self-care. (Orem et al., 2003 p. 104)

*"Self-care is the self-initiated and self-directed actions of people to know their current and future requirements for regulating their own functioning and development and to select and use means to meet these requirements in order to sustain life and to promote health and well-being"* (Orem et al., 2003 p. 217)

The theory of self-care can be structured into three main concepts:

1. Self-care requisites.
2. Therapeutic self-care demand.
3. Self-care operations. (Orem et al., 2003 p. 217)

### 5.1.1 Self-care requisites

We briefly went over this earlier, but to summarize, self-care requisites are human needs that arise due to the need to care for one-self's health, generally expressed in actions. These self-care requisites have been described in 3 different categories: Universal, developmental, and health-deviation. (Orem et al., 2003 p. 218)

- Universal type self-care requisites: These are needs that are common for maintenance of health and well-being in all people. Clearly these requisites must be redefined second to a person's age, developmental state, environmental factors, and health state, among others. Once the requisite has been redefined to the specific person, we can say that the requisites are individual. (Orem et al., 2003 p.218)

Self-care structured around specific factors allows for the concept to be individualized: thus, promoting positive health and well-being, also including prevention and maintenance. (Orem et al., 2003 p. 218)

- Developmental type self-care requisites: These are requisites that are concerned with human developmental processes (affective, cognitive, stages of maturation), with emotional behaviours associated with severe disease (also including end of life) and anaesthesia. (Orem et al., 2003 p.218)

These developmental self-care requisites can be further categorized into two different categories: the first concerning maintenance and promotion of health, which is closely related to the universal self-care requisites; the second concerning methods that promote prevention of detrimental lifestyle and social choices, as well as choices that affect development. (Orem et al., 2003 p. 218-219)

- Health-Deviation type self-care requisites: These are requisites that arise because of disorders to human function and structure, disease, injury, and the effects of medical diagnostics and treatments. (Orem et al., 2003 p.219)

The first and last self-care requisites (Universal and health-deviation) are the needs that are at the forefront when we are discussing the long-term rehabilitation of patients that have suffered a stroke.

### **5.1.2 Therapeutic self-care demand**

Therapeutic self-care demand is the realization of the different types of self-care requisites, these being universal, developmental and health-deviation requisites. (Orem et al., 2003 p. 219-220). There is usually one, or few, ways to meet the different self-care requisites.

When performing these methods, we call them care measures. These methods are investigated beforehand, typically by questioning if the care measure is the adequate measure under the specific conditions of the patient. (Orem et al., 2003 p. 220) For example, a question that would be used for a patient that suffers from aphasia and swallowing difficulties after an incident of stroke would be: "What is an adequate manner for a 55-year old man with difficulties swallowing to intake the necessary amount of nutrients required for maintenance of health?" For this example, some adequate measures could be the use of a speech therapist to train with swallowing or different consistency of foods that facilitate swallowing.

Nurses need to be able to calculate and formulate the best possible therapeutic self-care demand: this needs to address the patients need for self-care and dependent-care actions in day-to-day life, adjusting the actions thanks to observation of the patient during the rehabilitative process and observations from the patient itself. Patients should also be informed and educated in the calculation of therapeutic self-care demands, this allows the projects to cater for the specific needs of them. (Orem et al., 2003 p.220-221)

During the rehabilitative process, the design of the therapeutic self-care demand is of the upmost importance when promoting and maintaining the health and well-being of the patient. An optimal design includes all self-care requisites focusing on normal developmental processes. (Orem et al., 2003 p. 221)

### 5.1.3 Self-care measures (operations)

Self-care actions (measures, operations, practices) are deliberate and are performed by most people (also older children), these actions are acquired through time via familiar communications and relations. These operations are practical and promote conditions that are not actual when the measures are put into place. When the completion of these measures is done, the effects (or results) are what remain. When these procedures are performed in sequence, they conceptualize the self-care system that is put in place for individuals. (Orem et al. , 2003 p.223)

To summarize, the self-care actions reference all measures that are taken, in order for a specific requisite to be met. (Orem et al., 2003 p. 223) Nurses should have enough knowledge of the therapeutic self-care demand system so that the individuals self-care plan and the self-care measures are taken into account and actualized through one or multiple methods: this produces nursing results, which in of itself assures that the patients therapeutic self-care demands are adequately met, also that their ability to engage in self-care is protected and regulated. (Orem et al., 2003 p. 224)

## 5.2 Human caring & Transpersonal caring relationship

*"Quality nursing and healthcare today demand a humanistic respect for the functional unity of the human being."* (Watson, 2012 p. 35)

Jean Watson's Human Caring Science focuses on viewing the patient as a whole, "directed towards the person, it honours and integrates all parts into a whole". (Watson, 2012 p.35) The perspective of viewing the patient as a whole and thus healing all aspects of a person's life (socio-economical, physiological, physical) becomes integral in the rehabilitation of stroke patients since it is all of the aspects of their life that becomes uprooted.

### 5.2.1 Transpersonal Caring Relationship

A transpersonal caring relationship builds further on Watson's human caring science, stating that *"this caring connotes a special human care relationship – a connection with another person, a high regard for the whole person and their being-in-the-world."*(Watson, 2012 p. 75)

The aspect of this theory focuses on the patient's dignity and preservation of humanity. This process begins when the nurse enters the patient's life and connects with the patient's sense of being, allowing empathy to create a flow between the nurse and the patient, thus enabling an open environment for the patient to release feelings or thoughts he/she has had pent up or been wondering about. (Watson, 2012 p.75)

The release of pent-up thoughts or emotions allows for the replacement of negative thoughts/emotions with more positive and self-healing thoughts/emotions. The nurse's open-minded and open-hearted approach creates an open space where the patient is viewed and considered beyond the disease and diagnosis, this allows the patient to consider their own inner healing resources and not depending on solely medicinal/surgical treatments for one's improvement of health. (Watson, 2012 p.75)

### **5.2.2 Factors of Transpersonal Caring Relationships.**

There are several factors that allow for an adequate transpersonal caring relationship between nurse and patient:

1. Human dignity: a nurse's commitment to preserve and strengthen human dignity allows a person to determine their own self-worth. (Watson, 2012 p.76)
2. The nurse's non-judgemental affirmation of a patient's spiritual belief. (Watson, 2012 p.76)
3. The nurse needs to be capable of detecting correctly the inner-condition and feelings of a patient. (Watson, 2012 p. 76)
4. Mutuality: The nurse's ability to recognize the patient's place in life, building a human-to-human connection through this and valuing the patient's subjectivity the same as the nurse's subjectivity. (Watson, 2012 p.76)
5. Nurses own experiences: A nurse's own experiences, culture and life-history also has a significant effect on the ability to forming a good transpersonal caring relationship, allowing for empathy to convey a feeling of security for the patient, knowing that the person caring for one has been through a similar experience. This is directly related to an individual's personal growth and maturity. (Watson, 2012 p.76)

### **5.2.3 Use of entire self in nursing.**

The use of one's self in nursing is contradictory to the traditional nursing view, where healthcare professionals are suggested not to create a transpersonal caring relationship with the patient, as that may be perceived as unprofessional. (Watson, 2012 p. 77)

On the contrary, using ones whole self – the use of ones' unique skills, talents, knowledge, perceptions – as a resource to create a professional relationship is essential. (Watson, 2012 p. 77)

We can compare the transpersonal caring relationship between a nurse and a patient with personal relationships: a personal relationship has a give and take dynamic, where the individual that is more in need is receiving support from the other. This is not a one-way approach, in a healthy relationship there is a sense of reciprocity where each individual helps the other when required. A professional relationship between the patient and nurse can be somewhat similar, even though the nurse is seen as the professional, they can benefit and be influenced, the patient may be the conveyor of a message of meaning and healing, though it is up to the nurse to accept this message; an important point of the professional transpersonal caring relationship is that the nurse does not depend on receiving from the patient to be involved in their care. (Watson, 2012 p.77)

The nurse assists in incorporating the subjective emotions of the experience with the objective external view of the situation, thus allowing for a wholesome picture of the situation. (Watson, 2012 p.78)

## **6 Aim & Research question**

The aim of this study is to describe the long-term rehabilitation process of stroke patients and the role of nurses in this process.

The following research questions will be answered:

1. What is the nurse's role in the long-term rehabilitation process of stroke patients?
2. What are limitations or challenges faced in the long-term rehabilitation process?

3. What is the nurse's role in the long-term rehabilitation process in comparison with the nursing theories?

## **7 Methodology**

A deductive qualitative approach with the scoping review method as inspiration is used for this text. This approach was the most suitable for extracting the desired information from the articles in question, which are focused on stroke patients, nursing and rehabilitation.

A qualitative approach can be recognized (but not exclusively) by the researcher's closeness to the subject at hand. (Holme & Solvang 92-146, 1997 p.92)

### **7.1 Qualitative method**

Although the qualitative method is used with inspiration from scoping review (Subchapter 6.3 explains scoping review further), this text can not be classed as an actual content analysis of the texts, since the number of articles found and used are few. Nevertheless, it is pertinent to explain the qualitative approach as to get a broader perspective to why this method was chosen.

A Qualitative summary bases itself upon seeing beyond the subject-object relationship of an article, and instead puts itself in the position of the subject of the articles, in this case stroke patients during the long-term rehabilitative process. (Holme & Solvang 92-146, 1997 p.92)

There are certain points of views that cannot be seen by the researcher, until the researcher reflects upon subjects being researched. This allows the subject to be researched and studied from a different perspective other than the objective view. (Holme & Solvang 92-146, 1997 p.92)

The aim of the qualitative method is to be able to represent accurately the structure of a subject and to represent the experiences of the individuals in question. (Holme & Solvang 92-146, 1997 p.93)

The scoping review method was used as an inspiration when identifying and summarizing research that pertains to the subject.



The qualitative method works well for this study as the experience of the patients and nurses represented in medical articles give a good representation of the role of nurses in the long-term rehabilitative process.

## 7.2 Data collection

Using deductive literary content summarization, with scoping review as an inspiration, the role of nurses in the long-term rehabilitation of stroke patients can be defined. To research this the search engines for scholarly literature are used: mainly EBSCOhost with CINAHL full text. Through these search engines scholarly articles, journals, and clinical research can be found.

For collecting the relevant texts required for categorization and summarization, first it must be known what the text is. To find the correct texts that are relevant to the study, certain criteria was used. Firstly, the text must be an article that is scientific in nature, within the field of healthcare; secondly the texts must be relevant to the topic discussed in this study.

Criteria for searching the articles through EBSCOhost were as follows (key terms, years published, language of text) :

1. Nursing + Stroke Rehabilitation, 2016-2020, English : 263 Results → 4 abstracts read → 2 scientific articles chosen.
  - Aadal, Leena et. al : *"Nursing roles and functions addressing relatives during in-hospital rehabilitation following stroke. Care needs and involvement"*
  - Kidd, Lisa et. al : *"Development and evaluation of a nurse-led, tailored stroke self-management intervention"*
2. Nursing Interventions + Stroke + Rehabilitation, 2015-2020, English → 48 results → 3 abstracts read → 2 scientific articles chosen.
  - Frota Cavalcante, et. al : *"Nursing interventions to the stroke with stroke in rehabilitation"*
  - Bjartmarz et. al : *"Implementation and feasibility of the stroke nursing guideline in the care of patients with stroke: a mixed methods study"*

3. Acute nursing + stroke + rehabilitation, 2015-2020, English → 52 results → 2 abstracts read → 1 scientific article chosen.

- Luker, et. al : *"Implementing a complex rehabilitation intervention in a stroke trial: a mixed methods study"*

4. Nursing + self care + stroke + rehabilitation, 2015-2020, English → 115 results → 2 abstracts read → 1 scientific article chosen.

- Lo, et. al : *"A randomised, controlled trial of a nurse-led community-based self-management programme for improving recovery among community-residing stroke survivors"*

In total 6 articles are found to be relevant to the subject of this study and they are read through and summarized.

### **7.3 Content Summarization inspired by scoping review**

Often there is irrelevant material in sources, therefore it is important to have a clear idea and method to extract information from the pertinent texts. (Holme & Solvang 92-146, 1997 p. 124)

The aim of the study has a direct effect on the summarization of the articles, since the specific role of nurses in the rehabilitation process is being researched.

The texts are summarized with the scoping review method as inspiration: shortening them and highlighting phrases that are relevant to the study, creating a table with the pertinent information.

Scoping review is defined as a type of synthesis that answers a research question by defining main ideas, proof, and discrepancies found in texts, this specific scoping review was used as a tool to also be able to identify gaps between the texts. (Arksey & O'Malley, 2005)

Reasoning for using the scoping review as an inspiration is because it allows for the evaluation of the nature of the articles through their outline; this enabled also the cataloguing of common themes, and challenges, found throughout the articles. (Arksey & O'Malley, 2005)

Once the research questions were defined, it enabled the investigation and identification of texts that were relevant to the study; following a thorough reading of the texts they were condensed and common ideas throughout the texts were identified.

A problem with this study is that the scarce number of articles does not allow for an analyzation of the texts, rather it gives a general overview of the nurse's role in the rehabilitation process in recently published articles. This does not give a clear view of how the situation is, but there is a notable common theme between the texts.

No healthcare centre guidelines or hospital guidelines for stroke patients were used.

Through thorough reading of the available articles, categories relevant to the research questions are identified:

1. Nurses role in long term rehabilitation in recent studies
2. Possible role for nurses in long term rehabilitation
3. Nurses role in long term rehabilitation in recent studies and compared to the nursing theories used.

This study cannot be identified as a true scoping review, since that requires the research of grey literature, or literature that is not commonly found because they are not published in commercial organizations or protected by copyright restrictions. (Adams et. Al, 2016)

## **8 Results**

In this chapter, the results found throughout the articles are defined, phrases that relate to the 3 different categories founded have been put in a table (appendix 1), and the articles have been summarized (appendix 2).

The 3 different categories are given through the subchapter headings, while the sub-categories within the categories are written with bold text.

### **8.1 Nurses role in long-term rehabilitation**

Throughout the articles, a few different roles that the nurse has during long-term rehabilitation were identified.

The roles of the nurses found have been divided further into sub-categories:

- Educational and supportive
- Physical and rehabilitative (Goal-setting, patient activation and involvement of relatives)

One of the most common roles and interventions found were of **educational and supportive** purposes, to both the patient and the relatives/caregivers:

It is incredibly important for the nurse to be able to receive and make time for the relatives, supporting them throughout the rehabilitative process

*“Threefold purpose: [...] take care of the relative and to support the interaction between patients and relatives”* Article 1, Aadal et. al (2018);

Another important role for the nurse within an educational context is **educating both the relatives/caregivers and patient.**

*“... nurses perceived that they supported self-management by educating patients and signposting them to relevant resources and information”* Article 2, Kidd et. al (2015);

Also important is the actual involvement of the relatives in the care of the patient, since they are the ones that are most aware of the patients situation at home and have an important role in the flow and function of rehabilitation.

*“Nursing interventions directed to the relatives, considering they are a fundamental part of the rehabilitative process due to their experience of daily living with the patient”*  
Article 3, Frota et. al (2018);

*“Nurses reported enhanced patient and family teaching”* Article 4, Bjartmatz et. al (2017).

It is also important that the nurses receive training for these interventions and roles.

*“Implementation is challenging and in need of constant education of nursing staff”*  
Article 4, Bjartmatz et. al (2017);

In the educational and supportive context, the nurses role encompasses the education and support of the patient as well as their caregiver/relative. It is also important that nurses are aware of their own lack of education, building on it to allow for a better process for the patient.

Another common role found throughout the articles was more of a rehabilitative and physical care approach, citing **goal-setting, patient activation and involvement of relatives** as important tools:

Involving relatives and setting goals together with the patient creates a common “challenge” for them, something they can also bond over and look back upon.

*“A Nurse described one of the strategies to involve the relatives as setting targets along with the relative and the patient”* Article 1, Aadal et. al (2018);

**Activating the patients** is also a key role for the nurses, making the patient more involved and autonomous with their own rehabilitative process.

*“Concept of patient activation as a mechanism for assessing and understanding individuals’ self-management needs”* Article 2, Kidd et. al (2015);

Nurses also have the role of **physical rehabilitation** and **mobilization** of the patient in a ward or hospital setting.

*“Nursing interventions most found in the publications are motor and functional rehabilitation, evaluation of physiological functions and emotional care”* Article 3, Frota et. al (2018);

*“Nursing staff applied more mobility and ADL interventions”* Article 4, Bjartmatz et. al (2017);

*“Nurses delivered more mobilization into their daily patient care than previously”* Article 5, Luker et. al (2016);

**Goal setting** is a realistic tool used by nurses, that allows for the patient to train and set goals that have real-life situation applicability.

*“Nurse will work with the participants to establish a short-term goal of importance to stroke-recovery and develop a realistic action plan to achieve the goal”* Article 6, Lo et. al (2016).

A theme found in Article 5 by Luker et. al (2015) was the increased cooperation between physiotherapists and nurses:

*“Physiotherapists trusting nurses to mobilize patients in their absence was underpinned by good training and mentorship for nurses”;*

*“Mobilization was ideally considered the responsibility of the whole team”.*

This helps in speeding up the recovery process, since consistent and intensive mobilization greatly increases prognosis.

## 8.2 Challenges in long-term rehabilitation

Throughout the articles, a common challenge was identified that was found in nearly every article:

- Lack of time

Furthermore, challenges were found in single texts but were not common throughout all texts:

- Lack of patient cooperation
- Nursing staff's resistance to change

The nurses **lack of time** to implement certain rehabilitative interventions or to make time in shifts for educational and supportive interventions directed towards the patient and their relatives was common:

*“sometimes there's just no time for relatives in a busy clinical setting”* Article 1, Aadal et. al (2018);

*“The intervention as a whole did not appear to fit well into nurses daily clinical schedules, majority of nurses perceived the self-management approach followed in this intervention as time consuming and increasing their workload”* Article 2, Kidd et. al (2015);

*“Most staff described considerable challenges in managing the additional work associated with the trial”* Article 5, Luker et. al. (2016),

This challenge could be resolved by allocating resources and specific times for nurses to do nursing intervention that relate to rehabilitation, education and support.

In article 2 by Kidd et. al (2015) , a theme that was identified was the **lack of patient cooperation or motivation**:

*“Participants who spoke of a more nebulous desire to ‘get better’ were less able to easily identify and articulate specific goals, self-managing in a more passive style”, Kidd et. al (2015);*

This could be resolved through further patient activation and involving relatives into rehabilitation through their experience with the patient.

In article 5 by Luker et. al (2016), a challenge was the **nursing staffs resistance to change**, as well as the requirement of having experienced staff to be able to perform the interventions:

*“Overt resistance to the required change of practice was identified at some sites” Luker et. al (2016);*

*“Experienced staff were essential” Luker et. al (2016);*

This could be resolved by allowing the nurses to understand the benefits of rehabilitative interventions through educational moments and training unexperienced staff with new methods, they should be open to change in care if it improves the overall care and prognosis of the patient.

### **8.3 Nurses role in long-term rehabilitation in comparison with the nursing theories**

In the articles, interventions and phrases that relate to the nursing theories used by were identified.

The nursing theories used in comparison with the text are Jean Watson’s Theory of human caring and Dorothea Orem’s Theory of self-care, through these two sub-categories were identified:

- Viewing the patient as a whole (patient integrity) and promoting autonomy (Watson, 2012)

- Self-care (Orem, 2003)

In Article 1, Jean Watson's theory of human caring was the most relatable nursing theory:

*"Primary focus Is on preserving the patients integrity"* Article 1, Aadal et. al (2018);

Watson's theory states that human caring sciences focus on viewing the **patient as a whole**, caring for all aspects, being physical, psychological and social. (Watson, 2012)

In article 2, both Jean Watson's theory of human caring and Dorothea Orem's theory of self-care were identified:

*"...approach that is guided by the principle of the client, rather than the counsellor, evoking and voicing their motivations and arguments for change"* Article 2, Kidd et. al (2015);

This relates to Jean Watson's theory of human caring and viewing the **patient as a whole**.

*...findings suggested that it was the meaningfulness and the perceived value of the 'goals' [...] that acted as a key mechanism for understanding attitudes towards self-management"* Article 2, Kidd et. al (2015);

*"... goal setting perceived as an important strategy but the individuals had to be ready, prepared and confident to accept their part in the process, to take responsibility for self-managing"* Article 2, Kidd et. al (2015);

These relate directly to Dorothea Orem's theory of **self-care**, which is when an individual performs actions to acquire knowledge about one's own well-being and health status, and actively engages in activities that sustain and promote their quality of being. (Orem et. al, 2003)

In article 3, elements of Dorothea Orem's theory of self-care were identified:

*"nurses supervise and encourage the patient to carry out their self-care activities".*  
Article 3, Frota et. al (2018);



This relates to Orem's theory where individuals perform **self-care** activities, and in this case with encouragement from the nurse. (Orem et. al, 2003)

In article 4, both Dorothea Orem's and Jean Watson's theories were relevant:

*"Patients with higher functional status spent more time on therapeutic activities"*

Article 4, Bjartmatz et. al (2017);

This relates to Orem's theory that acknowledges the fact that only individuals that have a certain autonomy and state of condition will actively engage in **self-care**. (Orem et. al, 2003)

*"Highly important for the staff to activate the patient and provide them with opportunities to do exercise in between therapy sessions"* Article 4, Bjartmatz et. al (2017);

This instead relating to Watson, promoting their general recovery process by encouraging individuals to train independently (promoting **autonomy**). (Watson, 2012)

In article 5, Watson's theory of human caring was the most relevant:

*"Patient and family autonomy was promoted for patients who could cope with this"*

Article 5, Luker et. al (2016);

Relating to the promotion of **autonomy** and assisting the individual's family. (Watson, 2012)

In article 6, statistical analysis was done by the article's writer that relate to Orem's theory of self-care:

*"Stroke self-management behavior tests were conducted by the authors in relation to previous studies, results show that self-management behaviors in the community were relatively high"* Article 6, Lo et. al (2016);

This shows that in general, the number of individuals practicing **self-care** are significant.

## 9. Discussion of results

The findings of the summarized texts and subsequent categorization of key phrases lead to the comparison with the background, specifically the rehabilitative process; answering the research questions during the process.

- What is the role of nurses in the long-term rehabilitation of stroke patients?

From the results it can be noted that the role of nurses in the long-term rehabilitation of stroke patients in comparison with the background of the rehabilitative process are similar, but also broader than what is described:

in the background only physiotherapists are mentioned doing physical rehabilitation while in the articles, this intervention is also done by nurses; (Jönsson, 2012 p.73)

the educational and supportive roles with both the patients and relatives/caregivers are described in both the background and articles summarized; (Jönsson, 2012 p. 60)

goal-setting as a tool by nurses was described in both the articles and found in the background, stating it as a key tool to an effective rehabilitation; (Jönsson, 2012 p.81)

relative involvement was not discussed much in the background, but it was a key tool described by nurses in the articles; (Kidd et. al, 2015)

patient activation was not described in the background at all, but found throughout the articles, stating it as an important tool for the nurses, allowing for a general improvement in the process. (Aadal et. al, 2018) (Kidd et. al, 2015)

- What is lacking or a challenge in the long term-rehabilitation of stroke patients?

A common challenge found throughout the articles and stated repeated times was the nurses lack of time for certain nursing and rehabilitative interventions, both to the patient and to the relatives; in the background this issue is not discussed, but from a real-life perspective it is obvious that there isn't time for everything, this could be fixed by devoting specific time in the schedule for these interventions, or even devoting specific personnel for these purposes. (Aadal et. al, 2018) (Kidd et. Al, 2015) (Luker et. al, 2016)

Single challenges and limitations were found in other texts, these can give a broader view of all the challenges that can be faced in real-life clinical settings, although more research should have been done to be able to get a definite picture, since just single articles aren't substantial evidence:

Lack of patient cooperation was a challenge faced in one of the articles, this can also be identified in the background, since there may be instances where individuals are immobilized physically, mentally or even both; this could be resolved through the further use of patient activation, and individualization of the rehabilitative process to suit the individuals requirements. (Kidd et. Al, 2015)

A limitation in one of the articles was also the nurses resistance to change in practice, this was not discussed in the background; this creates a barrier because nurses refuse or are slow in adapting change in practice, resorting to old and/or inefficient methods rather than learning a more efficient or beneficial method that can increase the patients recovery process; this could be solved by introducing more educational instances for the nurses to be able to understand the benefits of the change in practice. (Luker et. al, 2016)

- What is the role of nurses role in long term rehabilitation in comparison with the nursing theories?

When the articles and phrases were put in comparison with the nursing theories, specifically Dorothea Orem's Theory of self-care and Jean Watson's Theory of human caring, it was interesting to see that several elements of the nursing theories can be identified throughout all the texts, giving a clear view how influential these theories are, specifically in the rehabilitative process where a patients autonomy, physical status, mental status, socioeconomic status, familiar status and ability to perform self-care actions regularly and promote health and well-being are essential. (Orem et. Al, 2003) (Watson, 2012)

What we can learn from this is that nurses should be able to incorporate elements of these theories into the care of patients, especially in the rehabilitative process, allowing for a better quality of life for the patient and a more effective recovery.

### Discrepancies with the articles

In article 3 by Frota et. al (2018), there was no nomination of self-care or care related to the patient in a home setting, only nursing interventions in a hospital and rehabilitation center setting, though this information is discussed in almost every other article summarized. (Frota et. al, 2018)

Article 6 was a quantitative statistical analysis study with not much information regarding discrepancies found in the long-term rehabilitative care, though through the summarization of the article it was clear that more frequent contact with stroke survivors can help with their self-management skills. (Lo et. al, 2016)

## **9 Discussion of method and limitations for the study**

Qualitative content analysis can be defined as the summarization and interpretation of data found in scientific texts; it is a systematic process of describing the ideas identified, for this to be possible the text must be condensed and categorized with its main concepts. (Elo et. al, 2014)

To make sure that the texts used are of a credible source, their trustworthiness must be determined; the trustworthiness of texts can be described through the examination of their credibility, conformability, authenticity, dependability and transferability. (Elo et. al, 2014)

A texts credibility can be viewed through the identification and description of the researchers (authors); conformability of a text can be observed via how two different readers interpret the text, if the same ideas can be identified by both readers; authenticity of a text can be identified through how faithful the authors (researchers) are in showing different ranges of realities within the text, not only conforming to one specific reality; dependability can be observed through how stable the data is over a longer period of time, and how stable the data is under different conditions; transferability refers to how easily the findings/concepts/ideas of the text can be transferred to a different group or setting. (Elo et. al, 2014)

To define even further the trustworthiness of a study, the process of defining the categories must be explained, as well as how the findings are presented, what method was used and how the analysis of the text(s) was conducted. (Elo et. al, 2014)

The data collection described method for this study was an inspiration from scoping reviews, which was the most suitable for identifying main concepts within the texts and summarizing them correctly; articles were found using combinations of different key words: nursing, nursing interventions, acute nursing, stroke, stroke rehabilitation, rehabilitation, self-care.

The summarizations and categorizations are presented to the reader in such a way that it can be easily interpreted, through the use of a categorization table and presentation of the summarized texts; conformability was demonstrated by providing quotations directly from the text that conform to the different categories formed.

The categories represent a direct link to the aim and research question of the thesis; transferability of the results can be determined by the reader itself, but the main idea's of the text can in theory be transferred to other patient groups that are in need of long-term rehabilitation.

The findings of this thesis are solely based on data found throughout the articles and that are relatable to both the background and nursing theories.

The data collection process is explained thoroughly, this allows also for the evaluation of the thesis' dependability as it allows for the readers to replicate the process themselves if necessary.

The writers interest in researching and writing this thesis comes from personal life experiences with the described patient group, as well as clinical practice experienced with the patient group; it was written to be able to clearly define the role of the nurses in the long-term rehabilitative setting within six (6) articles published the years 2010-2020, in comparison with the background texts that are pertinent to the rehabilitative process, allowing the writer to find clear differences between their described roles in background texts and the researched articles.

The small number of articles created a barrier for the writer, as it didn't allow for a complete and 100% trustworthy representation of how it is, rather only giving a small overview of how the situation is in specific situations.

The chapter relating to introduction gives a quick description of the importance of the topic of the thesis, in relation to nursing; including a rationalization of the writer as to why this topic is personally and topically important. The research questions and aim

of the thesis are defined in the chapter relating to Aim & Research Questions. Due to the broadness of this topic, multiple studies should be done relating to this, as to give a clearer view of the role of nurses in the long term rehabilitative process, as the results of this thesis are not trustworthy enough due to the number of articles. The chapter relating to background gives a description of stroke, the different types of strokes, risk factors leading to stroke and preventive measure that healthcare professionals should be aware of. The chapter relating to the rehabilitative process is still part of the background, but the writer chose to separate them as the main topic of the thesis is the role of nurses in the long-term rehabilitative process, and thus the rehabilitative process deserves a chapter for itself giving a description of the whole process, from the acute to the long-term process. The articles collected derive from many different countries, including China, Brazil, Denmark, Australia/New Zealand and the United Kingdom, giving an overview of how relevant this topic is globally.

Literature used for the background are mainly texts the writer found useful in describing stroke, its risk factors, preventive measures and the rehabilitative process encompassing stroke victims; the literature was found through the use of the local library, and consists of mainly older texts; quotations are not used for the background, instead paraphrasing in an adequate manner was found to be most effective.

The summarization of the articles used for the result was done in such a way to include important, pertinent information and giving a good view of what the idea behind the articles were.

The theoretical framework relates directly to the research question, as the nursing theories used are closely connected to the rehabilitation process and patient integrity, the writer viewed the theories as useful when categorizing and relating to the researched articles, showing that the rehabilitative process is greatly influenced by them.

The data examined for this thesis was done using the scoping review method as an inspiration, explained in the chapter pertaining to method. The results are categorized through the use of a table, allowing for a quick and easy understanding of the categorization, further subcategorization of the categories was done once all summarizations were completed, finding common themes throughout the articles.

The results found in the articles are put into comparison with the pertinent background text (the rehabilitative process), and nursing theories used.

Texts, tables and images that are referenced are located in the bibliography section of the thesis, referencing in a complete manner, allowing for readers to view the sources themselves if required.

The writer tried to write in such a way that medical knowledge should not be a prerequisite to be able to understand the text and tries to avoid difficult terms that are not known by the general public, the writer also tried to write in such a way that the text flows well, not just jumping from one topic to the other, allowing for a pleasant reading.

## **10 Conclusions**

The results show that the role of nurses in the long-term rehabilitation process are many and have a broad aspect, relating to all the different aspects that encompass a good healthcare for the patient: physical, emotional, familiar and socioeconomical aspects are all addressed in the related articles.

Results found throughout almost all articles show also that there was a certain aspect that was lacking in the long-term rehabilitative care, specifically pertaining to the lack of time of the nurses to be able to perform interventions relating to the physical, emotional, familiar and socioeconomic aspect of the patients.

Through the comparison with nursing theories, it was also observed that their influence in the long-term rehabilitative process is very pertinent, as the theories of self-care and human caring have a primary focus of enabling the patient to be autonomous and being able to make correct decisions regarding their own personal rehabilitative process.

## **11 Reflections**

For the writer, the topic of the thesis was easy to identify; the execution of the study was, on the other hand, quite difficult; without the assistance of the writer's supervisor this text would not have been completed, the guidance received throughout the whole writing process was absolutely essential in the formation of the text.

Due to the broadness of the topic, it was also important for the writer to be able to narrow down the research questions, as a broad research question would have provided a barrier to finding pertinent articles that could be easily relatable to the topic at hand.

The biggest difficulty about the writing of this thesis was finding the appropriate analysis method for extracting the most, and most important, information from the articles researched.

The biggest discrepancy of this thesis is the amount of articles, and the lack of grey texts, as without a larger number of articles and grey texts are what a true scoping review are defined as; another discrepancy was that the writer did not use any healthcare center or hospital guidelines for the stroke patient, as stated previously; the writer did not view them as essential to reaching the results, and time-restraints were also of concern.



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## Appendix 1. Content categorization

Articles	Role in long term rehabilitation	Possible role in long-term rehabilitation	Role in long-term rehabilitation in comparison with nursing theories
1. Nursing roles and functions addressing relatives during in-hospital rehabilitation following stroke. Care needs and involvement.	<p><i>"Threefold purpose: to take care of the patient, to take care of the relatives and to support the interaction between patient and relatives"</i></p> <p><i>"A task for nurses is to talk to the family about their feelings"</i></p> <p><i>"A nurse described one of the strategies to involve the relatives as setting targets along with the relative and the patient"</i></p>	<p><i>"sometime there's just no time for relatives in a busy clinical setting"</i> – Nurses could set aside specific time for addressing the relative and any concerns they might have.</p>	<p><i>"Primary focus is on preserving patients integrity"</i> – Jean Watson, Human Caring</p>
2. Development and evaluation of a nurse-led, tailored stroke management intervention.	<p><i>"Participants identified goal-setting as a fundamental component of stroke self-management"</i></p> <p><i>"...nurses could support individuals to become actively engaged in self-management"</i></p> <p><i>"Stroke nurses perceived that they supported self-management by educating patients and signposting them to relevant resources and information"</i></p> <p><i>"Participants reported they felt they had been offered appropriate, relevant and timely self-management information, this had helped increase their understanding of the effects of their stroke and their confidence to manage their lives"</i></p> <p><i>"nurses perceived the underlying philosophy of a person-centered approach [...] helped uncover stroke survivors' personal aspirations and priorities"</i></p>	<p><i>"Participants who spoke of a more nebulous desire to 'get better' were less able to easily identify and articulate specific goals, self-managing in a more passive style"</i> – the nurses could actively try to engage the patient, for example by asking the relatives, with more individualized goals.</p> <p><i>"the intervention as a whole did not appear to fit well into nurses daily clinical schedules, majority of nurses perceived the self-management approach followed in this intervention as time consuming and increasing their workload"</i> – interventions should be planned in such a way that they don't interfere with the clinical setting, or a specific nurse in the personnel could be assigned the interventions.</p>	<p><i>"...approach that is guided by the principle of the client, rather than the counsellor, evoking and voicing their motivations and arguments for change"</i> – Jean Watson, Human Caring</p> <p><i>"...findings suggested that it was the meaningfulness and perceived value of the 'goals' [...] that acted as a key mechanism for understanding attitudes towards self-management"</i> – Dorothea Orem, theory of self-care.</p> <p><i>"...goal setting perceived as an important strategy but individuals had to be ready, prepared and confident to accept their part in the process, to take some responsibility for self-managing."</i> – Dorothea Orem, Theory of self-care.</p> <p><i>"... was also acknowledged that the process of goal setting required a pre-existing degree of motivation on the individuals part"</i> – Dorothea Orem, theory of self-care.</p>
3. Nursing interventions to the patient with stroke in rehabilitation.	<p><i>"Nursing interventions most found in the publications are motor and functional rehabilitation, evaluation of physiological functions and emotional care"</i></p> <p><i>"Nursing interventions directed to the relatives, considering they are a fundamental part of the rehabilitative process due to their experience of daily living with the patient"</i></p>	No nominations of self-care or care in general related to the patient in a home setting, article describes only findings of nurses working in hospitals.	<p><i>"(nurses) supervise and encourage the patient to carry out their self-care activities."</i> – Dorothea Orem, theory of self-care</p>
4. Implementation and feasibility of the stroke nursing guideline in the care of patients with stroke: a mixed methods study.	<p><i>"Nursing staff applied more mobility and ADL interventions"</i></p> <p><i>"Nurses acknowledge the importance of assessing symptoms of depression"</i></p> <p><i>"Nurses reported enhanced patient and family teaching"</i></p>	<p><i>"Implementation is challenging and in need of constant education of nursing staff"</i> – Specific nurses or time of shifts can be dedicated to educational and implementational means.</p>	<p><i>"Patients with higher functional status spent more time on therapeutic activities"</i> – Dorothea Orem, theory of self-care.</p> <p><i>"Highly important for the staff to activate the patient and provide them with opportunities to do exercises"</i></p>

			<i>in between therapy sessions” - Jean Watson, theory Human caring.</i>
5. Implementing a complex rehabilitation intervention in a stroke trial: a qualitative process evaluation of AVERT.	<p><i>“Nurses [...] noticed changes in their professional roles”</i></p> <p><i>“Nurses delivered more mobilization into their daily patient care than previously”</i></p> <p><i>“Mobilization was ideally considered the responsibility of the whole team”</i></p> <p><i>“Physiotherapists trusting nurses to mobilize patients in their absence was underpinned by good training and mentorship for nurses”</i></p>	<p><i>“Overt resistance to the required change of practice was identified at some sites”</i> – healthcare professionals should be open to change in practice and care if it improves the overall care and prognosis of the patient.</p> <p><i>“Most staff described considerable challenges in managing the additional work associated with the trial”</i> – Time restrictions and workload should be dealt with accordingly, ex. Allocating specific time and sharing workloads.</p> <p><i>“Experienced, trained staff were essential”</i> – requirement of experienced staff creates a barrier for unexperienced staff to gain experience in these situations.</p>	<p><i>“Patient and family autonomy was promoted for patients who could cope with this”</i> – Jean Watson, theory of human caring</p>
6. A randomized controlled trial of a nurse-led community based self-management program for improving recovery amongst community-residing stroke survivors.	<p><i>“The nurse will schedule a home visit, during which the nurse will assess the participants current medical, emotional and role management of their post-stroke conditions.”</i></p> <p><i>“Nurse will work with the participants to establish a short-term goal of importance to stroke-recovery and develop a realistic action plan to achieve the goal”</i></p>	<p>The article was a quantitative statistical analysis study, not many references to the actual survivors’ experiences and stories.</p>	<p><i>“Stroke self-management behavior tests were conducted by the authors in relation to previous studies, results show that self-management behaviors in this community are high.”</i> – Dorothea Orem, Theory of self-care.</p>

## Appendix 2 Article Summaries

In this appendix the summarization of the articles are written down.

### 1.1.1 Article 1

Stroke usually causes a great amount of treatment, care and support, and this often causes a shift in dynamic in the family. (Aadal et. al, 2018)

Due to advances in medicine, hospital stays have greatly shortened, because of this, relatives are faced with the role of caretakers, and if not prepared, it can be difficult to cope with the changes; this influences the way nursing is done in rehabilitation. (Aadal et. al, 2018)

Traditionally, nursing has as main goal to care for and maintain bodily function while actively trying to prevent further complications, although through studies done by Kirkevold, four therapeutic aspects for guiding patients emotionally and developmentally during the process of rehabilitation were identified: interpreting, consoling, conserving and integration. (Aadal et. al, 2018)

These aspects are key in allowing for the involvement of relatives in the care of the patient. This is important for a personalization of rehabilitation through knowledge about the patients day to day life gained from the patient and relatives. (Aadal et. al, 2018)

The involvement of a relative with rehabilitation is a first step into the preparation for the relative as a caregiver. (Aadal et. al, 2018)

Nurses described 3 of their main roles in rehabilitation : caring for the patient, caring for the relative and supporting interactions between the relative and the patient. (Aadal et. al, 2018)

When caring for the relative, the interactions have a more educational aspect, while emotion can be a good tool for nurses, allowing for relatives to speak freely about their feelings. (Aadal et. al, 2018) This can be a “double edged sword”, as it can be useful to involve the relative into the care of the patient, but if the relative is in a crisis then the focus of the care could be shifted too much towards the relative instead of the patient, which is still at the center of the care plan. (Aadal et. al, 2018)

Risks aside, the relatives are described as being “an untapped resource in healthcare, especially in rehabilitation”, and nurses see themselves as a key component in allowing for the relative to start caring for the patient; a role of the nurse is to get the relative and the patient to share the entire process together, since it will be affecting their shared life (Aadal et. al, 2018)

Different methods for rehabilitation are used to involve the relative, and that are extremely beneficial for the patient: one for example is setting realistic goals that the patient and the relative can achieve together. (Aadal et. al, 2018)

Communication is regarded as an important tool, getting the patient and the relative to communicate during the process is essential to a stable rehabilitation. Nurses strive to talk, inform, teach and discuss with the patient and the relative at the same time to allow a mutual understanding of the situation. (Aadal et. al, 2018)

It is also important for nurses to understand the patients perspective, and the relatives can facilitate this. (Aadal et. al, 2018)

Specific nursing actions can also be taken towards the relatives, for example home training allows for the relative to visualize and learn how life will be at home, and how to assist the patient where and when needed. (Aadal et. al, 2018)

Nurses viewed their role in addressing the relatives of stroke patients as crucial, challenging and multi-faceted. (Aadal et. al, 2018)

### 1.1.2 Article 2

The physical and psychological impact of a person affected by stroke creates a barrier to the survivors engagement in self-management activities, which has been proven as an effective rehabilitation method, but not many studies have been done about the individualization of these self-management interventions. (Kidd et. al, 2015)

Self-management of long-term conditions is endorsed globally as an effective method of rehabilitation and general healthcare management. (Kidd et. al, 2015)

Many handbooks exist for healthcare workers to be able to help train stroke survivors, for example: “Bridges Self-Management Programme” trains practitioners to help stroke survivors to develop self-management skills, while “The Stroke workbook” works as a manual-based self-management program. (Kidd et. al, 2015)

The programs mentioned are focused mainly on the time of discharge of the stroke survivor, and early integration and transition back into a community; these handbooks are good for these instances, but long-term management needs often don’t reveal themselves until after discharge, once the patient is at home. (Kidd et. al, 2015)

It is a challenge to develop self-management support interventions that are individualized and tailored to the patient, partly because of healthcare professionals reluctancy to change practice. The programs that are usually developed often fail, because they are not individualized to the patient’s priorities and needs, in the clinical setting there is traditionally little, or none at all, assessment of a patients self-management skills. (Kidd et. al, 2015)

A tool described in the article is ‘Patient Activation’, which is useful for assessing and understanding a patients individual self-management needs, abilities and priorities, allowing for healthcare professionals to provide a person-centered self-management plan that tailors to the specific patients self-management aspects (Needs, abilities, priorities) (Kidd et. al, 2015)

Patient activation is “the readiness and ability to take on the role of managing both decisions and behaviors related to health and healthcare”, this lies at the center of self-management activities and decision making. (Kidd et. al, 2015)

Through patient activation different levels (1 through 4, 1 being lowest) of activation can be identified in patients, which indicates their current attitude towards self-management interventions, the level of needs and abilities, as well as the amount of support that may be required from healthcare professionals. (Kidd et. al, 2015)

Higher levels of activation have been associated with better success in self-management: better health promotion, more active engagement in health-related decision making. Lower



levels of activation have been associated with greater barriers in self-management activity. (Kidd et. al, 2015)

Personalized self-management action plans were the form of interventions used, and they were created by the stroke survivor and nurse working together using structured self-management assessment questionnaires (in this case PAM). (Kidd et. al, 2015)

Setting goals was considered the most effective strategy in promoting self-management behavior. Motivational interviews functioned as a complementary tool for the goal-setting process; the approach is structured in a way that it is the stroke survivor that guides the interview rather than the nurse, allowing the patients to express their motivations for changing goals. (Kidd et. al, 2015)

Results of the individually tailored self-management interventions demonstrate that they have had a positive effect on the patients quality of life, psychological functions and cognitive functions, expanding also on the individuals self-management behaviors. (Kidd et. al, 2015)

From both the patients and nurses perspectives, goal setting and motivational interviews were key components of stroke self-management; patients with a higher level of patient activation could create personally meaningful goals, they included getting back to work, or starting with a hobby again. (Kidd et. al, 2015)

### 1.1.3 Article 3

Nursing interventions in the acute and subacute phase has been thoroughly researched and explored, while care in the long-term rehabilitative phase hasn't been acknowledged as much; in this study their role will be explored. (Frota et. al, 2018)

Nursing care in the rehabilitative phase are aimed at recovery and adaptation to the possible disabilities caused by stroke; ideally the nurse works in a multidisciplinary team that builds and shares knowledge about the patient, but often the role of the nurse in these teams isn't clearly defined. (Frota et. al, 2018)

In this article, four main areas were defined where nursing care interventions take place: Patient care nursing interventions, nursing education interventions to the patient, interventions of managerial nursing and nursing interventions directed towards the relatives. (Frota et. al, 2018)

The interventions most found in patient care include motor and functional rehabilitation, evaluation of physiological functions, emotional care and daily living care. (Frota et. al, 2018)

Interventions relating to patient education include education and information about the disease and its results, education about care plans and stroke prevention, coping skills and nutritional guidelines. (Frota et. al, 2018)

Managerial interventions include coordination of care and follow-up of the patient, coordination of multidisciplinary assistance, coordination of patient referral and discharge and assistance in community services. (Frota et. al, 2018)

Nursing interventions directed towards the patients relatives include guidance about the disease, prevention of it, its rehabilitation process and training for the relative. (Frota et. al, 2018)

The results of the article can support the implementation of protocols and instruments for the nurse that cares for stroke patients in the rehabilitative phase, serving also as a guide for students or practical nurses. (Frota et. al, 2018)

#### 1.1.4 Article 4

This article was written to be able to define if the use of a Stroke Nursing Guideline would have any effect on patient care.

Generally, stroke results in life-altering conditions to both the patient and the relatives, where at the least a quarter of patients needing assistance in basic daily activities. (Bjartmatz et. al, 2017)

A third of patients have cognitive impairments, resulting in memory difficulties, changes in personality and their ability to function as a provider or parent/caregiver. (Bjartmatz et. al, 2017)

Rehabilitation of stroke patients is a long process which involves setting real and obtainable goals and activities, including the steps needed to reach the desired goals or activities. There is strong evidence that consistent and frequent task-oriented training can assist the natural recovery pattern. (Bjartmatz et. al, 2017)

Nurses provide specific rehabilitation interventions through the care process, training patients in daily living activities, while also trying to see opportunities for the patient to practice between the actual visits; for this to be effective, the patient activation level has to be relatively high. (Bjartmatz et. al, 2017)

Nurses also provide information and education to the patient and their relatives/caregiver, patients and caregivers have reported that they needed education about the disease itself, its risk factor and preventive measures; concerns also arose regarding the movement of the patients, as well as psychological and nutritional changes. (Bjartmatz et. al, 2017)

The use of the stroke nursing guideline, which suggests the aforementioned interventions, resulted in nursing staff applying more interventions to mobility and daily activities of daily life, while also screening more frequently for symptoms of depression. (Bjartmatz et. al, 2017)

The nurses found the implementation of the stroke nursing guideline useful and had an active part in its implementation; they found the guideline simple and easy to follow, allowing also for the patient and relative to see the guideline and use it themselves. (Bjartmatz et. al, 2017)

The implementation brought a wider view of mobility of stroke patients in their day to day life to the nurses, while also giving more importance to aspects of nursing care that were not recognized. (Bjartmatz et. al, 2017)

Through the stroke nursing guideline, essential components of rehabilitation were integrated into daily nursing care of patients. (Bjartmatz et. al, 2017)

#### 1.1.5 Article 5

Rehabilitation intervention in stroke are complex interventions, the aim of the article is to “understand the implementation of an acute stroke rehabilitation trial as perceived by healthcare professionals delivering it.”(Luker et. al, 2016)

The results of this article were obtained through the analyzation of the perspective of nursing staff involved with the trial, which gave three clear categories: staff experience of implementing the trial intervention, barriers to implementation, strategies used to overcome the barriers. (Luker et. al, 2016)

Staff described significant challenges in managing the extra work-load that came with the trial, but some found it beneficial. (Luker et. al, 2016)

Staff reported that there was a positive impact on teamwork, where nurses and physiotherapists were required to work together, this allowed for the improvement of organization, communication and planning. (Luker et. al, 2016)

Nurses noticed changes in their professional roles, implementing more mobilization into their patient care than before, patients were also mobilized earlier and more intensively than before. (Luker et. al, 2016)

The success of the intervention depended heavily on the enthusiasm of the leadership, when leaders left intervention became difficult. Experienced and trained staff were also essential to the interventions, as well as communication and teamwork. (Luker et. al, 2016)

Barriers to implementing the rehabilitative interventions includes the discharge driven culture of acute hospitals where rehabilitation doesn't have such a high priority, non-cooperative staff, and barriers caused by the patient's condition. (Luker et. al, 2016)

Patient and family autonomy was promoted for the patients that were suitable for it through different nursing interventions. (Luker et. al, 2016)

In conclusion, this rehabilitative intervention model was different to current care models, as it required a strong collaboration between nurses and physiotherapists, but it was effective in increasing the speed of recovery of the patients. (Luker et. al, 2016)

#### 1.1.6 Article 6

Disabilities caused by stroke are many and may cause a lower quality of life, as well as depressive symptoms, thus an effective rehabilitative process and support for these survivors is essential, since the process in its whole is long-term and demanding. (Lo et. al, 2016)

The rehabilitative process extends far greater than hospital stay and in-patient rehabilitation, it is a complex process involving many aspects of the survivors life which often are intensified when they reach their home: physical and psychosocial needs can be difficult for relatives to handle when a nurse isn't immediately available, and can cause them to decrease support due to stress caused by this. (Lo et. al, 2016)

When a patient's medical condition (stroke, in this case) is stabilized, they are either discharged directly home or to a rehabilitation hospital if required. For the patient that can go home directly, the amount of support groups available in the community is lacking; this article explores the effectiveness of a community-based nurse-led stroke self-management program. (Lo et. al, 2016)

Participants will be part of a 4-week community-based nurse-led self-management program which aims at improving community-living stroke survivors' capabilities in self-managing their post-stroke conditions. (Lo et. al, 2016)

During a home visit the nurse assesses the survivors medical, emotional and social post-stroke conditions, through this the nurse and survivor work together to create short-term goals that are important for the survivors rehabilitation, developing a realistic plan to achieve these goals. A DVD with other stroke survivors experiences is also given during these home visits and participants are recommended to watch through as many as they see fit. (Lo et. al, 2016)

After the initial home visit, two separate group sessions are held in a community center, where survivors are educated further on psychosocial and physical consequences of stroke, while encouraging reflection and sharing of one's own experiences. Nurses also act as facilitators for the survivors to explore their own barriers and how to overcome them. (Lo et. al, 2016)

After the group sessions were performed, three weekly follow-up calls are done, to discuss the patient's road to recovery and review ones goal-attainment process. (Lo et. al, 2016)

One last follow-up call was done at the end of the last week, reviewing the progress and setting new attainable goals for the next month. This process can repeat for as long as necessary for the survivor's benefit. (Lo et. al, 2016)