

Quality of life with Polyneuropathy autoimmune disease: CIDP and Guillain-Barrè Syndrome

A literature review

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<p>Abstract:</p> <p>The aim in this thesis is to increase knowledge about these rare neurological illnesses and to discover factors in the care in order to promote the patient wellbeing and quality of life. The study was carried out as a qualitative literature review. In addition, as a part to the background studies, patient comments were viewed from online discussion groups in order to gain deeper insight to the topic, and 10 books and 24 additional articles were studied. Data analysis of the literature was conducted using qualitative content analysis. The data was collected from 5 different databases, along with manual search from books. A total of 11 articles were selected and analyzed for the study using Search engines such as EBSCO, Cochrane, MedlinePlus, PubMed and Sage.</p> <p>This thesis was conducted in cooperation with Arcada University of Applied Sciences and the Helsinki University Hospital Neurological Unit Research Doctor, Mika Saarela. The purpose of this thesis was to explore and illustrate the nursing interventions for promoting factors, such as resilience and pain management, which affect the patient's quality of life in GBS/CIDP.</p> <p>According to the findings, the Nurse's ability to recognize the symptoms related to GBS and CIDP and early intervention in the care, together with the doctor's diagnosis, medical treatment and rehabilitation provided by the multi-professional team, is the key to provide the best available care to the patient with either GBS or CIDP. Becoming ill with GBS/CIDP affects the mental state of the patient. Nursing skills such as, listening and empathy, as well as, the ability to recognize developing anxiety in patients, are vital for the prevention of mental illnesses.</p> <p>The limited amount of research in the field of neurology relating to this topic provides the basis for future study.</p>	
Keywords:	Guillain-Barré Syndrome, Chronic Inflammatory Demyelinating Polyneuropathy, chronic pain, neuropathic pain, resilience, quality of life, nursing interventions for GBS/CIDP, medication for GBS/CIDP, holistic care, rehabilitation. Levine's Conservation Theory
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<p>Tiivistelmä:</p> <p>Tutkimuksen tarkoitus on lisätä tietoa näistä harvinaisista neurologisista sairauksista ja löytää hoitotyön keinoja potilaan hyvinvoinnin ja elämänlaadun edistämiseksi. Tutkimus toteutettiin kvalitatiivisena kirjallisuuskatsauksena. Lisäksi osana taustatutkimuksia tarkasteltiin potilaskommentteja Internetissä avoimilla tukiryhmien keskustelupalstoilla, tarkoituksena kerätä lisää tietoa taustatutkimusta varten sekä tutustua potilasnäkökulmien kautta aiheeseen. Tietojen analysointi kirjallisuuskatsauksessa suoritettiin käyttämällä laadullista sisällön analyysiä. Aineisto kerättiin 5 eri tietokannasta sekä lisäksi manuaalisesti kirjallisuudesta. Taustatutkimusta varten tarkasteltiin 10 kirjaa ja 24 tieteellistä artikkelia, kirjallisuuskatsauksessa käytettiin lisäksi 11 eri artikkelia.</p> <p>Yhteensä 11 artikkelia valittiin ja analysoitiin tutkimukseen käyttämällä hakukoneita kuten EBSCO, Cochrane, MedlinePlus, PubMed ja Sage. Opinnäytetyö toteutettiin yhteistyössä ammattikorkeakoulu Arcadan ja HYKS Neurologia yksikön kanssa. Tämän opinnäytetyön aiheena oli tutkia ja kuvata hoitotyön edistämiseksi tekijöitä, kuten resilienssiä ja kivunhoitoa, jotka suurimpina tekijöinä vaikuttavat GBS- ja CIDP potilaiden elämänlaatuun.</p> <p>Sairaanhoitajan kyky tunnistaa yllämainittujen sairauksien ensi-oireet yhdessä varhaisen hoitoon ohjauksen kanssa, sekä nopea lääkehoidon toteutus ja riittävät kuntoutusmahdollisuudet yhdessä moni-ammattillisen tukiryhmän voimin, ovat avainasemassa, jotta potilaalle voitaisiin tarjota parasta saatavilla olevaa hoitoa. GBS:aan ja CIDP:hen sairastumisella on vaikutus potilaan mielenterveyteen. Sairaanhoitajan kyky empatiaan ja kyky kuunnella potilasta hoitotoimien yhteydessä ovat tärkeitä mahdollisten ahdistuksen tai masennuksen alkuaireiden tunnistamiseksi.</p> <p>Sairaudet, erityisesti CIDP, ovat erityisen vähän tutkittuja, erityisesti hoitotieteen alalla ja Suomessa yleensäkin. Tämän vuoksi lisätutkimus alalla on tarpeen ja toivottavaa.</p>	
Avainsanat:	GBS, CIDP, polyneuropatia, neuropaattinen kipu, resilienssi, elämänlaatu, hyvinvointi, terveyden edistäminen, GBS/CIDP:n lääkehoito, kuntoutus, Levine's Conservation Theory
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FOREWORD

First of all, I would like to thank Mika Saarela for support, commissioning my thesis and encouraging me forward with the Nursing studies. Great support has also been my family: Kalle, Lumi and Stella, who have provided emotional support in coping with the study related stress. Thank you for being there for me. Special thanks to Tuula, who has given me insight to the life with CIDP, and ideas and inspiration for writing this thesis. Hopefully you will benefit from this study somehow as well.

Finally, I would like to thank my teachers in Arcada, especially Pamela Gray who has been a great support during the process, not only in providing instructions to the writing, but also by being there to encourage me throughout the whole process. Many thanks!

1 INTRODUCTION

The purpose of this thesis is to review and critically analyse scientific literature from two rare polyneuropathy autoimmune diseases: CIDP (chronic inflammatory demyelinating polyneuropathy) and GBS (Guillain-Barrè syndrome).

The aim of the thesis is to work as a study, which can be later used as a basis for an informative leaflet for a GBS/CIDP patient or other person of interest. This thesis may, in addition, operate as an informative package to both nurses and nursing students who wish to increase their knowledge about these rare neurological illnesses. Commissioner of this thesis is Medical Doctor Mika Saarela from HUS Neurological Ward in Meilahti Hospital, Helsinki. Saarela is a specialist in the field of Polyneuropathy illnesses in Finland and a member of The Peripheral Nerve Society.

The study is written from the nursing perspective for nursing students and other readers interested in the field. In the beginning it is essential to highlight the fact that the existing studies, articles and other literature relating to the two illnesses in question, are mainly a production of doctors and physiotherapists. The author of this thesis has not yet found literature dealing with GBS/CIDP, which is written from the nursing perspective. Thus this limits the study area and also brings additional challenge and interest to the thesis and research. Another reason why this area of study was chosen is because of personal interest in the field. Also, to the investigation of, the existing care and nursing methods for CIDP. GBS was added to the topic because of the similarity to CIDP and the scarce information available for CIDP. A vocabulary, list of abbreviations and concepts, is presented in the Appendix 3 in order to enhance the readability.

The background study in chapter 2 summarizes the data beginning with the brief description of the diseases, symptoms. Next, is introduced, some of the available care methods. The subclasses of the illnesses are left out of the study, purposefully, in order to limit the subject area, since there are other existing studies, for example in the field of physiotherapy, with similar topics.

This study, attempts to define some of the nurses' aims in promoting the patient quality of life and the effect of resilience and pain in an individual who is coping with an illness. The findings are introduced in chapter 6.

In addition, the thesis aims to view quality of life from the holistic perspective, which includes not only the patient, but also the family, friends and third sector support groups. The perspective is taken in the study by reviewing comments in online discussion groups provided for GBS-CIPD patients mainly in the Canada and US area. The domestic perspective is gained in studying some of the support groups provided Neuroliitto (Finnish foundation of Neurological diseases) as a part of the background studies.

The final chapter 8 introduces conclusions and suggestions to improve the patient quality of life. Also the need for further research is discussed in the final part of the thesis.

Since this is a Bachelors' degree in nursing -thesis, the work is completed from the nurse's perspective, even though the chapter 2 discusses the diagnoses of the diseases on a more general level, from the medical perspective. The medical discussion is essential in this context, in order to provide the reader of the thesis with a more complete understanding of the subject.

2 BACKGROUND

One of the aims of this thesis was to raise awareness of the two rare neurological conditions. It is important for nurses to identify and differentiate a neurological condition from other common stress related symptoms, which might drive people to contact the health care centre.

The inspiration and idea to write this thesis rose from a relative's personal experience, when she went to the healthcare centre because of tingling sensation in the feet and a sudden, very strong muscle weakness. The nurse advised the patient to take some ibuprofen and observe the effects. The nurse thought it was just a stress related condition. The person in question called the healthcare centre later that week and insisted to see a doctor. The doctor's advice was the same, take ibuprofen and massage to the neck. She had no fever, thus the presence of infection was ruled out. She was booked an appointment to a private clinic neurologist. She got the diagnosis. It was CIDP.

The intention here is not to criticize public health care professionals, but to highlight the importance of increase awareness concerning rare neurological conditions, which require immediate actions and treatment in order to be stopped from spreading and damaging the whole nervous system permanently. Naturally, doctors are always the ones doing diagnoses, nevertheless nurses should be able to evaluate and differentiate the condition of the patient that requires an immediate appointment with the doctor for further investigations. After having read this thesis, the reader should have a general picture about the illnesses in question and how they affect a patient's quality of life.

In the following are introduced some patient comments from online support forums to give more insight the background of the chosen topic: *“ I was 24 when I woke up one morning and had pins and needles feeling in the opposite arm and leg. I thought it was a pinched nerve at first but as the day went on both arms and legs were feeling the same; I went to the ER and they called a neurologist who wanted to do a spinal tap to rule out multiple sclerosis. They came back and said it was Guillain-Barrè syndrome (GBS). I was paralyzed from the neck down, had to have a tracheotomy and plasma fluoresces. It took at least a full year to recover, which included physical and*

occupational to learn to walk and function.” Comment from: Nina, 55-66 (Medicinet.com).

“ Last may I got a Tetanus Booster. Two weeks later my fingers and toes started going numb. I consulted my Dr who said I was low in Folate? Anyway, things worsened, September I was diagnosed with CIDP.” Comment from: Eric,46. (www.experienceproject.com/reviews).

The quotations above illustrate the aspects of the two illnesses studied for this thesis. Common to both Guillain-Barré Syndrome (GBS) and chronic inflammatory demyelinating polyneuropathy (CIDP), is the fact that they are demyelinating neuropathies, which have similar symptoms and treatment methods (Hietaharju, 2007; Färkkilä, 2016.)

Demyelination is the damage, which occurs in the myelin. Myelin is an insulating material, which when damaged or worn away, has a decreasing effect to the function of the nerve. Recovery is possible, since the Schwann cells have the ability to mitose and remyelinate the nerves. However, in some cases the Schwann cell's basement membrane can make the production of myelin impossible. In GBS the prognosis is said to be generally better when the damage affects the myelin sheath and not the myelin itself. When the damage has affected the axons of the peripheral nerves, their roots, the resumption of nervous activity will take much longer (McMahon-Parkes, et al 1997, p.43.)

Both GBS and CIDP belong to the group of autoimmune diseases, which have also become more common in recent years, since more than 80 clinically distinct autoimmune diseases have been recently discovered and 5-8% of the Finnish population is afflicted within the last years (Julkunen, et al 2011.)

Whilst the majority patients diagnosed with chronic-onset CIDP have a progressive or relapse-phase of 8 weeks or more, there are patients ultimately diagnosed with CIDP who have an acute onset similar to Guillain-Barré syndrome (GBS). Up to 16 percent of all CIDP patients may become apparent to the GBS. Patients initially diagnosed with GBS may develop 'acute-onset CIDP' in situations where deterioration progresses over

two months period from onset or if the impairment continues over three-months, treatment-related fluctuations occur. GBS patients with noticeable sensory symptoms and signs of decreased performance, should be suspected to have ‘Acute-onset CIDP’ (Van den Bergh, et al 2010.)

GBS and CIDP are classified as rare neurological illnesses, and are not as commonly known as Multiple sclerosis, for instance. CIDP diagnostics criteria has improved in recent years, which makes the area of study very interesting. Currently the illness is rare and not well known among medical professionals in other fields than neurology, especially nurses, who are not familiar with rare neurological diseases.

Awareness of both GBS and CIDP has spread because of the research, which has become more active in the 20th century. The U.S based GBS-CIDP foundation international, has published Guidelines for a Layperson in 2010 (Steinberg, et al 2010), which belongs to the most referred booklets of information in the field providing information about the two illnesses.

The domestic research from the field completed in Finland, includes only two published Bachelor theses, both published in 2015, one in the field of physiotherapy and the other one in the field of nursing (www.publications.theseus.fi). Other medical publications relating to this topic, which have been reviewed for this thesis, are going to be introduced in the methodology chapter.

2.1 Guillain-Barré Syndrome

The next chapter of the thesis examines the two illnesses in question. These are Guillain-Barré syndrome and CIDP. Both illnesses belong to the group of rare neurological diseases. Physicians became aware of the proper diagnosis for the latter as recently as the early nineties (1990) (Hietaharju, 2013; Steinberg, et al 2009). The rarity and awareness of the diseases in question, particularly CIDP, makes the study area highly current and interesting.

Guillain-Barré syndrome is a serious health problem that occurs when the defence (immune) system of the body mistakenly attacks part of the nervous system. In order to limit the sentences the abbreviation GBS is used in the text to indicate Guillain-Barré

Disease. GBS affects the reflecting peripheral nerves. This leads to nerve inflammation, which appears as muscle weakness or paralysis in muscles as well as other symptoms, especially numbness in peripheral nerves.

Peripheral nerves are the nerves located outside the brain and the spinal cord. The first symptom of the GBS is weakness in extremities, and often numbness in the legs together with the sensations of tingling and pain. GBS can occur in both males and females, of all age groups. It affects the muscles that control movements, the sensory nervous system and the autonomic nervous system, including pupil size, bladder movements, heartbeat and blood pressure. GBS can occur either with extremely severe conditions causing respiratory failure and complete paralysis or with very mild symptoms, which are necessarily not even diagnosed by doctors (Steinberg, et al 2010.)

Polyneuropathy is defined as a symmetric disease in both the motoric and sensory nervous system. Symptoms include muscles weakness and lack of sense in extremities, often followed by feelings of numbness and pain beginning from the toes and the feet. Sensory disturbances, such as weakening sense of touch sensation, vibration, paresthesia-numbness and tingling and hyperesthesia –increased sensation as well as sense of pain, are common to polyneuropathies. Sensory disturbances in muscles are rather proximal than distal in all types of polyneuropathies, including GBS. Polyneuropathies damage the autonomous nervous system over time and this affects the whole human body appearing with the symptoms discussed above. The changes in the protein levels used to diagnose GBS can be found by examining a sample of the spinal fluid. Clinical examinations include ENMG, electroneuromyography, and laboratory tests (Palo, et al. 1988.)

Initially the French neurologist, Jean-Baptiste Landry, discovered the disease in 1859. He described ten patients, who developed ascending weakness and paralysis of, in sequence, the legs, arms, neck and breathing muscles of the chest. Most of the patients recovered from the symptoms over a short time, some of the patients experienced more severe conditions, such as breathing difficulties and paralysis. The patients had in common sensations in toes and fingers and the ones experiencing more severe conditions had loss of motor skills and sensation first in the legs followed by the arms and upper body. During, recovery, the upper body improved, first and the legs last, conversely to the original symptoms.

The disorder was first known as acute ascending paralysis and after numerous reports followed from other countries with similar findings. Georges Guillain, Jean Alexander Barré and Andre Strohl, the French neurologists completed some of the further research. They discovered the elevated protein and albumin levels in the spinal fluid samples taken by soldiers who had developed acute paralysis with areflexia from which they recovered spontaneously in 1891(Steinberg, et al 2010; Fujimura, 2013).

The French Neurologists, after whom the GB Syndrome was then named, reported the combination in the cerebrospinal fluid (CSF) of increased protein concentration with a normal count of cells; this phenomenon, which was called albuminocytological dissociation, differentiated the condition from poliomyelitis, which was an epidemic disease at that time. Guillain G. Barrè, published the illness of GBS in its current form, in 1916, and named the syndrome as it is nowadays known, Guillain-Barrè syndrome (Fujimura, 2013.)

The Polyradiculitis – Guillain-Barrè syndrome is rare in Finland. Approximately 50 to 100 new cases are diagnosed each year (Atula, 2015). According to the U.S National Institute of Neurological Disorders and Stroke, Guillain-Barrè Syndrome affects one in every 100 000. GBS usually occurs a few days or weeks after the first symptoms of a respiratory or gastrointestinal viral infection. Occasionally surgery will trigger the syndrome. In rare instances vaccinations may increase the risk of GBS. GBS is not a contagious disease (http://www.ninds.nih.gov/disorders/gbs/detail_gbs.htm). Guillain-Barrè syndrome (GBS) is an autoimmune disease. With an autoimmune disease, the immune system of the body attacks itself by mistake. The exact cause of GBS is unknown. It can occur at any age. It is most common in people of both genders between ages 30 and 50.

GBS may occur with infections from viruses or bacteria, such as campylobacter, influenza, some gastrointestinal illnesses, pneumonia, mononucleosis, herpes and HIV (Steinberg et al 2010.) Some studies suggest that vaccinations may have triggered GBS, even though the evidence is yet not sufficient to prove the statement. (Fujimura, 2013) discusses the risk of GBS related to certain vaccinations. According to Fujimura (2013) first statistically significant increased risk of GBS was reported in years 1976 to 1977, 6-8 weeks after the influenza vaccinations to “swine flue” was identified in the New Jersey area, of the United States of America.

Some of the studies carried out after the seventies, reversely indicated that the risk was not statistically significant. Several other studies mentioned in Fujimura's article report the increased risk of GBS due to influenza vaccinations between years 1992 to 2006. After one study has raised the alert, there is another following the previous study, which claims the data is insufficient to be used as approval to elevated risk of GBS after injections. Again in 2009 a relatively high risk of GBS was reported for influenza vaccines among other virus vaccinations (Soyayah, et al 2009). The study of Hughes, et al (2005) reported recurrence of GBS after swine flue influenza vaccine in two previously reported cases.

According to a study of Recurrences, vaccinations, and residual long-term symptoms in GBS and CIDP patients: "Some case reports have been published that have linked vaccination to GBS/CIDP. Although hypothesized regularly as a cause of GBS/CIDP due to the effect of a vaccination on the immune system, little is known about the consequences and risks of having vaccinations (Bos-Eyssen, et al. Erasmus Journal of Medicine, vol 1 - nr 1 - May 2010)". In addition, infections caused after surgery are also classified as a possible cause for developing GBS. Studies also indicate the Zika-virus to trigger paralyzing Guillain-Barré syndrome (2016). This is result from the study completed in French Polynesia 2013 and 2014. As a result the study proved, that countries targeted at a risk in Zika-virus need to prepare sufficient amount of intensive care beds as capacity to manage patients with GBS (Cao-Lormeau, et al 2016). Guidance material is published from the World Health Organization in order to identification and management of GBS in context of the Zika-virus (The Lancet Feb26, 2016).

According to WHO during 2015 and 2016, eight countries and territories have reported and increased incidence of Guillain-Barré syndrome (GBS) and/or laboratory confirmation of a Zika-virus infection among GBS cases (GBS-CIDP Foundation, 2016).

2.2 Chronic inflammatory demyelinating polyneuropathy

CIDP is a chronic inflammatory demyelinating polyneuropathy, which leads to the damage of the peripheral nervous system. Peripheral nerves include the nerves outside the spinal cord or brain. CIDP may affect the whole body, including the nerves in the brain, especially nervus facialis, if the disease cannot be stopped from progressing, since it is a progressive disease. Usually polyneuropathy affects the both sides of the body the same time. First reactions and symptoms can be similar to GBS, numbness and loss of sense in feet, later in hands and arms. Symptoms include difficulty in walking due to weakness, difficulty in using arms, hands, legs or feet, facial weakness, general muscle weakness and loss of sensation, pain, burning or tingling sensations. Other symptoms, which can appear include abnormal or uncoordinated movement, bowel or bladder problems, fatigue, breathing difficulties, speech impairment, swallowing difficulty, hoarseness or changing voice, muscle atrophy or contractions and paralysis on the face (Lopate et al, 2005; Brannagan, 2014). First symptoms of classical or symmetric senso-motoric CIDP include muscular weakness in peripheries of arms and legs in 78 to 94 percent of patients and neuropathic pain in 20 to 35 percent of patients (Hietaharju, 2007; p.337.)

CIDP belongs to the group of autoimmune diseases, thus it is very un-common to become fully cured when once been affected by the disease. It is regenerating itself as well, and needs continuous treatment, which will be discussed below in more detail under the Medicine-section. Unlike many other autoimmune diseases, CIDP cannot be inherited, since it is caused by infection attacking the immune system of the body. The infection in CIDP attacks the nervous system, thus it affects the whole human body (Brannagan, 2014; GBS-CIDP Foundation 2016). Several tests may be carried out in diagnosing CIDP. These tests include: Electroneurography-test, which aims to measure sensitivity of nerves and proximal stimulation of upper limbs, Cerebrospinal fluid (CSF) examination, MRI of spinal roots, brachial or lumbar plexus. In addition nerve biopsy may be taken in order to gain additional proof for diagnosis, thus it is not sufficient as evidence of CIDP itself as the only test taken (Van den Bergh, et al 2010).

The tests can be carried out by medical professionals such as nurses, for instance when taking MRI's. Some tests such as taking nerve biopsies or cerebrospinal fluid samples are always carried out by doctors with expertise in the field.

Analysis of the test results and findings is always done by doctors specialized in the field, and the nurse's role is to assist in the preparations for the test and in caring of the patient. The nurse carrying out or assisting the testing is in essential role in providing assistance and support to the patient, since it is common to the patients to fear some of the test procedures. In MRI scans for example, the nurse can provide the patient headphones with music, in order to calm the patient down and to reduce the noise the patient is experiencing during the test. If needed the nurse may also administer pre-medication for the test (Medline Plus, 2016).

In Finland the following laboratory tests are taken in suspecting polyneuropathy: blood culture, La, fB-gluc, THS and B12 vitamin levels. Additionally, ENMG-tests and lumbar puncture are recommended to discover CIDP. The doctor might take a nerve biopsy in situation where the ENMG test results are not sufficient for the diagnosis (Palmio, et al 2014.).

Unlike Guillain-Barré Syndrome, CIDP is sometimes not self-limiting and, if untreated, about thirty percent of patients will progress to wheelchair dependence. Disability will be progressing but sixty percent of patients are able to continue to work with it. Early recognition and treatment can avoid a significant amount of this impairment. Patients with CIDP may have different types of clinical continuity. A progressive form of the illness can extend over several years. "Most CIDP patients, if treated early and aggressively, respond well to therapy that can limit the damage to peripheral nerves and contribute to improved function and quality of life" (Steinberg, et al 2010, p.47).

As discussed above in CIDP the peripheral nervous system is under a continuous attack of infection, unless treated. The peripheral nerves are in the state of continuous inflammation, until treated with medication, which obstructs the attack to the nervous system.

The aim of the medication is to reverse the attack from the nervous system into the molecules of the medication. This is one type of medication for the infection state of the CIDP and it is going to be discussed in more detail under the medication part of the thesis. The causes creating infection state in the nervous system are numerous.

There is no evidence in this research about studies, which indicate the exact number of the causes of CIDP and the current assumption is that the exact data on the matter is inexistent.

Van Den Bergh, et al (2010) agree that numerous diseases have been associated with CIDP according to their study based on case reports. These include diabetes mellitus, inflammatory bowel disease, HIV infection, chronic active hepatitis, thyroid disease, Systemic lupus erythematosus or other connective tissue disease, membranous glomerulonephritis – a progressive kidney disease, sarcoidosis, bone marrow or solid organ transplantation. Nevertheless, the evidence is insufficient considering CIDP associating with these diseases is different from idiopathic CIDP. Idiopathic in the terms of medicine meaning: “arising spontaneously or from an obscure or unknown cause” (www.merriam-webster.com/dictionary). Idiopathic CIDP includes the component of autoimmunity, since the causes of autoimmune disease can be rather obscure. As stated earlier in the study CIDP is an autoimmune disease. According to Julkunen & Miettinen findings in the autoimmune-disease related studies indicate rather many factors to cooperate together in triggering the disease, than only one factor, which would alone act as a trigger for the illness. These outer factors are numerous, and they affect continuously and alternating over a long period of time (Julkunen, et al 2011).

The cure of CIDP is dependent on the phase and form of the illness. The best available, is the combination of medical treatment, physiotherapy and occupational therapy. In addition nutrition, sports and activity level, as well as the personal history of the patient, are important factors when considering the individual cure process and the personal level of resilience. Important factors to consider when choosing the form of care are the age of the patient, previous and other illnesses and possible side effects and their effect to the patient. The most common medical treatments are discussed in detail under the following heading. It is possible the CIDP may progress and develop further for instance in lungs, where it can paralyze the muscles, which regulate the whole breathing system. This condition is somewhat similar to the symptoms of ALS and does usually lead to the death of the patient.

Around 3 to 7 percent of the patients will die to the complications caused by CIDP.

When treated early enough, the prognosis with the disease is usually good and up to 30 percent of the patients will manage to fully recover and up to 78 percent continue to live with CIDP without severe symptoms for the rest of their lives (Neuroliitto, 2016).

Primary medical treatments for GBS are plasma exchange and intravenous immunoglobulin treatment (abbreviated: IVIG). Intravenous immunoglobulin treatment is the preferred mode of medical treatment in Finland, due to reduced risk in side-effects (Hietaharju, 2009). Preferred amount of daily dosage in IVIG is 1g/kg, sometimes loading dose at the beginning is 2g/kg. The infusion time varies individually. Compared to plasma exchange the IVIG treatment is said to be easier to carry out, it is better available and the cost of the treatment is the same considering care in the intensive care unit. Nurses are allowed to perform IVIG treatments intravenously and for some patients, who are in better physical condition and do not require hospitalization, it is enough to visit the clinic or hospital only for a day for receiving the treatment. The treatment is designed and scheduled to be repeated according to individual needs and usually last as long as needed, even for several years.

According to Elovaara, et al (2001) due to these facts IVIG-treatment can be considered as the primary medical treatment for patients in all age groups with severe GBS in Finland. As an alternative treatment plasma exchange may be considered in Guillain-Barrè patients. Severe GBS includes patients with decreased ability to walk and patients in the need of respiratory machine. The IVIG-treatment should be commenced within two weeks of the symptoms in order to be effective. In case of relapses, where the symptoms renew after the treatment, the IVIG-treatment should be commenced again or then a plasma exchange should be performed. Primary medical treatments for CIDP include corticosteroids tablets or intravenous immunoglobulin-treatments. Secondary treatments include plasma exchange or cell blockers such as azathioprine, cyclophosphamide or cyclosporine (Neuroliitto, 2016). The latter group of medication, plasma exchange or cell blockers such as azathioprine, cyclophosphamide or cyclosporine, is generally used to treat several types of cancer (drugs.com, 2016). Due to new research completed after the nineties (1992; 1996) IVIG-treatment was shown to be as effective as the plasma exchange in treatment of GBS. The latter 1996 research was completed with 150 patients (Elovaara, et al 2001.)

In medical treatment for CIDP corticosteroids have been the most popular for the past 40 years. Unlike in GBS studies about the treatment of CIDP do not have proof on the most effective medical treatment. Corticosteroids, plasma exchange and Immunoglobulin have all been used for treating CIDP (Van Doorn, et al 2005.)

According to Van Doorn (2005) the first indications of the effects of corticosteroids medication appear in approximately two months from the beginning of the medication, but the maximum effects appear after half a year from the beginning of the treatment. As stated by Merkies, et al (2009) long-term therapy with immune globulin IV has been showed to improve and maintain health-related quality of life in CIDP. The study included 117 patients from which a part was receiving IV immunoglobulin treatment and part of the patients were receiving placebo.

Elovaara, et al (2001) suggest that CIDP is not an illness as such, but instead a condition and combination of several yet unknown illnesses. This is why there is no one specific treatment available for the illness and the treatment and medication should be selected considering each patient and his or her condition individually. According to Hietaharju (2007) corticosteroids have not been significantly effective in treating Guillain-Barré syndrome, even though in Holland they are used together with the IVIG-treatment.

Hietaharju (2007) states that 5 to 14 percent of the patients, who only experience mild symptoms of GBS, should not be treated with IVIG either, since the symptoms might go away themselves, without medical intervention. On the other hand, he highlights the importance of hospitalization of patients with severe symptoms, since GBS might develop respiratory failure in hours.

Thus, it can be agreed that proper situational awareness is essential among nurses participating in the care of these patients. The following comment from the GBS support forum illustrates the severity of the condition:

"I was diagnosed with Guillain-Barre March 17, 2015. I almost died. They called my family in to say their good-byes. I was in ICU for 2 1/2 weeks. My systolic blood pressure bounced around from 300 to 70. I was on a respirator, partially paralyzed, and mostly non-responsive. By the grace of God I survived. I was released from a rehabilitation center on May 1, 2015. The syndrome is much worse than medical journals give it credit for. Gwen, 21 March 2016."

(Source: <http://www.guillainbarresupport.org/forum/topics/pain-2>)

2.3 Health related quality of life and resilience

WHO (1996) definition of health:” Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity (WHO, 1996). These aspects are directly related to quality of life. Quality of life can be defined and categorized as physical wellbeing, material wellbeing, social wellbeing, emotional wellbeing, and development and activity (Felce, et al 1995.) At the structural level, quality of life is comprehended to be both subjective and multidimensional. Because its subjectivity, it is at best measured from the perspective of the patient. Since it is multidimensional, the measurement demands the researcher to find out about variety of areas of the life of the patient, including physical, social and emotional wellbeing as well as functional ability (Felce, et al 1995). Health-related quality of life is an enormously wide concept, in which numerous measurement scales can be used in validating quality of life in different above-mentioned sectors (Bowling, 2001). This research is narrowed to cover the two illnesses and a few aspects, which are related to the overall quality of life experiences. These aspects include resilience and pain management, which can be strongly tied into the coping with both of the illnesses in question. Bowling highlights the need for disease-specific quality of life scales to ensure sensitivity to clinically significant changes in health status and levels of disease severity (Bowling, 2001. P.16).

Resilience (Finnish: Resilienssi) means “positive coping of an individual despite the adversities in life (Joutsenniemi & Lipponen, 2015).” Resilience can be described as the way of performance of an individual or society, which maintain the capability to perform tasks and individual functionality in situations where obstacles and insecurity are faced. In both GBS and CIDP recovery stage functionality is closely attached to the resilience, which determines the ability and capability of an individual to cope with the existing changed health conditions (Joutsenniemi, et al 2015.) Forsberg touches upon the resilience in her research when describing coherence as a coping capacity. In the study she discusses the sense of coherence as the ability to manage different stressors in life, such as falling ill with the GBS. Forsberg states in her study of Guillain-Barré Syndrome the following: ”The general view is that a person with a strong sense of coherence, tends to manage the stresses of life better, whereas individuals with a weak sense of coherence tend to be more vulnerable to ill health” (Forsberg, 2006.)

Davydov, et al (2010) describe resilience as a defence mechanism, which enables individuals to cope with obstacles affecting the state of their mental health. Their research aimed to describe the complex chain of events related to host resistance in infectious disease. The common goal for resilience related studies was to indicate potential points of intervention for increasing resilience and positive mental health (2010).

2.4 Neuropathic pain

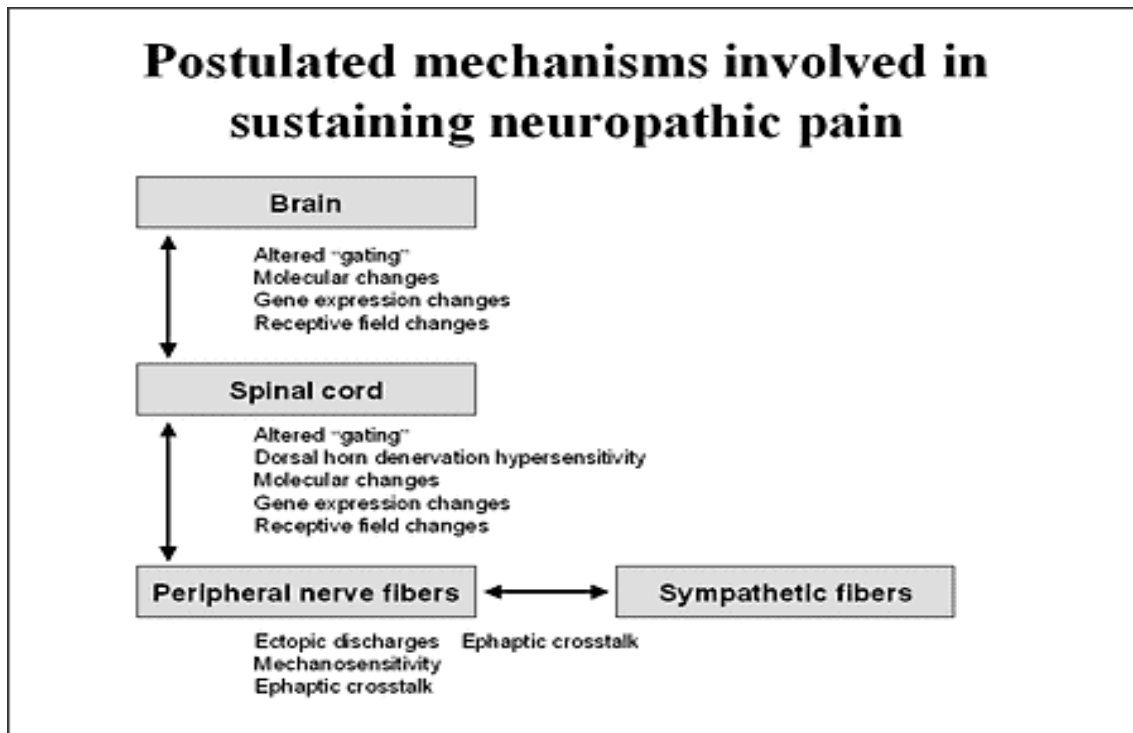
The article of Management of pain associated with peripheral neuropathy in the book of Grabois (2002) Pain Management in rehabilitation, states that the pain accompanying polyneuropathy has a significant impact on a patient's quality of life, because it decreases activity and causes depression and suffering.

In addition he admits that the scarcity of information regarding the rehabilitative interventions towards improvement among this patient group and the impact of functional status have not been studied properly. Patients with abnormal functions in the peripheral nervous system, such as the CIDP patients, experience the development and persistence of pain in all levels of the nervous system (Grabois, 2002).

According to Hietaharju (2007) 20-30 percent of the patients with CIDP experience neuropathic pain. Naturally, not all patients experience neuropathic pain even though it is brought out in this study in order to increase awareness about the matter and conditions that some of the patients may be experiencing.

Neuropathic pain in patients with peripheral neuropathies may arise from the increase in mechanosensitivity in regenerating axons. The pain experiences have suggested to be arising from the chemical and electrical communication between the afferent fibres of nerves, which are normally isolated, or between the fibres from the sympathetic nervous system and the peripheral nervous system (Grabois, 2002.) The picture illustrating the Neuropathic pain mechanisms below, demonstrates the body mechanisms involved in sustaining neuropathic pain.

Picture 1. Neuropathic pain mechanisms



(Medscape, 2016).

Medications used to treat neuropathic pain often includes pathophysiological mechanisms, thus it is essential to understand that one medication is not always sufficient when treating this type of pain.

The best results in treating neuropathic pain have been reached using combinations of different pain medication, which each need to be tested on the patient individually. The effects, indications and contraindications need to be introduced to the patient prior testing the medication and discussed properly. Analgesia is a term often used in pain related discussions. The simple definition in medical terms for analgesia is the loss of the ability to feel pain while conscious (Merriam-Webster, 2016). The definition is opened up here since the pain and pain management are going to be discussed later in the study in chapters 6 and 7.

According to Maija Haanpää, a neurologist and specialist in pain care and rehabilitation from the Helsinki University hospital, several hospital-visits and many different trials are required before the suitable "satisfactory" level and right combination of pain medication is found.

Satisfactory level, which is considered to ease the pain at the meaningful level in the Medical Response of the pain medication according to Haanpää, is 30 percent (Haanpää, 2004). Medication of neuropathic pain is dependent on the type of the pain. In Nociceptive pain, which is the pain caused from the damage in the nervous tissue, the nervous system itself is not damaged and thus traditional pain medication such as ibuprofens can be used. In neuropathic pain the damage is in the nerve itself. This type of pain requires different medication such as gabapentin ie. Neurontin and pregabalin ie. Lyrica. Muscle penetrating pain or electric shock type of pain can be treated with medications such as carbamazepine ad 200mg x 2-3 slow start. Pain, hyperesthesia, and pain affecting sleep can be treated with amitriptyline, 10 to 25mg/ day doses given in the evening, and the dosage may be increased according to the doctor's prescription. In addition mycophenolate mofetil can be used as a part of treatment affecting the immune system. Etiology of the disease is essential when considering the specific type of treatment for neuropathic pain (Mervaala, et al 2011).

2.5 The Nurse's role in caring

Watson defines the term on caring with the following words: “caring is often considered as an ethical worldview, an ontology, an intentionality, a consciousness, a way of being in contrast of outward doing of something that can manifest itself in the physical, external, objective realm (Watson, 2008).” Watson defines nursing as acts, which combine the action, doing, and aspects of the Human behaviour. The definition includes in addition the significance and effect, which nursing may have to the patient experiencing it (Watson, 1999). According to the ethical guidelines for the Finnish nurses the nurse should whenever possible relieve suffering, promote the wellbeing of the patient, promote comfort and to maintain the patient's dignity (sairaanhoitajalitto.fi).

Nurses' role in monitoring of the illness progression in both GBS and CIDP is extremely important in order to react quickly as possible to changes in condition. After the acute symptoms are taken care of the second most important step is proper rehabilitation, which is always realized according to individual situation and needs of the patient (Atula, 2015.)

The holistic nursing perspective is taken into consideration in this study, due to the fact that most scientific articles related to the research topic are studies from the field of Physiotherapy and Rehabilitation. Nurses' role in pain management is in key focus throughout the study, since the majority of the patients experience pain. The death rate among the patients with these two rare Neuropathies is 4-15% (Hughes, 2005).

Here, after having very briefly defined the concept of Caring, the study proceeds forward by introducing the Myra Levine's Nursing theory under the following chapter 3. The theory operates as a background for the analytical inductive literature review, which is in the key role of this research. The Nurses role in the process is introduced through the findings under the chapter 6. The chapter 6 introduces the nurse as a caregiver from the holistic nursing perspective and concentrates to the Nursing interference in pain alleviation and providing support. Further Nursing interventions are going to be discussed under the Discussion part in chapter 7.

3 THEORETICAL FRAMEWORK

Need for the Nursing theory as the base for research: “The theory helps explain how structures such as race, gender, sexual orientation and economic class affect patient experiences and health outcomes” (Kozier et al; 2012, p.199.) The Nursing theory chosen to support the research is Myra Levine’s four Conservation Principles theory. Levine’s theory was chosen because it is an original, interesting theory, which is not widely used in common theses and could earn more recognition in the field. Levine’s perspective is in holistic nursing, which itself is an interesting field for further studies. Levine’s theory complies well with the themes of health promotion and management of illness and resilience, which form the core emphasis of this thesis.

In the state of chronic illness it is essential to maintain the health and aim to improve towards healing of a state of restoration of the existing level of the health. Managing the illness affects all areas of life, and Levine’s aspect of wholeness discusses the “keeping together” of the wholeness of the individual. The theory deliberates both internal and external environment of the human being, as well as the organismic response, which is discussed also later in this study under resilience in chapter 8.2. Levine’s Conservation Model introduces the Person as a holistic being, a system of systems. Organismic responses include fight or flight, stress, basic orienting system, visual system, auditory system, haptic system and taste-smell system. Levine’s environment may be operational, perceptual or conceptual. Health is defined in the terms of health and disease being patterns of adaptive change. Levine defines the term of nursing as a human interaction, in which the goal is promotion of wholeness for people, sick or well. Nursing Actions consist of conservation of energy, structural integrity, social integrity and personal integrity. According to Fawcett (1993) *coping of the person is determined by the focal, contextual, and residual stimuli.*

Fawcett states in her book of *Nursing Theories* that different perspectives of the phenomena are identified by the nursing meta-paradigm (person, health, environment, nursing) are evident in the major conceptual models including The Levine’s Conservation Model from 1991 (Fawcett, 1993.)

These perspectives or areas are a fundamental part of this thesis as well, when reviewing the factors affecting the quality of life in different phases of the two illnesses. Levine's Four Conservation Principles include four steps, which include the *Conservation of energy, conservation of structural integrity, conservation of personal integrity* and *conservation of social integrity*. Step 1 refers to input and output energy balancing in order to avoid excessive fatigue. In both GBS and CIDP muscle weakness increases the amount of fatigue experienced by the patient. Conservation of energy includes adequate nutrition, rest and exercise. From the nurse's perspective the aim to provide good care includes these factors. The aim of the nurse is to monitor and give guidance to the patient in all the above mentioned fields together with the multi-professional team, which consists of doctors, nurses, occupational therapists, physiotherapists and if needed, a speech therapist (www.chsft.nhs.uk/neurological-pysiotherapy/).

Step 2 Refers to *maintaining or restoring the structure of body preventing physical breakdown and promoting healing* (<http://currentnursing.com>). As stated in the ICN ethical codes for Nurses (2012), the Nurses four fundamental responsibilities include *to promote health, to prevent illness, to restore health and to alleviate suffering* (www.icn.ch). Thus, the Nurses role in preventing physical breakdown and promoting healing is essential and in the care process the nurse's aim is to promote the patient wellbeing and healing at all stages. Conservation of structural integrity may apply for instance as assisting the patient in the daily exercises and activities while being hospitalized and/ or maintaining the patient's personal hygiene at the time of hospitalization and the most active phase of illness in situation where the patient has for instance, become paralysed. The topic is going to be discussed in more detail in chapter 6.

In the Step 3 the individual is recognised as *one who strives for recognition, respect, self-awareness, selfhood and self-determination* (<http://currentnursing.com>). Nurses' aim is thus to recognize and respect the patients need for personal space and dignity. Especially in the very early stages of the illness it can be very hard to accept the changes in the self and the patient is in need of both respect but also encouragement for coping with the changed current condition.

Step 4 conservation of social integrity recognises the individual as someone who resides within a family, a community, or a religious group, an ethnic group, a political system and a nation. The nurses' aim here would be to promote the patient's social wellbeing and offer information about support groups and assistance to family. It might as well include promoting the patient's use of newspapers, radio or TV in order to be actively aware of the social world outside the hospital as well as to encourage conversation as a part of rehabilitation program. *Neuroliitto* provides support groups for both GBS/CIDP patients, which may be useful to the patients and their families in order to be able to meet other people with the same illness and share experiences and thoughts. According to the GBS/CIDP Foundation international (2009) the group-support groups seem to be the most effective ones for the patients in order to gain information and share experiences about the illness and the different stages of the illness. In the Levine's theory the goal of Nursing is *to promote wholeness, realizing that every individual requires a unique and separate cluster of activities* (<http://currentnursing.com>).

4 AIM AND RESEARCH QUESTIONS

The aim in this thesis is to raise awareness among nursing students and other readers of the thesis about the two rare neurological illnesses Guillain-Barré Syndrome and Chronic Inflammatory Demyelinating Polyneuropathy. Additional aims include discovery of nursing tools in order to assist the patient to cope with the illness and pain, as well as providing information for patient guidance. The research intends to answer the questions: *What are the Nursing interventions in terms of the Levine's Conservation Principles and which factors affect the coping with the illnesses?*

The research is carried out as an inductive literature review, which is done in a qualitative basis. Literature is reviewed from 11 articles. A complete list of articles is presented in the Methodology section chapter 5 and the reference section. Literature review focuses on topics mentioned in the research questions: pain management, neuropathic pain and resilience. The Aim was to investigate the factors to promote the patients' quality of life, pain management and the role of resilience in coping with the illness. As an additional part for the background and discussion chapters of the thesis, the subjective experiences of falling ill with CIDP/GBS were reviewed from online discussion forums in order to give the reader a deeper insight to the topic. Some of the comments were included to the background chapter 2 as well as final discussion part in chapter 7.

5 METHODOLOGY AND DATA

The methodology and the process of data analysis and collection are presented in this chapter. The role of Methodology in the research is to present information of the data as well as methods and the process of the data analysis (Bowling, 2006). The thesis is completed a qualitative literature review. Articles chosen for the literature review of this study are presented in Appendix 1 and the full list of articles is presented in the reference section. In addition to the literature review a brief survey of online support groups for GBS/CIDP patients, was completed as a part to the background studies for the thesis.

5.1 Background research

The background research was done in order to gain deeper understanding to the topic, especially towards factors and experiences affecting the quality of life with the illnesses. For the background studies a variety of articles and books were reviewed. In addition a brief survey was performed in online open discussion forums for GBS/CIDP patients, in order to discover individual experiences regarding symptoms related to the illnesses and performed actions to cope with the symptoms, such as pain. The forums viewed online are presented in the list of online references in the reference-section 8.2.

5.2 Literature Review

The literature review was completed as an inductive content analysis of the collected articles. Inductive reasoning begins with the observations and builds up ideas and more general statements and testable hypotheses from them for further testing on the basis of further observations (Bowling, 2006; p.121). In total 11 articles were chosen and analysed critically. The literature review is conducted to gain perspective to the previous research made in the study area. The articles reviewed are selected according to the determined criteria. The literature review determines significant findings obtained from the previous research and operates as a base for the study and a tool for the researcher to collect data on the desired field. The data may be then analysed and used

for comparison between articles and as a base for further research (Doheny et al, 1982; p. 147).

The articles for the literature review were chosen from the perspective of the Levine's theory. Articles include holistic nursing articles, articles from nursing and pain management and specific articles from the treatment of the illness. Since CIDP is such a rare illness, the articles from nursing perspective do not exist yet, thus the study had to be limited to articles of GBS, due to the similarities of the illnesses, especially the fact that both are demyelinating neuropathies and similarities in symptoms.

Holistic nursing and pain management were selected as key issues for this study, because of their usefulness for both of the illnesses in question and strong relation to the Levine's theory, the thesis is based on (conservation principle no.2). Furthermore, articles discussing resilience were chosen, because the conservation principle no.3 in Levine's theory. Turner-Stroke's article is tangent to the especially the no.1 and no.4 conservation principles from the Levine's theory, even though the article is not illness specific and discusses the neurological long-term illnesses in a more general perspective.

5.3 Data Collection

The data was collected using search engines, such as EBSCO, ScienceDirect, MedlinePlus, PubMed, Ebrary, and Sage. Articles were searched from these online search engines with key words for CIDP, and Guillain-Barré syndrome. Nursing theory and holistic nursing were in addition used as corresponding key words in searching theories for the theoretical framework of this thesis. Keywords used to the articles selected for the literature review included: rehabilitation, pain experiences, neuropathic pain, resilience, self-care, treatment and care. In addition Cochrane and Google-search resulted to several interesting articles, which were used for the background studies and were excluded from the literature review because of the nature of the articles. Selection-criteria introduced below. A complete list of articles and references used for this thesis is to be found in the Appendix -section.

Selection criteria for the articles included in the literature review was: selection of full text articles, articles had to be found in scientific databases and type of source preferred

was academic journals and scientific magazines. Articles from the books, magazines and websites were excluded from the literature review. An important selection criteria was exclusion of articles, which were not free of charge.

Some of the most current articles needed to be unfortunately excluded due to the accessibility. Nevertheless, the excluded articles were mainly medical and could have only been used for the background and discussion section of the thesis.

Selection criteria for the background studies included websites, books, magazines and other relevant publications. The data used for description of the illnesses was no older than from year 1992, most of the articles were from years 2006-2016. Some older books from 1982 and 1993 were used to study nursing theories. All of the sources are listed in the reference section of the thesis.

5.4 Data Analysis

Scientific literature is reviewed in a qualitative prospective. The analysis of the data can be seen as a process of selection and summarizing the relevant articles and gathering the salient information for the purposes of this study. The research is carried out as an inductive content analysis. Searching the symptoms for the GBS, the words 'GBS' and 'Symptoms' occurred in all the articles analysed and reviewed and further reading and going back to the same articles in the qualitative analysis. The additional key concepts 'rehabilitation', 'neuropathic pain' and 'resilience' were present in most of the articles, while the words 'treatment' and 'quality of life' were present in mainly medical articles. Due to the vast amount of results in search engines with some the keywords, the main search was contributed concentrating in the key words 'quality of life AND CIDP', 'CIDP AND Nursing', 'Guillain-Barre syndrome AND Nursing' or 'Quality of life AND Guillain-Barre syndrome'. In addition these keywords, the articles including the above-mentioned additional concepts, were searched through a manual qualitative content analysis.

In the qualitative analysis of the data, the personal knowledge of persons currently living with these illnesses outside this research, guided the way in which certain theories were looked into. It is at an utter importance to emphasize here that no data on these people has been used for this research, since it is a literature review.

Knowing them only gave more insight to the researcher to complete this study and an ability to search for certain issues for the research in order to gain deeper understanding to the quality of life with the two illnesses as well as a deeper perspective in the matter. As an example the theory about flue vaccinations to relation in causing GBS was interesting to research, because of the existing comments in the discussion forums, which claimed the vaccinations to be the trigger to the illness.

5.5 Ethical aspects of the research

The research is carried out as a review of literature. Originally some interviews were planned, but they were left out because of the requirement for the ethical permissions and the schedule of the thesis process. Further research part discusses the alternative or further research, which is possible to be continued in the future, for instance as a part of masters degree studies. The patient comments of the thesis are taken from open Internet discussion forums. All comments viewed for this thesis have been read as anonymous name-marks, without having viewed, requested or gained any detailed contact information or personal information of the writers of the online patient comments. Thus anyone searching the internet may access those comments and online links to the discussion forums viewed for this thesis, is presented in the online references section of the thesis on page 55.

6 FINDINGS

This part of the thesis presents the findings and results from the literature review.

Research topics included: What are the Nursing interventions in terms of the Levine's Conservation Principles and which factors affect the coping with the illnesses?

The aim of the findings section is to discuss the findings based on the literature review and to provide tools for nurses to intervene in the daily care of the patients from the target group. In addition the aim of the findings section is to provide insight into the life with GBS and CIDP as well as to raise questions and ideas for the nurses working in the field. The component of autoimmune disease and individual response and resilience, have been taken into account throughout the study. There is no one-way or method of nursing, which may universally, or commonly be applied to all patients. The findings aim to offer some guidelines for the possible nursing interventions, which according to the author are useful and necessary in providing care to the patients suffering from Guillain-Barré syndrome or Chronic Inflammatory Demyelinating Polyneuropathy.

6.1 Nursing interventions in terms of Levine's conservation principles

Holistic nursing is a term, which is lacking in definition. Several studies have been aiming to define the concept and to import new terminology through research. One of these studies, *"Making Special", A Framework for Understanding the Art of Holistic Nursing* written by H. Lea Barbato-Gaydos from University of Colorado, Nursing and Health Sciences (2004), is aiming to create a greater understanding to the topic and clarifying the terminology behind. According to Barbato-Gaydos, in the concept of Holistic Nursing, Nursing is defined as *an aesthetic, and an art of doing*. In the Art of Nursing the Nurses' ability is to: *"grasp meaning in patient encounters, establish meaningful connection with the patient, skillfully perform nursing activities, rationally determine the appropriate course of nursing action, and morally conduct his or her nursing practice* (Barbato-Gaydos, 2004, p.154.)"

These conceptualizations, which originally have been introduced by Johnson in 1994, but later presented in the above-mentioned article from Barbato-Gaydos, have similarities with the Levine's Four Conservation principles theory introduced in chapter 3. Both theories aim to promote the wholeness in the care considering different in-depth-aspects in nursing. The framework for understanding Holistic Nursing introduced by Barbato-Gaydos (2004) covers all the four Conservation Principles introduced in Levine's Theory, the conservation of integrity in all forms (2-3) and conservation of energy (1), which is closely tied to the nursing activities needed to be performed in order to maintain and improve the energy of the patient. Additionally, Forsberg discovered in their study of *Disability and health-related quality of life in Guillain-Barre syndrome during the first two years after onset* (2005) that the findings of their research confirmed the impact of Guillain-Barre syndrome, which affected several life areas, and suggested that a long-term and broad perspective is required from health care professionals when treating patients with this illness.

The study revealed that health related quality of life was affected decreasingly in all the evaluations and two weeks after the onset, the impact of GBS was proved to affect fifty percent of the patients who had a higher score in the overall sickness impact profile, than the same score measured among the general population. After 2 years from the diagnosis the twenty-four percent of the patients showed decrease in the frequency of lifestyle- and social activities compared to the levels before the illness. According to the study the impact of the GBS to quality of life of the patients, was at highest, after two weeks after the onset. Impact on working life seemed to be the highest according to the Forsberg's study, since the data shows that only one out of six patients returned to their workplace after getting ill with GBS (Forsberg, et al 2005.) Haldeman, et al (2005) agree that Financial Issues are a concern that may trigger depression in the patients, due to the complete or partial loss of their workplaces in the acute-phase of the illness and also during recovery. Turner-Strokes, et al illustrate in the research of *interphase between neurology, rehabilitation and palliative care in managing people with long-term neurological conditions* (2014) that an emphasis should be made in the cooperation of specialists providing services for patients with long-term neurological conditions. A general shortfall was highlighted in the provision of services for patients experiencing long-term neurological conditions, especially in the community.

In addition the research indicated the absence of coordination between services. The research came in to the conclusion that: “neurologists quite frequently had rehabilitation, palliative care and pain consultants working on their teams (*Turner-Strokes, et al. 2014.p.132*)”.

The research introduces following core elements of service for patients with long-term neurological conditions:

1. Assessment and diagnosis 2. Control of disease progression and prevention of complications 3. Management of symptoms, eg pain, depression, breathlessness etc. 4. Provision of therapy, spasticity management etc. 5 Provision of aids, equipment, eg aids to daily living, environmental control systems 6 practical coordination of support services including NHS, voluntary, social services etc. 7 Social, psychological support 8 Spiritual support 9 management of death 10 aftercare, bereavement support (*Turner-Strokes et al, 2014*).

Hence this was a citation from research discussing palliative care in neurology, it can be agreed that the above mentioned factors are essential parts of the care path of neurological patient and areas, which the nurse taking care of the patient needs to take into account when considering the care path as a whole. Naturally, the steps nine and ten can be left outside the consideration in situation where the patient begins to improve in condition or will heal totally. Anyhow, the sections 9 management of death and 10 aftercare, bereavement and support need to be considered with the 5% of the patients who will face the death (Hughes et al, 2005; McMahon-Parkes, et al 1997; Forsberg, et al 2005.)

Lugg (2010) defines Nursing interventions when GBS is suspected. The aim of the Lugg’s article was to offer diagnostic advice to ER practitioners, with the help of the article. To this research it operated as a great support tool to prove the authors own outcomes and ideas, which have been raised with the inductive analysis of the literature. Lugg’s Nursing interventions include: Measuring patient’s temperature, pulse and pulse oximetry, respiratory rate and blood pressure, thus the basic Vital signs. In addition, Lugg advises to take blood samples, including blood cultures, and taking electroneuromyographies to find out whether the patient his experiencing cardiac arrhythmias, which may arise with GBS. In Emergency Departments (ED’s), where Lugg himself is a practitioner, it is suggested in the article, that patients who present

with airway or respiratory dysfunction will require appropriate specialist support beginning in a resuscitation area.

Assessing the airway and breathing is in high importance since the cranial and trunk nerves of the patient might be affected by the GBS as well, and early critical intervention is thus essential together with close monitoring of the patient. In order to identify the potential airway risk due to the involvement of the cranial nerve, it is important to observe the swallowing of the patient carefully. In a situation where cranial nerve involvement can be detected, it has to be ensured that the patient is nil by mouth until formal swallow assessment has taken place. In addition it has to be ensured that the patient receives adequate analgesia. Medical interventions for GBS patient in the Lugg's article include: Computed tomography of the head or body of the patient, Nerve conduction study and lumbar puncture. These are medical assessment tools, which were introduced already in the background chapter 2 (Lugg, 2010.)

McMahon-Parkes, et al (1997) emphasises the role of the Nurse in their article *Guillain-Barré Syndrome: biological basis, treatment and care*. Despite the older age of the article it was selected to the literature review, because of its importance to the research as an article written from Nurse researchers, whilst majority of the articles chosen, were written by other health care practitioners. Mahon-Parkes, et al (1997) emphasizes the importance of the good biological knowledge the nurses should have from Guillain-Barré syndrome, in order to assist and nurse patients in their condition. The article is written from the perspective that the GBS is likely to progress, rather than the progression to be ended. Guillain-Barré symptoms usually develop over 10 to 14 days and the extent of cell demyelination varies greatly between individuals. In milder cases of demyelination, symptoms are often limited to pain and tingling or pins/needles feelings in muscles and general tiredness.

Severe cases may include complete paralysis of all muscles, which are either skeletal or neurologically mediated. Total paralysis may occur within 48 hours of the onset. In 5% of the patients the GBS is fatal and 15 to 30% experience death. These facts discussed in the article of McMahon-Parkes, et al are almost identical to the discoveries of Forsberg, et al discussed earlier in the article above (chapter 6). McMahon-Parkes, et al (1997) state in the article that Nurses should carry out all assessments frequently in order to determine the deterioration rate (*the worsening of the condition*) of the patients.

They suggest that throughout assessment of both Nurses and Doctors involved in the care, will give indications on the severity of the illness at the current stage and in longer term. The medication and treatment will thus be determined based on these observations.

The Nursing interventions in addition to assessment and monitoring include testing the motor function of the patient, since *weakness* is stated to be *typically ascending and often occurring in 'steps'*. The role of the nurse is to assess the progression or extent of the motor weakness by regular monitoring of muscle strength and deep tendon reflexes. Variety of other Assessment criteria is introduced in the article, which the Nurse should become familiar with, in order to properly identify the changes in the condition of the patient. The fields included in the assessment are: cranial nerve function, respiratory function, motor function, cardiovascular function, nutrition, elimination and pain (McMahon-Parkes, et al 1997.) Hughes et *al* state that respiratory failure is common and life-threatening condition among GBS patients, which may lead to series of other respiratory related complications (2). According to the findings the article introduced the same or similar care interventions for GBS patients than the previous article reviewed for the study, from McMahon-Parkes, et *al*.

In the study, the Nurses role in monitoring the patient at the ICU is at utter importance in order to detect changes, which may indicate neuromuscular respiratory failure. Monitoring and care procedures of the Nurse include (1) conservation of energy, which is ensured with correct interventions related to nutrition, sleep and basic-care procedures for the patients. The assistance naturally varies according to the condition of the patient, and the ward. In ICU the monitoring of vitals, blood pressure and oxygen level, respiratory rate, heart rate together of the basic care include in the nursing interventions together with administration of the medical products. The Nurse's understanding and knowledge of the medicine administered to the patient is important regarding the care of the patient, and this is why the medical part is introduced in this study as well.

Basic care procedures at all wards, not only ICU, naturally include management of bladder and bowel function. Areflexia and disturbed bladder sensation have been documented in Urodynamic studies of the GBS patients.

Constipation and ileus are have, according to the studies of Hughes *et al*, occurred in bed-ridden patients especially in acute phase of the illness. The Nurse needs to be aware of these possible complications when performing catheterization and other hygiene related duties. Abdominal auscultation is also recommended in the article and need to be performed in order to detect development of gut silence and to find out the proper functioning of the intestines.

The article of Hughes *et al* (2005) discusses in addition of the importance of physiotherapy, which is not opened up in this study in detail, since there are other recent studies in the field from GBS. Instead the presence of excessive fatigue needs to be pointed out, since according to the authors 80% of GBS patients suffer from illness related fatigue. It is mentioned in the article that fatigue is also related to several other neuropathies, including CIDP. Fatigue is caused mainly due to muscle deconditioning and inactivity during the illnesses. There is evidence that both functional abilities and fatigue were improved with supervised exercise programs (Hughes *et al*, 2005.)

Haldeman, *et al* (2005) article reviewed for the thesis is a case study, which is written from the nursing perspective by two Registered Nurses operating in the field of Critical Care. The findings related to the article, are similar to the other articles despite the fact that it is a case study of one particular patient. This aspect allows gaining more detailed information about the individual coping with the illness and the nurse's role in the process. The study emphasizes the role of holistic care, which the nurse has to be able to provide according to the demands of the diagnosis. The findings underline the collaboration of the whole healthcare team, and state that the patient their close relatives should be prepared to the extended period of treatment provided by the nursing staff, in order to help the patient to gain the previous level of independence (Levine's step 4). The study pointed out the importance of the illness-related psychological issues, which include depression and communication issues. The person of the particular case study did develop depression, but did not have communicational issues, however other patients, including some of the CIDP patients, might face these issues as well.

The Nurse's role with patients who develop depression is to evaluate the patient's mood and observe for other psychological symptoms such as presence of blocking nerve

impulses. Nursing interventions discovered from the Case Study article include among medical interventions provision of empathy, support, keen listening skills, provision of positive feedback towards reinforcement gained in physical achievements and activities. The Nurse's role was emphasized as well in the education of the patient and the family to all the care-related issues. The nurse should in addition give guidance and suggestions of the existing support groups, which the patient may contact after the time in hospital (Haldeman, et al 2005.) Harms (2011) discovered severe psychiatric complications in patients with GBS. He states in the article that these complications occur due to the dramatic loss of independence, prolonged hospitalization periods and sometimes loss off communication. According to Harms, anxiety occurs in 82% of the patients and moderate or severe depression in two thirds of the patients. He emphasizes the importance of care providers to ask patients specifically questions about the symptoms of depression or anxiety to be able to detect and treat them. Harms suspects that due to the possibility of central nervous system inflammation, in severe cases of GBS patients, even psychosis and depersonalization have been detected. As a conclusion to the study he highlights the importance of careful attention to the supportive care issues and the need for better therapies (Harms, 2011.)

Considering a GBS/CIDP patient at early stage of illness, which usually requires intense Medical treatment, the nurse has a greater role in providing support and assistance for the patient in managing with the pain experienced as well as individual changes in the body, which may appear in several ways, such as complete paralysis of arms or legs. Bed-ridden patients require careful monitoring of the skin in order to detect possible pressure ulcer points. Especially patients who are intubated or seated require frequent position changes. Patient's experiencing breathlessness may require respiratory assistance at the acute phase of the illness together with other medication. Later when the acute phase of the illness has been overcome, it is time to implement the individual care plan, which consists of all the above mentioned areas including physiotherapy, provision or aids and equipment to support daily living, guidance in managing with the self-care, functional therapy, social services in situations where getting back to the work is not an option, etcetera (Haldeman, et al 2005; Harms, 2011.)

The Turner-Strokes' study emphasizes the role of neurologist in becoming greater in providing therapy and symptom control, whereas physicians role emphasized the assessment and diagnosis.

Nurses' role in the process is great in patient monitoring, and implementing the medicine as well as providing guidance and care according to the individual needs and the ward, which can be depending on the situation, either intensive-care or neurological ward. As discussed earlier in the study, a progressive form of CIDP can extend over several years. The staff working in the same nursing unit where the patient comes to receive medical treatment and rehabilitation have the possibility to actually to get to know their patients very well. This improves the ability to build good care-relationships and trust between the patient and the caregiver (Turner-Strokes et al, 2014.)

6.2 Factors, which affect the coping with the illness: resilience and pain management

Pain is a common feature of GBS, which occurs in 55% to 89% of patients. Pain is related in inflammation of the proximal nerve-roots and immobility of the weakening muscles. According to Harms the patient need to be frequently inquired about the pain experiences, including the presence and severity of the pain. In administering the medication for the pain the presence of potential sedation and ileus must be noticed, since opiates, which are said to be the have the most reliable analgesic effect, cannot be used with these conditions (Harms, 2011.)

The systematic review of resilience in the physically ill written by Stewart and Yuen published in *Psychosomatics May-June issue 2011* resulted in the conclusion that psychological factors, which are associated with resilience include self-efficacy, self-esteem, internal locus of control, mastery, optimism, hope, hardiness, self-empowerment, acceptance of illness and determination. In addition coping strategies: cognitive appraisal, spirituality, active coping and mastery were associated with resilience. The study indicated that resilience factors were highly relevant in physical illnesses. These factors included self-care, adherence to treatment, health related quality of life, illness perception, pain perception and exercise adherence. Physical outcomes were found as well (Stewart, et al 2011).

Neuropathic pain is often undiagnosed and has a huge impact on life and that pain-related limitations result in social withdrawal (Lönnsted, et al 2011.) According to the article *Living with long-lasting pain – patients' experiences of neuropathic pain* (2011), patients confronted feelings of vulnerability and loneliness when the trust with healthcare professionals was not met. This occurred often in situations where in example the nurses or doctors were questioning the patients pain experience.

The study highlights in the findings the importance of positive attitude and empathy from the healthcare professionals towards the patient and states that the neuropathic pain brings major changes in the daily- and social life of the patient, which can be seen in affecting the patient's quality of life in full impact (Lönnsted, et al 2011).

A study of *nurses' interference of patients' physical pain* completed in 2006 indicates the cognitive strategies of post-registration and clinical experience to ease cognitive dissonance of the nurse, however as a result they may increase patient suffering. The conclusion of the study was that clinical experience and education affect the knowledge of the nurses, as well as pain related attitudes and beliefs. However, it would appear that the working environment and knowledge base of the specialist nurses produces a gap between practice and theory. As a result the nurses become less sensitive to patients physical pain (Wilson, et al 2006.)

Hughes et Al (2005) state that observational analyses have detected pain in 89% of the patients and half of these patients have experienced severe pain. Hughes discusses pain medication in the article from a very medical perspective, in which this study is not going to go into in too much detail, only to mention the wide variety of pain medication used from anti-inflammatory drugs into parenteral opiates and morphine-infusions, which according to the article, 30% of the patients required in addition to the 75 % who required parenteral opiates in order to cope with the pain. According to the article, nonsteroidal anti-inflammatory drugs and simple analgesia were not sufficient in relieving the pain of the patients. It is suggested that the pain is treated in the ICU (intensive care units) at the early stage of the illness. In addition the application of narcotic medicine requires careful monitoring of the patient, in order to detect adverse effects in the setting of autonomic denervation, which is a condition where the nerves get 'cut' due to the inflammation and quit functioning.

Hughes et Al suggest the use of *adjuvant therapy* with tricyclic antidepressant medication and various muscle relaxants, such as tramadol, in order to facilitate the management of neuropathic pain, which is often a long-term condition. The correct administration of medicine ensures the conservation of structural integrity (2) in the terms of pain management of the patient as well as the (3) conservation of personal integrity, which can be promoted with encouraging the patient to take the medication and to actively participate in all care-related procedures (Hughes, et al 2005.)

7 DISCUSSION

Nurses may encounter GBS/CIDP patients for instance in health care centres, hospital neurological wards or even in ICU's in situation where the illness is in the very acute phase. Understanding the wholeness of the illness facilitates the nurses' understanding towards the patient and the decision-making in care procedures. Nurses need to support the patient in pain management and investigate whether there are changes in the condition of the patients. Patient monitoring is in the key role in order to identify changes in the condition and to react to the changes accordingly. Especially the changes in basic vital signs, such as blood pressure, heart rate and breathing need to be carefully observed in order to act and provide rapid treatment when changes occur. These sometimes life-saving nursing actions are very important and should not be underestimated in any occasion (Steinberg, et al 2010.)

The nurses' role includes, in addition to providing information of the care procedures, providing emotional support to the patient and the family of the patient as well. The role of the support should not be underestimated. As stated in the findings of the thesis the pain experiences of the patients are individual and majority of the patients experience pain at some stage of the illness. Nurses should thus become more sensitive to the patient's pain experiences and demands and to be prepared to provide support in all possible ways. At the stage of illness in which the patient is no longer being hospitalized and can survive at home with the help of regular visits to the hospital, for instance to receive the medical treatment, the role of the family becomes especially important in the terms of giving support and understanding.

The family can encourage the patient in a different way and possibly with more direct methods than the hospital caregivers, since the communication is possible on a daily basis and continuously. The reassurance of the family-members may provide support and good results in all areas in relation to the quality of life: including physical activity, amount of daily exercise, correct nutrition, adequate amount of sleep and rest and the psychological issues, which have a direct effect to the individual resilience and the fact how the individual is experiencing and coping with the illness. The overall support given by family members and relatives can have a positive impact to patient and the healing process (Steinberg, et al 2010).

Effort should be placed in asking the right questions and in detecting possible early symptoms of anxiety and depression, which according to the studies introduced above occur in several patients especially at the early stage of the illness. Detecting anxiety early enough can prevent the condition to become worse and facilitates the whole recovery process. It is important that the information, which is relevant regarding the illness and care, gained from the conversations with the patient is accurately registered in the hospital database in order to design or implement the existing care plan and to consider the holistic aspects of the patient care (Harms, 2011; Lugg, 2010; McMahon-Parkes, et al 1997.)

Nurse's role in the care is dependant on the stage of the illness and the patient him- or herself. The person in the very beginning and acute state of illness is probably more vulnerable than a patient who has been living with the illness and who has possibly had good experiences and improvement in the condition due to right and effective treatment. Thus in the very beginning the nurse's role is to be the patient advocate, adviser and support. The symptoms, which may have become from other conditions gained because of GBS or CIDP, need to be properly taken care of. These conditions may include depression, malnutrition, pulmonary disease, thromboembolism including deep vein thrombosis and pulmonary embolism (Harms, 2011.)

Among mosquitos, which may trigger Zika-virus in tropical countries, in Finland there is a common insect, the *tick* (finnish: *puutiainen* or *punkki*), which can cause borreliosis and later develop polyradiculitis GBS in some patients (Kärppä, 2009.) This is essential knowledge for instance for nurses operating in Emergency Care or Health Centers, where people might be driven to because of the symptoms of borreliosis. Recognising the early symptoms of GBS or CIDP, which also may occur as a result from Borreliosis, the nurse can initiate the needed actions in order to the patient to receive correct type of care and treatment. In addition, symptoms arising after *Campylobacter* infection need to be carefully monitored since it has been proved to act as a major trigger for GBS (Steinberg, et al 2010).

It is important to provide the information about the CIDP and GBS and the possible outcomes to the whole family of the patient, in order to prepare them to be able to face the relative who has been strongly affected by the illness, and to be able to provide support and understanding for the patient (GBS-CIDP Foundation, 2016).

According to the National Act of Patients rights (1993), everyone has the right to receive care and medication in Finland, thus each individual may enjoy the hospital care despite the financial status. Also, everyone in Finland has the right to live pain free life! Despite the Act, 6 months waiting time is often too long for patients with acute onset and since the dramatic condition may develop within days. This highlights the urgency of proper assessment already in the Nurse-Patient encountering.

Due to personal interest in the field and a relative suffering from CIDP, the author of this thesis has studied a variety of material in addition to the articles selected for the literature review. Part of the material was utilized in the background chapter and in addition a deeper insight to the topic and patient experiences was gained from reviewing the online discussion groups for the GBS/CIDP patients and their families.

The interest towards further studies in Holistic Nursing and pain management, were raised after reviewing comments in the discussion groups. According to the review of online discussion forums, most of the patients have pain experiences, some of them extreme- and some very mild experiences. The stage and type of the illness affects in the background of individual experience. There are success and recovery stories online, on how individuals with GBS or CIDP have fought the illness and reached the stabile stage where the illness is not currently progressing. Other comments relate the beginning of GBS to stress: according to one patient the GBS symptoms occurred together with stress or begun right after a stress-full event in the patient's life. The author's conclusions are that the mental wellbeing of the patients and their families and relatives who are affected by the disease, play a great role in supporting the patient wellbeing and recovery.

After reviewing the scientific articles for the study, the author's ideas of the impact of nutrition and sleep in the recovery process were reinforced. Current studies mainly discussed the usage of nasogastric-tube in providing nutrition for patients in severe conditions and the importance of nutrition in the general level.

It would be interesting to read studies in the future from specialists who would have investigated the impact of nutrition in both the acute and the recovery stage of the illness and especially the impact of nutrition supplements in the muscle reinforcement.

Fowler, et al (1992) introduced the use of hypnosis for pain relief for GBS patients in the magazine of *Australian Physiotherapy*. As several other articles discussed in the literature review, this one in addition stated the GBS patients to experience pain due to the anxiety and muscle weakness during the performed exercises. The pain was said to impede the rehabilitation of the GBS patients, and according to the study, the use of hypnotherapy has proved efficacy to a safe form of pain control as the only non-invasive adequate form of pain relief. As well according to the information gained from the online discussion groups and information booklets provided from the third sector patient support groups, it can be mentioned that some of the patients may experience alternative medication helpful in the relief of the illness related symptoms, since the illness, individual resilience and response, and the way of experiencing the care is individual and thus cannot be easily compared between people (<https://forum.gbs-cidp.org/forums/>.)

8 CONCLUSIONS AND FURTHER RESEARCH

In the current model of Health Care Centres' operations in Finland, where the nurse is often the first person to encounter with and assess the patient before consulting the doctor or forwarding the patient to the doctor's appointment, it is vital that the nurses are familiar with the neurological symptoms, which require immediate action. Nurses' ability to identify the neurological symptoms, such as the mal-functioning and weakened peripheries, patients' commenting about symptoms of tingling and numbness, should alert the trained nursing staff to forward the patient to the doctor. In addition the nurse's ability in ER to identify changes in the patient's condition is essential in order to act rapidly with the right nursing interventions, which can be sometimes lifesaving. The studied illnesses affect individuals in all age groups, thus the patients can be met in all fields from pediatric-care to geriatrics.

All the articles studied for this thesis, clearly highlight the urgency for rapid symptom treatment and initiation of medication in order to prevent and stop the prognosis of the illness. This applies to both Guillain-Barrè syndrome and Chronic Inflammatory Demyelinating Polyneuropathy. It is commonly agreed in all of the studies that immediate medical treatment and effective care improve the health-related quality of life of the patient (Merkies, et al 2009; Hughes 2005; McMahon-Parkes, et al 1997.) Treatment of CIDP focuses on treatment for symptoms of CIDP such as pain and fatigue. According to the study completed by Van den Bergh et al (2010) the study around CIDP is lacking in research into the value of exercise and physical and occupational therapy in the management of the illness (*Journal of Peripheral nervous system 15:1-9, 2010*). Articles introducing Nursing interventions for CIDP only are scarce or inexistent; at least the author did not come across to any. Most articles were purely medical concentrating to the available treatments and their effects.

The nursing interventions in the care of CIDP patients, is a field, which requires to be further investigated. Since the illness is a chronic autoimmune disease where the conditions and symptoms vary patient to patient, it makes the study area highly interesting and challenging. Methods concentrating to preventing the progression with proper nursing interventions, in addition to medical care and physiotherapy, need to be further investigated.

Patients with Guillain-Barré syndrome face not only physical difficulties, but emotionally painful periods as well. It is often extremely difficult for patients to adjust to sudden paralysis and dependence on others for help with routine daily activities. Patients sometimes need psychological counselling to help them adapt. Nurse's role in patient monitoring has a great importance in identifying changes in the mood of the patient and to early discover the possible psychological problems, which are arising from the situation.

Both of the illnesses discussed in this thesis are relatively new in the Nursing research, especially CIDP. This fact itself raises the need for further research from the nursing perspective. The author of the thesis is as well willing to continue the research, perhaps as a part of the Master Degree studies in the future and in example in creating informative leaflets or publications for the 3rd sector. Rehabilitation is in key role in the both diseases GBS and CIDP. This is also why the need for research among the physiotherapy is essential as well. Since the healing process is individual and results vary between patients according to their self-determination and commitment to the care, the need for cooperation in the whole rehabilitation process between the different groups: public, individual and third sector, is important. The more research there is, the more is to be done to promote the quality of life and the patient wellbeing. The chances to get fully cured from the disease are rare, since it includes the characteristics of an autoimmune disease, which is reproductive and regenerating itself. There are possibilities to get cured and there is an interest for further research to study whether or not certain care methods (discussed in this study) are functioning. From nurse's perspective the care process would be interesting to study from a holistic point of view, including researching the available methods to promote the patient wellbeing and self-esteem as well as the patient's commitment to care.

Getting ill with GBS/CIDP does not affect only the patient but the whole family. The care and guidance should be provided in a way that it reaches all members of the family, in order to promote the resilience and to achieve maximum care results.

It would as well include taking into the process the whole family of the patient and planning activities to promote the patients' family-members' commitment and participation in the rehabilitation process.

The support to the family members of the patient is significant already from the stage of diagnosing the illness, since it most often brings dramatic changes to the person's life, and affects the whole family in different ways. Especially in situations where children are getting ill with these rare neurological diseases, the family members are even in a greater need of support since they are the primary caregivers of the child also during hospitalization. The emotional stress presented with the new situation in the family requires increased attention and support from the nurses and other hospital staff (Carley, 1989).

As an example, a topic for further research in the field of the commitment to the care would be developing ways and tools for patients in different age groups to support and encourage autonomy after muscle paralysis in the face where the patient's condition begins to improve. The methods should be taken into account from all fields, not only occupational- and physiotherapy, but also in the considerations how the family members could affect the quality of life the patient has, beginning from the point of the initial diagnosis of the doctor to the recovery and rehabilitation phase.

The further research could be carried out as a qualitative research where the patients and their families are interviewed and the care plan from both physiotherapists and occupational therapists would be studied in order to create a model of a care plan, which could still be modified considering the individual needs of each patient. The research could include a part, which could be carried out even as an additional research from the field, in which the commitment of the family-members who are acting as caregivers cope with the situational stress and emotions. According to the third sector discussion groups, the impact on the family-members is in a major role, since the illness of the individual affects the whole family and close friends of the individual. No previous research was to be found from the field of psychological coping of the family-members of the patients, thus this in addition raises the need to further research in the field, which is highly important.

In conclusion, the research as such was very challenging because of the scarce amount of data and the Nursing perspective. Most of the articles and data from the field are written from medical perspective or from the field of physiotherapy.

The author came across only five papers, which were written from nursing students or research nurses from Guillain-Barré syndrome (2 of them were theses, which could not be used for this study), and 0 articles written from nursing students or RN's from CIDP. Thus, it can be agreed that the research is as such very innovative. The perspective to the study was obtained from adding the study of GBS into the thesis, even though the intention at first was to study only CIDP. Due to the similarities of the two illnesses in question, which were explained already in the background chapter no. 2, the match was suitable for the topic and the research from the area. Another difficulty in completing the study was the accessibility of articles. Majority of the most interesting and current articles were accessible only with payment, especially in search engines and databases such as Science direct, and needed to be excluded from the study. Anyhow, the result probably would have been the same, since the articles did not include the nursing perspective and were mainly medical.

As agreed above due to the scarce amount of Nursing Articles from the field, one article from 1997 needed to be added into the literature review. In addition an article from 1989 was added to the discussion, since it was the only article resulting from the search of *family support AND Guillain-Barre syndrome*. Otherwise, the intention was to review newest possible data. As a conclusion can be agreed that the data selected for the literature review served the purpose and the huge amount of literature, both books and articles studied for the background information, served as a completion for the study. Quality of life as a term is holding itself enormous possibilities, and can as such be included in further studies.

It can be agreed that the thesis may operate as a good base for further studies and offer a great tool for nursing students to gain a deeper insight into the field, both from the perspective of the patient in understanding the experiences with the illness, and as a tool for knowledge about the nursing and medical interventions, which need to be begun, when encountering patients with either CIDP or GBS.

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APPENDIX

Appendix 1. Presentation of the articles used in the literature review

Author / Year	Title/ Source	Aim	Methods	Results	Country
1. Barbatto-Gaydos, H.L, 2004	"Making Special", A Framework for Understanding the Art of Holistic Nursing. Journal of Holistic Nursing, Vol. 22 No. 2, June 2004 152-163. American Holistic Nurses' Association 2004.	Is to create greater understanding of holistic nursing by introducing the holistic nursing values and standards of practice.	A review of the art of nursing theories and a brief summary of the available scholarships on the topic	Holistic nursing is by definition, aesthetic. It includes the deeper comprehension of caring and a special nurse-patient relationship. The definitions introduced in the article comply with the Levine's conservation theory used in the thesis.	USA
2. Forsberg <i>et al</i> , 2005	Disability and health-related quality of life in Guillain-Barre syndrome during the first two years after onset: a prospective study. Clinical Rehabilitation 2005; 19: 900-909.	Provide description of changes in disability and health-related quality of life in Guillain-Barré patients in Sweden during the first two years after onset.	Clinical follow-up and usage of several measurement scales such as the Activities of Daily Living Index and the Barthel Index etc.	Getting ill with GBS affects several areas of life and results in the ability to continue in the working life. It is suggested that a long-term and broad perspective is required from health care professionals when treating the patients.	SWE-DEN
3. Hal-deman <i>et al</i> , 2005	Treatment and Nursing Care for a patient with Guillain-Barre Syndrome; Dimensions of Critical Care Nursing (DCCN), Nov/Dec2005;	Providing information for critical care nurses in order to adapt	Presentation of a clinical case study	Nursing interventions include: observation of psychologi-	USA

	24(6): 267-272	to the changing care plan.		cal symptoms. Provision of empathy and support, keen listening skills, and giving support. Provision of Education among the illness and care related issues. Providing information of the 3 rd sector support groups.	
4. Harms, Matthew; 2011	Inpatient management of Guillain-Barré Syndrome The neurohospitalist 1 (2) 78-84, 2011	To provide a review of key issues in the inpatient management of GBS.	A survey of the evidence base for treatment with plasma exchange or intravenous immunoglobulins is presented.	GBS patients are at risk of several complications, including respiratory failure, autonomic dysfunction, thromboembolic disease, pain, and psychiatric disorders. Awareness of these complications, their detection and management, may help limit the morbidity of GBS.	USA
5. Hughes et al, 2005	Supportive care for Patients with Guillain-Barré syndrome. Neurological Review, August 2005; 62(8):1194-1198	To prepare recommendations for supportive care of Guillain-Barré syndrome	MEDLINE search by the consensus group from years 1966 to 2003.	80% of GBS patients suffer from illness related fatigue. Fatigue is related also to CIDP. Occupational and physiotherapy are the key tools in coping with the fatigue.	ENGLAND

6. Lugg, Jason; 2010	Recognising and managing Guillain-Barré syndrome, <i>Emergency Nurse -Journal</i> , June 2010, Vol 18 No. 3	The article examines the aetiology, clinical presentation, diagnosis and treatment of the condition, and reviews the case of a 16-year-old girl diagnosed with GBS	Clinical practice, The author of the article is an emergency care practitioner at NHS South Gloucestershire, UK	In order to detect changes in function of the cranial nerve, it is essential to monitor breathing and swallowing of the patient.	ENGLAND
7. Lönnstedt et al, 2011	Living with long-lasting pain – patients’ experiences of neuropathic pain/ <i>Journal of Nursing and healthcare of chronic illness</i> , Dec 2011	Description of the lived experiences of patients with neuropathic pain.	Qualitative inductive approach, in which Single semi-structured interviews were conducted during 2008 .	Positive attitude and empathy from the healthcare professionals towards the patient is needed since the neuropathic pain brings major changes in the daily- and social life of the patient, which can be seen in affecting the patient’s quality of life in full impact.	SWEDEN
8. McMahon-Parkes et al, 1997	Guillain-Barré syndrome: biological basis, treatment and care. <i>Intensive care and critical care nursing</i> (1997) 13, 42-48. Pearson Professional Ltd	To provide information of the nurse’s role in management of the GB syndrome in individual patient evaluation in the clinical area.	A UK-based clinical study combining statistical information and practice.	Proper continuous assessment of cranial nerve function, respiratory function, motor function, cardiovascular function, nutrition, elimination and pain is needed in order to detect early changes and intervene.	ENGLAND

9. Stewart et al, 2011	A systematic review of resilience in the physically ill, <i>Psychosomatics</i> 2011: May-Jun; 52(3):199-209	To conduct a systematic review of resilience and related concepts in the physically ill to determine factors associated with predicting or promoting resilience.	An electronic search of PsychInfo, Medline, and CINAHL databases between 1950 and May 2009 was performed using the terms resilience, and various types of physical illnesses	The study highlights several psychological factors and coping strategies, such as resilience, which are relevant in coping with the physical illness.	USA
10. Turner-Stokes et al, 2008	Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care <i>Journal of Clinical Medicine</i> ; Vol 8, No2, April 2008	To provide guidelines built of Quality Requirements for the UK National Service framework for Long-term neurological Conditions.	The guidance was prepared on behalf of the multi-disciplinary Guideline Development Group (GDG) convened by the National Council for Palliative Care and the British Society of Rehabilitation Medicine in association with the Clinical Standards Department of the Royal College of Physicians	Getting to know the patients receiving care in the same unit improves the ability to build good care-relationships and trust between the patient and the caregiver.	ENGLAND
11. Wilson et al, 2006	A study of nurses' inferences of patients' physical pain, <i>Journal of Clinical Nursing</i> , April 15, 2006, issue 4 p.459-486	to establish if postregistration education and clinical experience influence nurses' inferences of patients' physical pain	Questionnaires completed by 86 Nurses, SPSS and qualitative analysis of the written responses.	Study resulted that the nurses become less sensitive to patients physical pain. This needs to be evaluated in the daily care.	ENGLAND

Appendix 2 Presentation of the Data Collection and Search Procedure

Engine	Key words	Hits	Relevant hits	Chosen articles	No of articles used in the study
EBSCO	Nursing interventions AND Guillain-Barrè Syndrome	36	2	1	1
EBSCO	Nursing interventions AND CIDP	0	0	0	0
EBSCO	Quality of life AND Guillain-Barrè Syndrome	36	11	4	4
EBSCO	Quality of life AND CIDP	15	3	3	3
ScienceDirect	Guillain-Barrè Syndrome AND Nursing	517	25	4	3
ScienceDirect	CIDP AND Nursing	128	5	1	1
ScienceDirect	CIDP AND Quality of life	222	N/A	3	3
Sage	CIDP AND Nursing	14	1	1	1
Sage	GUILLAIN-BARRÈ Syndrome AND Nursing	0	0	0	0
Cochrane	GUILLAIN-BARRÈ Syndrome AND Nursing	4	0	0	0

Engine	Key words	Hits	Relevant hits	Chosen articles	No of the chosen article/s
PubMed	CIDP AND Nursing	2	1	0	0
PubMed	GUILLAIN-BARRÈ Syndrome AND Nursing	105	N/A	5	5
PubMed	GUILLAIN-BARRÈ Syndrome AND Quality of life	65	N/A	4	4
PubMed	CIDP AND Quality of life	41	12	3	3
Medline/Ovid	GUILLAIN-BARRÈ Syndrome AND Nursing	48	6	0	0
Medline/Ovid	CIDP AND Nursing	0	0	0	0
Medline/Ovid	GUILLAIN-BARRÈ Syndrome AND Quality of life	0	0	0	0
Medline/Ovid	CIDP AND Quality of life	0	0	0	0

Appendix 3 Abbreviations and concepts used in the thesis:

CIDP – Chronic Inflammatory Demyelinating Polyneuropathy, a condition, in which the inflammation occurs in the nerves resulting into various symptoms

GBS – Guillain-Barré Syndrome. The condition occurs when the defence (immune) system of the body mistakenly attacks part of the nervous system

Autoimmune disease – A condition, in which the immune system of the body attacks itself by mistake

Myelin - an insulating material, which when damaged or worn away, has a decreasing effect to the function of the nerve

Demyelination - the damage, which occurs in the myelin

Proximal – located towards the center of the body

Distal – situated away from the point of the central point of the body

IVIG – a highly purified preparation of gammaglobulin or antibodies, a blood product preparation, which is derived from 1000 to 10 000 persons is present in each unit of IVIG. The product is carefully purified and screened from all known transmissible diseases such as HIV, Hepatitis, Malaria etc.

Paresthesia – sensation of numbness and tingling

Hyperesthesia –increased sensation

Blood culture, which is performed to find an infection in the blood and to detect bacteria or viruses

CBC – complete blood count, which is performed to detect kinds and numbers of cells in blood

ENMG – electroneuromyography is used to investigate functionality of the neuromuscular system (the recording the electrical activity of muscles and nerves).