

The Challenges of Nursing Stroke Management in Rehabilitation Centres

Bianca Buijck
Gerard Ribbers
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 Springer

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Preface

Nurses have a very important role in rehabilitation, education, counseling, prevention, and caring for patients with a cerebrovascular accident (CVA). In caring for stroke patients, nurses need specific competences and abilities that go beyond the general neurologic knowledge and experience. Nurses need to collaborate in an efficient and effective manner with multidisciplinary team members in their organization as well as across organizations. This book provides integral knowledge of all aspects of stroke care and rehabilitation after stroke and is therefore highly relevant for nurses who work in rehabilitation centers and skilled nursing facilities.

In this book, medical aspects and specific symptoms of a stroke are discussed, as well as the limitations that patients experience, and which interventions are indicated for recovery. The several phases after stroke are outlined, for example which care patients may receive in the acute phase in the hospital and in the chronic phase in their home situation. By using this book, nurses obtain knowledge about treatment, importance of observation, and caring. Furthermore, in this book there is information about communication and swallowing problems after stroke. Also, nursing care concerning ADL, urinary incontinence, and problems with the shoulder and hand are discussed. Using photos in the chapter “skills,” nurses learn to transfer patients in the adequate positions. There is also an emphasis on neuropsychiatric symptoms, behavior, and cognitive functioning after stroke.

In several chapters, nurses are provided with examples of effective and efficient collaboration with multidisciplinary professionals, informal caregivers, and patients themselves. And lastly, in a few chapters we highlight the organization of rehabilitation in a therapeutic climate, scholarship, and integrated care issues.

With this book we aim to provide insights into all relevant issues in rehabilitation after stroke.

Rotterdam, The Netherlands

Bianca Buijck

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Stroke: Medical Aspects

1

D. W. J. Dippel and N. E. LeCouffe

Abstracts

This chapter deals with cerebral infarction and cerebral hemorrhage. The symptoms of cerebral infarction and cerebral hemorrhage may be rather similar, but an important and major difference lies in the acute treatment and in the prevention of a second stroke. This chapters will deal with symptoms and phenomena of stroke, and how they affect the daily life of the patient, even long after the event. Preventing a next stroke is very important in people who have already experienced one. The second stroke is often the cause of more severe constraints and a much lower quality of life. We will also discuss how preventive measures, such as physical exercise, quitting smoking, and especially medication, can help prevent a new stroke.

Keywords

Stroke · Symptoms · Causes · Treatment · Prevention

1.1 Introduction

This chapter deals with two types of stroke: cerebral infarction and cerebral hemorrhage. Both can be attributed to an acute disturbance in the blood supply of the brain. The symptoms of cerebral infarction and cerebral hemorrhage are rather similar. In the chronic phase, for instance, patients who have suffered a cerebral

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infarction cannot be distinguished from those who have suffered a cerebral hemorrhage. In the acute phase, however, there are differences, which are directly related to the pathophysiological mechanism of the disease, i.e. a blood clot versus a torn blood vessel. An important and major difference lies in the acute treatment and in the prevention of a second stroke.

We will deal with symptoms and phenomena of stroke, and how they affect the daily life of the patient, even long after the event. Preventing a next stroke is very important in people who have already experienced one. The second stroke is often the cause of more severe constraints and a much lower quality of life. We will also discuss how preventive measures, such as physical exercise, quitting smoking, and especially medication, can help prevent a new stroke.

1.2 Blood Supply to the Brain

The brain requires a lot of blood. Even though it only makes up around 2% of the total body weight, it takes up around 20% of the blood flow and it consumes the most energy of all our organs. This is because the brain is continuously active. Not only do we think and dream, but the brain is also constantly working to process observations (image, sound, tactile sense, taste, smell), control movements and body balance. It also coordinates all kinds of unconscious processes. This requires a lot of oxygen and glucose. Glucose is a sugar that is converted into energy by the brain's cells. Oxygen and glucose are passed through the arteries to the brain. The arteries extend to all parts of the brain to supply it with blood and nutrients.

Four arteries run directly to the brain. These are the carotid arteries and the vertebral arteries which first fuse into the basilar artery (see Fig. 1.1a). In the brain, these arteries branch off and ultimately end up in a complex network of capillaries, where oxygen and glucose are released (Fig. 1.1b). The blood drains through a network of increasingly larger veins, back through the neck to the heart.

1.3 Epidemiology of Stroke

Stroke is one of the most important causes of death and the most important cause of acquired dependency in the US and Europe. Typically, 1–3 per 1000 persons will experience a stroke each year. This implies that in the Netherlands, a country with 17,000,000 inhabitants, the annual number of patients with a stroke who are admitted to hospital exceeds 30,000. In the US, more than 600,000 people experience a stroke each year. A similar number applies to Europe. About 80% of these cases involve an ischemic stroke, or brain infarction. The older people are, the higher the chance they will one day experience a stroke. The average age of this occurring is over 70. But it is not just a disease of the elderly. More than three out of ten patients with a stroke are under 60 years old (Fig. 1.2) (Mozaffarian et al. 2016; Heuschmann et al. 2009). Because of the amount of care it requires, stroke is also one of the most expensive diseases. The largest expense concerns the long-term care for patients with a stroke who can no longer live independently.

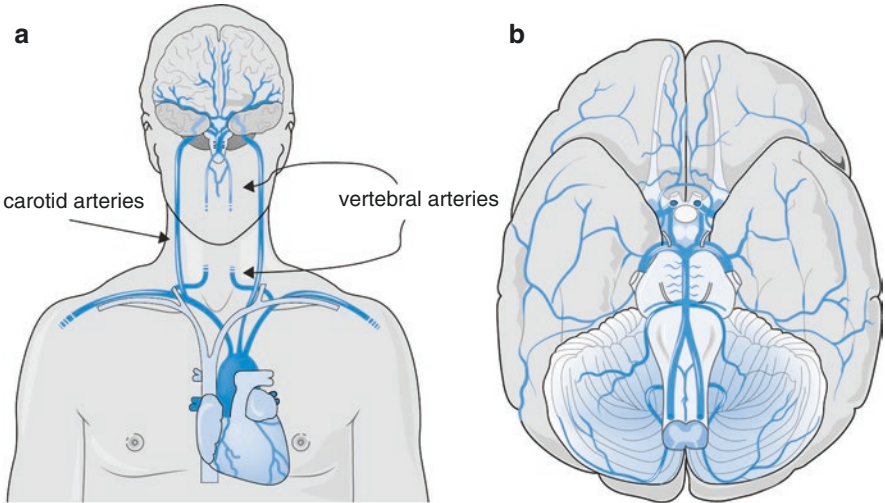
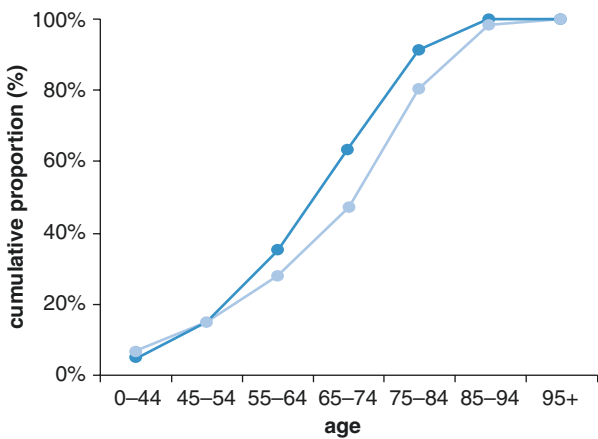


Fig. 1.1 (a) Blood supply to the brain (light blue = oxygen-poor; dark blue = oxygen-rich). (b) Bottom view of the brain; from the carotid and vertebral arteries, there are branches of the arteries to the brain (oxygenated blood)

Fig. 1.2 Age distribution of people with a stroke (dark blue: men, light blue: women)



1.4 Brain Infarction

When there is a blockage of one of the arteries in the head, it causes insufficient blood supply to a particular part of the brain. Within minutes, the first cells in that brain tissue will die. This is because brain cells can survive only a very short time without glucose and oxygen. This leads to brain infarction.

1.4.1 Anatomy and Function

A brain infarction manifests itself suddenly. The blood supply of a section of the brain is terminated, causing the brain cells in that section to stop functioning immediately.

The brain, like almost all body parts, consists of two nearly mirrored halves, including the cerebellum and brainstem. It is made up of the forebrain and the hindbrain.

In the forebrain, or cerebrum (Fig. 1.3), the left half of the brain controls the right side of the body, and the right half of the brain controls the left side of the body. A lesion in the right half of the cerebrum causes paralysis or a sensory disorder of the left half of the body. In case of a lesion in the left half of the cerebrum, it is the other way around. Also, a lesion of the right visual cortex in the posterior cerebrum causes loss of vision or distorted images on the left. The forebrain is mainly supplied by the carotid arteries and their branches.

The hindbrain consists of the brainstem and the cerebellum. The brainstem connects the cerebellum with the forebrain (cerebrum) and the spinal cord. It houses the nuclei of the neurons that, among other things, connect to nerves leading to the muscles of the eyes, the face, the tongue and pharynx. The brain stem also contains centers for respiration and wakefulness. Lesions in the brainstem may thus lead to weakness of the left and right arms and legs, problems with eye movement and swallowing, loss of respiratory drive and sometimes even loss of consciousness. Luckily, these infarctions are not very common.

The cerebellum coordinates movements and makes them smooth. Lesions in the cerebellum mainly result in problems in coordination and balance. This may manifest itself as failure to initiate and decelerate a motion, causing a patient to slip or to knock something over. This is called dysmetria. Another example is loss of smoothness of movements, called ataxia. Lesions in the right cerebellar hemisphere cause symptoms on the right side of the body.

The cerebellum collaborates intensively with the vestibular system and the eyes. A disruption in this collaboration may lead to jerky movements of the eyes, called nystagmus. When a part of the cerebellum fails, a patient often suffers from vertigo (rotatory dizziness) and has a tendency to fall down.

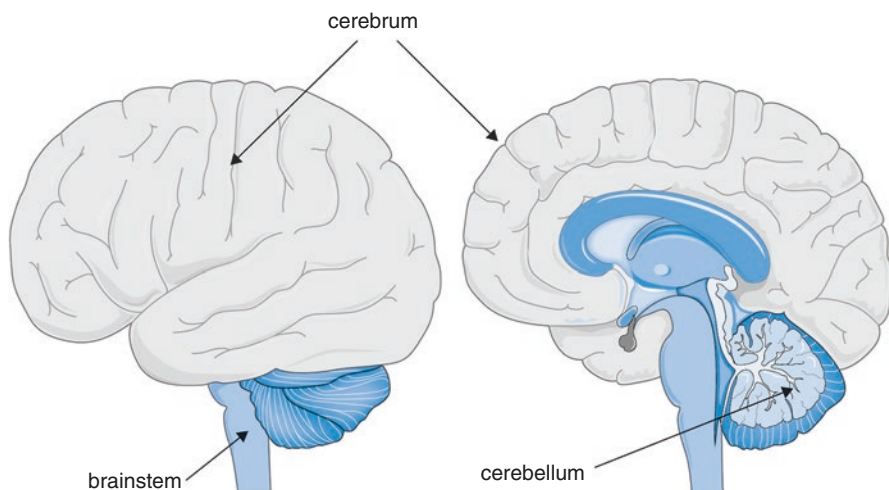
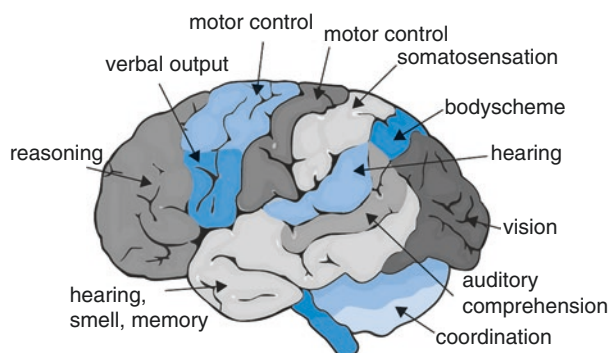


Fig. 1.3 The brain

Fig. 1.4 Localization of functions in the left hemisphere and cerebellum



The hindbrain is mainly supplied by the vertebral arteries, which fuse into the basilar artery, and their branches.

Figure 1.4 provides a general overview of which functions fail when a particular part of the brain is affected.

1.4.2 Symptoms

When a stroke occurs, people often do not realize what is happening. This may be because the part of the brain that controls awareness of a body part or bodily function has also stopped functioning properly. Thus, a patient with a paralyzed arm may be convinced that nothing is wrong. This is also one of the reasons why some people are late in calling for help and may be too late to undergo immediate treatment. We will now discuss a few symptoms of stroke.

1.4.2.1 Paralysis of the Arm or Leg

Oftentimes, muscle strength is still high in a paralyzed arm or leg, especially the muscles that bend the arm and the muscles that help to extend the leg. In the weeks to follow, this apparent resistance may get worse. This is called a reflex spasm. Although muscle strength may appear to be present, its function is poor, or may even be absent. Particularly the voluntary and fine movements are disturbed. This means that someone may be able to put a shopping bag around their arm, but cannot push a button on a smartphone.

1.4.2.2 Facial Paralysis

Mostly, this concerns the muscles on one side of the mouth. The corner of the mouth is lower on the affected side. Sometimes the muscles may contract during certain emotions, but this movement is involuntary. This indicates once again that, predominantly, the voluntary motor system has been affected.

1.4.2.3 Sensory Disorders

Stroke often causes a disorder in tactile sense, pain and sense of temperature. Sometimes the sensory disturbances appear to be modest, but integrating stimuli turns out to be a challenge. For example, patients may feel that they have something in their hand, but they do not recognize by touch that the object is a coin.

1.4.2.4 Neglect

This is a brief description for a complex problem. Patients with neglect do not use their arm, nor are they aware of their arm. Paradoxically, they do not have the strength to use their arm and tactile senses seem fully functional. The problem here, is that the body scheme is disrupted. The patients no longer experience their arm as part of themselves and therefore no longer use it. This is a serious disorder that makes rehabilitation difficult and does not respond well to therapy.

1.4.2.5 Aphasia

Aphasia is a language disorder. Verbal expressions and pronunciation are not necessarily impaired. The impairment concerns the formulation and comprehension of language. The severity may vary between a complete inability to speak, to speaking simple sentences and using standard phrases, or the occasional difficulty in finding words. Others often overestimate language comprehension in people with aphasia. Because patients often use all types of non-verbal communication, they appear to understand you better than they actually do. It is important that a patient with possible aphasia is thoroughly tested by a neuropsychologist, linguist or speech therapist to assess the severity and nature of the disorder and to develop a therapy plan. It is likely that therapy is helpful, but it is not certain what the intensity of the speech therapy should be, nor when the patient should start with therapy—immediately after the stroke or only after a few weeks.

1.4.2.6 Dysarthria

Dysarthria is the inability to articulate clearly. Language is not necessarily affected. Dysarthria occurs because the motor function of the tongue and the mouth and facial muscles are impaired. The disorder may be located in the cerebrum and/or the cerebellum. Dysarthria often improves by itself, but speech therapy can also be very helpful.

1.4.2.7 Disorders in Visual Fields

Some patients have hemianopia. This is a disturbance in one visual field in both eyes (homonymous visual loss). Patients cannot see anything on this side. They are often not quite aware of this deficit. This can be very dangerous, especially in traffic and while crossing streets.

1.4.2.8 Ataxia

Ataxia is the inability to coordinate movements, whilst sensation and muscle strength remain intact. It is a disorder of the cerebellum. Patients may slip after sudden movements, for instance while catching an object, or are unable to perform fast repetitive movements, such as clapping hands.

1.4.2.9 Apraxia

Apraxia is the inability to perform a task or series of operations while motor skill and coordination are undisturbed. For example, patients hold a cup while standing at the kitchen counter and are unable to prepare coffee in the correct order: Insert filter, add coffee, add water, and so on. The patients could also be holding a comb and do not

know how to comb their hair. The disorder is usually located in the left (dominant) hemisphere. The term apraxia is often used incorrectly, for example as in the next item.

1.4.2.10 Dressing Apraxia

Dressing apraxia, the inability to get dressed, is not usually an apraxia, but the result of a disturbed body scheme, and disturbed spatial awareness. This disorder is usually located in the right hemisphere.

1.4.3 Causes of Cerebral Infarction

1.4.3.1 Atherosclerosis

The main cause of an ischemic stroke is atherosclerosis (Hankey 2017). Atherosclerotic plaques are frequently seen in the carotid arteries and the aorta. During this gradual process, fat and calcifications accumulate on the walls of large and smaller arteries. In these accumulations, hemorrhages and inflammation occur. Eventually, the thickened artery wall cracks open on the inside. The body reacts to this injury by forming a clot on the damaged artery wall. Parts of such a clot may be transported in the bloodstream and cause an obstruction of smaller arteries in the brain (see Fig. 1.5).

1.4.3.2 Atrial Fibrillation

Another known cause is atrial fibrillation. This occurs in about 20% of all patients with acute ischemic stroke. The electrical impulse formation in the atria of the heart is irregular. The atria do not contract properly and receive their electric pulse irregularly. The heart's pump function is reduced. Even worse is that the blood flow comes to a

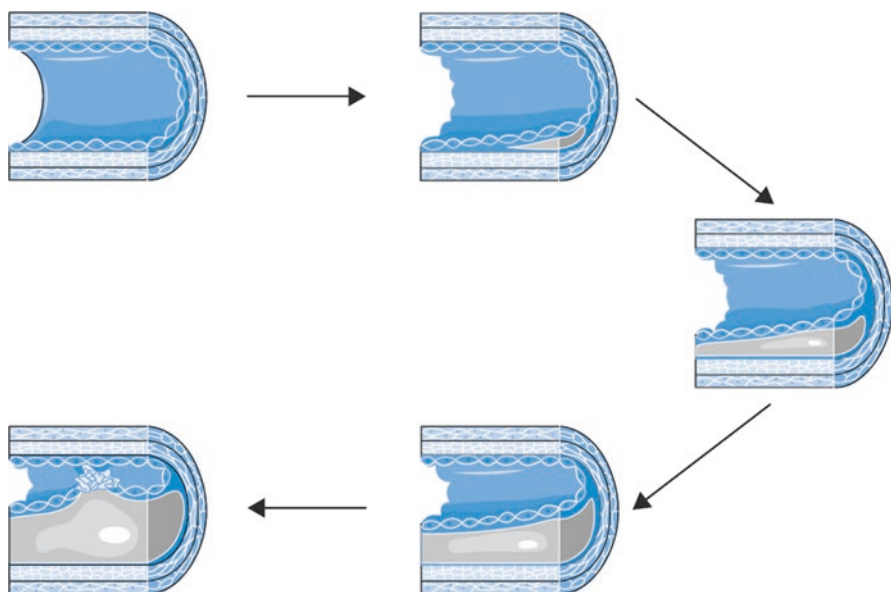
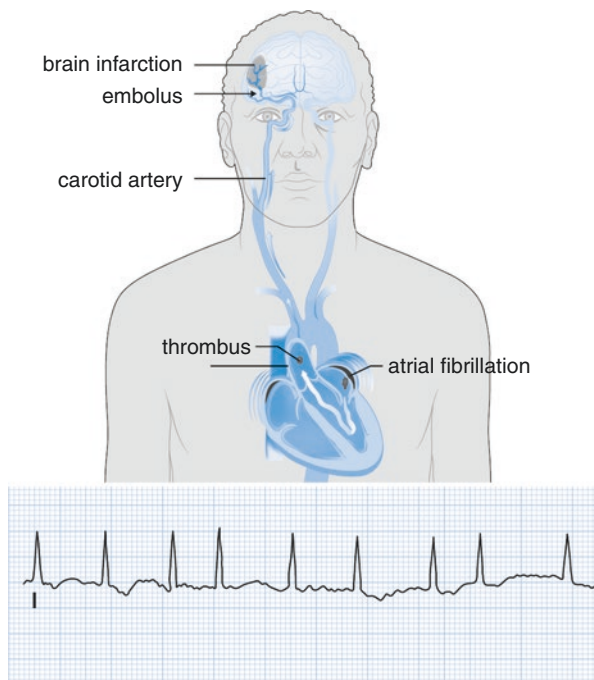


Fig. 1.5 Development of atherosclerosis with thrombus

Fig. 1.6 Atrial fibrillation

standstill in the atria. Clots can form here, which can then be pumped through the arteries towards the brain, where they cause a infarction by blocking an artery (see Fig. 1.6).

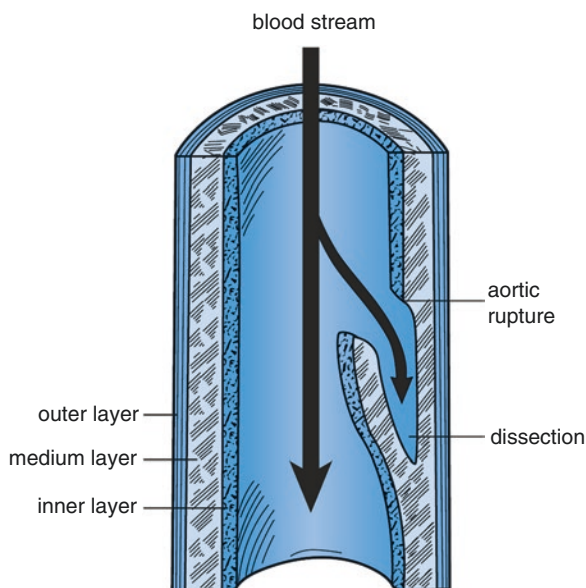
1.4.3.3 Dissection

Specifically in younger patients, a dissection of the carotid artery may be the cause of ischemic stroke (Fig. 1.7). In case of a dissection, an unfortunate movement of the neck causes a tear on the inside of the arterial wall. Bleeding occurs between the layers of the wall, leading to a narrowing (stenosis) and sometimes occlusion of the artery. At the site of the tear a thrombus or clot may arise. Parts of the clot may travel with the blood and occlude an artery in the brain, with infarction as a result.

1.5 Brain Hemorrhage

Brain hemorrhage, or intracerebral hemorrhage as it is mostly called, is bleeding in the brain tissue. Roughly 15% of all patients with stroke suffer from this. The symptoms of a brain hemorrhage are very similar to those of ischemic stroke, especially if the stroke occurred a few days ago. In the first hours however, there are some striking differences. At the onset, patients with a brain hemorrhage often have manifestations of increased intracranial pressure: decreased consciousness (from drowsiness to coma), vomiting, and a headache. In the first weeks after a brain hemorrhage, more than a third of the patients die, usually as a result of severe brain damage. This is about three times as often as after an ischemic stroke.

Fig. 1.7 Dissection of the carotid artery



1.5.1 Causes and Risk Factors for Brain Hemorrhage

Just like in ischemic stroke, brain hemorrhages also occur more often in elderly people. Furthermore, high blood pressure is a major risk factor, as well as alcohol use, especially binge drinking, and of course antithrombotic drugs, such as warfarin and direct oral anticoagulants. Note however, that the benefits of these drugs far outweigh their risks, as long as they have been prescribed on sound indications, such as symptomatic atrial fibrillation. Other causes of hemorrhagic stroke may include: a combination of a brittle artery wall due to atherosclerosis or senile amyloid angiopathy, (which is caused by accumulation of certain proteins in the arterial wall) and high blood pressure. This is common in older people. Also disorders in blood clotting, due to illness or as a side effect of medication, may be a cause. There are also rather uncommon causes, such as congenital vascular anomalies. These are usually seen in patients of a younger age.

1.6 Other, More Rare Forms of Stroke

1.6.1 Subarachnoid Hemorrhage

A subarachnoid hemorrhage (SAH) occurs in about 5% of all patients with acute stroke. This usually affects younger patients, with an average age at onset of 55 years. The cause is an aneurysm at the bottom side of the brain. An aneurysm develops at a thin spot in the wall of a brain artery, usually at a junction. Blood pressure causes the thin spot in the artery wall to form a kind of balloon (spherical herniation), which may grow. Sometimes the balloon bursts, resulting in a hemorrhage. The hemorrhage is located mainly around the brain, usually not in the brain tissue. This type of hemorrhage can be fatal, sometimes immediately because of the high

intracranial pressure that occurs, sometimes later on due to complications. The aneurysm may rebleed, which may also be deadly. Not infrequently, brain infarction occurs because of impaired arterial perfusion. Sometimes hydrocephalus occurs. This is a dilation of the cerebral cavities, because the normal drainage of cerebrospinal fluid is blocked by the blood around the brain.

1.6.2 Venous Sinus Thrombosis

Venous sinus thrombosis is another rare cause of stroke. This is a thrombosis of the veins and sinuses in the cranial cavity. The symptoms include headaches, seizures, and occasionally decreased consciousness, brain infarction and hemorrhage. It is relatively common in women; the use of oral contraceptives is a major risk factor.

1.7 Diagnostics and Treatment

1.7.1 Specific Treatment

In a patient with a diagnosis of acute ischemic stroke, treatment should be started as soon as possible in hospital. This of course also applies to patients residing in a nursing home or a geriatric rehabilitation unit. Every minute counts, because, each minute, around two million brain cells are lost, and in case of hemorrhage, a patient may sometimes undergo life-saving surgery or medical treatment.

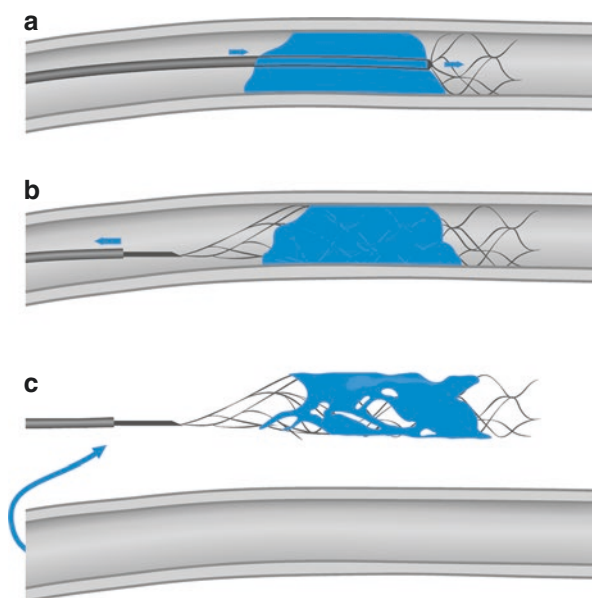
Patients who arrive at the emergency room of the hospital are examined by a neurologist or stroke physician. Blood samples are taken and a CT-scan is made. This usually makes it clear whether or not it concerns a brain hemorrhage, subarachnoid hemorrhage, or an ischemic stroke. In the latter case, there are no abnormalities visible on the CT-scan. The history, together with the clinical symptoms, can help form the clinical diagnosis of ischemic stroke, or cerebral infarction.

1.7.2 Treatment for Cerebral Infarction

When it is possible to start treatment for brain infarction within 4.5 h from onset, the patient will be given IV alteplase, a clot-dissolving drug. Alteplase binds to fibrin and promotes the degradation of fibrin strands, one of the major constituents of a clot. The sooner the clot is dissolved, the better. Of the patients who are treated within 1.5 h, more than 33% recovers. Of patients who are treated within 3 h, 15% recover and of those who are treated within 4.5 h, between 3 and 7% recover because of the treatment. The treatment may also cause hemorrhages, but that risk is relatively low compared to its positive effect.

The next step in the process is a CT angiography. With CT angiography, an occlusion of the intracranial artery can be visualized. This is the case in approximately 30% of acute patients. In the other 70% the occluded artery is either too small to be seen, or there is a different cause of the infarction. If an occlusion of an

Fig. 1.8 Thrombectomy. (a) Blood vessel with an occluding clot. The stent catheter has already pierced the clot. (b) The stent is deployed. (c) The stent has been removed with the clot from the blood vessel



intracranial artery is identified, additional treatment should be started as soon as possible. This is done by interventional radiologists, neurosurgeons or neurologists. A microcatheter is inserted in the femoral artery and with a guidewire shoved up into the occluded cerebral artery. Next, the clot is removed (see Fig. 1.8). In 2015, a Dutch study first demonstrated that this treatment is effective and safe. This was confirmed in four similar studies (Goyal et al. 2016). This treatment is now increasingly performed worldwide. Just like treatment with clot-dissolving drugs, this treatment must be carried out as soon as possible, too: Time is brain!

1.7.3 Cerebral Hemorrhage

In patients with a cerebral hemorrhage, you need to correct a coagulation disturbance immediately if they are on anticoagulants, such as dabigatran, acenocoumarol, fenprocoumon, warfarin or heparin. This step can be life-saving. If a patient deteriorates because the cerebral hemorrhage increases, surgery may be necessary remove the hematoma.

1.7.4 Subarachnoid Hemorrhage (SAH)

In patients with a SAH (due to an aneurysm), the best treatment is to close the aneurysm as quickly as possible before it can bleed again. This can be done by platinum coils, placed in the aneurysm with a small catheter. An older treatment consists of clipping the aneurysm. This is a neurosurgical treatment, where the skull must be opened. This procedure is done if coiling is not feasible (see Fig. 1.9).

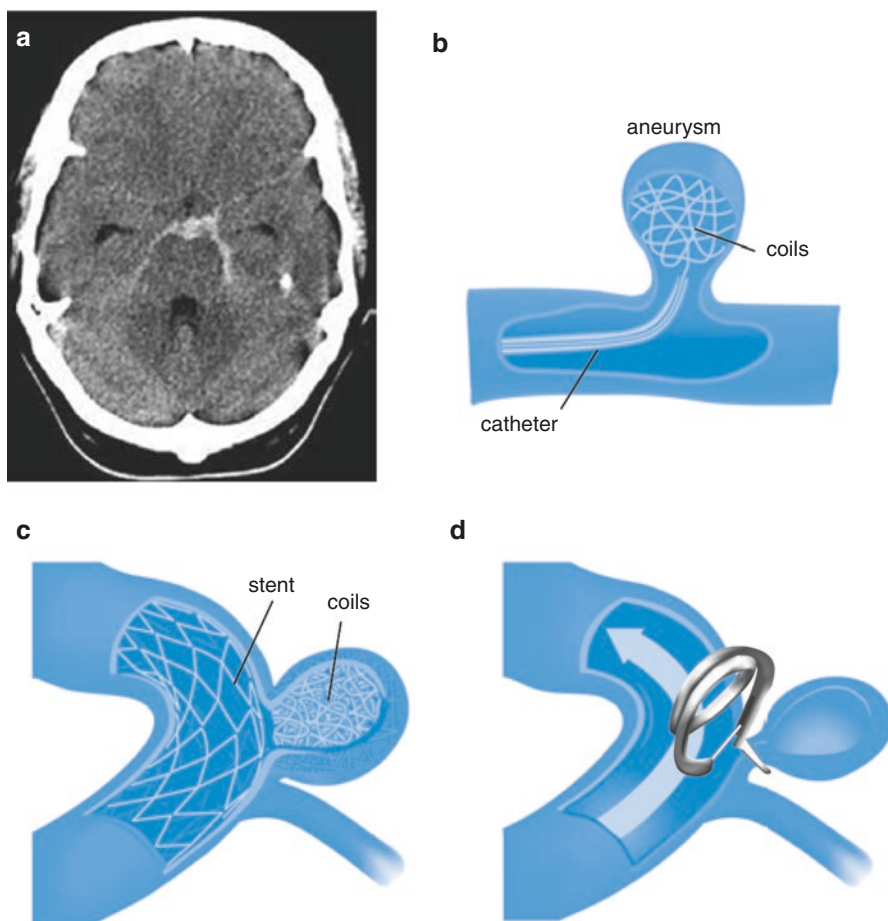


Fig. 1.9 (a) Subarachnoid hemorrhage on CT, (b) coiling of an aneurysm, (c) coiling with stent and (d) clipping of an aneurysm

1.7.5 Venous Sinus Thrombosis

In patients with venous sinus thrombosis, treatment consists of antithrombotic agents, i.e. low molecular weight heparin and warfarin.

1.7.6 General Treatment

Patients with stroke are at a high risk for complications. First of all, patients often have swallowing difficulties and a slightly lower level of consciousness, which means that they cannot drink fluids. Therefore, dehydration should be prevented. A standard isotonic NaCl infusion of 1–1.5 L/24 hrs should be prescribed. Only if it appears that the patient is able to drink sufficiently or when fluids can be administered through a nasogastric tube, should the infusion be terminated. Immediately

upon admission, a swallowing test is performed and the patient will not receive fluids or food orally, only through a nasogastric tube. Swallowing is monitored and slowly, a normal diet is introduced. This regimen prevents pneumonia in a substantial proportion of patients (Carnaby et al. 2006).

Patients who are bedridden and walk less than 2 h a day need low dose subcutaneous low molecular weight heparin in order to prevent deep venous thrombosis. In patients with cerebral hemorrhage, this treatment is delayed for 3 days, until it is considered safe to administer heparin. Compression stockings do not prevent deep venous thrombosis in patients with stroke. They are expensive and cumbersome to manage, and should therefore not be used at all (Dennis et al. 2009). When possible, a patient should be encouraged to sit up, stand and walk. It is likely that sitting, standing and walking instead of lying in bed reduces the risk of complications, because voiding is easier (less urinary tract infections), lung atelectasis will be prevented, (less pneumonia), leg muscles are used more often, (lower risk of deep venous thrombosis) and metabolism will be activated (lower blood sugar, less hyperglycemia). Note, however, that a large study has shown that too rapid mobilization of bedridden patients leads to poorer outcomes. Patients should therefore not be forced out of bed, if they are still completely bedridden by the stroke (AVERT 2015).

1.8 Risk Factors

Risk factors for cardiovascular disease (including stroke) are factors that increase the risk of stroke without always being the sole and sufficient cause for a stroke. It is important to distinguish between risk factors that may be influenced and risk factors that may not. In the latter category, we have age, gender, hereditary factors, previous stroke or myocardial infarction. Among the first category we have high blood pressure, smoking, excessive alcohol consumption, drug use (cocaine), hypercholesterolemia, obesity, low physical activity and diabetes mellitus. Of these factors, smoking and high blood pressure are the most important.

Elevated blood pressure occurs in more than half of patients with a stroke. For every 10 mmHg increase in systolic blood pressure, the risk of a next stroke increases with more than 25%. The total cholesterol is also an important risk factor for stroke, especially LDL cholesterol levels. The level of cholesterol in the blood is partly determined by diet, but for a large part it depends on genetic predisposition.

Smoking is also a very important risk factor. Nicotine has a negative influence on blood vessel walls. Smoking causes constriction of the blood vessels in the brain, thereby increasing the blood pressure. The risk of stroke increases with the number of cigarettes that one smokes. Smoking less is therefore encouraged, but quitting is much better altogether.

Diabetes mellitus is directly related to the severity of atherosclerotic disease in patients. Diabetes increases the risk of stroke and heart attacks. A poorly controlled blood sugar level makes the brain even more prone to damage if a stroke occurs.

Substance abuse is a major risk factor. The use of cocaine can cause serious heart rhythm disturbances, vasoconstriction in the brain, and local vasculitis (inflammation of the arterial wall) in the brain. All these factors can lead to a stroke.

Risk factors for a brain hemorrhage and a stroke are partly the same. Of the risk factors that cannot be influenced, age and cerebral amyloid angiopathy are important. Renal disease is also a major risk factor, because this is accompanied by high blood pressure and disorders of blood clotting. High blood pressure in itself and excessive alcohol consumption, especially binge drinking, may lead to brain hemorrhage.

1.9 Prevention

Immediately after admission of a patient with a stroke, the hospital is already working on prevention. The cause of the stroke and risk factors will be determined by doctors, nurses and other personnel. Lifestyle advice is always given, but in-depth counseling and guidance take place in an outpatient setting (Hankey 2017).

Patients with transient or lasting symptoms of cerebral infarction and severe atherosclerosis of the extracranial carotid artery in the neck, with narrowing of the vessel lumen, often undergo surgery. The inside of the vessel is then “cleaned out” (see Fig. 1.10). An alternative is to place a stent. However, this is not more effective than surgical treatment, and may more often lead to complications, especially in elderly patients.

Patients with ischemic stroke are treated with platelet aggregation inhibitors, or in short, antiplatelet treatment. In most cases, this treatment consists of clopidogrel 75 mg, or acetylsalicylic acid 100 mg, once daily, the latter often in combination with dipyridamole 200 mg twice daily. Platelets are involved in initial thrombus formation, and by blocking their function enzymatically, the risk of a new stroke or myocardial infarction is reduced by approximately 30%. The risk of side effects (intestinal bleeding, bruising) is small when weighed against the benefits.



Fig. 1.10 Surgery for carotid stenosis

Patients with symptomatic atrial fibrillation need oral anticoagulants to prevent another ischemic stroke from occurring. For some time now, direct oral anticoagulants (DOACs) are gaining in popularity. They have the advantage that their dosage is the same every day, and that the international normalized ratio (INR), an international measure for blood anticoagulation intensity, no longer needs to be checked. Examples are dabigatran, rivaroxaban, edoxaban and apixaban. In addition, patients with ischemic stroke thought to be caused by atherosclerosis (and that is almost everyone) receive a statin, usually simvastatin, 40 mg daily or atorvastatin, 10–80 mg. This reduces cholesterol levels, especially LDL cholesterol, thereby reducing the risk of a new stroke by about 20%. It is only effective if the drug is taken as prescribed, and for over a year. Cholesterol levels are checked regularly to see if the intended reduction of LDL has been achieved.

Patients who have had a cerebral hemorrhage will usually not receive platelet inhibitors or anticoagulants for prevention, as this will increase the risk of recurrent bleeding. They mostly do not get cholesterol lowering medication because we know that very low cholesterol levels are associated with intracerebral hemorrhage. For patients with atherosclerotic disease, and high risk of ischemic stroke, who had an intracerebral hematoma, this poses a clinical dilemma.

The common risk factor to both patients with cerebral hemorrhage and cerebral infarction is high blood pressure. The aim should be to reduce blood pressure to at least 130/80 mmHg, but lower if the patient can tolerate this. Often a thiazide diuretic such as hydrochlorothiazide 12.5 mg is prescribed as well as an ACE inhibitor, such as enalapril 10–20 mg. Perindopril is also commonly prescribed. It does not matter much if an ACE inhibitor, diuretic or calcium antagonist or combination is prescribed as long as the blood pressure is managed properly.

All these medical and lifestyle measures only work if patients understand why they are necessary, and if they are motivated and able to adhere to them. This means that providing information and guidance are of the utmost importance.

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Abstract

What does stroke-care entails in the acute phase in the hospital in terms of diagnosis, the effects a stroke has on a patient, treatments and issues professionals in the hospital should be focusing on? In the hospital, mobilization and rehabilitation of the patient starts as soon as possible. The objective is to discharge the patient within 5 days, if the patient is clinically stable. In this period secondary prevention is started: a patient is treated, the aftercare trajectory will be started and interventions are applied to prevent recurrence of stroke.

Keywords

Acute care · Early treatment and rehabilitation

2.1 Introduction

In this chapter we discuss what stroke-care entails in the acute phase in the hospital. We will cover diagnosis, which effects stroke has on a patient, which treatments are available and what the aspects are that professionals in the hospital should be focusing on. In the hospital, mobilization and rehabilitation of the patient starts as soon as possible. The objective is to discharge the patient within 5 days, if the patient is clinically stable. In this period secondary prevention is started: a patient is treated,

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the aftercare trajectory will be started and interventions are applied to prevent recurrence of stroke.

2.2 Hospital Admission

In case of an infarction, the treatment has to be started as soon as possible: time is brain! Therefore, it is of high importance to raise awareness of the symptoms of stroke and the urgency of treatment. When there is suspect that someone has a stroke, there is a need to react immediately. The patient or the people surrounding the patient need to call the emergency number straight away to ask for an ambulance, which will bring the patient immediately to the first aid of the nearest hospital with a neurological ward. In a number of cases the patient calls his general practitioner (GP). The GP runs the FAST (Face-Arm-Speech test) and if this test is positive he needs to call an ambulance immediately (preferably without seeing the patient because of the urgency of treatment). The ambulance notifies the GP to which hospital the patient is transferred. The GP contacts that hospital to hand over the patients' medical file.

Even when neurological symptoms are disappearing, for example in case of a Transient Ischemic Attack (TIA), the patient will be transferred to the hospital urgently, since in the first hours after a TIA the chance of having a stroke is very high.

2.3 Three Phases After Stroke

The acute phase is the first stage after the occurrence of the stroke and usually lasts a few days to 1 week. The main objective of this phase is the prevention of further brain damage and other complications. Key components are observation, diagnosis, specific treatment and stabilization of health condition. The acute phase lasts until the moment the patient is stable and the acute physical treatment has ended.

The following phase is the rehabilitation phase. The main objective of this phase is to reduce adverse effects of the stroke, to prevent complications, and to restore functioning in daily life as much as possible. The rehabilitation phase ends when there is hardly any recovery of functions. The most intensive stroke rehabilitation programs are provided in an inpatient setting (usually rehabilitation centre) staffed by a multidisciplinary team, specialized in stroke rehabilitation.

The third phase is the chronic phase. Stroke is not only an acute condition, but is increasingly more recognised as a life-long condition. When it is clear that there are permanent limitations, disorders or disabilities, the chronic phase starts. The aims of this phase is to recover to the previous level of functioning or to cope with the consequences of stroke in the field of ADL, iADL and work/leisure activities. Persistent effects, visible to the environment or not, will have to be accepted by the patient. At this stage, the patient is usually at home or in case of severe or too complex nursing needs in a long-term care department in a nursing home.

2.4 The Stroke Care Nurse

During the acute phase in the hospital, mainly the following three issues are addressed (Fagan 2004):

1. diagnosis;
2. treatment;
3. rehabilitation.

For patients and informal caregivers, the acute phase is often dominated by distress and anxiety: Why did this happen to me? Will my husband survive? There are often questions of life and death. Sufficient care and guidance are therefore essential. In the hospital, the stroke care nurse (SCN) has a very important role in this care and guidance of the stroke patient.

The SCN provides patient and informal caregivers guidance, education and information (such as information about diagnosis, risk factors, treatment and possible follow-up after hospitalization). The SCN works very closely together with the neurologist. After discharge from the hospital, the SCN is available for questions from patient and informal caregivers and will see the patient again in the hospital for consultation after 4–7 weeks (outpatient care).

A stroke can cause considerable complications, which can worsen the condition of the patient seriously. During the acute phase, nurses monitor the occurrence of i.e. lung inflammation, bedsores, urinary tract infections, thrombosis, delirium, depression, the degree of consciousness of the patient, injury of the affected side caused by neglect, inadequate posture, inadequate food or fluid intake. The SCN applies preventive interventions on the Stroke Care Unit (SCU) according to the hospital protocols to decrease the risk of those complications.

2.5 The Hospital Stroke Care Unit

The Stroke Care Unit (SCU) is a specialized department, specifically equipped for patients with stroke. The multidisciplinary team at the SCU includes a neurologist, specially trained SCN, experienced neurology nurses, rehabilitation physician, physical therapist, occupational therapist, speech therapist and transfer nurse. The treatment on an SCU promotes recovery and the stay at the SCU lasts only shortly. If the patient is clinically stable, he is transferred to the rehabilitation facility or to the community, mostly within a few days.

The patients on the SCU are connected to the monitor in the first days of their hospitalization. The nurses check on vital functions regularly, such as temperature, blood pressure, pulse rate, oxygen and sugar levels in the blood. If there are any deviations in these vital functions, nurses can act quickly and according to the hospital protocol. In most cases, the cardiologist is also called upon. For example, when a patient has a deviating electrocardiography (ECG) or heart—rhythm disturbances. These conditions may cause a clot and therefore the follow-up of stroke patients by nurses is a matter of life and death.

2.6 The Glasgow Coma Scale and the National Institutes of Health Stroke Scale

An important tool on the SCU is the Glasgow Coma Scale (GCS-scale). The purpose of the GCS scale is to determine the degree of consciousness of the patient. By regularly measuring the GCS-scale, nurses can discover a decline in consciousness in time, and can consequently intervene according to the hospital protocol. The GCS is based on three different reaction patterns of a patient, namely:

- E: best **E**ye reaction;
- M: best **M**otoric (motion) response;
- V: best **V**erbal (speech/producing sounds) response.

For each element (E, M and V) the nurse assesses the patient and gives a score: the EMV scores. The scores are added together and the total score indicates the seriousness of unconsciousness. The lower the score, the lower the awareness. The patient is in a coma if he does not open his eyes when spoken to, does not perform assignments and does not give verbal responses (<http://www.glasgowcomascale.org/>).

Another important tool is the National Institutes of Health Stroke Scale (NIHSS). The NIHSS is a 15-item neurologic examination scale (consciousness, language, neglect, visual-field loss, extraocular movement, motor strength, ataxia, dysarthria, and sensory loss) which is used as an assessment tool to evaluate and document neurological status in acute stroke patients. It gives a measure of stroke severity and can be administered by physicians, nurses or therapists (<http://www.nihstrokescale.org/>).

2.7 Start-Up of Rehabilitation Phase

Most recovery takes place in the first few months after a stroke. Therefore, rehabilitation is started as soon as possible. Even while still in the hospital, the multidisciplinary team is looking for what is achievable for the patient. A number of factors are important here: the nature of the disabilities and limitations, condition, motivation and home situation. To this end, the multidisciplinary team sets up a multidisciplinary plan.

In most hospitals, a multidisciplinary consultation (MDC) is organized one to three times a week (this differs in frequency according to which hospital the patient is staying). Present at this consultation are the: physician (neurologist and/or medical assistant), rehabilitation physician, elderly care specialist, SCN and/or specialized nurse of the department, physical therapist, speech therapist, occupational therapist, transfer nurse.

- The neurologist treats the patient during the acute phase in the hospital and is the chairman of the MDC.

- The rehabilitation physician and elderly care physician assess what type of rehabilitation the patient needs and in which location it is best done.
- The physical therapist provides training and rehabilitation on the hospital ward, looks at what issues someone has and gives advice about the patients' mobility.
- The (stroke care) nurse informs, instructs and guides the stroke patient and informal caregivers during the hospital stay, and provides outpatient care after 4–7 weeks.
- The transfer nurse coordinates the transfer of patients from the hospital to other institutions/the community.
- The speech therapist gives advice on swallowing and speech problems.
- The occupational therapist helps improve the hand function and allows the patient to perform daily activities independently.

During the MDC, every stroke patient at the SCU is discussed, so that the different professionals that are involved with patient care are aware of the patients' disabilities and the treatment plan. The current situation of the patient is discussed as well as which rehabilitation program is best after hospital admission. In addition, the multidisciplinary team looks at:

- What can the patient do independently? (ADL, eating, drinking, moving, medication intake);
- Living situation: does he live alone or together? What type of house is he living in? Is there a need to walk the stairs or is there an elevator available? Are there doorsteps in the house or any other obstacles which hinders the patient in self-managing?
- Age of the patient and functioning before stroke. Did the patient already experienced disabilities? Was he active? Was he already walking with a device?

After the hospital admission there a few choices:

1. The patient returns home without clinical rehabilitation
Physical therapy is available in the community and also speech therapy, occupational therapy and psychological treatment are possible. If necessary, the SCN can arrange meal service, walking aids and community nursing care for the patient. Also there may be a social worker needed in the home situation.
2. The patient rehabilitates in a rehabilitation hospital
The purpose of rehabilitation is to support patients to live as independent as possible, perhaps with the help of adjustments. The multidisciplinary team provides treatment, guide and care to support the patients with practicing for living in the home situation. The pace of rehabilitation is rather high and patients are guided (if necessary) to be again part of the working process.
3. The patient rehabilitates in a skilled nursing facility (SNF)
The purpose of rehabilitation in a SNF is to function as independently as possible. The pace of rehabilitation in a SNF is slower in comparison to a rehabilitation hospital, and the treatment is less intensive. After that, the multidisciplinary

team looks at the best living situation for the patient. Can he go home, or does he need to go to a nursing home for long term care?

2.8 Prevention

During their hospital stay, patients are treated with medication and receive therapy. In addition to treating stroke, there is a considerable attention to the prevention of stroke recurrence. When preventing for stroke recurrence, three topics are important: medication, risk factors and lifestyle. Those three topics are the main focus of the nursing team.

2.8.1 Medication

Certain medications protect against stroke recurrence and therefore patients should continue to take medications for the rest of their life. Therapy adherence is essential. It is important that patients know what medication they have to take and why. In Chap. 1, medication after stroke was described extensively. It is a nurses' key role to inform patients about their medication and therapy adherence.

2.8.2 Risk Factors

The factors that increase the risk of cardiovascular disease, include:

- *High blood pressure*
A blood pressure above 130/80 mmHg is a high risk, therefore, reduction in blood pressure reduces the chance of a recurrent stroke (Zhang et al. 2006). When the blood pressure is too high, medication is prescribed. However, an adverse reaction of blood pressure reducers may be too low blood pressure and nurses should be aware of this complication!
- *Elevated Cholesterol*
An elevated cholesterol level (low density lipoprotein (LDL) of 2.5 or more) is an increased risk. An elevated cholesterol level causes arterial impairment and almost all stroke patients have increased cholesterol levels. Cholesterol is a body-like substance and is important for muscle development. Therefore, when patients express muscle pain, it is good to discuss this with the neurologist, since muscle pain may indicate muscle degeneration: the heart is also a muscle and can be affected too.
- *Diabetes mellitus*
People with diabetes mellitus have an increased risk of cardiovascular disease. This is because, among other things, the fat metabolism is disturbed and the arterial calcification proceeds faster. It is important that the blood sugar levels are well controlled, because patients with prediabetes have an increased risk of

getting diabetes. Therefore, also the GP is advised to keep monitoring blood glucose levels in the home situation, since a third of people with impaired glucose tolerance develops diabetes in the next 5 years.

2.8.3 Lifestyle

There is sufficient evidence that lifestyle factors, such as smoking, overweight, excessive alcohol consumption and inactivity will increase the risk of a having a (recurrent) stroke. Lifestyle adjustments have a beneficial effect on risk factors and nurses need to discuss the importance of a healthy lifestyle. Patients can thus help reduce the risk of cardiovascular disease, including a (recurrent) stroke.

- *Smoking*

By quitting smoking, the risk of cardiovascular disease is reduced by 30–50% (Redfern et al. 2000). It has a beneficial effect on blood vessels, even though the patient has been smoking for many years. After 3 months to 1 year, the risk of cardiovascular disease is reduced by 50%. There is also less risk of vascular damage, clot formation and there is an improvement in high density lipoprotein (HDL) cholesterol. When a patient keeps smoking during treatment with medication after a stroke, the effect of medication is eliminated by 50%. By influencing the risk profile positively, the patient keeps the blood vessels in good condition, thus reducing the chance of a recurrent stroke.

- *Alcohol intake*

Recent excessive alcohol consumption is an independent risk factor for stroke and due to the effect on blood pressure (hypertension), it increases the risk of (recurrent) stroke (Hillbom et al. 1999).

- *Exercise*

The relationship between LDL, HDL, and high density lipoprotein (VLDL) is very important for health and the risk of cardiovascular disease. With moderately intensive exercise for at least 30 min, the patient reduces the risk of cardiovascular disease. Because of the exercise, good cholesterol rises, which improves the cholesterol level (ratio between good HDL cholesterol and poor LDL cholesterol). Exercise keeps the heart and blood vessels in condition and lowers blood pressure. In addition, it has a beneficial effect on diabetes and weight control.

- *Healthy weight*

A healthy weight is defined as having a body mass index (BMI) between 20 and 25. This can be calculated by dividing the weight by the length squared. For example, someone is 1.70 m and weighs 65 kilos: $65 / (1.70 * 1.70) = 22.5$, which means this is a healthy weight. Currently, we know that a large waist circumference (belly fat) doubles the risk of a stroke. A waist circumference over 88 cm for women and over 102 cm for men, is called abdominal obesity. Being overweight is not a risk factor in itself, but it increases the risk of diabetes mellitus, hypertension and hypercholesterolemia.

- *Eating healthy*

Healthy food is important: as many unsaturated fats as possible, such as olive oil, 2 ounces of vegetables and two pieces of fruit every day, reduced salt. In the hospital, the physician and SCN spend extensive attention on that subject. The information need to be given verbally and must be supported by written information. The nurses in the rehabilitation facilities will discuss this again with the patient and his informal caregivers.

2.9 Coping with the Consequences

Most recovery takes place within the first 6 months after stroke. After that, recovery may occur, but it will slow down. It is important to tell patients that due to brain injury, things will not be like they were in the past. It is the intention that the patient can continue living as independently as possible. Sufficient information and education about the causes and consequences of stroke are important to understand these consequences.

Patients must learn how to overcome them, and accept that the stroke can have permanent consequences. They must also learn how to deal with limitations; for example, a patient with hemianopsia learns to turn his head to the side he misses in the field of vision. Fear of recurrence often plays a role and for example fellow sufferer's contact can offer support, but also supervision by a social worker or psychologist.

Following, the issues are listed that patients might suffer from after stroke.

- *Fatigue*

Fatigue is a very common phenomenon after stroke. It is still unclear what the exact etiology is, but it is assumed that the recovery in the brain can lead to fatigue. Some activities are also more exhausting than before for patients and they constantly need to consider how something needs to be done. Appropriate exercise can help the body to become stronger and improves condition.

- *Concentration*

Problems with concentration can arise after stroke. Patients find it difficult to be in hectic areas, with many stimuli. Furthermore, reading a book can be challenging or difficult.

- *Paralysis of an arm or leg*

Paralysis restricts patients in their daily lives. An early start of rehabilitation provides an increased chance of functional recovery. Nurses need to explain this to the patient and together, they can try to recover strength and function as much as possible. However, the extent to which this succeeds is difficult to predict.

- *Speech and language*

Speech and language disorders can have a major impact on patients because they have difficulties in expressing themselves and others do not understand them. This may cause sadness, agitation, aggression and frustration.

- *Incontinence*

Incontinence of both urine and feces can be a result of a stroke. Sometimes this passes, sometimes not, but patients are often very burdened with this.

- *Memory disorders*

Memory disorders of especially short-term memory occurs frequently after stroke and it is important to estimate how serious the problems are. Does the patient only forget a name sometimes, or does he forget to turn off the gas after cooking? Extended neuropsychological tests can provide more clarity.

- *Apraxia*

Difficulty in performing actions in correct order or not using an instrument accordingly to where it has been developed for. Like combing the hair with a fork.

- *Character changes*

Character changes makes people more impatient, or certain characteristics can be amplified, such as anger. Sometimes patients are slower or burst into tears quicker. This is burdensome for patients and informal caregivers.

- *Depression*

Depression is very common following a stroke. Research shows that one-third of the patients with stroke struggle with depressive symptoms. They may be lethargic and have no motivation to do anything. That is disastrous for a good rehabilitation, which revolves around active participation in therapy. Depression after stroke is often overlooked, however an easy screening instrument in the acute phase is the Hospital Anxiety and Depression Scale (HADS) (Bjelland et al. 2002; Caeiro et al. 2006).

- *Driving*

Patients are mostly not allowed to drive until 2 weeks after stroke. If there are still physical or cognitive issues after those 2 weeks that may interfere with driving (e.g. concentration disorders or severe fatigue), the patient may not drive for 3 months and a procedure will commence. For professional drivers, the procedures are more stringent.

- *Sexuality*

An important part of the sexuality takes place in the brain and consequently, brain dysfunction can lead to sexual problems. Sexuality covers a much larger area than having intercourse: it also comprises romantic love, caressing, kissing, intimacy, comfort. Every individual gives his personal interpretation to sexuality and a sexual problem is evident when someone does not experience sexuality in a way he would like.

- *Spasticity*

After a stroke about 30% of patients suffer of spasticity. Spasticity is a neuromuscular condition which is caused by damage in that part of the brain where voluntary movement is controlled, and leads to adverse effects such as overactive reflexes. The most common used scale to quantify the degree of spasticity is the Modified Ashworth Scale (MAS). Spasticity can be treated in several ways i.e. oral medication, surgery, injections, physical therapy, orthoses (Thibaut et al. 2013).

2.10 Outpatient Aftercare

All patients who have been admitted on the SCU, are invited to come back to the hospital for a consultation with the SCN within 4–7 weeks. The frequency and content of this aftercare may vary by hospital, but the purpose of the consultation is mainly the same.

In the hospital, the nurse discusses the risk factors and lifestyle with the patient. A neuropsychological screening can be performed, and the nurse will also look at the cognition and mood of patients. For example, the Mini Mental State Examination can be used to screen for cognitive decline (<https://www.strokingengine.ca/assess/mmse/>). Issues that patients frequently experience are memory problems or apraxia (for example, making coffee). If necessary, the psychologist is consulted and will perform extensive neuropsychological research according to the issues. Some patients have also a consultation with the neurologist, for example, if there was an epileptic insult in addition to the stroke.

The patient gives blood, which is required for blood cholesterol determination, liver and kidney function, and, if necessary, extensive laboratory testing takes place. Furthermore, the nurse measures the blood pressure a number of times during the consultation. During the consultation the SCN discusses these points:

- the (clinical) issues, with the possible cause;
- medication;
- risk factors;
- lifestyle.

The GP receives a letter about this outpatient visit. Patients don't generally return to the hospital after this visit; the GP takes over the subsequent treatment.

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Recovery After a Stroke

3

G. Ribbers and T. Bushnik

Abstract

The severity and nature of the sequelae of a stroke are determined by the cause, location and extent of the injury, the general physical condition of the patient, his or hers psychological make-up such as the preferred coping style and the social context such as being involved in a relationship or not. The process of stroke rehabilitation is aimed at reducing the (impact) of these sequelae, to regain independence and optimal participation in society. As such outcomes of stroke rehabilitation may be broadly defined ranging from body functions, to coping to social participation. This chapter focuses on recovery ranging from spontaneous neurological recovery, treatment induced recovery to social participation and points out the important role of the stroke nurse.

Keywords

Recovery · International Classification of Functioning · Interdisciplinary rehabilitation · Stroke nurse

3.1 Introduction

Injuries to the brain such as in stroke may leave sequelae involving motor, language and cognitive functions. Patients may for example suffer from a paresis, memory or attention deficits, from aphasia or from emotional problems such as depression or apathy. Other

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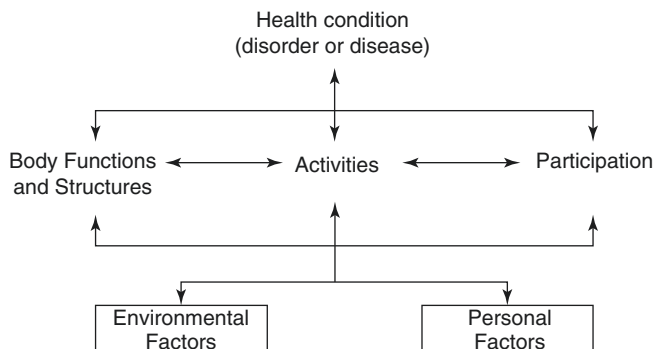
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Fig. 3.1 Components of the ICF model



problems may also occur, such as loss of a part of the visual field (anopsy) or incontinence for urine or stools. The severity and nature of the sequelae are determined by the cause, location and extent of the injury, the general physical condition of the patient, his or hers psychological make-up such as the preferred coping style and the social context such as being involved in a relationship or not. The process of stroke rehabilitation is aimed at reducing the (impact) of these sequelae, to regain independence and optimal participation in society. As such outcomes of stroke rehabilitation may be broadly defined ranging from body functions, to coping to social participation.

This broad scope on health is captured in the International Classification of Functioning, Disability and Health (ICF) (<http://www.who.int/classifications/icf/en/>). The ICF recognizes the role of environmental factors as well as of associated health conditions (see Fig. 3.1). It is a biopsychosocial model in which a person's level of functioning results from a dynamic interaction between health conditions, environmental factors, and personal factors. Body functions relate to physiological functions of the body, body structures to anatomical parts such organs and limbs. Motor control, cognition and cardiorespiratory fitness are examples of body functions. Body functions and structures determine one's potential or capacity to perform activities, one's ability to execute a task or action. This relates to what a person can do for example under supervision of a therapist such as walking, communicating or making use of public transport. Performance relates to what the person actually does in daily life. Patients may be able to do house hold activities but may decide not to do so for several reasons. A caregiver who takes over these activities or the patient's lack of self-confidence are examples that may cause a mismatch between capacity and performance. Participation relates to one's involvement in vocation, recreation and social and family life. Environmental and personal factors may be barriers or facilitators of performance and participation. For example the presence or absence of a primary caregiver may determine whether a patient can be discharged at home or needs to be discharged to a sheltered living situation.

3.2 Recovery

This chapter discusses recovery after stroke (Bernhardt et al. 2017). **Neurological recovery** will occur in the first weeks/months after a stroke. Currently there is little evidence that stroke rehabilitation actually improves neurological recovery beyond

the level of spontaneous recovery. For example early upper extremity training is not likely to reduce paresis or to improve the ability to perform fractionated movements. However treating spasticity may increase the potential for functional use of an extremity, or decrease pain. Likewise, training attention functions is not likely to improve attention span. However attention span can be improved with medication. So, despite the fact that it is questionable that rehabilitation improves spontaneous neurological recovery, rehabilitation may increase an individual's potential or capacity to perform activities. Improving one's potential to perform may be referred to as **structural recovery**. As such structural recovery is determined by (spontaneous) neurological recovery and (medical) rehabilitation interventions. Besides improving one's potential, rehabilitation is focused at improving performance (**functional recovery**). Being able to ambulate or to walk stairs despite a paresis, to become independent in self-care despite visuo-spatial disorders or to convey messages despite being aphasic, are examples of functional recovery. Where structural recovery relates to recovery of bodily functions, functional recovery relates to activities or one's performance. The ultimate goal of rehabilitation is to enable the patient to participate in society as independently as possible in terms of vocation, recreation, and in a family context. The process of rehabilitation is therefore aimed at improving potential (structural recovery), improving performance (functional recovery) and improving participation. The ICF model underlines that there is no linear relationship between one's potential, performance and participation. External and personal factors affect this relationship. For example, a paretic leg may hinder an independent walking function. If the employer can adjust work and workplace (external factors) allowing the individual to work despite a lost ability to walk, then that part of social participation is maintained.

Recovery therefore encompasses more than recovery of functions and anatomical features. The purpose of rehabilitation is to optimize performance and participation.

3.3 Recovery and Neuroplasticity

It was long thought that the brain was static and thus unchangeable. In this perspective, loss of brain tissue was considered irrevocable. While the brain was previously seen as a static organ, it is now known that the brain is plastic. Neuroplasticity (or 'brain plasticity' or 'neural plasticity') refers to lasting changes to the brain throughout an individual's life course. It can be observed at multiple scales, from microscopic changes in individual neurons to larger-scale changes such as cortical remapping. Neuroplasticity may occur related and unrelated to brain injury.

The brain may reorganize its neural networks by forming new connections (synapses) between neurons. Learned skills translate into new connections between nerve cells. Individual synaptic connections are constantly being removed or recreated. Hebbian learning implies that if two neurons are activated in close temporal proximity, they start making connections ("neurons that fire together, wire together"). This is called long term potentiation (LTP), in which the strength of synaptic connections increases. Conversely, a weakening of synaptic connections, called long term depression (LTD), occurs in absence of simultaneous activation.

Sensory experience and learning are important drivers of these processes. After reading this chapter, the reader will remember possibly some 30% after one day because new connections have been formed. If this chapter is reread once every week during 2 months, more and more connections will be formed and more and more will be remembered. This is an example of long term potentiation. The synaptic strength increases through repetition. If no more effort is put in memorizing the content of this chapter, the student will forget ever having read it. The neural connections will weaken due to long term depression. Learning-dependent neuronal reorganization is considered an important substrate of rehabilitation after stroke. Learning to dress with a paretic arm, to walk with a paretic leg or to communicate with aphasia involves reorganization of neural networks. This process of relearning skills after stroke is called “treatment induced recovery” and may continue over years with continued practice and effort. A largely unresolved question is if and how treatment induced recovery relates to spontaneous neurological recovery.

Spontaneous neurological recovery typically occurs within the first weeks after stroke. The penumbra is an hypoxic area surrounding the ischemic core. It is electrically silent, but metabolism is sufficient to keep the neurons alive. Salvation of penumbral tissue contributes to spontaneous neurological recovery. Salvation of penumbral tissue by reperfusion may occur spontaneously or as a result of therapy such as with alteplase or thrombectomy. Outside the penumbra diaschizis or ‘cerebral shock’ occurs. It involves a down regulation of metabolic activity in brain areas remote but anatomically connected to the lesion. The volume of brain tissue involved in diaschizis may be much larger than the ischemic core. Alleviation of diaschizis is another mechanism involved in recovery from stroke and again it is unknown if and how therapy has an effect on this process.

So, the mechanisms by which learning-dependent neuronal reorganization may restore lost cortical and cortico-spinal functions are poorly understood. In fact there is little evidence that rehabilitation actually contributes to what is called “true neurological recovery”.

3.4 Principles of Rehabilitation

Intensive practice is one of the most important components of training to promote learning. The physical, occupational and speech therapist as well as the cognitive trainer teach new skills. Therefore, rehabilitation is resource intensive and therapy time per patient is limited because of the need to cover many patients. Even patients in inpatient rehabilitation after stroke may spend much time lying in bed or sitting with only a few hours per day spent with a therapist. The rehabilitation nurses’ (RN) all-day, all-week presence guarantees spending a lot of time with the patient and the family. For matters such as continence training, training of spatial orientation and calendar training, rehabilitation nurses actually often hold the primary responsibility. The RN fulfills a number of crucial roles for the person rehabilitating from a stroke: care provider, facilitating personal recovery, and care

manager (Burton 2000). As care provider, the RN is pivotal in insuring the consistent incorporation of newly acquired skills in daily activities thus significantly extending therapy time by not only doing needed tasks but also continuing to educate and reinforce skill acquisition. As facilitator of personal recovery, the RN provides support for the emotional and social aspects of recovery for both the patient and the family. Finally, as care manager, the RN has primary roles in collaborating with physicians and other members of the interdisciplinary team to help patients deal with limitations on a daily basis, organizing smooth transitions of care and rehabilitation, and focusing on the well-being of the patient and family. RN's therefore are in the ideal position to maintain an holistic overview of care and to communicate information about the patient's health status, activity levels over the day and the interaction with family or care givers to the other members of the team. As such the RN plays a vital role in the interdisciplinary rehabilitation team and functions as a fully-fledged co-worker with the duties and responsibilities involved (Low 2003).

Conclusion

A lot of research is focused on plasticity of the brain. Although this leads to new insights, rehabilitation does not seem to contribute to spontaneous neurological recovery. We are not yet able to gain activity in a totally paralyzed arm, to regain language functions if someone has global aphasia or to cure apraxia. However, we are getting better in guiding the patient to optimal performance on multiple domains, to regain an autonomous life as much possible and as soon as possible and to empower the primary caregivers. This is a resource intensive process where a team of practitioners creates a learning environment tailored to the patient's specific needs taking into account his sociocultural context. In the inpatient setting, rehabilitation nurses can make a difference. As co-therapists they are integral members of the treatment team. They are the eyes and ears of the team, monitoring how patients actually function in daily life. That is a task that comes with the caring role and requires education, expertise and social skills.

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B. I. Buijck and T. Bushnik

Abstract

Postacute stroke rehabilitation may be either in in- or outpatient rehabilitation clinics, skilled nursing facilities or community based. Therapy intensity is important but may depend on availability of resources and comorbidity of the patient. Further differences in national legislation, health care regulation and reimbursements policies may explain differences between countries and even outcomes. This chapter highlights the differences between skilled nursing facilities, rehabilitation centers and the importance of a dedicated interdisciplinary stroke rehabilitation team.

Keywords

Postacute rehabilitation · Skilled nursing facilities · Rehabilitation centre · Interdisciplinary stroke team

4.1 Introduction

Post-stroke rehabilitation depends on functional status and age, availability in hospitals, rehabilitation centers and skilled nursing facilities. This rehabilitation takes place on specialized rehabilitation units after the acute stage in the hospital. The purpose of rehabilitation is to recover to the same level of participation and

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activities as before, with the intention of discharge to home. The emphasis is on treatment of the physical consequences of stroke, multimorbidity and coping with disabilities. Each patient receives an individual tailored rehabilitation program. The therapy intensity depends on ability of the patient and the financing options of an organization. In the Netherlands, there are two main procedures of rehabilitation: geriatric rehabilitation care (GRC) in skilled nursing facilities and the medical specialist rehabilitation (MSR) in rehabilitation hospitals. In particular, the geriatric rehabilitation care is a challenge for professionals.

4.2 Higher Therapy Intensity: Medical Specialist Rehabilitation for the Elderly

Innovation is necessary, in order to cope with the growing challenges in elderly care and specific in rehabilitation. This concerns initiatives that have benefit to the patient. That is, vulnerable older people should have every opportunity for maximum functional recovery and have every chance to return to their own community and network. The problems concerning older rehabilitation patients are often more complex than for the younger rehabilitation patient, and there is an aging population. Multimorbidity plays an important role, and delirium occurs regularly. This patient group often receives GRC, where the patient is given a maximum of 4–6 treatment hours a week (including specialist nursing, elderly care specialist, physical therapy, occupational therapy, social work, speech therapy, and psychology). A younger patient with stroke, but without complex multimorbidity, receives twice as many treatment hours in the rehabilitation hospital with MSR.

4.3 Combination GRC and MSR in a Nursing Home

The multidisciplinary team of professionals consists of an elderly care specialist, rehabilitation physician, physical therapist, occupational therapist, speech therapist, psychologist, dietitian, social worker and nurses. Professionals, with their unique expertise and capabilities, are able to give vulnerable older people the opportunity for maximal functional recovery and a return to their own living situation. This can be achieved with a well-organized combination of GRC and MSR. However, soon after a stroke, some patients are limited in their endurance and physical capacity; therefore, GRC alone is initially sufficient. As soon as the patient's capacity and endurance increase, the patient and the treatment team can consider the transition to MSR. The combination of GRC and MSR is often possible, but therapists do not consider this choice often enough.

4.4 Thinking in Possibilities

What can a patient still achieve despite his disabilities? How can this patient function well again as quickly as possible, if necessary with assistance (aids)? A rehabilitation physician is well versed in the field of rehabilitation in terms of content,

allowing him to guide the treatment team. In addition, a rehabilitation physician has the knowledge about the (neuro) psychological component. The physician determines the rehabilitation intensity by looking at the network and the living situation of the patient.

The rehabilitation physician thinks in possibilities of recovery. The expertise of the elderly care specialist is also important because the elderly care specialist has very specific knowledge and expertise in the area of complex disorders and limitations of the older patient. His special medical knowledge in the field of disorders and limitations is a meaningful addition to the knowledge of the rehabilitation physician. In addition, knowledge of polypharmacy and multimorbidity is an important contribution by the elderly care specialist. He creates the basic conditions for rehabilitation in this group of vulnerable elderly people.

4.5 Therapeutic Rehabilitation Climate

It is important that patients perform activities in a therapeutic climate. A therapeutic rehabilitation climate is characterized by:

- The use of structured evidence-based rehabilitation programs tailored to the patient;
- The use of evidence-based guidelines;
- Setting explicitly formulated goals;
- ‘Hands on the back’ nursing
- A motivating climate;
- Interaction with other people;
- Awareness of the patient and their environment, that the patient is in the skilled nursing facility for rehabilitation;
- Deployment of all people close to the patient during rehabilitation;
- All activities focusing constantly on returning home.

Patients receive a treatment program based on their profile upon admission (Wissink et al. 2014). In most cases, physical activity is taken into account, such as balance and ADL. However, research shows that psychosocial factors, such as mood and the presence of family/friend support, also affect the rehabilitation process. Patients who were permanently admitted to the nursing home appeared to show an increase in neuropsychiatric symptoms and depressive symptoms in addition to physical deterioration (Buijck et al. 2012b).

4.6 Consequences of Stroke for Rehabilitation

Too much time spent alone can lead to feelings of loneliness, and mulling over the impact a stroke has. This can contribute to loss of motivation and an increase in neuropsychiatric symptoms and depressive symptoms (Buijck et al. 2012a, b). Furthermore, after rehabilitation, neuropsychiatric symptoms and depressive

symptoms can lead to a reduced quality of life, with a possible consequence of needing more informal caregiving. The prevention and treatment of neuropsychiatric symptoms and depressive complaints in an early stage of rehabilitation may result in a better rehabilitation outcome and as a result a better quality of life for patients and their caregivers (Buijck et al. 2014).

4.7 Nurses in Rehabilitation

Despite the fact that nurses express their desire to integrate therapy into their daily work, achieving that goal is a challenge. These professionals should therefore be encouraged and empowered in their diverse roles by their management team and the multidisciplinary team of the skilled nursing facility. Nurses can be the initiators of a therapeutic climate in the department. If they encourage the use of newly acquired functional skills and the practice of new skills with their patients on a daily basis, they significantly contribute to the (functional) recovery of the patient. As mentioned earlier, a therapeutic climate is characterized by structured evidence-based rehabilitation programs tailored to the patient, use of directives, explicitly formulated goals, ‘hands on the back’ nursing, a motivating climate and interaction with other patients. All of these activities are constantly focused on giving the patient the chance to return home (Buijck et al. 2012a).

4.8 Practicing with Patients

Nurses can often do short exercises with the patients, for example reaching for things on the table and walking (Schuurmans and Hafsteinsdóttir 2008). The realization of a therapeutic climate is an ideal role for nurses because they are present 24 h a day at the rehabilitation department! The information collected by nurses, preferably collected with instruments developed specifically for that purpose (for example, neuropsychiatric symptoms, ADL), should be discussed with the multidisciplinary team. Then, immediate action needs to be taken to deal with any complaints. Because the strain on the informal caregiver increases in case of neuropsychiatric symptoms and depressive complaints, it is useful that nurses involve the informal caregivers in rehabilitation. They can then offer guidance on adjusting to the possible new role as caregiver. Also, the nurse can offer aftercare in the psychosocial area.

4.9 Developments That Play a Role in Rehabilitation

The results of rehabilitation for the average patient are indicated by predictive models (Spruit-van Eijk et al. 2012). These, however, are not necessarily valid for each individual patient. It can be difficult for treating physicians to predict whether a patient will return home or when the patient will be able to return home, because so

many different factors affect a successful rehabilitation. When they consider only the functional status, there is a risk that they give little attention to patients in an unfavorable condition, while they often have enough potential to be able to go home again after rehabilitation. Therefore, rehabilitation should be a combination of specific care programs and individually tailored activities. Patients in an unfavorable condition at the time of admission stand to benefit from a higher-intensity therapy, with a build-up phase stretching for a longer period. However, the treating physician must be aware that a longer period is needed, where the patient is not being transferred prematurely to a department for long-term care, where much less an essential therapeutic climate prevails.

Patients on a rehabilitation department are often alone and undertake few therapeutic activities or are offered too few (Vermeulen et al. 2013). Therefore, opportunities exist for improving the quality and intensity of rehabilitation, for example, through a combination of individual and group therapies, using technological developments and through new ways to work smarter. The deployment of nurses as practitioner in rehabilitation is also an example. In addition, the deployment of specialized outpatient rehabilitation teams may shorten the admission time or prevent that people appropriate for rehabilitation have to be admitted to a nursing home for long-term care. This can help prevent the rising costs in health care. It is also important to make use of evidence-based guidelines, implement innovations, and develop research activities. In addition, it is preferred that professionals at all levels search for a platform (inter)nationally to present their project and research results. Exchanging knowledge and learning from each other are key.

4.10 Implementing a Therapeutic Climate

A therapeutic climate is not easily developed. Since all professionals have priorities in their field, the development and implementation of a project such as a 'therapeutic climate' is often a job 'on the side'. Therefore, it is best to appoint a project leader. The project leader is constantly focused on the development and implementation of a therapeutic climate. The project leader creates, sends, writes and consults as needed. First, the project manager writes a project plan. He develops this along with the professionals involved in rehabilitation. Some key issues when writing and developing are:

- What is the specific question/need of a target audience?
- How can this question be answered as effectively as possible?
- Which offering, method and approach are needed?
- How to leverage talents/expertise? Who would like to help?
- Why is a new approach needed? Specify the reasons!

Measurable criteria are then formulated. How do you measure whether or not a therapeutic climate after implementation is successful? If the project plan is developed, you will start with the implementation. This requires serious attention. Simply

writing a good document will not take care of the implementation. The following are some points that the project leader should take into account:

- Let authoritative persons convey the messages: the right power of expression (and that may not be directors, but rather that one colleague to whom everyone likes to listen).
- Know your early adopters!
- Allow space for questions, criticism.
- Evaluate periodically.
- Organize meetings.
- Ensure good conditions for implementation: resources (time, money, material).
- Celebrate successes!
- Evaluate, review whether the successes are due to the new method.

What you give attention, grows ... Therefore, make sure the topic of therapeutic climate is on all possible relevant agendas within the organization and talk about the subject frequently.

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Multidisciplinary Collaboration

5

E. T. M. Sarr-Jansman and C. Sier

Abstract

Multidisciplinary collaboration means working jointly and cooperatively with different disciplines within a team. It is a type of collaboration often used in primary care and between primary care and other sectors. When working with others in a multidisciplinary approach, it is possible to untangle complex problems and to establish a sustainable and affordable health care system. It allows professionals to perform a greater variety of roles and offers better health outcomes and higher satisfaction for patients.

Keywords

Multidisciplinary rehabilitation · Team

5.1 Introduction

After a stroke life changes radically, since the limitations after stroke are acute, but the recovery often takes a long time. During the entire period of recovery and rehabilitation, the stroke patient has to deal with many different healthcare providers. In order to make the rehabilitation as successful as possible, it is important that continuity and coherence is offered in care and treatment. This requires good multidisciplinary collaboration. In this chapter the principles of multidisciplinary collaboration are discussed.

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5.2 Multidisciplinary Collaboration

Multidisciplinary collaboration means working jointly and cooperatively with different disciplines within a team. It is a type of collaboration often used in primary care and between primary care and other sectors. Multidisciplinary collaboration is a way to establish a sustainable and affordable health care system. It allows professionals to perform a greater variety of roles and offers better health outcomes and higher satisfaction for patients (Clarke and Forster 2015). Taking a multidisciplinary approach and working with others can help to find interrelated factors that influence rehabilitation. When working with others in a multidisciplinary approach, it is possible to untangle complex problems.

Cooperation is a competence in which you show that you have the incentive to work with others for a common purpose, with the knowledge and skills to learn from your own and other people's qualities. Having a common goal is a basis for good cooperation. In order to determine a common goal, it is necessary to form a common vision with all concerned. Because problems of patients can be broken down into partial problems, the different disciplines depend on each other and it is necessary to cooperate well.

Modern healthcare is based on a multidisciplinary approach. Multidisciplinary teams are an essential part of the delivery of care. In the increasingly complex world of modern healthcare, it is virtually impossible to work isolated from other health care disciplines. For the best care to the patient, the different healthcare professionals must work together. The purpose of multidisciplinary cooperation is to deliver consistent, high quality care, which results in a seamless connection in all areas of health and social care, and it can reduce length of stay in hospital or rehabilitation facility (Schouten et al. 2008).

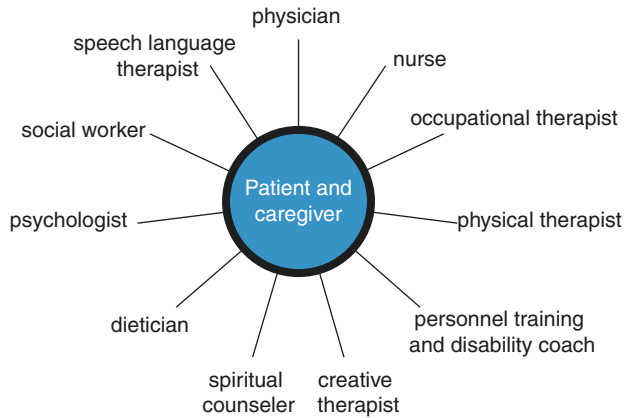
5.3 Multidisciplinary Team

Multidisciplinary teams are groups of professionals from different disciplines who work together. Various professionals can be part of a multidisciplinary team. The composition of the team depends on the patient and the individual needs. Figure 5.1 shows which disciplines a stroke patient comes into contact with during his recovery and rehabilitation.

In recent years, the emphasis has been on health care, in which the patient and the patient's needs are the starting point. One of the key components of this is the team approach. The different professionals must work together in teams in the interests of the patient.

For effective collaboration of a multidisciplinary team, good communication is of great importance. Regular multidisciplinary team discussions make it possible to discuss individual cases, care plans and goals. Multidisciplinary team discussions can take place in various forms, and aim to establish a joint plan for good care. This avoids unnecessary repetition and improves effectiveness. One of the forms in which multidisciplinary team discussions can take place is a multidisciplinary

Fig. 5.1 Multidisciplinary team



consultation (MDC). For the success of multidisciplinary cooperation in a team the following is required:

- mutual respect for each other's knowledge and ability;
- communicating well in a group;
- engaging others in a discussion;
- wording the problem in a clear manner;
- the message can be matched to the level of the disciplines involved;
- taking on an advisory and/or coordinating role;
- no competition, but cooperation;
- correct and relevant reporting;
- evaluation and adjustment;
- being willing to listen to each other
- willingness to compromise.

5.4 Rehabilitation Offered by the Multidisciplinary Team

Professionals in the multidisciplinary team need to have knowledge about health and social problems, learning how to deal with limitations, the use of medical/technical resources and pharmacology, psychosocial consequences of disorders, limitations and handicaps. In addition, skills are required for the re-learning of skills and communication skills in order to act as an intermediary between patient (system) and multidisciplinary team members. Every professional must also be able to monitor care-related and organizational processes for the progress of the rehabilitation process.

To this end, it is important that everyone in the multidisciplinary team adheres to the arrangements in the rehabilitation plan:

- What are the needs of the patient and his relatives?
- Which (ADL) tasks are being exercised? (And which are not!)

- At what level are the (ADL) tasks exercised?
- What guidance or instruction should be offered?
- Are there any requirements for the environment where the activity takes place?
- When and in what way does evaluation take place?

Cooperating with the patient and his relatives requires clear goals, strong agreements and open communication. The centralization of the patient with his care question is sometimes a challenge, but a prerequisite for successful rehabilitation. The rehabilitation that is given by the multidisciplinary team needs to be specifically tailored to the goals, possibilities and limitations of the patient. The purpose of rehabilitation is to achieve optimal recovery, self-reliance, participation and re-participation in society. It is ultimately aiming at living with the consequences of stroke and the best possible quality of life. Rehabilitation is therefore intended at improving activities that are important for the patient and that promotes patient participation in social activities. What the rehabilitation treatment looks like depends on the disorders and limitations the patient suffers from as a result of the stroke. The multidisciplinary team provides:

- Therapy on weekends and/or evenings;
- Everyday activities;
- Exercise books and personal exercise program for the patient;
- Possibility for practicing with family and friends;
- Both individual and group treatments;
- Education as part of rehabilitation;
- Solid agreements between care and therapists about the training activities and the manner of supervision;
- Full use of the patient's own goals.

5.5 Rehabilitation Relevance in Daily Functioning

Rehabilitation can be viewed as a (continuous) learning process. For practice this means that the learned task should be relevant in the patients' daily functioning.

5.5.1 Example

Mrs. Smith does the cooking and all the domestic activities, while her husband Mr. Smith looks after the garden. If Mr. Smith suffers a stroke, the training of domestic activities may not be relevant for him. However, if Mrs. Smith is the stroke patient, it is expected that the training of domestic activities is part of her rehabilitation plan.

This means that:

- *The intensity of rehabilitation must be offered in doses.*
The task must be feasible in terms of difficulty and time. Exercising non-feasible tasks causes frustration and may be burdensome. The multidisciplinary team coordinates the various activities from different professionals.

- *The treatment must have a logical structure (from easy to difficult).*
For example, when practicing mobility, it is often in a fixed order: sitting—standing—transfers—walking—walking up and down stairs.
Concerning self-care, some parts are usually practiced first, such as washing the upper body at the sink or getting (un)dressed. At a later stage, the patient practices the more complex activities, such as taking a shower or going to the toilet. The professionals in the team need to fine tune their activities very carefully to be beneficial for the patient.
- *The exercises have sufficient variation and must be repeated.*
To reach full ADL independence the patient needs an adequate amount of repetition. This also applies for walking, performing domestic activities, speaking and swallowing. The activities are planned logically in the multidisciplinary team.
- *The professional stimulates the patient and gives feedback when necessary.*
A patient may learn more from his practice and experiences if he receives clear feedback. In addition to oral feedback, a professional can use video or sound recordings and show test results.

5.6 Factors That May Influence Rehabilitation

For most stroke patients, the rehabilitation starts in the hospital. A large number of them continue the rehabilitation on a stroke unit in a skilled nursing facility or a rehabilitation center. Independent of the setting, several factors may influence rehabilitation:

- *Coherence in offering rehabilitation*
An important feature of a stroke team is multidisciplinary collaboration in healthcare. That is, the rehabilitation is coordinated through multiple disciplines that work together in one treatment team. The neurologist in the hospital usually coordinates the treatment team, a rehabilitation physician does this in the rehabilitation center and an elderly care specialist in the skilled nursing facility. In a multidisciplinary consultation, the team regularly discusses the treatment goals and their treatment strategies.
- *Time of start*
Rehabilitation is most effective when rehabilitation starts early after the onset of stroke. Currently, it is assumed that the start of rehabilitation, preferably within 24 h, but in any case within 72 h after the occurrence of stroke, can effectively influence the adverse effects of immobilization. Nevertheless, mobilization should be tailored to patient needs, as early mobilization may not always result in a favorable outcome (Avert 2015).
- *Intensity of rehabilitation*
Intensive (long-term and frequent) exercising of stroke patients increases the degree of recovery and ADL-independency.
- *Goal-orientation and task specificity*
The patient should especially practice relevant tasks. Improving certain functions, such as strength and coordination, does not automatically lead to improvements in the performance of activities. It is important that the patient performs

task-specific training; that is, focused on the specific features or subtasks of the activity.

– *The way skills are taught*

Skills must be taught in the patient's own living environment as much as possible. The environment can significantly affect the functioning of the patient. It is therefore important that patients apply what they have learned in their own environment. In many rehabilitation centers, the patient is offered a day or weekend leave to facilitate this.

– *Provision of information*

It is important that the patient and his relatives know how they can deal with the changed situation. Information about stroke, physical, cognitive and behavioral changes, communication, role changes and treatment options are necessary for a successful rehabilitation. Information is provided by all the multidisciplinary team members.

– *Adherence to guidelines*

All the professionals in the multidisciplinary team should use evidence based guidelines and protocols for treatment of patients after stroke. Every professional is responsible for implementing and using up to date evidence based guidelines despite possible identified barriers (Munce et al. 2017).

Finally, it should be noted that if a stroke patient has had ADL training and thus has improved his skill in washing and dressing, this does not mean that the performance of domestic activities has also improved. Another example is that practicing with a ball does not automatically lead to improvement of skills, as is necessary for closing buttons for example. Training with the ball can help to increase the flexibility and some skill. The translation to the task itself is not self-evident. To do so, the caregiver must include the task 'closing buttons' in the training.

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L. Kooijmans and P. Gao

Abstract

An intact central nervous system is redundant in its movement control allowing us to move in a varied and targeted manner. Individuals differ in how they sit, stand and walk. This depends on the person and on the situational demands. Besides personal factors such as age and sex, environmental demands and task specific factors will play an important role in the way we perform a movement. After stroke movements are usually less varied, less targeted and less fluent. This chapter focuses on how to support and help a patient getting into bed, changing seats or comfortably lying in bed or changing from position while in bed. Subsequently, we will discuss, bed position, and movements in sitting, standing and getting up from the ground.

Keywords

Making transfers · Bed position · Supporting movement

6.1 Introduction

An intact central nervous system is redundant in its movement control allowing us to move in a varied and targeted manner. Individuals differ in how they sit, stand and walk. This depends on the person and on the situational demands. Besides personal factors such as age and sex, environmental demands (such as walking on

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a smooth carpet or an side walk) and task specific factors (rising from a chair or getting up from a chair with a full cup of coffee in your hand), will play an important role in the way we perform a movement. After stroke movements are usually less varied, less targeted and less fluent. This chapter focuses on how to support and help a patient getting into bed, changing seats or comfortably lying in bed or changing from position while in bed. Moving from a bed to a wheelchair or from a wheel chair to a chair is called a transfer. Making a transfer is potentially dangerous as the patient may fall or traumatize for example an ankle or shoulder. In this chapter, we describe different ways in which the transfer can be adjusted to the level of functioning of the patient. We also indicate how to support and collaborate with patient in making a transfer. Subsequently, we will discuss, bed position, and movements in sitting, standing and getting up from the ground.

6.2 Preparatory Actions

6.2.1 Shoulder Monitoring

Figures 6.1 and 6.2.



Fig. 6.1 Moving the shoulder blade relative to the torso



Fig. 6.2 Moving the torso relative to the shoulder blade

6.2.2 Safety Handle Hand and Arm

Figures 6.3 and 6.4.

6.3 Transfers in Recumbency

Due to a loss in motor control the patient is less able to take a comfortable position in bed which may lead to complications such as excessive muscle tension or shoulder problems. Not only the position itself, but also the way the patient moves himself and the way the patient gets help are very important.

6.3.1 Moving Hips in Supine Position

Figures 6.5, 6.6 and 6.7.

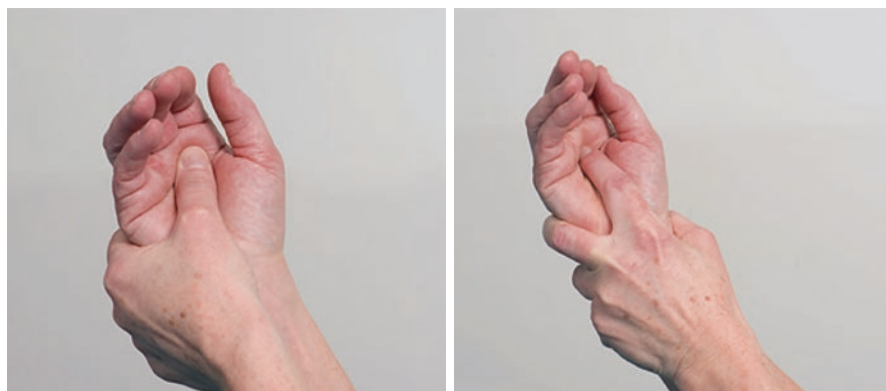


Fig. 6.3 Protective hand position



Fig. 6.4 Protective arm position

Fig. 6.5 Preparation: stimulating while flex the leg



Fig. 6.6 Hands on the pelvis



Fig. 6.7 (a) Hands-on when slipping away from the foot. (b) Hands-on to pelvis and knee

6.3.2 Moving Shoulders in Supine Position with Lifting of the Head

Figure 6.8.

6.3.3 Turning over from Supine Position to Lateral Position

Figures 6.9, 6.10 and 6.11.

Fig. 6.8 Moving shoulders in supine position with lifting of the head



Fig. 6.9 Turning over with hands on both arms



Fig. 6.10 Turning over with hemispheric arm on the side



Fig. 6.11 Turning over with safety handle arm



Fig. 6.12 (a) Moving hip into lateral position. (b) Moving shoulders into lateral position

6.3.4 Moving Hips in Lateral Position and Shoulders in Lateral Position

Figure 6.12.

6.4 Bed Position

6.4.1 Lying Down on the Affected Side

Figure 6.13.

6.4.2 Lying Down on the Healthy Side and Lying Down on the Back

Figure 6.14.

Fig. 6.13 The affected shoulder is slightly positioned forward and the arm and hand are supported by a pillow



Fig. 6.14 (a) Lying down on the healthy side, (b) lying down on the back

6.5 Transfer from Lying Down to Sitting/Sitting to Lying Down

The stroke patient will try to sit up independently, sometimes using the possibilities available (for example, the bed rails). This is certainly not always the best method. The images show how the transfer to seated or supine position can be supported adequately.

6.5.1 Transfer from Lying Down to Seated Position

Figures [6.15](#), [6.16](#), [6.17](#) and [6.18](#).

Fig. 6.15 The patient helps with all the transfers shown with the healthy arm. The patient is encouraged to use the affected arm



Fig. 6.16 Hands-on legs and torso



Fig. 6.17 Hands-on pelvis and torso

6.5.2 Transfer from Seated Position to Lying Down

Figure 6.19.



Fig. 6.18 Hands-on pelvis and shoulder healthy side; patient places leg out of bed on his own



Fig. 6.19 Transfer from sitting position to lying down. Take care of sufficient weight displacement to the affected side and ensure that the affected shoulder turns forward

6.6 Sitting

We cannot sit in a fixed position for prolonged period of time. However, the stroke patient is often unable to maintain balance or change posture. Keeping an adequate posture during an activity is often difficult. These images show a passive and active sitting posture subsequently and show the hand position when moving into a seating position.

6.6.1 Seating Positions

Figure 6.20.

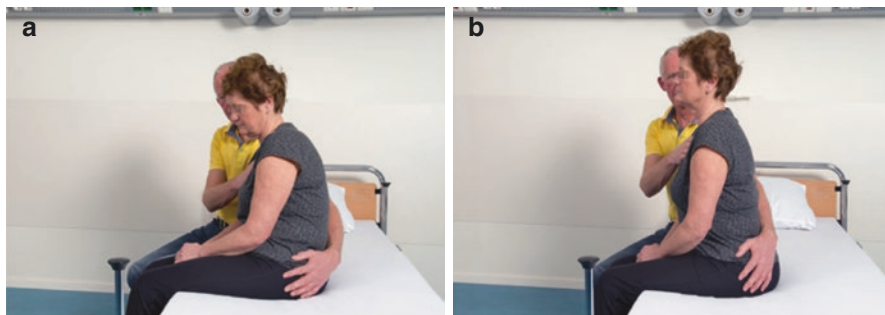


Fig. 6.20 (a) Passive sitting position. (b) Active sitting position



Fig. 6.21 Hand position when moving buttocks

6.6.2 Moving the Buttocks into Sitting Position

Figure 6.21.

6.7 Transfer from Bed to Chair

The transfer from bed to chair or into a chair requires insight into motion and a lot of practice.

6.7.1 Moving from Bed to Chair with Reduced Torso Function

Figure 6.22.



Fig. 6.22 Hand position with a lot of support at the torso



Fig. 6.23 Hand position with steering of the torso

6.7.2 Moving from Bed to Chair with Reasonable Torso Function

Figure 6.23.

6.7.3 Moving from Bed to Chair with Good Torso Function: Three Variants

Figures 6.24, 6.25 and 6.26.

6.8 Correction Sitting Position in the (Wheel) Chair

Sitting in and moving around with a wheelchair may be challenging for a stroke patient. Figures 6.27, 6.28, 6.29 and 6.30 show the correcting of the sitting position.



Fig. 6.24 Moving with hand positioned on pelvis and knee



Fig. 6.25 Independent movement from bed to chair with support at bed under supervision



Fig. 6.26 Moving by standing up and making steps to chair. Hand positioned on pelvis and knee affected side



Fig. 6.27 (a) Starting position. (b) Placing the foot under the knee



Fig. 6.28 (a) Moving forward with the torso. (b) Hand position on the torso

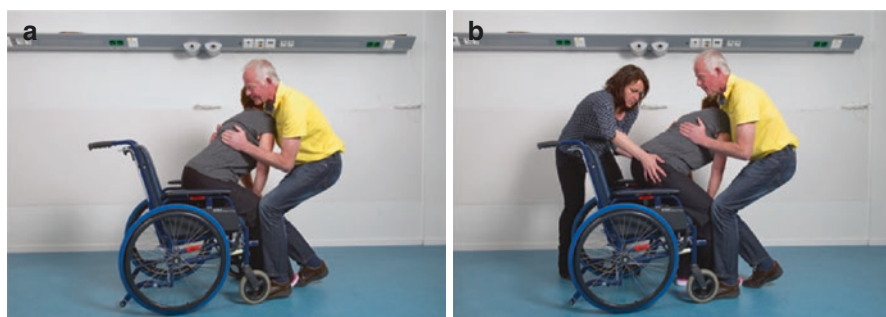


Fig. 6.29 (a) Lifting and moving the buttocks back. (b) The steps can also be carried out with two persons and, if possible, the patient helps

Fig. 6.30 Hand position on pelvis and knee. Patient assists by using healthy arm



6.9 Getting Up from the Floor

Figures 6.31, 6.32, 6.33, 6.34 and 6.35 show the sequence when rising from the floor.

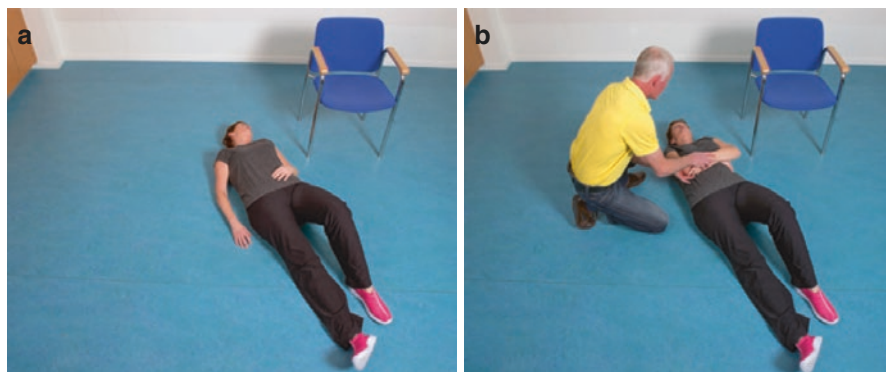


Fig. 6.31 (a) Starting position. (b) Arm in safety hold



Fig. 6.32 (a) Moving into sitting position. (b) Side-sitting, with patient resting on the healthy arm



Fig. 6.33 (a) Moving into crawling position. (b) Patient gets up on knees

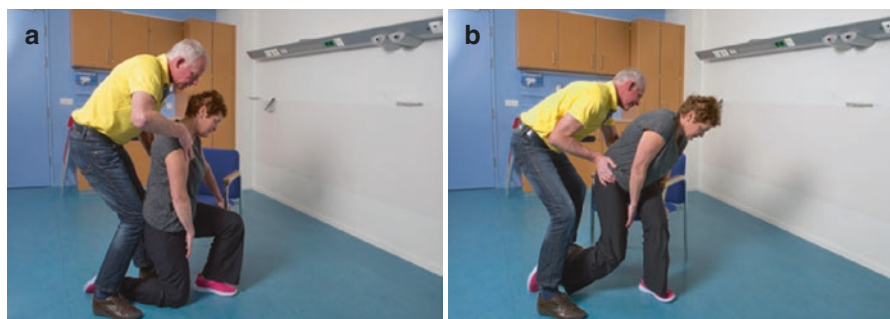


Fig. 6.34 (a) Patient places healthy leg forward and is supported by the affected side. (b) Patient lifts up the buttocks and is supported by a turn towards the chair

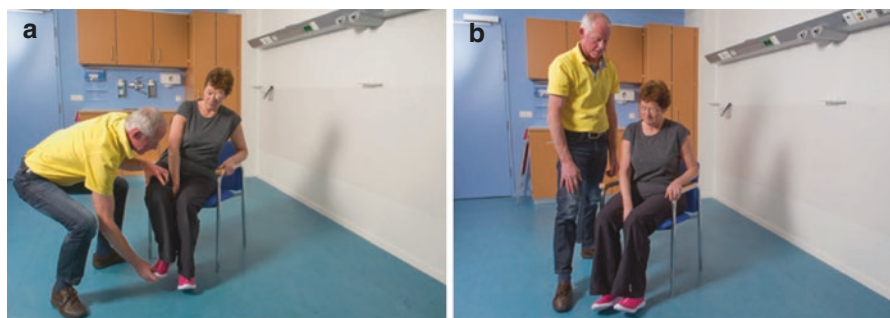


Fig. 6.35 (a) The position of the foot is corrected. (b) Final position

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Swallowing Disorders

7

J. E. Bernouw-van Tol and S. M. Wielaert

Abstract

Eating and drinking are among the first human needs of life. Swallowing and eating disorders can cause nutritional problems or pneumonia. Eating and drinking also play a large role in social life. Sitting down for a meal or having a cup of coffee or tea are important moments in our daily life when we relax and socialize, increasing our quality of life. This chapter is dedicated to swallowing disorders caused by stroke. First the normal swallowing process is explained after which characteristics of swallowing disorders are discussed and the role of nurses and speech and language therapists in the management of swallowing disorders.

Keywords

Swallowing · Causes · Treatment · In case of emergency

7.1 Introduction

Eating and drinking are among the first human needs of life. In order to stay healthy, it is necessary to eat and drink enough daily. When someone is no longer capable of this, their health is at risk. Swallowing and eating disorders can cause nutritional problems when someone does not get enough nutrition, and becomes malnourished and/or dehydrated. Other causes of nutritional problems are bad appetite, anxiety, stomach and intestinal problems, a serious illness, and fatigue.

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Eating and drinking also play a large role in social life. Sitting down for a meal or having a cup of coffee or tea are important moments in our daily life when we relax and socialize, increasing our quality of life.

This chapter is dedicated to swallowing disorders caused by stroke. First the normal swallowing process is explained after which characteristics of swallowing disorders are discussed and the role of nurses and speech and language therapists in the management of swallowing disorders.

7.2 The Swallowing Process

In swallowing disorders, also called ‘dysphagia’, there are problems in transporting liquids or solid food from the mouth to the stomach (Rosenbek 2009). The normal reflex to choking, when food is going down the wrong way into the trachea instead of the esophagus, is through coughing. This way the food is forced back up again. When someone can no longer cough or can only cough very weakly, food can end up in the lungs. This may lead to aspiration pneumonia, which in some cases may be life threatening.

To understand swallowing disorders, it is important to be aware of the normal swallowing process, in which we distinguish four phases: the preparatory oral phase; the oral transport phase; the pharyngeal phase; the esophageal phase (see also Fig. 7.1).

7.2.1 Preparatory Oral Phase

During the preparatory oral phase (Fig. 7.1a) a sip or a bite is taken, which is then chewed if necessary and saliva mixes with the food. In this way, the food is turned into a bolus that is safe to swallow. After chewing the food, the bolus is collected on the tongue and the actual swallowing movement can be executed.

7.2.2 Oral Transport Phase

When the food is collected at the center of the tongue, the swallowing action is initiated (Fig. 7.1c). The tongue makes a wavy motion, bringing the food towards the throat cavity.

7.2.3 Pharyngeal Phase

During the pharyngeal phase (Fig. 7.1b), the nasal cavity is closed by the soft palate, making sure no food gets out through the nose. The trachea is closed by the epiglottis, preventing food from getting into the trachea. As a result, breathing is not possible during swallowing. By contracting the muscles in the throat cavity, the food is transported into the esophagus.

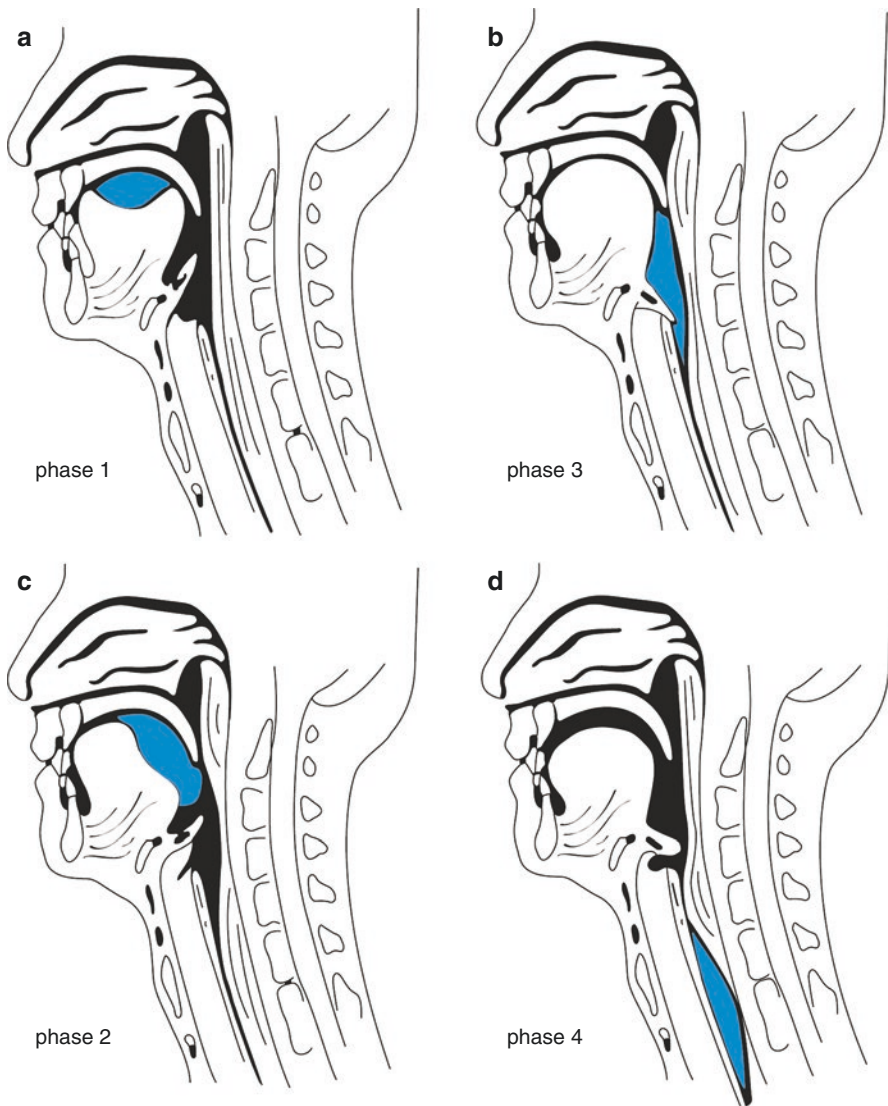


Fig. 7.1 (a) Preparatory oral phase; (c) (phase 2) oral transport phase; (b) (Phase 3) pharyngeal phase; (d) (phase 4) esophageal phase

7.2.4 Esophageal Phase

The food has entered the esophagus and is brought into the stomach by contracting movements of the esophagus. The muscles in the throat area relax again, the trachea and nasal cavity are opened and it is possible to breathe again.

7.3 How Are Swallowing Problems Caused?

There are many different reasons why someone has trouble swallowing. Swallowing disorders may arise due to age, neurological conditions and drug use.

7.3.1 Age

With aging, changes occur in swallowing. Strength reduction in the chewing muscles causes chewing of hard food to become slower and harder. Problems with teeth and dentures can also make chewing more difficult. As a consequence, someone is more likely to chew less and swallow larger pieces.

Swallowing solid food is often also more difficult due to reduced mobility of the esophageal muscles. Moreover, older people choke more easily on thin drinks like tea and coffee. Thin beverages require quick swallowing. In the elderly, the swallowing is often delayed which makes it easier for fluid to get into the trachea.

7.3.2 Neurological Disorders

Neurological disorders, such as a stroke or Parkinson's disease, can lead to coordination problems in the swallowing motion. This means that a disorder occurs in the interaction of the muscle groups involved in swallowing. Reduced sensibility (sense) in the oral cavity may lead to reduced control of the bolus and consequently can cause choking.

7.3.3 Drugs

Drugs can also cause swallowing disorders mainly due to side effects. For example, certain drugs may cause muscle and coordination disorders, and some drugs affect the amount of saliva in the mouth. Both side effects make swallowing more difficult.

7.4 Recognizing Swallowing Disorders

Patients at risk for swallowing disorders are screened by a nurse or speech and language therapist, using a swallowing screening, for which usually a protocol is used.

Swallowing problems are often recognized by a doctor or speech therapist. Nurses also play an important role in detecting swallowing problems, by observing the patient during meals or having a drink. Other therapists, the patient himself or family may also notice that there are problems with eating and drinking. It is important to detect swallowing problems at an early stage.

The following characteristics may be signs of a swallowing disorder:

- Coughing just before, during or after swallowing; coughing sometime after the meal can also indicate a swallowing disorder;
- chronic cough;
- hoarseness after eating or drinking;
- difficulty to start swallowing;
- delayed swallowing motion;
- loss of saliva, food or fluid from the mouth (mouth is not fully closing);
- chewing excessively long;
- reduced sensitivity in the mouth;
- food accumulates in the cheeks;
- the sensation that food stays in the throat;
- pain or irritation when swallowing;
- swallowing several times to pass one bolus;
- red face and/or teary eyes during or after eating;
- difficulty breathing/audible breathing during or after eating or drinking (chest tightness);
- head/neck movements (e.g. bending the neck) during swallowing;
- reduced eating speed;
- avoidance of eating/drinking;
- weight loss;
- temperature increase or fever;
- dehydration;
- stomach acid (heartburn).

Swallowing disorders may have several consequences:

- aspiration pneumonia (pneumonia due to choking);
- insufficient food intake;
- suffocation;
- dehydration (lack of fluids);
- malnutrition;
- constipation (obstruction in the intestines);
- poor functional health condition;
- longer or permanent (hospital) admission;
- in a very small group of patients there is an increased risk of death.

7.5 Responsibilities of the Nurse

Nurses have an important task in recognizing swallowing problems, in management of swallowing disorders and in oral hygiene (Tanner and Culbertson 2014).

Nurses may be the first to recognize swallowing disorders as they are often present when patients eat and drink. They can signal and report swallowing problems to a doctor or speech and language therapist.

When measures are taken to treat a swallowing disorder, nurses assure that the patient takes in sufficient water and food. They must also be aware of instructions provided by the speech and language therapist for example in posture adjustment, manner of swallowing and adjustments in food or drink. Collaboration with a dietician is advised as well to control the nutritional value of the adjusted food intake.

Oral hygiene is another important issue, in order to prevent changes in the oral mucosa and tooth decay in the oral cavity. These may cause pain or infections which in turn make it difficult to chew and swallow. Nurses can assist the patient or can see to it that the patient rinses his mouth and brushes his teeth.

7.5.1 Dealing with Choking

When a patient is at risk of choking, it is important that nurses know what to do.

There are a number of ways to deal with choking:

- *Remove piece of food by hand*
Press the fingers on the underside of the chin to open the mouth as wide as possible. Remove any denture from the mouth. Now try to feel the piece of food in the throat with the middle finger and remove it from the throat with your finger.
- *Hit between the shoulders*
Let the patient lean forward while sitting or standing, so that the head is lower than the shoulders. Use the flat hand to hit between the shoulder blades a few times until the piece of food dislodges. However, the use of this action is questionable, because hitting can also be accompanied by a shock reaction during inhalation, which can cause the food to get stuck even deeper. When choking on beverages, this action is of no use.
- *Heimlich maneuver*
The Heimlich maneuver (Fig. 7.2) is often very effective when choking. The caretaker stands behind the patient, who is either standing or sitting. Put your arms around the patient's waist and make a fist with one hand. Grab the fist with your other hand, put it right above the belly button in the middle of the abdomen. Make a strong upward motion with both hands. If necessary, repeat this action until the piece of food is released.

Important when choking:

Stay calm	Keep calm in all cases. When the nurse panics, the situation becomes even more dangerous for the patient.
Notify a doctor	In case of severe choking, call for help and let someone else warn a doctor. Make sure you stay with the patient.

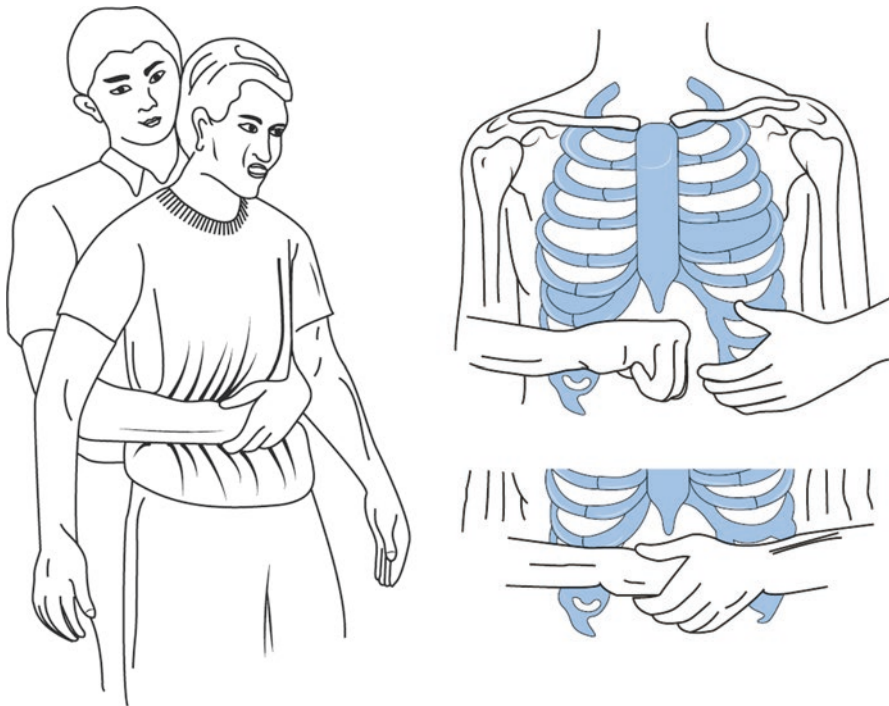


Fig. 7.2 Heimlich maneuver

7.6 Management of Swallowing Disorders in Stroke Patients

The speech and language therapist has several possibilities to treat and coach a patient with swallowing problems. Treatment can be focused on:

- training of the swallowing movements, strengthening of the muscles.
- resources and compensation (e.g. Heidi cup, collar cup);
- adjustment food and drinks (mashing food, thickening drinks);
- adjustments in eating methods (smaller bites, longer breaks, getting used to not doing two things at once, such as talking and eating, or reading and drinking).

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Communication Disorders

8

J. E. Bernouw-van Tol and S. M. Wielaert

Abstract

Communication disorders are among the invisible consequences of stroke but may have a huge impact on the social life of patients, when they are no longer able to share their thoughts, ideas and needs with the people surrounding them. Also, family members themselves suffer from these communication disorders, when it has become difficult to communicate with their loved one. In general, three types of communication disorders after stroke are distinguished: aphasia, cognitive communication disorder and dysarthria (Borrie et al., 2012). In this chapter, the disorders are described by their impact on the patients themselves and on their conversation partners. In the last paragraph conditions for good communication in a nursing environment are discussed.

Keywords

Communication · Aphasia · Communication partner

8.1 Introduction

Communication disorders are among the invisible consequences of stroke, just as other cognitive disorders such as memory loss and attention disorders. Despite their invisibility, communication disorders can have a huge impact on the social life of patients, when they are no longer able to share their thoughts, ideas and needs with

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the people surrounding them. Also, family members themselves suffer from these communication disorders, when it has become difficult to communicate with their loved one. In general, three types of communication disorders after stroke are distinguished: aphasia, cognitive communication disorder and dysarthria (Borrie et al. 2012). In this chapter, the disorders are described by their impact on the patients themselves and on their conversation partners. In the last paragraph conditions for good communication in a nursing environment are discussed. We start this chapter with a description of the normal communication process.

8.2 Communication Process

8.2.1 What Is Communication?

Communication is an important part of being human. Through communication we share our thoughts, ideas and needs with other people. The information we exchange may be brief and factual, like ordering bread at the bakery store or making an appointment with a friend. The information may also be more complex and abstract, like a discussion at work or talking about your feelings about a recent event in your life. The communication process is shown in Fig. 8.1.

In communication, one person (the ‘sender’) conveys a message to another person (the ‘recipient’). The other is then expected to respond to that message. To convey a message, we use language. Through written and spoken language we can convey ideas, feelings and thoughts so that someone else can understand them. Besides the choice of words and sentences, the way in which we use our voice is also part of verbal communication. In our voice, we can convey emotions through prosody and intonation, such as anger, joy or sadness.

Language is not our only means of communication. Using gestures, eye contact, posture or facial expressions (non-verbal communication), people can also communicate and support their linguistic messages. In a conversation, we need to take our conversation partner into account. For example, what does your conversation partner know about the topic you are talking about and what is your relationship with this person? Talking to another adult is different from talking to a child. And talking to someone you know, such as a family member or a good friend, is different from talking to someone you don’t really know, such as a sales person or a doctor in hospital.

These examples show that many aspects play a role in our daily conversations, such as shared knowledge about a topic and the situation (context) in which a conversation takes place. A conversation between husband and wife about a holiday trip in the past, relies on their shared knowledge about that trip and their shared emotions of the adventures they experienced. Whereas in a first job interview, the topic is set by the job description and the context is set by the roles each person has in that conversation and the environment in which the interview takes place.

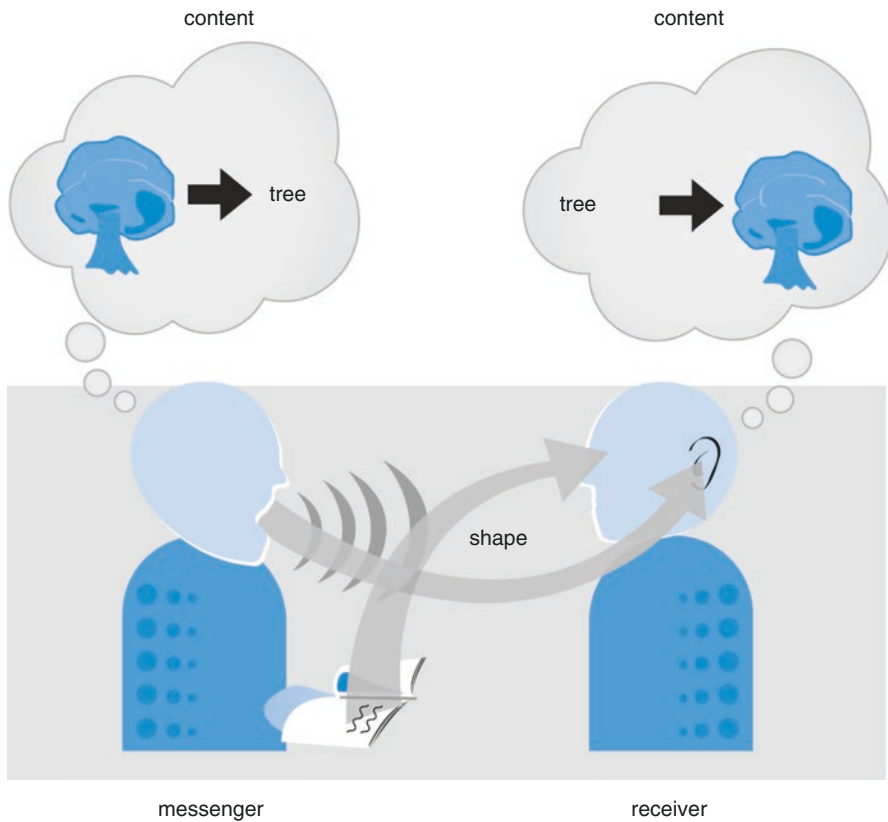


Fig. 8.1 Communication process

8.2.2 Conversation Rules

People use conversation rules automatically when talking with each other. These rules have been learned from early childhood, alongside acquiring vocabulary and grammatical rules. The following are some very important rules:

- *Eye contact*: Having eye contact is important when having a conversation.
- *Considering the other party*: for a smooth transfer of information it is important to be aware of the background and situation of the conversation partner. What do they know (or not know) about the topic you are talking about?
- *Turn taking*: two or more people who are having a conversation take turns at talking. They seldom overlap in their turns and there are no long pauses between turns, emphasis is on *conversational flow*.

8.3 Communication Disorders After a Stroke

Communication appears to be an automatic and unconscious process. After a stroke, communicating is no longer an automatic process. The three types of communication disorders are discussed in this section; aphasia, cognitive communication disorders and dysarthria.

8.3.1 Aphasia

Aphasia is an acquired language disorder which masks the inherent competence of the person with aphasia and has dramatic consequences for conversational interactions (speaking and understanding) as well as for the ability to read and write. A stroke is the most common cause of aphasia, approximately 30% of all stroke survivors have aphasia. Also brain trauma, tumors and brain infections can cause aphasia. In most people, the areas related to language in the brain are in the left side of the brain (left hemisphere). An aphasia is often accompanied by a right-side hemiparesis.

The extent to which a patient will recover cannot be determined with certainty. This depends on multiple factors. In addition to the size and location of the brain damage, the patient's personal and environmental background are determining factors. In the first few weeks up to 3 months spontaneous recovery occurs. After this, further recovery is still possible, but will slow down. Language therapy by a speech and language therapist (SLT) has been proven effective, both in the acute phase as well as in the chronic phase.

Aphasia can be recognized by several frequently occurring symptoms:

1. Word finding difficulties; these are central to any type of aphasia and can be very mild, shown by a brief hesitation before saying a word, to very severe shown by long silences in which a word is searched.
2. Paraphasias; words are used incorrectly, either by meaning (semantic paraphasia) or form (phonemic paraphasia). In semantic paraphasias the word used is often related in meaning to the word a person means to say, for example *chair* instead of *table* or *sister* instead of *mother*. This can lead to misunderstandings in a conversation. In phonemic paraphasias the sounds in the word are incorrect. Sometimes the word is still recognizable, for example *fitticuly* instead of *difficulty*. It may also be unrecognizable, for example *barrella* instead of *umbrella*. Phonemic paraphasias create less misunderstandings in conversation, because they are recognized by the conversation partner as incorrect.
3. Grammatical problems; building sentences is often a problem for people with aphasia. One reason for this is that they cannot find the right words; they do not finish their sentence or start making a new sentence midway the first sentence. This sometimes makes it hard to understand what they are talking about. Another reason is because grammar in itself is a difficult linguistic process, especially the use of verbs may be impaired.
4. Comprehension problems; the problems in understanding language often mirror the difficulties in speaking. The more a person with aphasia can still express him

or herself, the more they also understand of what others are saying. Someone with severe aphasia, who cannot express him or herself at all, often also has difficulties in understanding what is said to them. In general comprehension is relatively intact for topics and situations close to the person with aphasia in the ‘here and now.’ Most people with aphasia experience comprehension problems in noisy environments, with more people present, such as dinner parties or social clubs.

The symptoms described above can occur in spoken language but also in written language, resulting in reading and writing problems. Therefore it is usually not helpful to ask the person with aphasia to write something when they cannot speak, because the word is not available to them at all. Because these symptoms are so complex and can vary according to the size and site of the brain lesion a language test by an SLT is necessary to determine someone’s individual linguistic problems and abilities. Based on the various symptoms four different types of aphasia are distinguished, they are shown in Table 8.1. The symptoms described for each type

Table 8.1 Four different types of aphasia with their main symptoms and examples

Aphasia type	Symptoms	Examples
Anomia	<ul style="list-style-type: none"> – Predominantly word-finding difficulties – Comprehension mostly intact – Able to communicate independently 	“I’ll tell you about then ehh and where was it again? We were in Zeeland, which I always find so wonderful to be there in ehh Zee eh Zeeland. We go there every year”.
Broca’s aphasia	<ul style="list-style-type: none"> – Severe word finding difficulties – Grammatical problems (telegraphic speech with long pauses) – Semantic paraphasias – Comprehension fairly intact – Able to communicate with some help of a conversation partner and by using gestures themselves 	“Eh, I groceries, I did ehh ... Yesterday, groceries, and ehh, then when there, ehh then ... groceries and I ehh, fe ... ehh ... I was not feeling well.”
Wernicke’s aphasia	<ul style="list-style-type: none"> – Word finding difficulties obscured by using many phonemic and semantic paraphasias – Grammatical problems (long, complex sentences, but grammatically incorrect) – Comprehension problems – May be able to communicate independently with familiar people; otherwise dependent of conversation partner 	“... now and then west has been so super and they said just wet like of ropes. That’s something eh wom those walls that’s something. Well, that’s what they won’t and stuff.”
Global aphasia	<ul style="list-style-type: none"> – Not able to speak, sometimes a few words, some meaningful, some ‘empty speech’ – Comprehension problems – Not able to communicate independently; fully dependent of conversation partner 	‘that was ... that too, was, ... was, that too’

are the most frequently occurring, but other symptoms also may occur. Sometimes it is hard to label a person with aphasia within any of these four types.

Although all four types of aphasia exist in differing degrees of severity, in general global aphasia is considered the most severe as all language modalities are impaired. Anomia is considered the mildest type of aphasia, because persons with anomia only have word finding difficulties and their comprehension is relatively intact.

8.3.2 Communication Advice in Case of Aphasia

Try not to avoid having a conversation with someone who has aphasia, however challenging it may be. About 70% of the people with aphasia report that people in their environment avoid them. This causes social isolation and missing out on changes to practice communication in the real world. Discuss with the SLT how to best communicate with the person with aphasia. He/she can give you advice that suits the person's communication level. Moreover, the SLT can practice some of the communication strategies listed in Table 8.2, as they are not always easy to use in your daily routine. Research shows that people with aphasia communicate better with staff and family members who are trained to support their own communication (Kagan, 1998).

Table 8.2 Communication advice in case of aphasia

Form of advice	Advices
<i>General advice</i>	<ul style="list-style-type: none"> – Make sure you are in a quiet environment. Keep pen and paper at hand – Take enough time for a conversation – Make eye contact – Take fatigue into account
<i>When the person with aphasia does not understand you</i>	<ul style="list-style-type: none"> – Speak in simple sentences, but do not sound childish or condescending – Make clear what you are talking about, by stating the topic, e.g. '<i>Here is today's menu; I would like to discuss with you, what you would like to eat</i>'. – Use supportive gestures and movements while speaking – Write down keywords – Emphasize important words – Make drawings to clarify the conversation – Repeat what you want to say in other words
<i>When the person with aphasia is not able to express him/herself</i>	<ul style="list-style-type: none"> – Stimulate pointing in the environment – Stimulate gestures/movements – Encourage making a drawing – Repeat what you understood about what the person has indicated – Ask questions that can be answered with yes/no and ask one thing at a time; e.g. <i>Did you sleep well?</i> [wait for answer] <i>Did your shoulder hurt you?</i> Instead of: <i>Did you sleep well or did your shoulder hurt you?</i> – Accompany your questions with some possible options that the person with aphasia can choose from, e.g. sleep well—not well? Shoulder pain—worries—headache?

8.4 Cognitive Communication Disorder

When someone is affected in the right hemisphere, communication disorders may occur. As language usually resides in the left hemisphere, the communication disorders caused by right hemisphere lesions are linked to deficits in other cognitive domains and emotional changes. Therefore, these communication disorders are referred to as cognitive communication disorder.

8.4.1 Functions of the Right Hemisphere

In order to recognize a cognitive communication disorder it is necessary to be aware of some right hemisphere functions that can affect communication. These are:

1. Understanding emotional content of what is said;
2. Using and understanding intonation, and prosody
3. Understanding facial expressions and gestures that are important in non-verbal communication;
4. Structuring information;
5. Understanding and gauging social behavior.

8.4.2 Consequences of Stroke in Right Hemisphere with Regard to Communication

A cognitive communication disorder may not be detected immediately. This is because it is not so much about the actual linguistic information that is impaired as in aphasia. Cognitive communication disorders are more subtle and have to do with using language in a meta-linguistic, abstract way. For example, 'reading' or understanding a situation, structuring information (making connections, drawing conclusions), understanding humor, and using and understanding intonation. Just after a stroke in the right hemisphere has occurred, family members are often relieved to find that the person can still communicate through language. The subtle cognitive communication problems often show in a later phase, when people are living at home again and family members notice he or she is not the same anymore.

The following examples are illustrations of some frequently occurring cognitive communication disorders and highlight the impact they have on the life of the persons themselves and their environment.

1. Interpreting information literally, not understanding the 'figure of speech'

Taking information literally and not understanding humor or cynicism are all examples of not being able to fathom the emotional content of language. A doctor

may ask during examination: “What issues are you running into?”, the person with cognitive communication disorder may answer: “the door”.

The patient does not understand that the doctor is asking about problems in the broader sense.

- Or when someone says “That’s going well,” after three failed attempts to call someone. The person with cognitive communication disorder does not understand that the message was meant cynically.

2. **Trouble using and/or understanding intonation and prosody**

The sentence “You’re going home now?” (With rising intonation) is clearly meant as a question. The same sentence spoken in a determined voice “You’re going home *nów*!” is meant as an order. Without recognizing prosody and intonation, persons with cognitive communication disorder may have trouble grasping the true meaning of the sentence as a question or an order. When the person with cognitive communication disorder speaks in a monotonous way, without prosody and intonation, they may come across as indifferent or uninterested.

3. **Difficulty identifying non-verbal communication**

Someone with cognitive communication disorder may have difficulty interpreting non-verbal signals from a conversation partner, like checking the time and yawning, as a signal that it is “time to stop”, and they may simply continue with their story.

4. **Difficulty in structuring information**

Persons with cognitive communication disorder often have difficulty identifying the main storyline. When telling a story they may talk about various details without making clear what the story is really about. The same difficulties may arise when reading the newspaper; they are not able to understand the main storyline, but do remember details which they cannot connect.

5. **Not considering the position and feelings of a conversation partner**

Being inconsiderate of the other may manifest itself on different levels, for example towards prior knowledge of the other, current mood of the other and relationship with the other.

- *Prior knowledge of the conversation partner.* For example, the patient tells an extensive story about someone called Marie, while the conversation partner does not know who Marie is.
- *Mood of the conversation partner.* For example, the patient makes jokes while the conversation partner has just received unpleasant news. The patient is not sensitive to the mood of the conversation partner.
- *Relationship with the conversation partner.* The patient speaks to a stranger in a very amicable way, which is not appropriate in that situation.

The interaction with patients with cognitive communication disorders often leads to misunderstandings or irritation or sometimes even hilarity. In order to ensure that the communication with a person with cognitive communication disorder is optimal, some rules can be applied. This communication advice is shown in Table 8.3.

Table 8.3 Communication advice in case of cognitive communication disorder

• Ensure eye contact
• Concentrate on the topic at hand, this way you cannot be led astray by wrong interpretations
• Use concrete language, be clear; do not leave room for multiple interpretations
• Ensure that the patient is given the opportunity to develop solutions independently; this prevents frustration. Then it is possible to compare the patient's solution and that of the nurse/therapist
• Provide encouragement through honesty/empathy
• Provide feedback, by thinking aloud during an activity or by evaluating the activity
• Give the patient the sense of control by building activities step by step and/or structuring the activity
• Always check if the patient still understands you
• Interrupt the patient in a friendly manner in case he continues to talk
• Briefly summarize what the patient has said, so that there is an optimal coordination
• Support the conversation, if possible, by making notes of agreements of matters discussed

8.5 Dysarthria

Dysarthria is a motor speech disorder (Borrie et al., 2012). As in hemiparesis of arms and legs, the muscles themselves are intact, but the control from the brain is disrupted. Muscles that control breathing, voice, lower jaw, soft palate, tongue and lips can be affected and cause dysarthria. In case of dysarthria, language is still intact; a person with dysarthria still can find words and build sentences, but pronouncing them is impaired. Also language comprehension is intact, as are reading and writing. The latter may be difficult due to hemiparesis of the dominant hand.

8.5.1 Causes and Characteristics of Dysarthria

Dysarthria is often caused by neurological diseases of which Parkinson's disease is most well-known. Other causes are stroke and traumatic brain injury and neurological diseases like Motor Neuron Disease and Multiple Sclerosis. In case of neurological diseases, the symptoms of dysarthria may worsen over time, until speech becomes totally impossible, which is especially the case in Parkinson's disease and in Motor Neuron Disease. In the later stages of Parkinson's disease, other cognitive deficits will manifest itself, resulting in dementia, whilst in Motor Neuron Disease cognitive capacities remain intact. In general two types of dysarthria can be distinguished, characterized by the sound of speech production (van der Worp, 2012):

- In hypokinetic dysarthria, speech is flaccid. The voice sounds weak and speech sounds are not well pronounced. Often air escapes through the nose (nasality), making speech unintelligible.

- In hyperkinetic dysarthria, speech sounds strained and strangled. The voice can be harsh and sometimes loud. Speech sounds are pronounced with a lot of effort, making speech unintelligible.

A speech examination by an SLT is necessary to describe the individual speech profile of a person with dysarthria. Dysarthria is often accompanied by swallowing disorders, as the oral musculature is affected. Swallowing disorders are discussed in Chap. 7.

8.5.2 Communicating with a Person with Dysarthria

Because language is still intact, a conversation partner does need to take comprehension problems into account when talking with a person with dysarthria. Unless that person also has cognitive deficits (including language deficits), which may be the case in stroke or trauma. When language is intact, the person with aphasia may be capable of writing or typing his/her messages, when speech is unintelligible. In Table 8.4 the most important rules for communicating with someone with dysarthria are described.

When unsure about the communication with a person with dysarthria, contact the SLT who will be able to give you individual advice and assist in communication when necessary.

Table 8.4 Communication advice in case of dysarthria

– Ensure a quiet environment without noise and distractions
– Ensure eye contact
– Talk in a normal tone, avoid sounding childish or condescending
– Ask only one question at a time
– Make time to have a conversation; when there is no time, ask the patient whether it is urgent or if it can wait until a little later
– When you have misunderstood some words, ask the person to repeat it, possibly with another word. You can also repeat a sentence up to the word you did not understand, this way the person only needs to complete your sentence instead of starting again; e.g. patient says: ‘Will you get me my xxxxx’, repeat, ‘Sorry, you want me to get you your ...’
– When an assistive device is used, like the “light writer”, make sure you have enough time to listen and respond to the patient

Conclusion

In this chapter the most common communication problems caused by stroke are described; aphasia, cognitive communication disorders and dysarthria. There are of course other causes that can affect communication, such as hearing impairment and dementia. Communication problems not only affect the person with the disorder, they also affect their conversation partners, including staff and family members. When communication problems are mild, people will respond well to speech and language therapy and may become independent communicators. When communication problems are more severe, people may remain dependent of their conversation partner in certain situations. The SLT is there to help, he/she can provide communication advice geared to the individual and may assist other professionals in adapting their communication behavior. This way patients with communication disorders will get the information they have a right to and will be included in conversations.

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Activities in Daily Life (ADL)

9

E. Franssen, E. T. M. Sarr-Jansman, and D. J. Rowberry

Abstract

Our everyday activities are ideal for patients post stroke to practice their motor and cognitive skills as these are activities that are repeated often throughout the day. ADL actions are not universal. The way in which someone performs his daily activities is determined by, amongst other things, habits and preferences, culture and environmental factors. The rehabilitation must have a logical structure, with the easy tasks being taught first before training for more difficult tasks. Repetition is key. In (re)learning of ADL activities, different phases can be distinguished: (1) the learning phase, (2) the automation phase, (3) the generalisation phase. Especially in the first period after stroke, many patients will need help from the nurse when washing, showering, shaving and dressing themselves. Dependence in this area makes many patients feel uncomfortable and the ability to for example wash themselves independently, is therefore an important goal for many stroke patients. Nurses should be matching the help and guidance to the level of functioning of the patient, since failure, frustration or insufficient stimulus can demotivate the patient.

Keywords

Stroke · ADL · Rehabilitation · Nurse · Washing · Dressing

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9.1 Introduction

This chapter will discuss the Activities of Daily Living for patients suffering a stroke, especially the self-care activities. Patients experiencing a stroke can suffer limitations in such activities, particularly when attending to personal hygiene needs. For these important reasons, ADL's are a big part of rehabilitation. (Re)learning activities during rehabilitation is a key focus. In addition, the considerations for the ADL training are devised. The chapter will conclude with the Barthel Index, a widely used assessment tool relating to ADL's (Mahoney and Barthel 1965).

9.2 ADL Training with the Stroke Patient

When a stroke occurs, an area of the brain becomes damaged. The location of the damage is particularly important as it is this that determines any deficits the patient may experience. Post-stroke symptoms will be very individual to the patient but they may experience such things as; limb weakness or paralysis; facial paralysis; loss of motor skills. In addition, there are less visible symptoms that may occur such as; concentration, perception or attention deficits; the ability to plan and organise tasks can be affected as well as suffering short or long term, ongoing memory problems. Because of these, many patients can experience limits to their daily activities following a stroke (Bertolin et al. 2017).

Our everyday activities are ideal for patients post stroke to practice their motor and cognitive skills as these are activities that are repeated often throughout the day (Bertolin et al. 2017). These activities can encourage the patient to see both their affected and non-affected limbs. Performing such activities means that the patient must also engage neuropsychological skills in the planning of the task; the order of the task and the execution of it. In most cases, the skills are functional and have a purpose. It often involves obvious activities that we already do throughout our lives. As a result, we automatically execute them and it's easier to relearn these activities. ADL actions are not universal. The way in which someone performs his daily activities is determined by, amongst other things, habits and preferences, culture and environmental factors (van Peppen and Beurskens 2010).

Because of their presence 24/7, nurses play an important role in rehabilitation. It is vital that the nurses working in rehabilitation utilise the 24 h period well for the patient. Rehabilitation continues all the time and does not happen only at the therapist's office, but in many locations and with many members of the Multi-Disciplinary Team (MDT). In addition, rehabilitation involves planning work, monitoring changes and progress. It is important that the nurse has good observational and assessment skills, good reporting skills and has knowledge if when to escalate issues.

Rehabilitation is aimed at increasing patient independence and autonomy. This can be done by working on recovery, learning or relearning activities and dealing with restrictions or limitations. Often, the main rehabilitation goal is returning home. To be able to go home, patients must learn a lot of skills and activities, incorporated in the ADL's, thus performing them independently (Langhammer et al. 2017). In line with patient centred care, returning home is vitally important to the

patient. However, barriers may stand in the way of this and can cause anxiety to the patient.

9.3 Rehabilitation Is Effective Learning

Rehabilitation can be considered as a (continuous) learning process, which speeds up the recovery of functionality and maximises it where possible. This means that rehabilitation must contain the elements of an effective learning process.

The learned task must be relevant and meaningful for the daily functioning of the patient. People learn better if what they learn is relevant to them. The training offered must therefore match the patient's needs and abilities and be individualised. It is important that the intensity of the training is monitored. The duration and complexity of the training should be in line with the patient's abilities. That is, the task to be learned for the patient must be realistic.

The rehabilitation must have a logical structure, with the easy tasks being taught first before training for more difficult tasks. Repetition is key. Make sure that there is sufficient repetition during the training of tasks and activities. Finally, it is important that patients receive feedback about their performance and the quality of the training provided. Explanation, incentives, correction and coherence of the following learning objectives are steps required for effective learning.

The following points further contribute to an effective learning process:

- formulate instructions that are as complete as possible, short, direct and simple;
- provide instructions in the right way and at the appropriate level, to help the patient understand;
- adjust the tasks and information to be learned and to the patient's abilities;
- adjust the speed to that of the patient;
- stimulate response at all times;
- try and learn, improvise without preparation;
- encourage positive behaviour, aimed at realising the desired behaviour;
- be a role model: you are the model for the patient, after which the patient may imitate you.

In (re)learning of activities, different phases can be distinguished (Gillen [2016](#)):

- *The learning phase*
in the learning phase, the patient learns a task that is new to them (again). One example of this is to put on a sweater with one hand.
- *The automation phase*
if the patient has understood the instruction and performed the task a few times, the automation phase begins. In this phase, a lot of repetition is needed to ensure that the patient can perform the task easily, smoothly and quickly. At this stage, the environment must be conducive to patient learning, optimising their abilities.

– *The generalisation phase*

in the final phase, the generalisation phase, the patient is able to apply the learned tasks in a variety of circumstances. That means a patient who practiced showering in a wheelchair-friendly bathroom in the nursing home or rehabilitation centre, can also apply these skills at home (in a totally different bathroom).

9.4 Washing

Especially in the first period after stroke, many patients will need help from the nurse when washing themselves. Dependence in this area makes many patients feel uncomfortable and the ability to wash themselves independently, is therefore an important goal for many stroke patients.

Importance of training in washing:

- the patient is less dependent and finally achieves optimal independence;
- the patient makes direct contact with the affected, often alienated body part and learns how to engage it in the activity as well as possible;
- ADL training is a 24 h approach.

General principles of washing:

- symmetry and torso balance are conditions for optimal independence. Pay constant attention to:
 - posture;
 - sitting actively upright;
 - the affected side of the body is turned forward;
- actively involve the patient as much as possible when washing, even if they are not able to do much themselves and have to be washed in bed, for example, because of a poor upper body balance;
- allow the patient to wash their face, arms and chest as quickly as possible. If the patient can only be taken care of in bed, then ensure they sit upright, supported;
- if a patient can sit well and stand up (with help), they can wash themselves at the sink, sitting on an ordinary chair or in their own wheelchair. Then let the affected arm rest on the basin, with the affected body half and shoulder facing forward;
- approach the patient via the affected side (provided the limitation is not too severe) and engage the affected side as much as possible;
- Build automation by:
 - keeping the same order;
 - sticking to the same time and environment as much as possible;
 - keeping activities as individual to the patient as much as possible.

Arrangement during ADL training washing.

The following arrangement can be used in the ADL-rehabilitation—‘washing’.

Imbalance

The patient is unable to sit without support and, for example, would possibly fall down when sitting on the bed edge. The care happens (largely) by nurse and in the bed.

Fair balance

Patient is able to sit down unsupported short-term or long-term with some support. The care takes place partially on the bed, partly at the washbasin with a lot of help from a nurse.

Sufficient balance

Patient is not limited in self-care by torso imbalance. Caring is done completely at the basin, (largely) by the patient himself.

Sometimes we take what we believe is obvious, for granted. For example we wash our top half first, then the bottom. Work with what the patient wants and can do now. Think outside the norms and this may help the patient more.

9.4.1 Unaffected Arm

Try holding the sponge or washcloth between the legs and move the arm past it. Or hang the washcloth over the upper leg and move the arm past it. Take the affected area to the cloth rather than the cloth to the area.

9.4.2 Drying

Drying the back is possible by hanging the towel over the back and then pulling it away at the bottom. The unaffected arm can be dried by hanging the towel over the not-affected leg and moving the arm over it.

9.4.3 Showering

Sitting showers will be easier for patients after stroke. The shower is a wet area, thus creating a significant risk of falling. A good anti-slip mat is advisable. The order of washing in the shower is less important than it is at the basin.

9.4.4 Shaving

One-hand electric shaving is often possible. Be careful with sensory disorders. Cognitive problems can also make personal hygiene, such as shaving, difficult.

9.4.5 Dental Care

Brushing teeth with one hand is usually possible, but cleaning a dental prosthesis with one hand is much more difficult. Using a nail brush on a suction cup or effervescent tablets can provide a solution.

9.5 Dressing

9.5.1 Starting Attitude

When dressing, pay attention to a good symmetrical sitting position. Make sure both feet are on the ground. If possible, let the patient sit on a chair without arm-rests. When sitting on the bed edge or a soft surface, balance problems and unwanted movements may occur.

9.5.2 Help/Guidance/Instruction

Matching the help and guidance to the level of functioning of the patient. Failure, frustration or insufficient stimulus can demotivate the patient. Take your time, make sure the patient does not have to rush. Keep in mind the possibilities and progress of the patient. For example, if at any given time the patient is able to stand up, also implement this into the training. Depending on the communication difficulties of the patient, you can either choose verbal or non-verbal instruction.

9.5.3 Involvement of the Affected Side

When dressing, start with the affected side as much as possible (provided that the restrictions are not too big). Stand next to the affected side or in front of the patient.

9.5.4 Fixed Sequence When Dressing

A fixed order gives structure to the patient, but also to all treating physicians and family. Realise that everyone has their own order/habit and try to take this into account as much as possible. Put clothes on the affected side (if possible), so the patient has to reach for the clothes on this side. In cognitive disorders, there are sometimes specific issues regarding order, organisation and control of the task.

9.5.5 Practicing Step by Step

Start with a specific part of self-care and try to build it slowly. Getting undressed is easier than getting dressed. When getting undressed, the order is more or less fixed. Handling clothes is also easier than when dressing. Often a patient cannot perform an entire operation independently. The one who helps the patient can start the action and teach the patient to complete the action. The aim is that the patient can ultimately perform all operations independently, provided that this is also their wish and matches their abilities and potential abilities.

9.5.6 Care

It is important that the patient looks well kempt. Therefore, ensure that the patient gets clean clothes and that all clothes are put on correctly. When achievable, let the patient wear ordinary clothes instead of nightwear. Choose clothes with simple fastenings and that go on with ease. Make sure everyone who helps the patient in care does this in the same way.

9.6 Attention Points for Washing and Dressing in Case of Imbalance

Table 9.1 contains point-by-point steps that can be followed for ADL training with the CVA patient with an imbalance.

Table 9.1 ADL training stroke patient with imbalance

	ADL activity	Instruction
1	baseline	– lying on back – standing on the affected side
2	shoulder control	possibly ‘loose rolling’ of affected shoulder
3	<i>getting undressed</i>	
	– sweater/shirt	– rolling down and back up – over the head – rolling down sleeves on affected arm
	– blouse/pyjama coat	– item as a sweater
	– (under)pants	– assuming a bridge position in bed – rolling down trouser leg on affected side
	– socks/shoes	– leg under armpit or prayer position around knee
4	<i>washing/drying</i>	– start on the affected side each time – head: guide patient’s hand – affected arm: by (non-affected) “good” hand – chest/abdomen: guiding patient’s affected arm – unaffected arm: guiding patient’s affected arm – affected leg: leg under armpit or prayer position around knee – unaffected leg: with unaffected hand – back: rolling on affected side
5	<i>getting dressed</i>	
	– blouse and sweater/shirt	– rolling up sleeve affected arm first – over the head – back down
	– pants	– rolling up affected pipe – making bridge on bed to pull pants up
	– socks/shoes	– affected leg under armpit or prayer position around knee

9.7 Attention Points Washing and Dressing with Reasonable Balance

Table 9.2 systematically shows the different steps that can be followed in the ADL training for patients with a reasonable balance.

9.8 Attention Points for Washing and Dressing with Sufficient Balance

Table 9.3 shows step-by-step tips and methods for ADL training with the CVA patient with sufficient balance.

9.9 Measuring Is Knowing: Clinimetry Within the ADL

To check whether the ADL training is effective, measuring instruments can be used. At the start you determine the zero point (the starting level), and during the evaluation you measure on the same scale. For the ADL, various measuring

Table 9.2 ADL training of the CVA patient with reasonable balance

	ADL activity	Instruction
1	Baseline	<ul style="list-style-type: none"> – active sitting – (wheel)chair angled in front of wash basin
2	shoulder control	<ul style="list-style-type: none"> – leave affected shoulder low, possibly ‘hanging’
3	<i>getting undressed</i>	
	– sweater/shirt	<ul style="list-style-type: none"> – over the head – rolling down sleeves affected arm
	– blouse/pyjama coat	<ul style="list-style-type: none"> – unaffected arm out of sleeve first – rolling down sleeves affected arm
	– (under)pants	<ul style="list-style-type: none"> – prepare in seat (opening fasteners) – toilet hold
	– socks/shoes	<ul style="list-style-type: none"> – untying shoes on floor – cross the legs one by one
4	washing/drying	<ul style="list-style-type: none"> – start on the affected side each time – buttocks: toilet hold – legs: cross one for one for washing/drying legs/feet
5	<i>getting dressed</i>	
	– blouse and sweater/shirt	<ul style="list-style-type: none"> – first sleeve affected arm between legs and rolling up – releasing shoulder at blouse – crossing legs
	– pants	<ul style="list-style-type: none"> – toilet hold – tying shoes on the floor
	– socks/shoes	

Table 9.3 ADL training with the CVA patient with sufficient balance

	ADL activity	Instruction patient	Instruction to carer
1	baseline	active sitting	
2	shoulder control	keep affected shoulder low, possibly 'hanging'	
3	<i>getting undressed</i>		
	– sweater/shirt	– over the head – rolling down sleeves affected arm	
	– blouse/pyjama coat	– freeing affected shoulder – unaffected arm out of sleeve first – rolling down sleeves affected arm	possibly offer help; help with fasteners
	– (under)pants	– prepare in seat (opening fasteners)	
	– socks/shoes	– stand up	possibly supervision; Please note: let patient stand on both legs
		– untying shoes on floor – cross the legs one by one	help in weight shifting when sitting
4	washing/drying	– head: with unaffected hand – affected arm: with unaffected hand – abdomen/chest: with unaffected hand – genital area/ramp: washing while standing – legs: cross affected leg	
5	<i>getting dressed</i>		
	– blouse and sweater/shirt	– putting down label	
	– pants	– first sleeve affected arm between legs and rolling up – releasing shoulder at blouse	possibly help with fasteners
	– socks/shoes	– crossing legs – pulling up pants when standing – tying shoes on the floor	possibly help with fasteners please note: let patient stand on both legs possibly help with laces

instruments (also known as clinimetry) are available. In Table 9.4 is an example of such an ADL measuring instrument: the Barthel Index (Mahoney and Barthel 1965). This measurement scale is used in many settings and in many studies.

Table 9.4 Barthel Index for measuring activities in daily life (ADL). The Barthel Index

Bowels
0 = incontinent (or needs to be given enemata)
1 = occasional accident (once/week)
2 = continent
<i>Patient's Score:</i>
Bladder
0 = incontinent, or catheterized and unable to manage
1 = occasional accident (max. once per 24 h)
2 = continent (for over 7 days)
<i>Patient's Score:</i>
Grooming
0 = needs help with personal care
1 = independent face/hair/teeth/shaving (implements provided)
<i>Patient's Score:</i>
Toilet use
0 = dependent
1 = needs some help, but can do something alone
2 = independent (on and off, dressing, wiping)
<i>Patient's Score:</i>
Feeding
0 = unable
1 = needs help cutting, spreading butter, etc.
2 = independent (food provided within reach)
<i>Patient's Score:</i>
Transfer
0 = unable—no sitting balance
1 = major help (one or two people, physical), can sit
2 = minor help (verbal or physical)
3 = independent
<i>Patient's Score:</i>
Mobility
0 = immobile
1 = wheelchair independent, including corners, etc.
2 = walks with help of one person (verbal or physical)
3 = independent (but may use any aid, e.g., stick)
<i>Patient's Score:</i>
Dressing
0 = dependent
1 = needs help, but can do about half unaided
2 = independent (including buttons, zips, laces, etc.)
<i>Patient's Score:</i>
Stairs
0 = unable
1 = needs help (verbal, physical, carrying aid)
2 = independent up and down
<i>Patient's Score:</i>

Table 9.4 (continued)

Bathing
0 = dependent
1 = independent (or in shower)
Patient's Score:
Total Score:
Collin et al. (1988)

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Urinary Incontinence After Stroke

10

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Abstract

The role of the nurse when signaling problems around the patient's continence is of great importance. With the theory of the different types of incontinence as a guideline, the knowledge on offering appropriate interventions in the stroke unit is essential. The impact of functional incontinence and the susceptibility to influence thereof, are clarified on the basis of types incontinence: (1) stress incontinence, (2) urge incontinence, (3) mixed incontinence, (4) functional incontinence, (5) overflow incontinence, (6) total Incontinence. Incontinence is a symptom of a disorder in function of the bladder. Depending on the reason for this disorder, materials and/or resources must be used. For instance, support and advice about toilet use, reducing obstacles and improving mobility, preventing and limiting incontinence injury, dealing with embarrassment and social isolation, dealing with cognitive disorders and sight deficits.

Keywords

Urinary incontinence · Stroke · Nurse · Toilet · Prevention

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10.1 Introduction

In the rehabilitation phase of patients after a stroke, the focus is on increasing the capabilities of the patient. The attention for motor development and ADL skills is a priority. Issues surrounding the continence of the patient are often mistakenly considered as insurmountable and a normal part of ageing. Knowledge about types of incontinence and their influence can play an important role in the rehabilitation process in the context of self-esteem and well-being of a patient. The nurse takes on an active role in these issues when it comes to identifying problems and involving team members in the treatment of these problems (Leandro et al. 2015).

10.2 Role of the Nurse

The role of the nurse when signaling problems around the patient's continence is of great importance. With the theory of the different types of incontinence as a guideline, the knowledge on offering appropriate interventions in the stroke unit is essential. The impact of functional incontinence and the susceptibility to influence thereof, are clarified on the basis of a number of examples. In this way, we translate the theory from motor skills and cognition directly to the daily practice in the stroke unit and emphasize the important role of the nurse within the team (Leandro et al. 2015).

10.3 Different Types of Incontinence

There are a number of different types of urine-incontinence (Thomas et al. 2014). Here, we will list six different types of incontinence.

1. Stress incontinence is characterized by involuntary urinary loss during pressure increase in the abdomen, for example when laughing, sneezing, coughing, bending, heavy lifting, and/or hurried movement, during sports activities for example. The rest of the micturition pattern is normal.
2. Urge incontinence is a strong urge to urinate that cannot be stopped. The patient often has a (continuous) urge to urinate without warning or limited warning.
3. Mixed incontinence consists of a combination of stress and urge incontinence, with one of the two types becoming more pronounced.
4. Functional incontinence occurs when people are unable to go to the toilet independently because of physical or practical limitations. The cause of urinary incontinence is not urogenital in nature. Examples include side effects of anaesthesia or medication, disorientation, mental/physical/visual impairments, troublesome clothes, long distances or obstacles when finding the toilet.
5. Overflow incontinence is the involuntary loss of small amounts of urine from a full bladder. It occurs when the bladder, by chronic retention of urine, becomes enlarged. The pressure in the bladder is then so high that small amounts of urine leak out.

6. Total Incontinence is characterized by the continuous dripping of urine from the urethra, both during daytime and at night. It occurs when the bladder's sphincter does not close properly.

10.4 Signaling Rather than Registration

In many stroke units, assessment of incontinence takes place with the aim of using the correct incontinence approach or products. This often ignores the fact that incontinence is a symptom of a disorder in function of the bladder. Depending on the reason for this disorder, materials and/or resources must be used.

For instance, support and advice about:

- toilet use;
- reducing obstacles and improving mobility;
- preventing and limiting incontinence injury;
- dealing with embarrassment and social isolation;
- referral to continence nurse.

10.4.1 Support with Toilet Use

Nurses offer support for toilet use. They assess, on the basis of the diagnosis, a choice together with the patient to use one or a combination of interventions (Thomas et al. 2014). The purpose of this is to help the patient become continent again, as much as possible. For all interventions improving mobility plays a role.

- Directly address the request of the patient to go to the toilet.
This is usually the starting point, but can be problematic due to high working pressure.
- Toilet schedules.
Set frequent, fixed times to help someone to the toilet. This is set up selectively. You determine the time and the frequency per patient. This method is suitable for patients who do not feel an urge, have no toilet habits and are no longer able to learn consciously.
- Engaging the patient (*Prompted voiding*)
This method is suitable for patients who still feel that they have a full bladder. You ask the patient if they would like to go to the toilet. You then assist the patient and offer positive encouragement. This will be repeated at set intervals, the patient also needs to be aware that can request help to attend to continence at any time in between.
- Habit schemes
Patients can have a personal schedule while they are not aware of it. Based on these habits, you create an individually customized schedule.

- **Bladder training**
This training is used for patients who are afraid of incontinence or patients with weak pelvic floor muscles, amongst other things.

10.5 Common Issues

Post-stroke a patient can be less mobile due to limited motor skills. The walking speed is slower or is unsafe. As a result of this, the toilet may not be reached on time. A patient who uses a wheelchair is not skilled in maneuvering this chair next to the toilet. Folding the footplates and putting on the brake requires a lot of extra time and attention. This patient will probably not reach the toilet on time either. In addition to the slowed pace, the loss of fine motor skills plays a role in handling the clothes and properly applying continence products.

As a result of cognitive disorders, the patient may face problems with the action plan, for example, losing the order of action.

In addition, disorientation and sight deficits can make it difficult to find and recognize the toilet.

10.6 Practical Tips for Limiting Functional Incontinence

Some practical tips for limiting functional incontinence are:

- instruction on the location of the toilet and explaining things at a level the patient can understand;
- repetition of this instruction if necessary;
- increasing the visibility of the toilet, by means of a sign on the door;
- a clear procedure followed by all employees helps the patient getting used to the new action;
- referral to rehabilitative care and occupational therapy.

10.7 Passing Information to Team Members

After identifying the presence of functional incontinence, the nurse in the stroke unit must share this information within the team. In the rehabilitation plan, goals should be formulated that are directly related to the prevention of injury (wounds, falling hazard for example) due to incontinence. For the patient, these goals are strongly focused on independence, self-reliance and well-being.

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Presentation of the Shoulder and Hand Due to Hemiplegia

11

L. A. Vroon van der Blom and T. M. Silveira

Abstract

Depending on the definition and instrument with which shoulder pain is recorded, the prevalence of shoulder pain experienced by stroke patients varies from 16 to 84%. Hemiplegic shoulder pain is a multifactorial problem for both the patient and the carer; patients may be prone to traumatizing the shoulder due to resultant cognitive impairments such as neglect and/or resultant spasticity, and caregivers who have not had appropriate training in guiding the transfer of patients may also trigger hemiplegic shoulder pain. In this chapter we discuss the anatomy of the shoulder and the causes of shoulder pain: paralysis, weakness and/or spasticity, contracture formation, reduced attention to the arm and repeated micro trauma. Resultant issues with the upper limb due to stroke onset including shoulder subluxation, shoulder pain and edema of the hand are further explained. Moreover, knowledge about healthy and deviating movement is provided. In the case of shoulder pain, further traumatizing the joint should be prevented; therefore we conclude with appropriate preventative methods for shoulder pain in stroke.

Keywords

Stroke · Shoulder pain · Hemiplegia · Prevention · Movement

11.1 Introduction

Hemiparesis is the unilateral weakness of the body. Hemiparesis is the most frequent outcome of stroke and affects 80% of survivors (Hattem et al. 2016). Further, 50% of stroke patients with hemiparesis will have ongoing difficulties with the use

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of their upper extremity (shoulder, arm and hand) (Intercollegiate Stroke Working Party 2016). In severe cases, stroke survivors may have resultant hemiplegia, or unilateral paralysis of the body.

Hemiplegic shoulder pain is a common symptom after stroke and may impact the patient's engagement and progress throughout rehabilitation. Hemiplegic shoulder pain can be prevented with early and appropriate intervention (Lohman 2008). This chapter discusses the anatomy of the shoulder as well as normal and pathological movement patterns of the shoulder due to hemiplegia. Further, specific conditions such as shoulder subluxation, shoulder soreness and edema of the hand will be explored.

11.2 Shoulder Pain

Depending on the definition and instrument with which shoulder pain is recorded, the prevalence of shoulder pain experienced by stroke patients varies from 16 to 84% (Harrison & Field, 2015). In many patients, its presence leads to symptoms of depression and a reduced quality of life, which may hinder the rehabilitation process. Hemiplegic shoulder pain is a multifactorial problem for both the patient and the carer; patients may be prone to traumatizing the shoulder due to resultant cognitive impairments such as neglect and/or resultant spasticity, and caregivers who have not had the appropriate training in guiding the transfer of patients may also trigger hemiplegic shoulder pain. Current literature therefore advises a multidisciplinary approach to treating hemiplegic shoulder pain (Lindgren et al. 2017) as it greatly impacts the individuals therapy outcomes, mood, quality of life, and ability to engage in activities of daily living. The pain experienced often becomes distracting and may interfere with concentration when learning new skills in therapy, or may hinder the individuals quality of engagement in therapy. Persistent pain may lead to difficulty with sleeping, thereby increasing fatigue during daily therapy, which in turn is likely to reduce the therapeutic engagement and potentially eventuate depressive symptoms.

Shoulder pain may impede the rehabilitation process by causing distress to the patient. Therefore prevention and treatment of hemiplegic shoulder pain is of high priority.

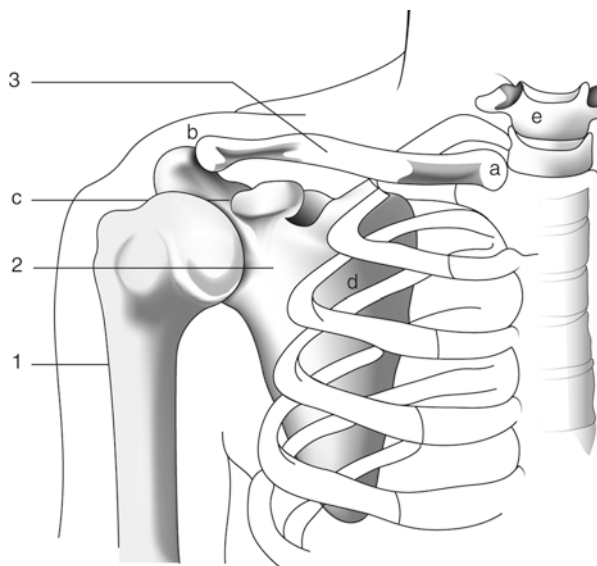
11.3 Anatomy of the Shoulder

The human shoulder (Fig. 11.1) is formed by a ball-and-socket joint with many degrees of freedom. The structures of the shoulder joint allow for a large range of movement enabling the individual to move their hands and arms in many directions. Muscle activity ensures stability around the shoulder joint. This requires a coordinated motion of multiple joints at the same time, also known as the shoulder belt.

The shoulder consists of three bones:

1. the upper arm;
2. the shoulder blade;
3. the clavicle.

Fig. 11.1 Anatomy of the shoulder joint. 1 Upper arm/upper limb, 2 Shoulder blade, 3 Clavicle (a) joint between the clavicle and the breastbone (b) Joint between collar bone and shoulder blade (c) Joint between shoulder blade and upper arm (d) Sliding surface between shoulder blade and chest (e) Vertebrae in the transverse neck and thoracic spine



The shoulder belt consists of the following joints:

- Joint between the clavicle and the breastbone;
- Joint between the clavicle and the shoulder blade (this joint forms the ‘shoulder roof’);
- Joint between the shoulder blade and the shoulder head (this is the upper end of the upper arm);
- The sliding surface between the shoulder blade and chest;
- The spinal column and the upper part of the spinal column.

11.4 Causes of Shoulder Pain

There are several causes linked to developing shoulder pain:

- Paralysis, weakness and/or spasticity:
- The muscles around the shoulder joint ensure its stability. After stroke onset, paralysis, weakness and/or spasticity are common. This may involve subluxation, the stretching of muscular and/or nerve tissue and a disturbed movement pattern of the shoulder belt.
- Contracture formation:
- Contracture formation is the permanent contraction or shortening of muscle (groups), which cause deformation or stiffening of the affected body part.
- Reduced attention to the arm due to:
 - Hemi inattention (reduced attention of the affected side);
 - Reduced sensitivity (sensation);

Reduced cognition (e.g. attention).

- Repeated micro trauma:
- Repeated micro trauma, such as laying or sitting on the affected arm, laying in an uncomfortable position for a long time, poorly lifting or pulling on the affected arm or falling on the affected arm (for example, from the bed or the wheelchair). Multiple simultaneous micro trauma can ultimately lead to shoulder pain. It is important to note that this pain can occur both instantly and after an elapsed period of time from causation.

The following problems with the shoulder and hand, as a result of stroke onset, are further explained:

- Shoulder subluxation;
- Shoulder pain;
- Edema of the hand.

11.5 Shoulder Subluxation

After stroke, there is often a reduction in muscle activity around the shoulder joint. Hemiparesis may be characterized by weak or spastic muscles that change the patterns in which muscles keep the shoulder joint and the shoulder belt in place, which often lead to a changed position of the shoulder blade. Due to this altered position, the shoulder head may partially leave the shoulder blade by sliding out—this is known as shoulder subluxation (see Fig. 11.2).

A subluxation can be felt if you are able to place your index finger between the shoulder roof and the head of the upper arm, and in severe cases, the subluxation can also be seen. Though the shoulder subluxation is not painful in itself, it may give rise to the development of a painful shoulder as the subcutaneous joint is now in a fragile state (as a result of the subluxation).

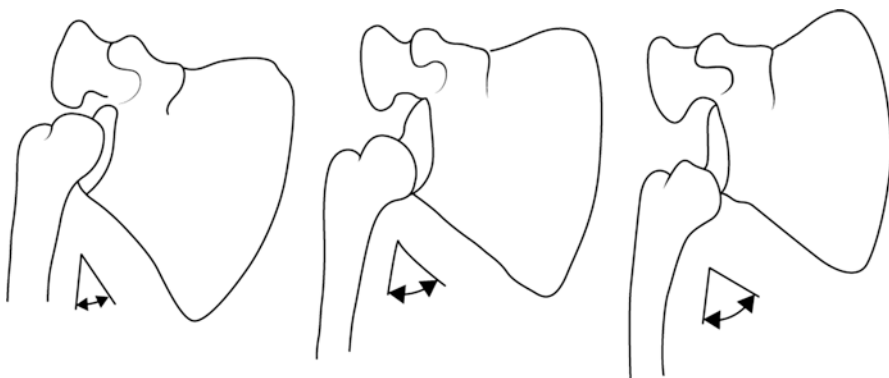


Fig. 11.2 The healthy shoulder and subluxation of the shoulder

11.5.1 Prevention and Treatment of Shoulder Subluxation

Preventative measures for shoulder subluxation include the following:

- The use of a worktop on the wheelchair;
- The use of a sling during transfers and walking;
- Do not lift the patient from under the arms/armpits during ADL activities such as transfers;
- Good positioning of the arm in bed and in the (wheel) chair;
- Protecting the vulnerable shoulder from injury, by stimulating the patient to pay attention to the hemiplegic shoulder/arm.

11.6 Shoulder Pain

In order to understand how hemiplegic shoulder pain can eventuate, it is important to understand the movement mechanisms of a healthy shoulder. The shoulder belt consists of multiple complex joints involved in generating fluid and completely pain free movements. Disturbance of this coordinated motion can cause either pain or movement constraints.

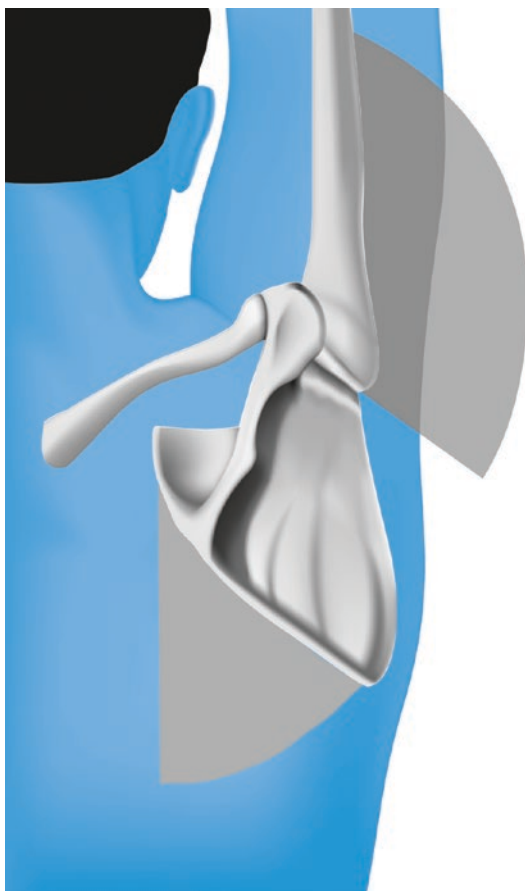
11.6.1 Healthy Movement

When the arm is raised forward or laterally, the movement largely occurs in the joint between the upper arm (head) and the shoulder blade (bowl). Thereafter, movement takes place in the remaining joints of the shoulder belt, moving the shoulder blade into the sliding surface between the shoulder blade and the chest (see Fig. 11.3). To raise the arm completely to the ears, sufficient motility of the neck and chest vertebrae is necessary.

11.6.2 Deviating Movement

In a patient with hemiplegia, the mechanism described above is disturbed by abnormal or insufficient muscle tension in the shoulders. When the arm of a hemiplegic patient is raised, the shoulder belt does not move properly causing the shoulder blade to cease sliding. As a result, the shoulder head may cling to the shoulder belt and the tissue becomes stuck. This can cause sharp pain at the end of the movement when the hemiparetic arm is passively moved during therapy or during ADL practice. At these moments, the patient can precisely identify the painful area. Initially, this pain immediately disappears when the arm moves downwards. However, the pain may increase gradually or rapidly if causal factors are not removed. When the pain increases, the patient may have difficulty in identifying the exact location of the pain. This will then lead the patient to experience pain throughout the day and night if the therapist does not appropriately revise and adjust the therapeutic

Fig. 11.3 Moving the shoulder blade while lifting the arm



approach. If the therapeutic approach is not adjusted, the patient may no longer engage in any movement using their arm, and may also complain of general pain (in some cases, reporting pain in their entire arm and even in the hand). The pain can be so intense that the patient presents as distressed and pleads with the caregiver, nurse and/or therapist to not touch or move the arm. If this plea is not met, the patient may present in a seemingly aggressive manner, forbidding others to touch them.

11.6.3 Prevention and Treatment of Shoulder Pain

In the case of shoulder pain, further traumatizing the joint should be prevented. Preventative methods require the collaborative efforts of caregivers, nurses and therapists and the patient (Dutch Heart Foundation 2001). Traumatizing the shoulder can be prevented in the following ways;

- Position the arm well in the bed and/or in the (wheel) chair.
- Support the shoulder during transfers.

- First mobilize the shoulder blade before moving the arm passively (for example during ADL practice and/or during therapy).
- If a particular position or activity causes pain, the therapists should work with the patient to immediately change this approach and perform it in such a way that the patients' reported pain ceases.
- If there is pain in an affected limb, one is likely to keep this painful body part steady, thereby reducing movement and potentially causing more pain. Therefore, it is important to encourage the patient to keep the arm moving.
- Different activities can cause repetitive trauma of the affected side. Try to prevent this by focusing on activities that the patient is comfortable and confident in engaging with. Then, prior to trialing new activities, ensure that a careful explanation is given prior to and when implementing the activity with the patient so that they are mindful and aware.

The following activities can cause repetitive trauma of the affected arm:

- When the patient is only supported at the arm during transfers and there is insufficient control of the torso.
- By offering inappropriate assistance to the patient in getting them into a chair after a fall. For example, it is not appropriate to use your hands to support a patient under their armpits when assisting them in sitting down in the chair.
- Inadequate support of the shoulder during nursing operations of the arm. For example, during dressing, bathing, turning in bed and measuring blood pressure.
- Lifting the arm too actively or repeatedly with insufficient control over the shoulder blade during exercise.

11.7 Edema of the Hand

Hemiparetic shoulder pain may be associated with edema of the hand. An untreated edematous hand can lead to irreversible contractures of the hand and fingers that interfere with potential functional use of the hand in the future. This condition is also referred to as the shoulder hand syndrome or complex regional pain syndrome (CRPS), sympathetic reflex dystrophy, causalgia or sudeatrophie. The reported incidence of Shoulder hand syndrome after stroke varies, with an estimated prevalence between 2 and 49% (Chae, 2010). The symptoms of the edema to the hand are divided into three stages:

- *First stage*
- There is sudden swelling of the whole hand and fingers, leading to movement restriction at the joints of the hand and the wrist. The edema is mainly visible on the back of the hand and usually ends just above the wrist joint. Wrinkles of the skin disappear and the tendons of the hand are no longer visible. The swelling feels soft and the color of the hand changes; usually a pink or purple tint will appear. The hand feels warm and sometimes moist. The nails look whiter and

less translucent than those of the non-affected hand. There is also noticeable pain that exacerbates throughout exercise and practice.

- *Second stage*
- When the hand is not treated properly, the pain becomes so severe that the patient no longer tolerates the caregiver exercising minimal pressure on their hand or fingers. Hard knots may appear on the back of the hand and typically osteoporotic changes may be visible upon X-ray examination.
- *Third stage*
- When a hand is not treated, the edema will disappear, as will the pain. In this stage mobility has been lost and there is atrophy in hand. This results in serious deformation of the hand and fingers, which can no longer be effectively used by the patient.

11.7.1 Causes

The sudden onset of symptoms, in patients who did not previously suffer from pain or restriction of movement, seems to indicate that there is a specific cause of the edema and that inactivity and the “hanging” of the arm subsequently maintain these symptoms. Several studies indicate the role of reduced shoulder stability as a cause of CRPS development.

Different causes can contribute to the emergence of the edema:

- Palmar flexion:
- Palmar flexion is the prolonged flexion in the wrist, with the palm to the forearm. The patient is often resting in the bed or sitting in their wheelchair for a long time, in which the wrist is often unnoticeably positioned in palmar flexion. Due to this state of the wrist, the venous drainage of the hand is blocked.
- Dorsal flexion:
- Dorsal flexion is the overstretching of the wrist, with the hand bending to the forearm. This can occur during ADL practice or during therapy session, where the patient rests on their hemiplegic arm on the couch or the bed, thereby pushing the movement toward dorsal flexion.
- Light injury
- In case of reduced sensation or inattention of the affected side, the patient may suffer light injury. For example, the hand may get caught in the wheelchair wheel without the patient being aware of it. This can also lead to edema of the hand.

11.7.2 Prevention and Treatment of the Edema

In order to prevent edema of the hand, the patient, caregiver and multidisciplinary team must pay attention to the following issues:

- Good positioning of the arm in bed and in the (wheel) chair;
- Avoid excessive bending or stretching of the wrist;

- Prevention of trauma at the hand/arm;
- A wheelchair worktop and/or a preventive splint can be considered when the patient is unable to take good care of his hand.

When there is an edema, it is important that treatment commences at the first stage of the condition. The primary treatment goals are: reduction of the edema, pain relief, retention of mobility and functional recovery.

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E. T. M. Sarr-Jansman and D. J. Rowberry

Abstract

A stroke often has more effects than what can be observed physically, for example paralysis of a limb or problems with speech. The “invisible” effects often come to light later on. The damage to the brain can bring changes in the patients’ thinking, actions and feelings, so that his live will never be the same. In cognitive disorders, the patient may for example have problems with perceiving, acting or dealing with language. Research shows that about 80% of patients with cerebral hemorrhage and about 50% of patients with a stroke have acute cognitive impairment. In order to be able to perform an (apparently) simple daily operation, many steps must be taken. These steps are described in the ‘process of information processing’. Also, behavior can be subject to change. After stroke, patients often respond to events differently than they themselves and the people around them are used to. The changes in emotions and behavior of the stroke patient can severely disturb the relationship with their partner and children. Understanding of the invisible effects is therefore of great importance. The treatment of patients with cognitive impairments can focus on function recovery, strategy training (Internal compensation) and adjustment of the environment (External compensation). However, the success of the treatment, depends on the severity of the injury. In addition, actually recognizing the disorders in relation to daily functioning is of importance.

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Clear planning and consistent implementation, treatment and guidance by all those involved increase the likelihood of success in the rehabilitation.

Keywords

Stroke · Nurse · Rehabilitation · Cognition · Emotion · Behavior

12.1 Introduction

The rehabilitation of stroke patients is intended to make them function once again in their home situation as soon as possible. Many people who have suffered a stroke, also have “invisible” disorders in addition to motor and sensory disorders. They are limited in the field of cognition, emotion and/or behavior. This can be very upsetting, for both the patient and their families. It has an influence on thinking and acting, but also on social functioning and this may influence quality of life of stroke patients (van Mierlo et al. 2014). It is important to take this into account from the start of rehabilitation. In this chapter, disorders of cognition, emotion and behavior after a stroke are discussed. In addition, we discuss the possibilities for treatment and guidance.

12.2 Cognitive Disorders

A stroke often has more effects than what can be observed physically, for example paralysis of a limb or problems with speech. The “invisible” effects often come to light later on. In the first few months after stroke, most attention is paid to the restoration of the movement functions. This usually takes a lot of time and effort, causing other symptoms to disappear in the background.

Those affected who do not have to rehabilitate in a rehabilitation center, may also have to deal with these issues. The damage to the brain can bring changes in their thinking, actions and feelings, so that their lives will never be the same (Fig. 12.1). Unfortunately, not everyone is prepared for that. Partners, children and friends are often unaware of the invisible effects they might have to deal with after stroke.

After stroke, people often have “elusive” issues that hinder them in day to day functioning. For example, they are extremely tired because they cannot keep up with the pace of the world around them. This is not only due to physical disabilities. Often they do not manage to do the things they did before they had a stroke. Reading, listening to music or having a conversation can be very difficult for stroke patients. They cannot concentrate as well and are easily distracted. After a stroke, many people have trouble doing two or more things at once. Having a conversation while walking or listening to music, can be impossible for some. Also, due to the loss of spatial insight, fine motor skills may now be very difficult.

Their memory can be less than desirable in terms of functioning. This goes far beyond the usual forgetfulness that develops over time. For example, some patients cannot remember things anymore, even if they are repeated several times.

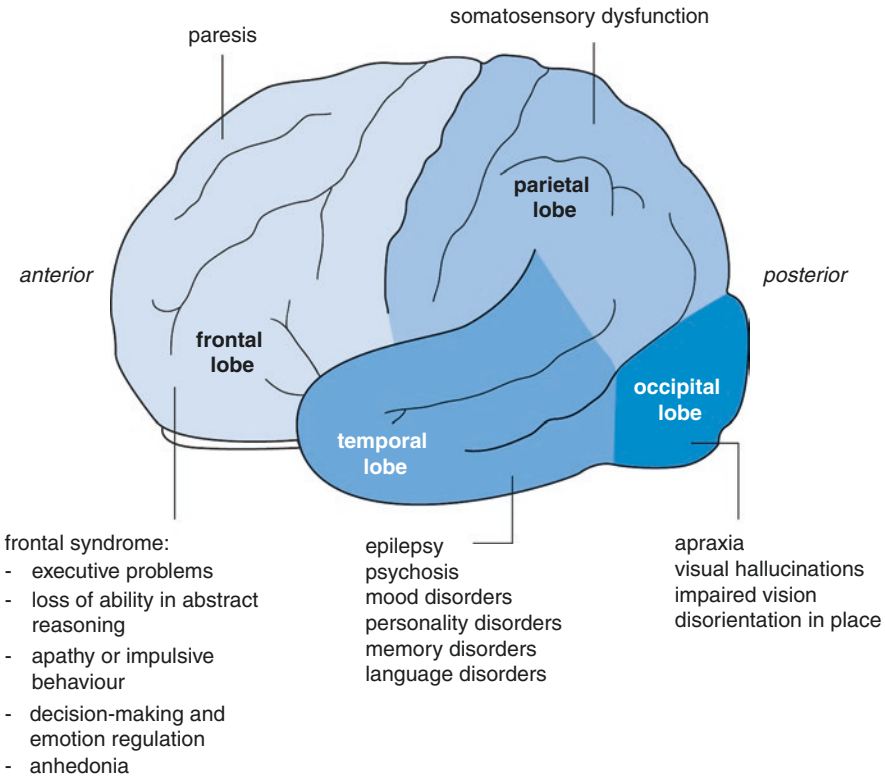


Fig. 12.1 Brief overview of the brain

In people who have had a stroke, performing activities that require different steps is usually not possible anymore. This is because they are unable to plan well and may forget things. They often want to do something but cannot think about how to achieve it.

Table 12.1 Changes in cognition, emotion and behavior in relation to location brains.

Some stroke patients are unable to express what they want to say. This is often very frustrating, especially if they lose contact with others because of this.

Practical example	
A patient cannot dress themselves well or needs a lot of time	
Visible problems:	Possible causes could be:
<ul style="list-style-type: none">– Patient cannot find the opening of the sleeve– Patient puts on clothes incorrectly– The patient spends a lot of time “messaging around” with clothes– Patient does not know the order of the garments– Patient cannot find the items on his left– Patient wants to put a sweater on his feet	<ul style="list-style-type: none">– Patient has problems recognizing objects– Patient no longer knows how to use objects– Patient cannot properly plan, organize and order– Patient has no spatial insight– Patient does not check their actions

Table 12.1 Process of information processing

	Process	Disorders
1.	Being alert	After a stroke, patients are alert to a varying extent: they don't seem to be fully awake. Especially in the acute phase, this often occurs. This may also play a role in fatigue and/or certain medication use. These are disorders in the consciousness'
2.	Being oriented	Not all stroke patients are well-oriented. Some patients are wrong about the time, have little sense of time or turn around day and night rhythm. Others have difficulty finding the way (back), especially in a new environment. There are also patients who no longer recognize (often new) people. This is we called 'orientation disorders'
3.	Focusing, distributing and persevering	In order to act, concentration is required. Often people do—without a lot of effort—several things at once. And they do so for extended periods. For most stroke patients this is not so easy. These are 'attention disturbances'. Often patients have also become slower in their thinking. They then have 'delayed information processing'
4.	Perceiving a situation	In everyday life, people perceive, hear, feel, taste and smell with their senses. Some stroke patients have a disturbed perception when it comes to senses. This is what we call 'sensory disorders'. Patients who do not seem to be aware of the affected side while not having a sensory disorder have a "hemi inattention" or a "neglect"
5.	Interpreting the perceived information	The information that people "pick up" through their senses is interpreted (understood) through the brain. This is how we give meaning to what we see, hear and feel. Stroke patients sometimes have difficulty detecting objects, even though they see/hear the objects. This disorder is called 'agnosia'. Being unable to perceive space and spatial relationships is called a 'spatial perception disorder'
6.	Estimating own possibilities and limitations	After interpreting the situation, our own possibilities and limitations must be estimated in order to be able to act correctly and safely. Many stroke patients overestimate or underestimate their own possibilities. Many stroke patients have a 'disturbed judgment and/or disease insight'
7.	Forming appropriate action plan and conducting targeted action	Action is done by performing specific sub steps in a particular order and by using objects correctly. Disorders in making or executing a plan of action are called 'apraxia' (Donkervoort 2003). Also, there are people who are struggling to get to an action
8.	Verifying and evaluating actions	When performing an activity, we verify subconsciously whether we have completed everything well. For example, looking in the mirror after washing ourselves, straightening the sweater after dressing, checking that the gas stove is off after cooking and so on. If this control step is skipped, there is usually an unfinished task and sometimes chaos. Mistakes in this step often coincide with problems in attention, judgment and sometimes with an apraxia

(continued)

Table 12.1 (continued)

	Process	Disorders
9.	Saving and generalizing experience	During the course of life, people memorize when carry out activities. They are learning these activities while performing them and saving the learning experiences. This allows the patient to apply learned skills in other situations. Disorders in this area are called memory disorders'
10.	Endurance	Healthy people can act, talk and think for a long time. They have a decent physical and mental ability. Many stroke patients become tired more easily: not just physically but also mentally. They suffer from a limited 'capacity of information processing'. This is associated with attention disorders

12.2.1 What Are Cognitive Disorders?

Cognitive disorders are caused by brain injury, for example a stroke. In cognitive disorders, the patient may for example have problems with perceiving, acting or dealing with language. Also, their behavior can be subject to change.

In order to understand “abnormal” actions, it is important to understand how an act usually occurs. In order to be able to perform an (apparently) simple daily operation, many steps must be taken. These steps are described in the ‘process of information processing’. If there is a problem in one or more steps, the action is distorted (Table 12.1).

12.3 Disorders in Emotion and Behavior

After stroke, patients often respond to events differently than they themselves and the people around them are used to. Often times, patients tolerate less light and noise than before. Also, patients may respond more violently because they are unable to control their feelings as well. Some patients are much more aggressive and start to curse at the slightest whim, which they never did so before. Others are much more passive and depressed than their family and friends are used to. Others may experience emotional responses much more quickly.

‘It seems as if there is another person in that same body’, you sometimes hear partners and children say. Changes in feelings and behavior also fall under the invisible effects of stroke. In most cases, extreme reactions are a direct consequence of the damage caused by a stroke. Patients themselves are unable to do anything about it. That’s important to know. Patients themselves are not always aware that they have changed. For family and friends, that may be a bitter pill to swallow. It can give them the lonely feeling that they lost someone.

For people who have had a stroke and their family, it often takes time to come to terms with these changes. The changes in emotions and behavior of the stroke patient can severely disturb the relationship with their partner and children. If others

think that the patient always intentionally reacts violently, finds arguments or is passive, it will often be impossible to live together. Understanding of the invisible effects is therefore of great importance.

Even partners who have a lot of patience and understanding are not always up for the task of taking care of a patient. The balance in relationships can be completely lost or changed. This sometimes tires their partners in such a way that they themselves become ill.

12.4 Cognitive Changes in the Elderly

Stroke is a disease that occurs frequently in older people. In addition to disorders caused by stroke, there may be changes as a result of aging. The following aspects should therefore be taken into consideration in rehabilitation of the elderly:

- *Slower information processing*
- The process of information processing and storage of information in memory is slower when aging. Information should therefore be offered longer or more often than in young people.
- *Greater selectivity*
- Remembering new information happens more selectively. The emphasis is on impressive or relevant information.
- *Completely new information is more difficult to remember*
- It is important to match the new information with existing knowledge, because as you grow older, it can be harder to remember new information.
- *More effort*
- The ability to store information adequately is not reduced, but it takes more energy, more effort. With ageing, the amount of energy generally decreases.
- *Less attention and concentration*
- When aging, attention and concentration will decrease slightly. Concentration is required in remembering new information.
- *Smaller memory span*
- The memory span, or the instant memory and working memory, diminishes in size and length somewhat when aging.
- *Emotions in relation to cognition*
- Older people can suffer anger emotions because of the greater chance of a variety of conditions, such as dementia. Reduce this fear, if possible, by giving clear information about the changing levels at the cognitive level.

12.5 Some Figures About Disorders in Cognition, Emotion and Behavior

Research shows that about 80% of patients with cerebral hemorrhage and about 50% of patients with a stroke have acute cognitive impairment. After 6 months, 30% of stroke patients still have cognitive problems. Overall, you see a strong advance

compared to the acute phase. Both the location and size of the brain damage play a major role in the degree of cognitive recovery that occurs, just as the age and (former) intelligence of the patient.

About half of the patients show depressive symptoms during the first few weeks. These depressive symptoms appear to be associated with the severity of cognitive and physical disorders, and not so much with the location of the brain injury. Often, depressive symptoms develop only a few months to a year after stroke. It then becomes clear for the patient what the consequences of stroke mean to him or her (van Mierlo et al. 2014; Nijse et al. 2015).

12.6 Research and Treatment in Disorders in Cognition, Emotion and Behavior

Often, nurses identify that something is wrong with the patient. To be able to handle patients, the problem must be clear first. Therefore, diagnostics take place. The better the nurse can describe objectively how the patient is acting, the more rigorous this diagnostic can take place. An occupational therapist uses special observation tools. A psychologist can take a neuropsychological examination. The patient performs all kinds of tests for this.

The treatment of patients with cognitive impairments can focus on:

(a) *Function recovery*

By training the impaired function, we try to improve these functions (for example, memory training). However, it has been found that this goal is difficult to achieve. Recovery of functions is often based on spontaneous recovery, in the first few weeks and months after stroke.

(b) *Strategy training (Internal compensation)*

The patient learns to compensate for the impaired functions by means of his intact functions. The patient also learns to use existing or new strategies. A notion is that the patient has insight into his own functioning. Examples include that the patient himself learns to take breaks, adjust his pace or remove distractors in his environment. To make it easier to act, to forget less and to keep a better overview.

(c) *Adjustment of the environment (External compensation)*

If it is not possible for the patient to compensate for the disrupted functions, it may be necessary to adjust the environment to the current possibilities of the patient. People from the immediate environment can be instructed on how to apply certain principles and strategies. You can also change the physical environment, for example, by using photos, calendars, or direction indicators. If the patient is dependent on others for this purpose, we talk about external compensation.

For both *b* and *c*, the same principles are used, for example, restricting information, structuring, using a calendar. The difference is that for *b*, the patient himself uses these strategies, while for *c*, the people around him need to help.

The success of the treatment, of course, depends on the severity of the injury. In addition, actually recognizing the disorders in relation to daily functioning is of importance. Clear planning and consistent implementation, treatment and guidance by all those involved increase the likelihood of success in the rehabilitation of people with these complex disorders (van Heugten et al. 2003).

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Post-stroke Neuropsychiatric Symptoms

13

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Abstract

The term ‘neuropsychiatric symptoms’ (NPS) collectively identify the following behavioral symptoms; psychosis, apathy, depression, difficulty with sleeping, aggression, agitation and disordered eating. Literature suggests that there is a high prevalence of these symptoms experienced by stroke survivors. Further, depression and anxiety have been identified as the most commonly experienced NPS in stroke. NPS typically occur later in the rehabilitation phase of treatment and may result if the patients’ expected progress does not eventuate. Knowledge about the prevalence and progression of NPS is vital for coordinating appropriate rehabilitation and implementing optimum treatment on the ward. This approach to the treatment of NPS not only contributes to a smoother rehabilitation phase but also may result in a potentially shorter rehabilitation period. Therefore, care-givers and nurses should be trained in recognizing NPS so that they can learn to promptly recognize signs of depression and other NPS. As the guidelines for stroke rehabilitation recommend a multidisciplinary approach, it is important to be aware of the different approaches to psychotherapy to ensure that the patient is referred appropriately.

Keywords

Neuropsychiatric symptoms · Stroke · Rehabilitation · Nurse · Treatment

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13.1 Introduction

Neuropsychiatric symptoms (NPS) are psychiatric symptoms caused by cerebral disorders encompassing anxiety, neurotic complaint, apathy, mood disorder, hallucinations, delusions, behavioral and personality changes, delirium, and cognitive impairment. In the past, NPS were generally related to older people suffering from Alzheimer's Disease or Dementia (Ismail et al. 2016; Sink et al. 2005). In recent years, there has been a growing awareness of NPS experienced by stroke survivors (Hackett et al. 2014).

In stroke survivors, NPS may have an organic basis or association with the emotional trauma of stroke onset and/or the changed abilities due to impairment. Further to this, literature suggests a possible correlation between the lesion location of the stroke and the resultant NPS (specifically post-stroke depression) (Huffman and Stern 2003; Wong et al. 2016). The individuals quality of life may be reduced, potentially hindering the rehabilitation phase of treatment due to a loss of motivation and a decrease in active involvement in rehabilitation. This in turn may result in prolonged length of stay in the rehabilitation facility and thus a slower return to home life. Therefore, NPS may have a significant impact on the stroke survivor and the family/caregiver.

13.2 Prevalence of NPS

The term 'neuropsychiatric symptoms' collectively identify the following behavioral symptoms; psychosis, apathy, depression, difficulty with sleeping, aggression, agitation and disordered eating (Buijck et al. 2012). Literature suggests that there is a high prevalence of these symptoms experienced by stroke survivors (Angelelli et al. 2004).

Recent literature identifies depression and anxiety as commonly experienced by stroke survivors (Mitchell et al. 2017). Post-stroke depression has been identified as the most common NPS, experienced by at least 33% of survivors (Hackett and Pickles 2014; Buijck et al. 2012). Further to this, 20–50% of stroke survivors experience post-stroke depression following the first year of stroke onset, peaking within the first 6 months (Dafer et al. 2008). Anxiety symptoms, such as agitation, have also been shown to have high prevalence in stroke, effecting 25–33% of stroke survivors (Vansimaey et al. 2017). A review of the literature suggests that anxiety symptoms are experienced by 20% of stroke survivors within 1 month of onset, 23% of stroke survivors within 1–5 months of onset, and 24% of stroke survivors 6 or more months post onset (Burton et al. 2013).

Hallucinations and delusions seem to be quite rare after stroke. However, the prevalence rate is dependent upon a number of factors, namely differences in population, rehabilitation setting, implemented clinical metrics and time elapsed post stroke (Buijck et al. 2012).

13.3 Causation of NPS

Though the specific causes of NPS post-stroke are still unclear, we can draw upon what is known to help infer potential causation. For example, depression has been noted to occur more frequently in left hemisphere brain injury, and often goes hand in hand with agitation in older patients. It is also known that people who suffer from a stroke at a young age are more easily agitated (Astrom 1996; Astrom et al. 1993). Though NPS can directly result from brain damage, they can also result from the individuals' poor coping strategies.

NPS typically occur later in the rehabilitation phase of treatment and may result if the patients' expected progress does not eventuate. The younger the patient is, the greater the chance they have of experiencing NPS due to their changing abilities and restrictions. Conversely, the older the patient is, the greater the likelihood for them to accept their changing abilities and resultant restrictions. Furthermore, the prevalence of NPS varies during the time elapsed after stroke onset; some NPS occur immediately after stroke onset as a direct consequence of neurological damage, whereas other NPS occur as a reactive phenomenon long after stroke onset. Poor coping strategies may lead to difficulty in accepting the changing abilities and overcoming obstacles during rehabilitation, thereby increasing the risk of NPS such as depression.

Even though it is important to be aware that psychological symptoms, such as NPS, can stand in the way of successful rehabilitation in stroke recovery, the implementation of successful rehabilitation can lead to an improvement in mental health and wellbeing outcomes. Therefore, knowledge about prevalence and progression of NPS is important for coordinating appropriate rehabilitation and implementing optimum treatment on the ward. This approach to the treatment of NPS not only contributes to a smoother rehabilitation phase but also a shorter rehabilitation period.

13.4 Neuropsychiatric Inventory

One of the most common assessments used for measuring NPS is the Neuropsychiatric Inventory (NPI) (Cummings 1997). This validated assessment has been identified as a reliable tool for measuring NPS in patients with brain damage such as dementia and stroke. A trained caregiver or nurse can easily implement the NPI assessment of a patient. The NPI identifies 12 NPS:

- delusions
- hallucinations
- agitation/aggression
- depression
- anxiety
- euphoria

- apathy
- irritation/lability
- disinhibitory behavior
- aimless repetitive behavior
- nightly restlessness
- disordered eating

The most common NPS observed on stroke rehabilitation wards in Dutch nursing homes are depression, nightly restlessness and eating disorders, followed by anxiety and irritation. In patients whose rehabilitation is successful, NPS are generally less present in comparison to those whose rehabilitation is ineffective (Buijck et al. 2012).

13.5 Recognizing Neuropsychiatric Symptoms

A stroke is a very profound event. Often too little attention is given to the psychological condition of patients during rehabilitation post-stroke. The psychological symptoms that occur during or after the rehabilitation period are often underestimated. During rehabilitation, patients start to acknowledge that their lives have been changed forever; it will never be as it was before as there will be limitations. Accepting these changes and living with this awareness is not easy for most people. Therefore it is only natural that many stroke survivors seem depressed and anxious when looking toward the future.

Research shows that inpatients have little interaction with a nurse or caregiver during the day. The main purpose for interaction with a nurse or caregiver seems to be during the assistance with activities of daily living such as bathing, dressing and eating. Even though the patients receive all prescribed nursing and paramedical care, they still spend half of the day alone, without contact with other patients, caregivers and/or meaningful relationships (such as family and friends). This time spent alone may lead to rumination resulting in worried thoughts and negative feelings (Vermeulen et al. 2013).

The life of someone who has survived a stroke can change considerably depending on its severity. Therefore, more attention must be given to the psychosocial side of the patient's process during rehabilitation. It is also important to involve the caregivers in this process as the psychological symptoms not only effect the quality of life of the patient after rehabilitation, but also place additional stress on the caregiver. Caregivers and nurses should be trained in recognizing NPS so that they can learn to promptly recognize signs of depression and other NPS (for example by referring to the NPI assessment). Further to this, caregivers can create "enriched environments" during inpatient rehabilitation; this could be in the form of simply putting up family photos or artwork around the patients' room and having pre-recorded music playing whilst the patient is in their room. The purpose of creating an enriched environment in acute stroke rehabilitation is to offer further stimulation for the patient. Enriched environments within this context have shown to not only have a positive effect on the mood of the patient, but also increase their active involvement in therapy (Burton et al. 2013).

13.6 Psychotherapy

Psychotherapy is an important component to rehabilitation in stroke recovery. Most patients will require some form of psychotherapy as part of their rehabilitation. As the guidelines for stroke rehabilitation recommend a multidisciplinary approach, it is important to be aware of the different approaches to psychotherapy to ensure that the patient is referred appropriately. For example, engagement in music therapy has shown to reduce depression and anxiety in a range of populations including stroke recovery (Raglio et al. 2017). The place of music therapy in stroke recovery is based on the premise that music making encourages the patient to access the emotional systems in the brain through non-verbal expression (Galińska 2015); something that is particularly important if the patient is having difficulty in verbally expressing themselves due to the psychological trauma and/or severity of their stroke. As each member of the multidisciplinary team has an integral role in the treatment of NPS, it is therefore of paramount importance that the presenting behaviour and appropriate method of therapy (e.g. Music Therapy) is discussed during team meetings.

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Care in the Chronic Phase: Care at Home

14

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Abstract

In the chronic phase, the stroke patient reaches the limits of his recovery, he becomes aware of his permanent limitations and has to learn to live with the consequences of stroke. In practice, this often means a shift from trying to recover from a disease (disease management) to learning how to deal with the consequences of a disease (disability management). The patient may experience health issues in ADL, in the field of psychological, emotional and cognitive functioning and in the field of social functioning and relationships. However, the consequences will vary for each patient, depending on the severity of the condition, the motivation of the patient, the support the patient receives from relatives, the help and care that are available and the interior of the home he is living in. Therefore, in the chronic phase, acceptance, secondary prevention, preventing aggravation of disabilities and finding a new balance are priorities. The health-care professionals discuss together with the patient how he can function best at home, they support patients with acceptance of disabilities and finding a new balance. In many cases, the patient still needs multidisciplinary treatment in the chronic phase to maintain his physical integrity and to prevent recurrence and secondary complications of stroke.

Keywords

Stroke · Nurse · Chronic phase · Prevention · Home situation

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14.1 Introduction

Internationally, rehabilitation takes place in different settings. More than half of the patients who have had a stroke returns home after hospitalization and more than a quarter of the patients rehabilitate on a stroke unit in a skilled nursing facility or rehabilitation center/hospital before they return home. A small part of the patients is referred for long term care in a nursing home. Worldwide one third of the stroke patients dies within 3 years after stroke (Thrift et al. 2014).

The effects of stroke are considerable and sometimes disabilities only manifest in the chronic phase. Some problems seems to be more difficult in the home situation, for example due to the absence of 24-h community care or informal care. Guiding the patient and his informal caregivers in the home situation is therefore of great importance. In this chapter we discuss the care in the chronic phase and the consequences of stroke for the patient in the home situation.

14.2 Care in Chronic Phase

In the chronic phase, the stroke patient reaches the limits of his recovery, he becomes aware of his permanent limitations and has to learn to live with the consequences of stroke. Care in the chronic phase occurs when the patient returns to the home situation. This may be after discharge from the hospital, the rehabilitation center, the skilled nursing facility or outpatient rehabilitation. This is the moment when the patient and his informal caregiver have to continue with their life again and learn to cope with the consequences of stroke. In practice, this often means a shift from trying to recover from a disease (disease management) to learning how to deal with the consequences of a disease (disability management). The moment this shift takes place differs by individual. In the chronic phase, acceptance, secondary prevention, preventing aggravation of disabilities and finding a new balance are priorities. This stage can take a lifetime, both for the patient with stroke and for his informal caregivers.

14.3 The Consequences of Stroke for the Patient in the Home Situation

The patient realizes that he no longer will recover (completely), the partner experiences that the relationship and the roles have been changed and the living environment is sometimes not appropriate anymore. The consequences will vary for each patient, depending on the severity of the condition, the motivation of the patient, the support the patient receives from relatives, the help and care that are available and the interior of the home he is living in.

We discuss the impact on activities of daily life (ADL), emotional-psychological functioning, participation, cognition, communication and relationship. They are dealt with by topic, but many health issues are related to each other: Cognitive

decline can reduce the ADL function, emotional-psychological health issues can affect the relationship and unfitting communication can affect participation.

14.3.1 Health Issues in ADL

Prior to stroke, everything was so self-evident, but regrettably circumstances have been changed dramatically. The patient needs to cope with disability and needs to learn new ways of doing the ordinary activities. When the patient is discharged from the hospital or rehabilitation facility, some degree of self-functioning and self-management is necessary to be able to live in the home situation (Kendall et al. 2007). A stroke patient can be limited to a greater or lesser extent, such as having difficulties in sitting down, walking, standing, reaching or to take care of personal hygiene. Depending on the severity of these limitations, functioning is hampered and performing every day activities in the home situation may be difficult.

The home is often not suitable for patients with disabilities: there are doorsteps, the stairs are steep, the toilet seat is too low, the shower may be hard to reach, the faucets are difficult to open, the kitchen cabinets are too high, the living room is stuffed with furniture, and the bed is not suitable to get in and out easily. Often the floor has long pile carpet, which makes walking more difficult. The chance of falling is therefore significant. Also, a large number of patients have unilateral spatial **neglect, which** is a failure to attend to the side opposite of the brain lesion. Because of neglect, moving in and around the home and getting dressed becomes more difficult and there is a higher chance of injuries by means of ignoring one side of the body. Therefore, the house may need to be refurbished and there may be adjustments needed in the home. Sometimes moving to a new home is necessary and this is a significant life event for both patient and partner.

The partner is probably not used to dealing with a patients' disabilities. In many cases, the partner takes over too much, so the patient is not encouraged in self-management or to practice. Unfortunately, what he has learned during rehabilitation may be eliminated in a short period. Furthermore, what the patient has learned during rehabilitation is not always directly transferable to the home situation. The staircase is steeper, the kitchen is decorated differently, and the shower is smaller than in the rehabilitation facility. It is necessary to either re-teach activities or to help the patient with activities.

14.3.2 Health Issues in the Field of Psychological, Emotional and Cognitive Functioning

After stroke, the emotional-psychological condition of the patient changes considerably. Not only for the patient, but also for the informal caregiver, which has a major influence on daily functioning. The personality and character changes are not always visible to the patient, but all the more for the informal caregiver. The partner sometimes has the feeling of having another spouse and has to cope with these

changes. The future perspective is shifting completely and partners need to adjust the expectations they had of their relationship. Often there is misunderstanding. For example when the patient is less flexible than before or if the patient has aphasia, it changes the way of communication with each other. Also, when the patient is overestimating his own possibilities it can create dangerous situations.

Moreover, the patient may suffer from neuropsychiatric symptoms, such as depression, aggression, agitation, anxiety, apathy (Buijck et al. 2012). People that are surrounding the patient do not always know how to cope with this and therefore stay away, deny or ignore the patient. This can lead to inactivity and eventually to social isolation. Better monitoring of (informal) caregivers may be needed, which unfortunately may lead to less independency for the patient.

Cognitive functioning of patients is often severely affected by stroke and problems with cognitive function affects almost all areas of daily life: ADL, relationship, participation and communication (Nijssse et al. 2015).

The patient may have attention and concentration problems in performing (complex) tasks, following conversations and reading. Some patients have memory problems and they cannot remember certain events anymore. The short term or long term memory is affected and there may be problems with recognizing persons, objects, sounds and odors (agnosia) or there may be problems with orientation in time, space and naming persons. Cognitive function is also hampered when the spatial perception is disturbed. The patient is not able to perceive and visually understand outside spatial information. For example, when the patient wants to cross the street he needs to visually understand the spatial information such as shape, position and motion of cars and bicycles.

And lastly, some patients experience trouble with planning and organizing everyday things (executive function disorder) or have difficulties with performing complex actions (apraxia). It causes frustration and is often misunderstood by the patient and the persons surrounding him.

14.3.3 Health Issues in the Field of Social Functioning and Relationships

Communication is very important in order to be able to function in daily life and to maintain relationships. (Serious) aphasia and dysarthria have major consequences for the patient and his environment, because the patient cannot express himself as he would like. To be able to function properly in the current society, communication is indispensable. Restrictions in this area mean serious restrictions in daily functioning. When communication is distorted, the relationship between partners changes completely if either of the two is unable to communicate properly. It is experienced by many patients and partners, resulting in anger, frustration and misunderstanding which can affect the relationship negatively. For the patient, maintaining social contacts is severely complicated. Not only the patient is hampered in expressing himself well, he often does not understand the humor, cannot

distinguish between main and secondary issues and doesn't understand comments that are intended figuratively.

Participation in society, such as work or social activities and relationships with friends or contacts with others, give life sense and offer joy. After a stroke, the obvious self-reliance in having social contacts conceivably has disappeared. For example, returning to work or even to work in general is not always possible for the stroke patient. The work has become too complex, the physical labor is too heavy due to fatigue, the pace of work to be done is too high and he may no longer be able to travel (driving, cycling, public transport). Furthermore, due to limitations after stroke, old hobbies and social activities may not always be possible anymore. For the search for new activities, the patient sometimes does not have the motivation and energy. Additionally, shame plays a role in social relations when a patient does not want anyone to notice that he has physical constraints, when he cannot follow a conversation properly, or has problems with communication. For that reason the patient may avoid social contacts, or others do not always understand the patient and find it difficult to get in contact. They meet someone who has changed, they do not know why he responds the way he does and are unable to communicate with him (well). This requires a lot of patience. Because some friends and colleagues drop out or because the patient himself avoids his contacts, there is the danger of social isolation.

The consequences of a stroke are significant, also when it comes to relationships. In a (long-term) relationship, certain patterns and expectations arise. Due to the consequences of stroke, these must be adjusted. The relationship between patient and partner changes from an intimate relationship into a care relationship. Older stroke patients often have an older partner and (physical) support of the patient may then become too heavy. Partners of young stroke patients have their own work, social life and the upbringing of the children. In those cases, informal caregiver strain is a risk. To conclude, the sexual relationship can change because the patient does not feel like having sex or intimacy, has erectile problems, and does not get aroused as quickly or may be sexually uninhibited. Problems in the sexual relationship may cause feelings of inferiority or aversion.

14.4 Guidance, Treatment and Care at Home

In the home situation, the stroke patient and the informal caregiver need treatment, care, guidance and information. Health care professionals use their clinical expertise, evidence based guidelines and measuring instruments to map the abovementioned (potential) health care issues.

The healthcare professionals are listening to the patient, discuss problems and search for solutions with the patient and his informal caregiver. They discuss together with the patient how he can function best at home, support patients for acceptance of disabilities and finding a new balance. They provide and stimulate self-management: the patient is encouraged to do as much as possible himself and

the informal caregiver is encouraged to do as little as possible. If necessary they seek for alternatives together with patient and partner.

In many cases, the patient still needs multidisciplinary treatment in the chronic phase to maintain their physical integrity and to prevent recurrence and secondary complications of stroke.

14.5 Advice and Information

The professional informs the patient and informal caregivers about the consequences of stroke, and advise them in the coping process. This does not solve the problems, but may stimulate acceptance of disabilities. The patient needs information about stroke, the consequences thereof and what they can do to improve or maintain the situation. Furthermore, the professional can bring the patient in contact with a patient association or stimulate contact with fellow sufferers. Professionals give advice that suits the patient's situation, such as lifestyle recommendations concerning smoking, alcohol, nutrition, overweight, exercise, stress. Also they give information about adjustments, services, orthotics, and aids. The information should be given verbally and should be supported by written material.

To prevent a recurrent stroke, cardiovascular risk management (CVRM) in the chronic phase is of great importance. It is important that the patient is aware of the risk factors. He needs to take his medication as prescribed and need to visit his general practitioner for checkups on cholesterol, blood sugar and blood pressure.

14.6 Disciplines Involved

Care in the home situation often involves many caregivers. In this section, we describe the care providers that may be involved in stroke care. For each discipline is briefly shown what care they provide (Table 14.1).

In the chronic phase, several healthcare providers are often involved in the care for the stroke patient and need to collaborate. Coordination is therefore necessary. Collaboration between different parties has a number of goals: care-based coordination, sufficient patient logistics (patient is referred at the right moment) and adequate information logistics (healthcare providers have the right information at the right time).

The multidisciplinary consultation between the healthcare providers is of great interest. Different care providers make arrangements with each other about who provides care, who is the contact for the patient and who ensures the coordination between healthcare providers. This is the process of integrated care we describe in Chap. 15. The community stroke nurse has, in most cases, an important role in this process.

The community stroke nurse is concerned with which primary care providers are involved with the patient in question. She will contact all concerned healthcare providers after discharge from hospital or rehabilitation, and coordinates the care in the

Table 14.1 Disciplines involved and care provided

Discipline	What does the care consist of?
General practitioner	Primary care in the community consists of: <ul style="list-style-type: none"> – Medication – Medical supervision – Reference to specialist – Giving information and advice
Physical therapist	The treatment is tailored to the care question and is aimed at: <ul style="list-style-type: none"> – Promote motor recovery – Optimize sensory functions – Enhance functional independence – Prevent secondary complications – Transfer training – Arm activities like reaching and supporting – Walking exercise with/without aids – CVRM, lifestyle, condition – Duplicate tasks – Functioning in home situation/work situation – ADL training – Stimulating self-management and self-reliance – Giving information and advice
Occupational therapist	The treatment is tailored to the care question and is aimed at: <ul style="list-style-type: none"> – ADL therapy – Taxability – Cognition – Arm-hand function training – Aids and adaptations – Mobility – Neglect/visibility – Giving information and advice
Speech therapist	The treatment is tailored to the care question and is aimed at: <ul style="list-style-type: none"> – Aphasia – Dysphagia – Dysarthria – Language disorder – Social contact – Hearing – Facial paralysis – Giving information and advice
Social worker	The social worker aims to improve the social functioning of persons or the interaction between persons and their social environment. Depending on the disabilities and needs of the patient and his network, the guidance is aimed at: <ul style="list-style-type: none"> – Acceptance of the disease and its consequences – Psychosocial functioning – Relationship issues – Financial issues
Dietitian	Depending on the care question, the dietitian focuses on: <ul style="list-style-type: none"> – Healthy diet – Nutritional advice on weight problems, increased cholesterol and blood pressure, diabetes – Eating and chewing problems

(continued)

Table 14.1 (continued)

Discipline	What does the care consist of?
Community care	Community care consists of personal care, nursing and counseling. Care will be provided by a community care organization
Housekeeping	Domestic care can be provided by a specialized care organization. The patient receives domestic help of the organization with which for example a municipality or care insurance has made agreements
Community stroke nurse	<p>The community stroke nurse usually works in or with a community care organization, according to the guidance and support she provides</p> <p>The community stroke nurse will assist the patient and caregiver in the home situation and focuses on:</p> <ul style="list-style-type: none"> – Patient guidance in shaping their daily life – Guidance in the mourning and acceptance process – Counseling and support of the caregiver – Stimulating self-reliance and support in improving self-management – Information about patient association and possibilities of discussion groups – Contact with other healthcare providers/agencies

home situation. Preferably there is a professional community network, in which professionals such as occupational therapists, physical therapists, speech therapists and psychologists with expertise in the field of stroke are united.

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Abstract

Time wise, the most common distinction of stroke is division to (1) acute phase, (2) rehabilitation phase, and (3) chronic/long-term care phase. There are not always clear-cut boundaries, but generally the nature and treatment goals of these phases differ substantially. The different phases of care provision, delivered by various independent providers and in different locations can make the patients' pathway rather fragmented. Integrated care can be a solution to this fragmentation by trying to achieve better connectivity, alignment and inter-sectoral cooperation. It is used synonymously to terms like coordinated or seamless care. Care organized in coordinated or integrated networks is a relatively new organizational form. It is not a 'classical' form of an organization, with a hierarchical (vertical) structure and clear decision powers. Networks are rather a joint venture, in which work is based on common goals, building relationships and trust, horizontal structure and particular provider transcending purpose. There is no hierarchical relationship in a network and no 'power' to get things done; for this it requires substantive motivation of all parties involved. Currently several approaches to measure the maturity or development of integrated care exist. For example, Minkmans' Development Model for Integrated Care takes a clinical or organisational perspective and focuses on nine elements (clusters) that are

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important for successful development of integrated care. By better care coordination or integrating providers into a network of systematically cooperating organisations, care can be improved (Mur 2003; Goodwin 2014). In this chapter we also provide examples of integrated care systems.

Keywords

Stroke · Integrated care · Stroke phases · Organization · Coordination

15.1 Introduction

Due to the complex nature of stroke and its long-lasting consequences post stroke care delivery requires good coordination and cooperation among various organizations and professionals within the health and social care sectors. To obtain optimal results for the patients, their families and the health system as a whole it is vital to assure fluid transitions between its key elements and settings—emergency, acute, post-acute rehabilitation and long-term care.

The need to assure continuity of care and better cooperation of often-fragmented services has been well recognized among professionals, managers, policy makers and researchers alike (Mur 2003; Goodwin 2014). Therefore, the concepts of care coordination or integrated care have received much attention in the last two decades as means to improve patient satisfaction and overall outcomes of care (Tummers 2012).

This chapter first describes different trajectories patient after stroke can take within the healthcare system. Then we focus on conceptualization of integrated care and why it is important to focus attention on assuring continuity of care within the cure and care systems. Further on, models of measurement of the levels of care integration are described. This might be especially relevant to those interested in further development of integrated care as the outcomes of measurements can enable to benchmark services and also to improve and optimize processes within the care provision. Finally, we provide an example of good practice and discuss how the continuum of care for stroke patients in Rotterdam area has been achieved through integration of services to one network—Rotterdam Stroke Service. We also provide an example of how professionals can improve the organization and quality of care through sharing of knowledge within the Dutch Stroke Knowledge Network.

15.2 Caring for Patients with a Stroke in Phases

Stroke results in complex needs and their treatment requires a whole spectrum of care including emergency and acute care, post-acute rehabilitation and long-term care with both in-hospital, outpatient and community-based care.

Time wise, the most common distinction is division to acute phase, rehabilitation phase and the chronic/long-term care phase. There are not always clear-cut boundaries, but generally the nature and treatment goals of these phases differ substantially.

15.2.1 Acute Phase in the Hospital

The acute phase is the first stage after the occurrence of the stroke and usually lasts a few days to 1 week. Most patients should be treated at the dedicated Stroke Units. The main objective of this phase is the prevention of brain damage and other complications. Key components are observation, diagnosis, specific treatment and stabilization of health condition. The acute phase lasts until the moment the patient is stable and the acute physical treatment has ended. The follow-up and discharge planning are important elements and are performed by a multidisciplinary team in communication with the patient or his family (Clark 2013). The central question here is where the patient can receive the care that best suits his or her possibilities and needs.

15.2.2 Rehabilitation Phase in the Rehabilitation Facility

The most intensive stroke rehabilitation programs are provided in an inpatient setting (usually rehabilitation centre) staffed by a multidisciplinary team, preferably specialized in stroke rehabilitation (Clark 2013). Patients with less severe impairment and appropriate home supports are discharged home and participate in rehabilitation programs on an outpatient basis. Those with complex care needs who are not able to benefit from or tolerate intensive rehabilitation sessions may require a slower pace rehabilitation in a regular rehabilitation department in a hospital or a skilled nursing facility. The main objective of this phase is to reduce adverse effects of the stroke, to prevent complications, and to restore functioning in daily life as much as possible. The intensive rehabilitation phase ends when there is hardly any recovery of functions.

15.2.3 Chronic Phase in the Community

Stroke is not only an acute condition, but is increasingly more recognised as a life-long condition. When it is clear that there are permanent limitations, disorders or disabilities, the chronic phase starts. The aims of this phase is to recover to the previous level of functioning or to cope with the consequences of stroke in the field of ADL, iADL, work/leisure activities. Persistent effects, visible to the environment or not, will have to be accepted by the patient. In the chronic phase, it is about acceptance, processing, learning to deal with persistent disabilities, preventing a

new stroke and supporting informal carers. At this stage, the patient is usually at home or in case of severe or too complex nursing needs in a long-term care department in a nursing home.

15.3 Pathways After Stroke

A stroke patient's encounters with the healthcare system are linked in sequence to create an episode of care that is usually called a pathway. The ideal pathway through the system of stroke care has received considerable attention in guidelines and best practice recommendations.

The most usual care pathways can be seen in Fig. 15.1 and are:

1. emergency department → acute care → home (with or without outpatient rehabilitation)
2. emergency department → acute care → intensive inpatient rehabilitation → home
3. emergency department → acute care → intensive inpatient rehabilitation → long-term care/nursing
4. emergency department → acute care → long-term care/nursing

15.4 Integrated Care

As discussed in the previous two paragraphs, different phases of care provision, delivered by various independent providers and in different locations can make the patients' pathway rather fragmented. Integrated care can be a solution to this

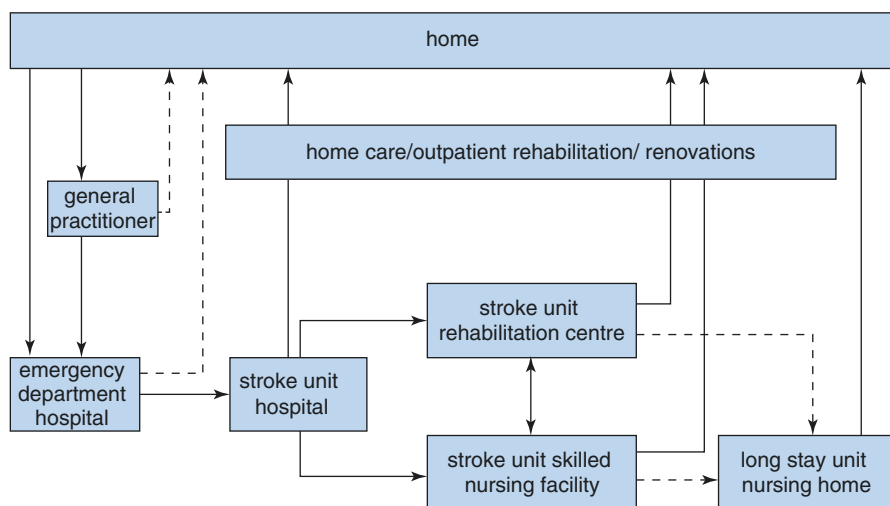


Fig. 15.1 Trajectory of a patient through the integrated system of care

fragmentation by trying to achieve better connectivity, alignment and inter-sectoral cooperation. It is used synonymously to terms like *coordinated* or *seamless care*.

15.4.1 What Is Integrated Care?

Recent review for World Health Organisation revealed there are more than 175 definitions of integrated care. Multiple definitions are common for integrated care emphasizing different aspects depending on the background of its author. Some of the definitions:

- Integrated care is care where different parties with different goals combining their efforts to improve the quality of life of a group of patients based on a new shared goal (Minkman et al. 2005).
- Integrated care entails achieving connectivity, alignment and collaboration within and between the “cure” and “care” sectors. It accomplishes this by ensuring easy links and seamless transitions for patients—both sequentially and simultaneously—at various points along the continuum of care, that is, between primary, secondary and tertiary care; between ambulatory, home-community-based and institutional care; and between medical/acute care, long-term care, mental health care, social services, and so forth (Kodner 2009).

Common features of the various definitions and integrated care models are:

A coherent person centered care supply, where different organizations within or from different sectors join forces, with a shared goal of organizing continuous and well-coordinated care for a certain patient group while taking into account the needs and goals of the individual patient and his environment instead of the interests and needs of the providers (van Dijk and Wapstra 2005).

15.4.2 Integrated Networks of Care

A care organized in coordinated or integrated networks is a relatively new organizational form. It is not a ‘classical’ form of an organization, with a hierarchical (vertical) structure and clear decision powers. Networks are rather a joint venture, in which work is based on common goals, building relationships and trust, horizontal structure and particular provider transcending purpose. There is no hierarchical relationship in a network and no ‘power’ to get things done; for this it requires substantive motivation of all parties involved (Minkman et al. 2005; Vat et al. 2016).

The organisations that participate in a network usually serve multiple patient groups. This means a varying cooperation with various partners. For example, the general practitioner, the hospital, the rehabilitation centre, the skilled nursing facility, home care agency and community rehabilitation team work together in a changing composition to serve the specific needs of patients after stroke. In addition to the

direct healthcare providers, health insurer, municipality, social services and other voluntary organizations regularly take an active part in helping people after stroke to return to regular life. These varying compositions and institutional cultures can form obstacles while building trust and good cooperative relationships that enable to work effectively across the care continuum.

Each network partner delivers independently its own contribution to the whole, but there is mutual dependence between various organizations. Although a hospital provides care to the patient independently, it does depend on the other parties in the network for a timely and correct flow of patients.

Finally, there might be conflicting interests that integrated care networks need to deal with. Independent providers in the network serve the interests of their own organizations, but at the same time are partly responsible for the interests and outcomes of the integrated network. And sometimes the interests of the network can be opposite to that of the individual organizations. Therefore, network governance needs to have mechanisms on reaching agreements and resolution of possible conflicts of interests. All this makes care networks complex organizational forms to govern.

15.5 Development Model for Integrated Care

Currently several approaches to measure the maturity or development of integrated care exist. The Maturity Model of Integrated Care, which has been developed recently, takes a whole of a system or regional perspective on the development of the integrated care (population based). It helps regions/countries to assess the maturity of integrated care from regional health system perspective. More can be learnt at <http://www.scirocco-project.eu/maturitymodel/>.

The Development Model for Integrated Care (Minkman et al. 2013; Vat et al. 2016) takes more of a clinical or organisational perspective and focuses on nine elements (clusters) that are important for successful development of integrated care. In this conceptual model, it becomes clear how cooperation works in networks and how professionals can improve care pathways. These nine clusters are the building blocks of integrated care for a specific patient group. In addition, the model shows how integrated care develops and cluster this development into four distinct phases.

Development Model for Integrated Care

1. Cluster Patient centeredness

This cluster involves matching the care and information flows to the needs of the target groups of patients. The integrated care system is able to tailor health care to individual needs or to subgroups (e.g. multimorbidity). Information is collectively offered in a language understandable to the patient and methods supporting self-management of the condition are applied.

2. Cluster Delivery system

This cluster is about streamlining care for the entire care pathway. This means adjusting cooperation among various providers, arranging right appointments (consultation, reference, research, admission and discharge) in the right time and the exchange of patient data and other information, for example through links between databases. Case management for patients with complex care needs is offered.

3. Cluster Performance management

This cluster is about naming performance and outcomes indicators and standards in order to evaluate and improve results in the integrated care system. It is about collecting and evaluation of patient-related outcomes, patient satisfaction, logistics as well as financial performance data.

4. Cluster Quality care

This cluster is about developing a multidisciplinary clinical pathway based on the needs of patients as they move through the system and on evidence-based guidelines. This requires an understanding of the needs of the patient group. Representatives of patients should be involved in developing, improving and monitoring these guidelines and how they are applied in practice.

5. Cluster results-focused learning

This cluster covers a learning climate that is aimed at the continuous improvement of results within the integrated care system. It includes a collective setting and evaluation of the goals, bottlenecks and deficiencies in the integrated care system and the sharing of knowledge in an open and supportive atmosphere.

6. Cluster Interprofessional teamwork

Interprofessional cooperation concerns cooperation between professionals. For example, working in multidisciplinary teams, describing when professionals are available/accessible to partners within the system and also defining the patient group needs the cooperation focuses on.

7. Cluster Roles and tasks

The cluster role and task distribution is about, for example, understanding each other's expertise and to agree on tasks, responsibilities and authority within the pathway. This also includes the coordination of the care pathway and coordination of the whole integrated network so that it functions effectively.

8. Cluster Commitment

This cluster is about the joint aspiration and goals of the whole of the integrated system, cooperation and commitment by executives of various institutions that are part of the integrated network. This also includes awareness that one works in an integrated care system and being aware of interdependencies among various professionals or institutions.

9. Cluster Transparent entrepreneurship

This cluster focuses on agreeing on a joint responsibility for the end result. Conditions and processes are also defined in a transparent manner, such as joint budget agreements, involvement of leaders/executives, scope on innovation and experimentation, and the use of a common language.

Development Phases of Integrated Care

Phase 1: Initiative and Design Phase

In this phase, the cooperation within organisations started or is intensified. There is a jointly recognized problem of fragmented care and also a chance and a necessity to join together to initiate better care coordination. The target group of patients' and providers' needs as well as the processes among providers have been mapped. The level of ambition, the motivation of those involved and the commitment of leaders determine the progress. On the basis of agreed goals and confidence level, a multi-disciplinary team creates a design for an experiment or a cooperation project which may be recorded in a letter of cooperation or intent.

Phase 2: Experiment and Execution Phase

Projects or experiments are performed. The goals and content of the cooperation are strengthened and care pathways are being developed and recorded. There is alignment between system partners through intense consultations and by appointing a person with a coordinating role. Information about processes, target groups, knowledge and skills are exchanged systematically among partners. Results are evaluated and thereafter common goals are updated. Framework and conditions for common projects are created and covered through joint engagements or resources.

Phase 3: Expansion and Monitoring Phase

The cooperation projects are embedded in an integrated care system. Agreements on content, tasks and roles of different stakeholders has been achieved and the organization of care pathway is clear and fixed. The cooperation of organisations is not optional anymore, but embedded within the system. The results and themes for improvement are systematically monitored and implemented. The population of patients is defined. More initiatives are following, such as development of training programs, exchange of staff, sharing or information etc. Financing of care coordination based on structural and regular resources has been established. There is a continuous commitment and an ambition to improve the system further.

Phase 4: Consolidation and Transformation Phase

The integrated care has become the regular organisational form. A coordination point on the system level has been introduced, information is shared and transferred. Organizational/governing structures of the network have been newly designed around the integrated care system. Financing is regulated within integrated care system contracts between provider(s) and funders. There is continuous strive for improvement and analysis of changing clients and stakeholder needs. The teams use successful results and experience for further development. New possibilities of cooperation are explored and weighted. A monitoring and benchmarking system periodically shows where results are being sustained and where improvement is possible.

15.6 How Can Integrated Care Improve Outcomes?

As previously discussed, integrated care is usually necessary for patients with complex health care needs that one provider may not individually cover. By better care coordination or integrating providers into a network of systematically cooperating organisations care can be improved. For example:

- A patient reaches the right caregiver, in the right place and the right time (access to services, continuity and timing improves,)
- Information and knowledge are shared—e.g. through shared (electronic) medical/care records;
- Duplicity and double execution of operations/scans or tests decreases;
- Gaps (incompleteness) in healthcare is prevented (reduction of fragmentation);
- More person centered care, tailored to the needs of the patients and their families;
- Increased patient and family caregiver satisfaction;
- More efficient and effective use of resources;
- Increased staff satisfaction and motivation;

By making arrangements with organizations within integrated care and by improvements in knowledge and information exchange among professionals, double execution of work and gaps in the care process can be reduced.

- An example of double execution of work is administering functional tests in the hospital, and a day later administering the same tests in the rehabilitation facility.
- Gaps mean that not all the necessary care is provided or professionals do not perform all the recommended actions. As a result, a patient may fall out of the system being without care that he or she would need to receive. Another example is that professionals might not have sufficient information to make the right decisions.

Double execution of work and gaps in the care process can be reduced by:

- applying person centered approach to care planning;
- discharge planning done by a multi-professional team;
- sharing of an agreed set of information;
- having a common goal;
- working together in a continuous manner;
- making agreements about care processes and transfers;
- having effective communication;
- coordinating care by dedicated personnel;

15.7 Organization of an Integrated Care System of Care/ Integrated Network of Providers

To provide the right care at the right place and the right time by the right provider, partners in the network must make various agreements with each other. These agreements may include:

- Agreements about the content of the treatment and care
- This can include the type of medication, measurement instruments (functional tests), and the use of guidelines and protocols.
- Agreements about the logistics
- These include agreements on capacity and admission pace, but also triage agreements (which patient goes to what type of rehabilitation setting).
- Agreements on the transfer of information
- This includes both information transfer agreements between professionals (type, content and timeliness of information) as well as information to the patient or his family.
- Agreements on financing care coordination and the integrated care system
- This includes agreements among providers or with health insurance companies on financing of care coordination across the integrated care system and financing of work connected to network governance/management.
- Agreements on knowledge sharing and exchange.
- For example, what educational/good practice activities should be organized, competency criteria, how new care approaches will be shared, specific hours that a specific professional should be present at the workplace to give consultations to others.

15.8 An Example of an Integrated Care System: Rotterdam Stroke Service

In Rotterdam in the Netherlands, hospitals, skilled nursing facilities, rehabilitation centres and community care work closely together within the integrated network of providers to organize care for patients with a stroke. Together, they ensure that stroke patients receive the highest possible quality of care, at the right time, by the right provider and at the right place. Together these institutions, organised locally into sub-networks, form the larger network Rotterdam Stroke Service (RSS). RSS is an integrated network of healthcare providers with the aim of providing the best possible care for patients with a stroke (www.rotterdamstrokeservice.nl).

The mission of the Rotterdam Stroke Service is *‘Achieving the best possible quality of life for every stroke patient in the Rotterdam region, based on current best practice and recommendations for the stroke care.’* The RSS is formed by several locally based sub-integrated care systems (hospital, local rehabilitation centre, skilled nursing facilities and home care and community care professionals) and governed by the board of directors of these institutions. The network is coordinated by network wide coordinator and eight sub-coordinators (coordinating each of the local networks).

There is a mix of different areas of practice, education and research, which form the basis of cooperation among partners in the network, mainly:

- Strengthening cooperation and communication:
 - governance and coordination of the whole network
 - defining shared goals and missions relevant for the whole network
 - organizing conferences for all institutions in the network;
 - organizing meetings between some institutions;
 - developing integrated information system;
 - developing website and newsletter;
 - sharing knowledge at regional and (inter)national congresses;
 - supporting other parties at project level;
- monitoring and improving quality and content of the integrated care system:
 - executing integrated care protocols;
 - monitoring the quality requirements;
 - organizing trainings for staff;
 - auditing and reviewing providers and sub-networks;
 - collecting, sharing and evaluating data;
 - adjusting of activities based on outcomes that can be improved;
- contact with external parties to link regional, national and international developments to the Rotterdam area:
 - membership in The Stroke Knowledge Network The Netherlands (www.kennisnetwerkcva.nl);
 - following laws and regulations;
 - perform activities on international Stroke Day.

15.9 Dutch Stroke Knowledge Network

The Dutch Foundation Stroke Knowledge Network aims to stimulate further improvement of care nationwide for patients with stroke. The foundation wishes to achieve this goal, among other things, by:

- encouraging stroke services in the Netherlands to exchange knowledge and experiences and to support them in doing so;
- reporting on certain quality of care indicators;
- providing information to professionals, patients and carers;
- establishing a training program (central and/or decentralized);
- stimulating coordination in the integrated care systems;
- stakeholder representation at agencies such as ministry of social services, health care insurers, professional associations;
- being initiator and stimulator of quality improvement;
- participating in research activities;
- developing information material.

Working groups have been set up to achieve these goals. The directors are easily accessible and many professionals share their knowledge on the website. There is also a forum on the website where various questions are asked and answered by colleagues in the country (www.kennisnetwerkcva.nl).

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An Example: Course Developed in the Rotterdam Stroke Service (The Netherlands)

16

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Abstract

The course in this book is intended for Licensed Practical Nurses, Registered Nurses (RN) and Advanced Practice Registered Nurses (APRN) working on a stroke unit in a skilled nursing facility and/or rehabilitation center. We used a competence profile to clarify what the level of education is and what is expected during and after the course, so that the results of the education can also be guaranteed in practice. The competence profile is based on the model ‘Miller’s Pyramid’ which is briefly described in this chapter. We discuss the core competences of nurses using the terms: “Knows”, “Knows how”, “Shows how” and “Does”. The top level of the pyramid concerns independent acting in complex situations. This requires an integrated whole of knowledge, skills, attitude and personal qualities. A student who works well at the level ‘Does’ can be considered competent. The stroke rehabilitation course for nurses concludes with a final assignment. This consists of writing a paper and presenting the findings to the group. In this chapter the criteria for the paper are described.

Keywords

Stroke · Nurse · Course · Millers pyramid · Competence profile

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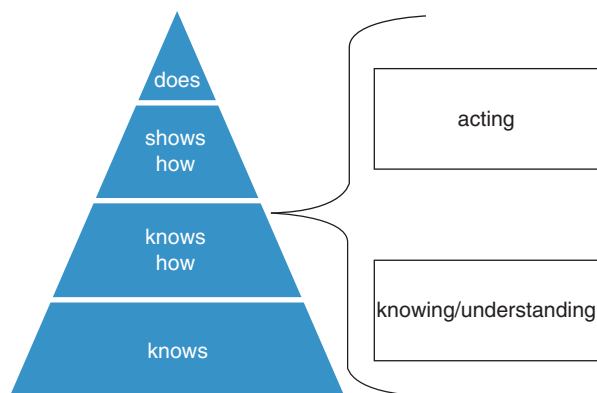


Fig. 16.1 Pyramid of Miller

16.1 Introduction

Based on this book, the Rotterdam Stroke Service (RSS) has developed a 7-day course for nurses which focusses on rehabilitation, education, prevention, care and support of patients with stroke (and their relatives). The course is intended for Licensed Practical Nurses, Registered Nurses (RN) and Advanced Practice Registered Nurses (APRN) working on a stroke unit in a skilled nursing facility and/or rehabilitation center. The course has been developed by members of the various institutions that are affiliated with the RSS, and the book is used to prepare the lessons of the course. Throughout the course, the pyramid of Miller is used as a competence profile (Miller 1990).

16.2 Competence Profile: Pyramid of Miller

This competence profile has been drawn up to clarify what the level of education is and what is expected during and after the course, so that the results of the education can also be guaranteed in practice. The competence profile is based on the model ‘Miller’s Pyramid’ (Fig. 16.1), which is briefly described in this section.

In the context of education, Miller uses a pyramid to draw the levels on which the competencies of the participants can be described. Underlying levels always form the basis for the above layer (Miller 1990).

Knows

The lowest level is the knowledge that a student must have to be able to perform the tasks as a nurse on the stroke unit.

Knows How

At this level, nurses know how to apply the acquired knowledge to the stroke patient and their environment.

Shows How

On the third level, the student shows in a supervised situation that he/she can take care of a stroke patient. This involves knowledge and action (cognition and behavior). The student not only knows how to take care of the patient, but also shows that he/she can actually do this.

Does

The top level of the pyramid concerns independent acting in complex situations. This requires an integrated whole of knowledge, skills, attitude and personal qualities. A student who works well at the level 'Does' can be considered competent.

After completion of the course, the student should be competent and have an integrated whole of knowledge, skills and attitude necessary for taking care of patients with stroke.

16.3 Core Competencies

Core Competence 1: Stroke-Specific Knowledge and Skills

The nurses have knowledge of specific symptoms of stroke and the limitations after stroke, and they are skilled in applying methods and interventions to address this. The following knowledge aspects are specifically intended to provide care to stroke patients (see box).

Core competence 1

Knows

The students know:

- causes and symptoms of various types of stroke (i.e. infarction, TIA, bleeding, SAB);
- mechanisms of neurological and functional recovery of disorders and limitations in the field of cognition, emotion and behavior, and the interventions they can apply;

- physical disorders and limitations, such as disabilities in strength, tone, coordination and balance;
- disorders and limitations of sensitivity and visibility;
- disorders and limitations in the field of communication (aphasia/dysarthria) and the interventions they can apply;
- shoulder/hand problems and interventions;
- swallowing disorders and interventions;
- bladder/bowel problems and interventions;
- restrictions and interventions in the field of ADL;
- multidisciplinary diagnosis and treatment offered during the acute phase;
- after-care interventions (prevention, advice, information and post-treatment);
- observation methods according to ‘what/how/why’;
- purpose, necessity and methods for the multidisciplinary rehabilitative caring/nursing;
- phases of integrated care.

Knows How

The students recognize and know how to deal with:

- disorders and limitations in the field of cognition, emotion and behavior;
- disorders and limitations in the field of communication (aphasia/dysarthria);
- shoulder/hand problems;
- swallowing disorders;
- bladder/bowel problems;
- restrictions in terms of ADL;

The students know how to:

- inform the stroke patient and his informal caregiver and advise on interventions that promote health, well-being and/or daily functioning during the rehabilitation period;
- inform the stroke patient and his informal caregiver and advise on post-care options (prevention, advice, information and post-treatment);
- through information transfer and multidisciplinary care, contribute to a qualitative and efficient continuity of care for the stroke patient (integrated care).

Shows How

The students can:

- apply strategies and interventions if there are disorders and limitations in cognition, emotion and behavior;
- apply strategies and interventions if there are disorders and limitations in the field of communication (aphasia/dysarthria);
- prevent or reduce shoulder/hand problems;
- apply interventions in case of swallowing disorders;
- apply interventions in case of bladder/bowel problems;
- apply strategies and techniques if there are limitations in the field of ADL;
- interpreting and using transfer information from the acute phase for continuation of the rehabilitation process;
- transfer information to after care for the quality and continuity of rehabilitation/care;
- observe the ‘what/how/why’ observation methodology and report and interpret this data objectively;
- signal and use training opportunities in daily care in line with the multidisciplinary rehabilitation plan;
- identify limitations, objectives, and interventions and name them as part of the rehabilitation plan.

The students:

- work in a targeted manner towards the stroke-specific goals as stated in the multidisciplinary rehabilitation plan;
- contribute to a rehabilitation-supporting climate;
- contribute to a stroke-specific professional multidisciplinary team and provide continuity of care (integrated care).

Does

The students:

- apply rehabilitative care in practice;
- act from the perspective of the patient and apply interventions that are feasible for a rehabilitative stroke patient;
- are able to negotiate with the rehabilitative stroke patient on a way in which the care/nursing component of the rehabilitation plan is completed;
- can move into the experience world of a rehabilitating stroke patient (shows empathy) and adjust the speed, communication and guidance based on this;
- can prepare, implement and adjust the care/nursing component of the multidisciplinary rehabilitation plan.

Core Competency 2: Cooperation

Nurses are able to effectively and efficiently work together with different professionals in the integrated care service.

This core competence includes various types of cooperation. First of all, it involves peer cooperation in a multidisciplinary setting both inside and outside the organization the nurse herself is working in: the integrated care system. The objective of integrated care is to provide continuity of care and that one adjusts the care and treatment to the ever-changing health needs of the stroke patient during the various phases (acute phase, rehabilitation phase, chronic phase). Lastly, the cooperation with the families of the stroke patient is also included in this core competence.

Core Competency 2

Knows

The students:

- know which disciplines are experts in the various problem areas of the stroke patient;
- know what integrated care is and what the importance is for the stroke patient;
- know that they themselves, and their own organization, are a link in the entire integrated care service;
- know common stroke-specific regional/national/international organizations and information networks;
- know the impact of impairments and limitations as a result of stroke on the families of the stroke patient.

Knows How

The students:

- know ways to access stroke-specific regional/national/international organizations and information networks;
- know how to involve different disciplines in the integrated care service;
- know how they can help the patient and his informal caregivers to cope with the consequences of stroke.

Shows How

The students:

- identify the need to involve the various disciplines and take action in accordance with mutual and standardized agreements;
- make use of expertise of professionals in the integrated care service and information from stroke-specific organizations/networks.

Does

The students:

- guard the self-reliance of the stroke patient in the overall care and encourage cooperation of the patients and their informal caregivers in this;
- communicate in a professional manner with the stroke patient, his informal caregivers, colleagues from the multidisciplinary team and within the integrated care system;
- can professionally communicate with the stroke patient and his relatives;
- signal the need for coordination/management between professionals and put the questions and issues arise thereof, in the concerned organizations.

Core Competency 3: Professionalism

The caretakers and nurses know (the limits of) their own expertise, work according to the most recent developments and standards related to stroke and use internal and external resources (Evidence Based Practice), so that optimal quality of care is provided.

Core Competency 3**Knows**

The students:

- know that there are national and regional stroke-specific protocols;
- know the importance of stroke-specific subject-related developments;
- know their own strong and weak (communication) skills in taking care of the patient and ask for help when necessary;
- are familiar with the relevant legal frameworks within which the rehabilitation care is given to stroke patients.

Knows How

The students:

- know how access can be obtained to regional and national stroke-specific protocols;
- know how access can be obtained to stroke-specific subject-related developments;
- know how to test their own actions in regards to stroke-specific protocols and developments.

Shows How

The students:

- A view to rehabilitation? Is that a better translation?
- show that they can work according to relevant stroke-specific protocols and professional standards and developments;
- find ways to further develop themselves.

Does

The students:

- integrate and implement the most recent developments, guidelines, protocols, and views in rehabilitation in daily practice;
- integrate their own expertise in the development of rehabilitation care in daily practice.

16.4 Final Assignment

The stroke rehabilitation course for nurses concludes with a final assignment. This consists of writing a paper and presenting the findings to the group on the 7th and final day of the course.

16.5 Objective Final Assignment

The final assignment completes the course, and students show that they have gained research skills and are also willing to look further than their own organization. The final assignment has to be based on a problem statement.

In the final assignment the students evolve their competences and those of other nurses. Improving the quality of care for the stroke patient is the main subject in this assignment.

After completing the final assignment they will be able to:

- find targeted information about stroke and related topics from theory and practice;
- compare/integrate theory and practice on stroke and related topics;
- signal developments in the care of stroke patients from their *own role* as a nurse;
- write a final assignment that gives an insight into a stroke-related theme from a nursing perspective.

16.6 Choice of Theme

For the choice of a theme for the final assignment, the theme must meet the following criteria:

- the theme is relevant to the stroke patient and the caregivers/nurses;
- the theme is applicable in practice;
- the research questions are relevant;
- there is sufficient literature or other sources (e.g. interview candidates, questionnaire) available to answer the research questions;
- there is adequate scope for self-contribution and reflection.

16.7 Number of Participants

The final assignment is made in groups, with at least two and up to three people. The group members monitor the task distribution and proportionality in their work. It must be clear what everyone's share has been. The groups must submit their group composition and the theme to the teacher for evaluation and guidance.

16.8 Guidance and Assessment

Participants are responsible for arranging any guidance from their own organization, for example an experienced colleague or practice trainer.

The assignments and presentations are assessed by a committee from the Rotterdam Stroke Service.

16.9 Structure of the Report

On the front page of the report, the title of the assignment is mentioned; for example: ‘Communication Plan for Multidisciplinary Cooperation’. In addition, the following information is written at the bottom of the page in the following order:

- given name, sur name
- organizations;
- date.

16.9.1 Introduction

In the introduction, the students give the reason for the theme of the assignment. The introduction covers the following;

- the students introduce themselves;
- they indicate the framework in which the assignment was written;
- describes why this theme was chosen;
- introduction of the organization (institution and department) where they work;
- brief description on how the report was built (a brief introduction to all chapters).
- acknowledge the people who have contributed to the content of the work.

16.9.2 Summary

In the summary, the most important topics presented in the report are briefly described. The summary is up to one page long. In any case, the following topics are discussed:

- the theme of the assignment;
- background of the theme;
- the models used for the plan and the research method used;
- results of the research;
- discussion, conclusions and recommendations that follow from the research.

16.9.3 Chapter 1: Background

In Chap. 1 the background of the theme will be explained. This chapter comprises a maximum of two pages. The students use literature and references.

In the background the students describe the following points:

- the problem definition;
- objective and research questions.

16.9.3.1 Problem Definition

What kind of challenge do they have on their department in the rehabilitation care for patients with stroke? What has been found in the literature concerning this theme?

16.9.3.2 Objective

What do they want to achieve with this assignment regarding the problem? Objectives are often too vague and formulated in a non-binding manner, such as wishes, intentions, or resolutions. Successful objectives clearly reflect the direction to be worked in and the time frame in which results should be achieved. To formulate an objective successfully, it is important to formulate this in a SMART manner.

SMART stands for:

- *Specific*: The result must be clearly and concretely defined. It must be a perceptible action.
- *Measurable*: it should be possible to indicate the quantity or percentages in quantity (how much?), in quality (how good?), in time (how long? When done?) Or in cash (costs?).
- *Acceptable* or demonstrable: there must be support. It must be clear who needs to do what to achieve the objective.
- *Realistic*: Is the objective achievable? Can the objective be achieved?
- *Time-bound*: the term within which the desired result, the objective, must be achieved. Short-term objectives must be SMART; for long-term objectives this is not always possible.

16.9.3.3 Research Questions

De students formulate a main research question and multiple secondary questions.

16.9.4 Chapter 2: Methods

Chapter 2 comprises the methodology of the assignment. The students describe the used methodology precise and concisely. The students are using literature and references.

In Chap. 2 there is description of:

- the analysis of the problem statement.
- how the information was gathered, which research methods?
- which methodology have been used in this assignment (literature study, interviews, questionnaire).
- how the information was analyzed?
- what sources have been used?
- how did the expertise of persons of the integrated care service help in the process?
- what is the role of the nurse?

16.9.5 Chapter 3: Results

Chapter 3 comprises the results of the assignment. For better readability, the students divide the text into paragraphs. For each sub-topic or research question the students make a paragraph. The results of the research are described briefly, without giving context to the results. It is recommended to use tables, figures and text. The students do not use literature and references in this chapter!

16.9.6 Chapter 4: Discussion

The most important results are mentioned and discussed in the discussion. There is a paragraph for every single important result. The students use literature and references in this chapter.

1. The discussion starts with a paragraph in which the main research question is answered.
2. There are no new issues emerging in the discussion.
3. There is a comparison been made between theory and practice.
4. There is a specific paragraph with strengths and limitations.
5. Every paragraph in which results are discussed comprise the following:
 - (a) What has been found in this research?
 - (b) What do other authors write: description of differences and similarities
 - (c) What is the meaning of these results for practice?
 - (d) Brief conclusion of this particular finding and recommendation for the future

16.9.7 Chapter 5: Conclusions and Recommendations

The final chapter contains the conclusions and recommendations.

16.9.7.1 Conclusion

The conclusion is the general conclusion of the research. What has been found and what are the implications for practice and further research?

16.9.7.2 Recommendations

Recommendations are advice to solve the problem. In the recommendations the students describe:

- what steps should be taken to use the solution in practice;
- the motivation for the recommendation (why do they recommend this?);
- what is the role of the nurse concerning this recommendation?

16.9.8 References

The reference list follows the last chapter. This includes all written sources (books, articles, websites/internet, etc.) that are consulted during the research and referred to in background, method and discussion. Herein, also mentioned which people were interviewed.

Without literature, the results of the final assignment are not credible. It is not possible to judge where the information comes from, if the students haven't used literature. The purpose of a reference list is that the reader can retrieve the information source himself. To be able to find literature, the following must be known:

- web page: the full page address and date of access.
- book: author(s), year of issue, title, place and publisher;
- article: author (s), title, title of journal, year, edition, and any page numbers.

The reference list is drawn up in alphabetical order.

Students need to use reliable websites, articles and literature. They can search via Google or PubMed (<https://www.ncbi.nlm.nih.gov/pubmed/>) for (full text) articles.

16.9.9 Attachments

In the attachments, the information is included that is closely related to, or part of, the assignment, but which can be placed better outside the document for technical reasons. They serve to support the document. In particular, this applies for example to extended tables, questionnaires of a survey, checklists, extensive schedules and legal guidelines. Only attachments which are referred to in the text, are included.

16.10 Presentation

Students need to present their research to the other nurses in the course. The research-questions, findings and recommendations are discussed. The presentation must meet the following criteria:

- made in PowerPoint or Prezi;
- may not take more than 15 min;
- up to ten slides.

Some tips for presenting:

Structure of a Presentation

- Presentations are created in Microsoft PowerPoint (PP) or Prezi.
- A presentation has a title page (title and authors/group members).

- A good visual organization of heads and paragraphs. A clear head indicates what this slide is about.
- The text on the slides is short. These are summaries that relate to what you are going to say.
- Fonts and color: Use easy-to-read fonts, not too small (*not* less than 18 points). If using color, note the color contrast of the text and the background. Make the contrast big, the text is then easy to read. Use good, calm color combinations. Also consider people with color blindness, do not put red on green or vice versa, which cannot be distinguished for them.
- Effects: Use transition effects (sounds, animations) to a degree, only use where they have added value to the presentation.
- Use pictures, charts, and other supporting visual images only where they provide a clear added value for the presentation. If used properly, images can be very powerful so you do not have to avoid them!
- Do not make spelling or grammar errors.

Content of a Presentation

- Make the purpose of the presentation clear immediately and do not add lateral information (i.e. what you are going to do and why, then do it, and do not go too far in this unnecessarily).
- Provide a clear structure in your presentation: Introduction, methods, results, discussion, conclusion, etc. (head, tail and structured center). Let the presentation connect to the listeners.
- Know what you're talking about! Know your theory, so that you can answer questions about it. Keep the listeners oriented, do they know where you are in your presentation?
- Also in terms of content, pictures, charts, all these must add value. It must have a clear goal that is related to your presentation topic, and the relationship must be clear to all.
- Keep the presentation within the given time limits.
- Make connection with your audience: eye contact, comments.
- Pronunciation: A good volume, not too fast, no uuhhs, hmmms, pronounce all words well and use standard formal language.

Reference

Miller GE. The assessment of clinical skills/competence/performance. Acad Med. 1990;65(9):63–7. PubMed: <https://www.ncbi.nlm.nih.gov/pubmed>. Consulted on December 5, 2017.