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An Occupational Therapists' Guide to Guillain-Barré Syndrome

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AN OCCUPATIONAL THERAPISTS' GUIDE TO GUILLAIN-BARRE SYNDROME

by

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Faculty Advisor

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Title An Occupational Therapists' Guide to Guillain-Barre Syndrome

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ABSTRACT

Guillain-Barre syndrome (GBS) is a rare polyneuropathy that affects 2,720 people per year in the United States (NIH, The National Women's Health Centre, 2004). Guillain-Barre syndrome has a rapid onset that causes the patient to lose sensation and muscle strength within 48-72 hours. This project provides a resource for occupational therapists treating Guillain-Barre Syndrome (GBS) to access information regarding the etiology, incidence/prognosis, assessments, and course of medical treatment. The Occupational Adaptation model serves as a foundation for treatment of the product-a guide for occupational therapy intervention. Interventions are organized to be compatible with the Occupational Therapy Practice Framework (American Occupational Therapy Association, 2008). The guide focuses on occupational therapy assessment and intervention methods appropriate to each of the three phases of recovery. Sample patient/caregiver education material is also provided to assist patients and caregivers in understanding the illness. Recommendations for further enhancement of the guide are included.

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CHAPTER I

INTRODUCTION

Guillain-Barre syndrome (GBS) is a rare polyneuropathy that affects 2,720 people per year in the United States (NIH, The National Women's Health Centre, 2004). According to Porth (2005), "GBS is a subacute polyneuropathy. The manifestations of the disease involve an infiltration of mononuclear cells around the capillaries of the peripheral neurons, edema of the endoneurial compartment, and demyelination of ventral spinal roots" (pg. 1204). Guillain-Barre syndrome has a rapid onset that causes the patient to lose sensation and muscle strength within 48-72 hours. According to Khan (2004), 40% of patients diagnosed with GBS require inpatient rehabilitation (especially those requiring ventilator support).

Due to the rarity of the syndrome, many therapists only see a few cases during their career. When a GBS patient is referred to occupational therapy, many therapists often need to research the pathology to effectively treat the patient. The current literature outlines the definition, possible causes, and medical interventions for GBS, but there is limited research on rehabilitation services.

The purpose of this project is to provide a resource for occupational therapists to access possible interventions for treatment. This guide will assist the therapists by providing a quick reference of definition, etiology, course of the disease, medical and therapeutic interventions. In addition, the guide includes an educational handout to give to the patient or caregivers about GBS. Guillain-Barre syndrome is often thought of as a physically debilitating disease; but this guide will ensure that efforts have been made to address both physical limitations, and the

psychosocial impact on the client and the caregivers. The information in the guide is based on current literature and evidence based practice.

The OT model used in this scholarly project is the Model of Occupational Adaptation (OA). OA was chosen due to the nature of GBS and the lingering affects it may have on the patient. These effects can be debilitating and the patient may have to adapt to a new lifestyle after recovery from GBS. The interventions in the guide are tailored around the adaptive response modes described in the model. The adaptive response modes are as follows:

Existing: This is the adaptive response used by the patient which is a familiar action to them. This could be adapting a cooking activity in which the patient sits down while cooking to conserve energy and sitting is the existing adaptation.

Modified: This is the adaptive response used by the patient which a part of the adaptation may not be familiar to the patient. This could be adapting a cooking activity in which the patient uses a reacher to obtain an object that is out of his/her reach. The reaching would be an existing activity but using the reacher is the modified adaptation.

New: This is the adaptive response used by the patient in which the adaptation is not familiar to the patient. This could be adapting a cooking activity for someone who has had a recent upper extremity weakness which could involve retraining the person to use one hand during cooking activities. The new adaptation would be considered using one hand to crack an egg because people usually use two.

When a therapist is collaborating with the patient to adapt a patient's environment and energy levels, there are two forms of energy that are used. The first form is called primary adaptation energy and is active when there is focused attention on the challenge an adaptive protocol is followed. The primary adaptation energy burns energy at a higher intensity than the

secondary form causing increased fatigue. The next form is called secondary adaptation energy and is active when the focused attention is not on the challenge. The secondary adaptation energy requires less energy output and therefore conserves energy for both the patient and the therapist.

The scholarly project is outlined as follows: Chapter two is the review of the current literature on GBS; Chapter three presents the methods used to complete the scholarly project; Chapter four is the finished guide to GBS for occupational therapists; and Chapter five summarizes the purpose of the project and provides recommendations for future application and research.

CHAPTER II REVIEW OF LITERATURE

Introduction

Each year approximately 2,720 people are diagnosed with Guillain-Barre Syndrome (GBS) in the United States (NIH, 2004). GBS is a significant cause of new long-term disability for at least 1000 persons per year in the United States. Approximately 40% of patients who are hospitalized with GBS will require admission to inpatient rehabilitation (Meythaler, 1997). Even though extensive research into the possible causes of GBS has been conducted, research on the actual treatment of the disorder by the rehabilitation team is limited.

This literature review presents aspects of GBS ranging from diagnoses to current treatment. The review includes the definition of GBS's, causes, and prevalence, how GBS affects different age groups, prognosis, and interdisciplinary care involving physicians, therapists and other healthcare workers within the realms of physical and psychosocial rehabilitation.

Diagnosis

According to Porth (2005), "GBS is a sub acute polyneuropathy. The manifestations of the disease involve an infiltration of mononuclear cells around the capillaries of the peripheral neurons, edema of the endoneurial compartment, and demyelination of ventral spinal roots" (pg. 1204). Patients are clinically diagnosed after admission based on universal symptoms of the syndrome such as slow, progressive muscle weakness, tingling in distal portions of extremities, and in extreme cases respiratory failure and total paralysis. Autonomic signs such as sinus arrhythmia, tachycardia, and hypertension often are associated with a diagnosis of GBS. The clinical diagnosis is confirmed using a number of diagnostic methods including nerve

conductions studies, lumbar punctures, and magnetic resonance imaging (MRI). According to Hadden (1998), the most useful confirmatory test is nerve conduction studies which are abnormal in 85% of GBS patients. Nerve Conduction studies are able to measure how fast nerves can send electrical signals throughout the patient's body. When these signals are blocked or take increased time to reach their destination, GBS can be a likely diagnosis. Another diagnostic method involves a lumbar puncture for cerebral spinal fluid (CSF) to check for albuminocytologic dissociation which is elevated protein levels without increased white blood cell count. Magnetic resonance imaging of the lumbrosacral area two weeks after presentation of symptoms can be an effective way of diagnosing GBS in 83% of acute GBS and 95% of all typical cases (Tseng, 2008).

Assessments

There are three main assessments that can be used to assess the patient's functional status after the onset of GBS. One assessment that is commonly used with all GBS patients is the Hughes scale. This scale is rated as follows:

- 0 - A healthy state
- 1 - Minor symptoms and capable of running
- 2 - Able to walk 10 meters or more without assistance, but unable to run
- 3 - Able to walk 10 meters across an open space with help
- 4 - Bed ridden or chair bound
- 5 - Requiring assisted ventilation for at least part of the day;
- 6 - Dead

(Koningsveld, Steyerberg, Hughes, Swan, van Doorn, & Jacobs, 2007).

The Hughes scale helps the practitioner develop a standardized measurement to document the level of disability. Another scale used to assess GBS is the Medical Research Council (MRC) sum score. This assessment is rated as follows:

0 - No visible contraction

1 - Visible contraction without movement of the limb

2 - Active movement of the limb, but not against gravity

3 - Active movement against gravity over (almost) the full range

4 - Active movement against gravity and resistance

5 - Normal power (Koningsveld et al., 2007). This assessment is used to determine the muscle function that has been lost and provide a measurement for documentation. The Functional Independence Measure (FIM) is another assessment tool commonly used to determine the degree of dependency in the following areas: self-care activities, sphincter control, mobility, locomotion, communication, and social cognition. The scale rates the patient from 1-7, 1 being dependent and 7 being independent. This assessment tool can be used to document improvement in functional tasks. All of the assessments mentioned above have been helpful in determining and measuring functional abilities throughout the phases of GBS (El Mhandi, Calmels, Camdessanche, Gautheron, & Feasson, 2007).

Etiology

Radcliff and Thomas (2007), described the cause of GBS as an autoimmune response that is thought to be triggered by a viral or bacterial infection, but the true cause is unknown. In addition, it was determined that in 60% of GBS cases, respiratory or GI viruses preceded the GBS diagnosis. “The cause of GBS probably has an immune component. Controlled

epidemiologic studies have linked it to infection with *Campylobacter jejuni* in addition to other viruses, including Cytomegalovirus and Epstein-Barr virus” (Porth, 2005, pg.1204).

Campylobacter Jejuni

The *Campylobacter jejuni* virus is the most frequently diagnosed bacterial cause of human gastroenteritis with an occurrence rate of 2.1 to 2.4 million cases in the U.S. each year (Altekruse, Stern, Fields, & Swerdlow, 1999). *C. jejuni* is a food borne pathogen that is transmitted to humans through raw milk, raw or undercooked poultry, untreated water, traveling abroad, and contact with cats and dogs especially pets with diarrhea. *C. jejuni* is rarely passed from human to human. In one out of every 1000 cases GBS is a secondary diagnosis associated with *C. jejuni* infection. *C. jejuni* infection is prevalent in up to 40% of patients with a diagnosis of GBS (Altekruse, Stern, Fields, & Swerdlow, 1999).

Cytomegalovirus

Another common link to a diagnosis of GBS is the cytomegalovirus (CMV). CMV is found in 50% to 80% of adults by the age of 40 and is the most common virus transmitted to a pregnant woman’s unborn child. Once a person has been exposed to the virus it will stay with the person for life, but in most cases will not show any signs or symptoms in an infected person. Approximately 1 in 750 infants are born with or develop permanent disabilities due to the transmission of CMV (Centers for Disease Control and Prevention [CDC], 2006). According to Khan (2004), the axonal form of GBS has been implicated with CMV and *C. jejuni*.

Epstein-Barr Virus

Epstein-Barr virus (EBV) has also been associated with the cause of GBS. Upwards of 95% of U.S. citizens between the ages of 35 and 40 have been infected with EBV. Infection with EBV is rare within childhood, but if the virus occurs during adolescence or young

adulthood, it is the cause of infectious mononucleosis 35% to 50% of the time (CDC, 2008). Infectious mononucleosis's symptoms usually resolve within one or two months, but EBV can remain dormant within a person's cells in the throat and blood for the rest of their lives. Transmission of this virus requires intimate contact with the infected person's saliva; transmission through air and blood rarely occurs (CDC, 2008). According to Curtis, Barnes, and Dupiche (2008), GBS has been associated with EBV; by the time symptoms of GBS appear, the symptoms of EBV have usually resolved.

Influenza Vaccine

A connection has been assumed between GBS and the influenza vaccine and has been a source of debate within the medical community. Juurlink et al. (2008) found that GBS is associated with the influenza vaccination and increases the risk for hospitalization. Barclay and Lie (2004) postulated "that campylobacter infection in chicken eggs used for producing influenza vaccine may be the reason for a link between influenza and GBS" (¶ 9).

Although there are many links to the onset of GBS, there are only a few associations that have been established (Winer, 2008). The cause of GBS in the literature all links back to these four different viral and bacterial infections. Each of the infections is generated from different sources and has different physiological effects, but all have been known to precede a diagnosis of GBS.

Incidence and Prognosis

The incidence rate of GBS is between 1.65 and 1.79 per 100,000 people (Alshekhlee, Hussain, Sultan, & Katirji, 2008). Prognosis of GBS patients can vary depending on numerous factors associated with the patient and the disease. Koningsveld et al. (2007) found a method of predicting a patient's prognosis based on clinical factors within the first two weeks of the

patients diagnosis. The factors that were associated with prognosis were age, sex, diarrhea, upper respiratory tract infection, infection serology, anti-ganglioside antibodies, GBS disability score, Medical Research Council (MRC) sum score, weakness before entry, cranial nerve involvement, and sensory deficits. Koningsveld et al. (2007) created a prognostic scoring system named Erasmus Outcome to predict the prognosis for patients with GBS. Erasmus predicts outcome using three factors: age at onset, diarrhea, and the GBS disability score. For example, the researchers found that an Erasmus score of 5.5 or more predicted that within 6 months clients would be unable to walk independently. According to Khan (2004), “Most patients with GBS are discharged home with outpatient and home rehabilitation programs. However, 40% of all GBS patients require inpatient rehabilitation (especially those requiring ventilator support)” (pg. 1014). In approximately 5% of GBS cases recurrence may occur even years after the initial diagnosis (eMedicine, 2006).

Although infrequent, individuals with GBS have died. Throughout a 5 year study, 2.58% of the population died during hospitalization due to complications from GBS. According to Lawn, Eelco, and Wijdicks (1999), “In a specialized center, the primary event leading to death in GBS was ventilator-associated pulmonary infection, predominantly in elderly patients with significant co morbidity” (pg. 635). The majority of GBS admissions in the United States were found in large urban hospitals with the southern hospitals displaying a slight predominance (Alshekhlee, Hussain, Sultan, & Katirji, 2008).

The Course of Guillain-Barre Syndrome and Medical Intervention

When a person is diagnosed with GBS, the course of the illness follows three phases. The first or initial phase of GBS is a rapid progression of symptoms that may take anywhere from 3-48 hours to reach the most severe symptoms and then continues for up to three weeks (Virtual

Medical Centre, 2008). The plateau phase is the second phase of the disease. This phase involves no change with the patient's symptoms and may last an additional two - four weeks (Demir & Koseoglu, 2008). The third phase, the recovery phase, can extend over a one - two year time frame (Demir & Koseoglu, 2008). The medical interventions vary between phases and multiple disciplines. The course taken to facilitate the improvement in medical status involves four main areas: physical disability, psychosocial, pharmaceutical, and occupational therapy (OT) intervention. The following is an explanation of the three phases and the course of treatment taken within each area of discipline.

Initial Phase

Physical Disability

The initial phase presents with symptoms that occur within the first 48-72 hours of onset. Patients could display any or all of the following symptoms: muscle weakness or paralysis, decreased sensation or numbness, tenderness, blurred vision, muscle contractions, palpitations, blood pressure, respiratory difficulties, difficulty swallowing, fainting, drooling, difficulty moving facial muscles, or uncoordinated movements (Mayo Clinic, 2007b). In severe cases of GBS, a catheter and aggressive bowel routine will be needed to assist the patient with toileting (Neurological Medicine Pocketbook, 2004).

Muscle weakness or paralysis can be one of the most debilitating symptoms of the disease if not treated properly in the initial phase of GBS. Interventions used by physical therapists (PT's) and OT's include passive range of motion (PROM) or active range of motion (AROM) to facilitate stretch and maintain strength in the upper extremities (UE) and lower extremities (LE) to decrease the risk of contractures and deformities (Mayo Clinic, 2007). Occupational therapists can be incorporated into the initial phase, but more often will not be

referred to a patient with GBS until the plateau phase has begun (Copperman, Forwell, & Hugos, 2002).

Respiratory difficulty is a common symptom and if severe can lead to fatality. Treatment of respiratory failure is mechanical lung ventilation. According to Lawn, Eelco, and Wijdicks (1999), “mechanically ventilated patients constitute the majority of GBS patients with a poor outcome, and mortality remains substantial in this subgroup (20%)” (pg. 635).

Swallowing difficulties can range in severity from diminished swallow reflex to severe aspiration that could cause pneumonia which could lead to death. According to Hwang, Choi, Ko, & Leem, (2007), a feeding tube or proper body positioning may be necessary to prevent choking during feeding due to the weak muscles involved in swallowing. Swallowing is often addressed by speech-language pathologists (SLP) to evaluate and treat the swallowing process.

Psychosocial

The psychosocial area of treatment is often one that is overlooked with GBS patients. The physical demands of the GBS patients can often overwhelm the medical staff leaving the psychosocial areas untreated. The patient is going through life threatening changes described by the patient as “an incomprehensible, prolonged increasing deterioration, or as a frightening rapid onset” (Forsberg, Ahlstrom, & Holmqvist, 2008, pg. 225). The researchers discovered that people diagnosed with GBS experienced a fear of dying when respiratory failure began. Feelings of abandonment have been described by patients who suffered from the loss of communication skills during the initial phase. The patients also felt feelings of insecurity when they were moved from ward to ward, leaving the people that they had become comfortable with. Patients who experienced a frightening onset of GBS longed for an explanation of why they contracted the disease. Most patients who are diagnosed with GBS have never heard of this

disease. After patient education on prognosis, the patient often held on to the positive prognosis like a “lifebuoy” improving motivation to recover (Forsberg, Ahlstrom, & Holmqvist, 2008, pg. 223).

Pharmaceutical

Pharmaceutical intervention plays a vital role in the recovery process of GBS. The initial phase requires the most intense pharmaceutical interventions. The two major interventions to treat GBS are plasmapheresis and intravenous immunoglobulin (IVIg). Additional pharmaceuticals used to treat the symptoms of GBS are pain medications, anxiety/depression medications, blood thinners and blood pressure medication.

Plasmapheresis is the treatment of choice when acute respiratory failure has occurred. “A total plasma exchange allows rapid elimination of auto-antibodies and pro-inflammatory cytokines giving hope for control over exacerbated autoimmune diseases, however, positive results have been obtained with only a few diseases, including GBS and myasthenic crisis” (Szczeklik, Jankowski, Wegrzyn, Krolikowski, Zwolinska & Mitka et al., 2008, pg. 240). Plasmapheresis is the separation of blood cells and the plasma fluid within the blood. This separation removes the anti-bodies within the blood that are attacking the body and replacing them with either donor plasma or a saline solution (Muscular Dystrophy Association [MDA], 2005). This treatment option can take up to several hours and three liters on average is replaced in one treatment session. The risk factors of plasmapheresis include allergic reaction to donor plasma, low blood pressure, bleeding secondary to the anti-coagulants, and excessive suppression of the immune system (MDA, 2005). The effects of this treatment can be seen anywhere from after one treatment to three to four treatments later.

Intravenous immunoglobulin (IVIg) therapy is another pharmaceutical treatment option for GBS. This form of treatment contains pooled immunoglobulin G (IgG), derived from blood donors, and is administered over two - five days in a series of treatments (Miller, Rodman, Sanders, Walker, Bromberg & Swenson, et al., 2003). The IVIg treatment consists of blood proteins being injected into the body in substitution of the body's natural antibodies (The Myositis Association, 2007). Side effects that are associated with IVIg treatment are fevers, headaches, and muscle aches. These side effects can often be treated before the IVIg therapy with ibuprofen and Benadryl (Miller, et al., 2003).

Pain is often an overlooked symptom of GBS due to physicians concentrating on the life threatening aspects of the disease (Parry, 1998). If pain develops, it is usually located along the spine and upper parts of the limbs. Patients tend to have a hard time describing the pain, but usually is a cramping or aching quality. In patients that are ventilated and unable to communicate, it is important to establish if there is pain. Pain, if severe enough, can cause dangerous heart irregularities and changes in blood pressure. Severe pain can be handled with analgesics such as morphine or steroids such as prednisone to decrease the pain. If the pain is not at a dangerous level, non-prescription drugs such as ibuprofen can be used (Parry, 1998).

Plateau Phase

Physical Disability

The symptoms in the plateau phase become stable and remain in that state for 14-28 days. The treatment for the symptoms remains identical to the initial phase due to the consistency in the degree of weakness. According to Morgan (1991), the length of the plateau phase directly correlates with the degree of disability. The longer the patient remains in this plateau phase with no improvement in their recovery the more extensive their recovery phase will be. During the

plateau phase, severe cases will still be ventilated due to the weakness in the respiratory muscles. Forsberg, Ahlstrom, and Holmqvist (2008) found that “the ventilator-treated persons all talked vividly about the nauseating and often disgusting experience of suctioning of mucus, which had to be done several times a day” (pg. 224). According to Hwang, Choi, Ko, and Leem (2007), in long-term intubated patients, early swallowing interventions while still intubated improved the recovery of swallowing functions. Speech language pathologists (SLP) could perform the stimulation using 5 different interventions. Those interventions would include: thermal-tactile sensation, oral stimulation, oral massage, digital manipulation, and cervical range of motion exercises which are all part of the SLP’s realm of practice. (Hwang, Choi, Ko, & Leem, 2007). In the plateau phase, OT’s are added to the treatment team and begin assessment. The areas that OT’s will assess include but are not limited to the following: environment, communication, comfort, level of anxiety, and functional ability (Copperman, Forwell, & Hugos, 2002). After assessment has been completed, the OT sets goals with the patient with the long-term goal being full recovery. The goals are met with multiple interventions during treatment. The main focus during the plateau phase is to provide maximum comfort and accessibility for the patient. The interventions may include development of communication tools; adapting hospital rooms to ensure access to the nurse call button, TV, light switches, and telephone; positioning; education about GBS; recommending support groups; and teaching anxiety reduction strategies. Due to the nature of the plateau phase, the patient is still medically unstable, and functional rehabilitation begins in the recovery phase (Copperman, Forwell, & Hugos, 2002).

Psychosocial

In addition to the emotional feelings the patients experience, mental status abnormalities have also been described. According to Cochen, Arnulf, Demeret, Neulat, Gourlet, and Drouot,

et al. (2005), patients can experience vivid dreams, hallucinations, illusions, paranoid delusions, and abnormal rapid eye movement (REM) sleep. These mental status abnormalities appeared on average on the ninth day after onset and lasted on average of eight days. The vivid dreams that patients experienced often were strange, colorful, and highly emotional. Some patients reported dreaming they were leaving their bodies at the hospital while they went on vacation. Nightmares were experienced with themes of dying and of poor recovery. These dreams would occur several times a day and were remembered with detail months later (Cochon, et al. 2005).

Illusions can consist of visual, tactile, or auditory sensations. Patients have described illusory body tilt in which they feel their environment has rotated 90°. For example, “the bed was vertical and the nurses and doctors were walking on the walls” (Cochon, et al. 2005, pg. 2538). The researchers found that 60% of patients with GBS reported hallucinations. These patients described their hallucinations as small, colorful moving figures such as animals or goblins running around their room and sometimes entertaining them. Other patients described tactile hallucination and required explanation as to why he felt soap or noodles on his hand. Many patients experienced the hallucinations the moment that they closed their eyes and therefore were afraid to close their eyes because the images were not avoidable, (Cochon, et al., 2005). According to Forsberg, Ahlstrom, and Holmqvist (2008), half of patients who received ventilator treatment described hallucinations that made them fearful and anxious. These hallucinations could be vividly remembered two years after treatment. One woman discussed knowing that the hospital staff wanted to kill her to end her suffering.

Delusions experienced by 70% of the GBS patients were described as faces changing, scared and astonished looks, or following invisible objects with their eyes. Patients could recall and describe the delusions several months after the plateau phase. Most of the delusions were

experienced as a paranoid experience of people trying to attack or harm them. According to Cochen, et al. (2005), REM sleep patterns were abnormal during the plateau phase of GBS. “Since the REM sleep executive mechanisms are located within the brain, the presence of abnormal REM sleep in GBS provides strong evidence that the disease affects not only the peripheral nervous system, but also central targets” (Cochen, et al., 2005, pg. 2543).

Anxiety and depression are two symptoms that are not always acknowledged and resolved throughout the treatment of GBS. The most common way to treat anxiety and depression in the plateau phase is using pharmaceutical intervention. The OT is often involved in treatment strategies to reduce anxiety and depression. Occupational therapists may recommend support groups and anxiety reduction strategies such as progressive relaxation and meditation (Copperman, Forwell, & Hugos, 2002).

Pharmaceutical

The plateau phase’s interventions are similar to those of the initial phase. The symptoms have ceased to progress and recovery has not begun. Treatment interventions such as plasmapheresis and IVIg are continued throughout this phase. Pain continues to be addressed as it was in the initial phase. Psychosocial concerns, although present in the initial phase, are addressed more thoroughly in the plateau phase. According to Brousseau, Arciniegas, and Harris (2005), “persons with anxiety and affective lability during recovery from GBS may benefit from judiciously applied pharmacotherapy, and that modest doses of SSRIs, alone or in combination with gabapentin, may be both more effective and better tolerated than benzodiazepines and opiates” (pg. 146). An aggressive bowel program should be initiated using milk of magnesia, colace or dulcolax to promote healthy bowel movements (Neurological Medicine Pocketbook, 2004).

Recovery Phase

Physical Disability

The recovery phase can extend from one - two years and involve intense therapy from several disciplines. Muscular strengthening can be a vital part of recovery and rehabilitation during this phase. In many situations, PT's will create a treatment plan to include muscular strengthening of LEs by developing an exercise program that will involve active range of motion (AROM) and some type of resistance training (Mayo Clinic, 2007). Often patients will be required to participate in resistance training which could involve moving the lower extremities (LE) against gravity then adding a one pound ankle weight. Eventually the patient will regain muscle strength and be able to increase resistance. When the patient regains LE muscle strength, gait training will begin. The PT will work with the client to discover the safety concerns and assess walking balance (The Merck Manual Online Medical Library, 2007). According to El Mhandi et al. (2007), patients who displayed significant progress were discharged home and received outpatient rehabilitation which included home exercise programs. An average of two - three weekly sessions of outpatient PT was completed by patients based on level of muscular strength in the LE's (El Mhandi et al., 2007).

When the patient enters the recovery phase, intense functional rehabilitation can begin. Occupational therapists may use the following interventions to help the patient resume previous occupations and occupational roles: instructing in safe mobility; transfer training; modified self-care techniques; providing temporary aides and equipment; adapting communication modes; encouraging community access; encouraging routine activities; adapting equipment for home, leisure and work activities; instructing in energy conservation; and providing information and

modifying employment roles and tasks (Copperman, Forwell, & Hugos, 2002). The OT may also perform an evaluation of the home to ensure a safe and accessible home environment.

By the recovery phase, the average patient is being weaned from mechanical ventilation. According to Forsberg, Press, Einarsson, Pedro-Cuesta and Holmqvist, (2004) the average patient was weaned from ventilator support within a 20 day time frame. MacIntire, (2002) reported that “6 weeks of bed rest have been shown to reduce skeletal muscle mass by 10% and muscle strength by 25%. In addition...respiratory muscles can atrophy after prolonged use of controlled (i.e., no spontaneous muscle activity) mechanical ventilation”.

When the patient begins to enter the recovery phase swallowing should be re-evaluated to determine the continued need for a feeding tube or simple swallowing exercises to help coordinate the swallowing reflex (Mayo Clinic, 2007a). After removing the feeding tube the speech therapist may lead the client through the Clinical Food Texture Modification Grading Scale and the Clinical Fluid Thickness Grading Scale (Speech Pathology Australia, 2007). Moving the patient through a food texture modified grading scale would include pureed, minced and moist, soft, and unmodified foods. The fluid thickness grading scale would include a pudding consistency, honey consistency, nectar consistency and unmodified liquids (“Australian standardised definitions,” 2007). Typically the SLP begins modification of liquids with a pudding consistency and food with a pureed texture to ensure that the patient does not aspirate. As the patient masters each consistency the patient may move up the scale towards unmodified foods and liquids (“Australian standardised definitions,” 2007).

Psychosocial

Once a patient has reached the recovery phase, the fear of dying has subsided secondary to noticeable improvements in function and look forward to regaining their lost abilities within

12 months. Over half of patients diagnosed with GBS continue to improve after a 12 month time frame. In the beginning of the recovery phase the loss of muscle control in the legs was perceived as disrupting by almost half of the patients (Bernsen, Jager, Meche, & Suurmeijer, 2005). Patients describe the frightening feeling of becoming dependent on other people for self care tasks. Some patients describe this as losing their identity and experience feelings of helplessness and shame associated with loss of basic body functions such as eating and toileting on their own (Forsberg, Ahlstrom, & Holmqvist, 2008). Demir and Koseoglu (2008) found that patients' quality of life (QOL) could be evaluated under six health related domains. These domains included energy level, pain, emotional reaction, sleep, social isolation and physical mobility. GBS patients were found to have more dissatisfaction with the difficulty participating in areas that required physical or psychosocial effort. Quality of life was shown to be better if the patient was male, did not require mechanical ventilation, higher education status and did not have signs of depression (Demir & Koseoglu, 2008).

An area that is often overlooked by practitioners treating patients with GBS is the burden placed on the caregivers or family members after a diagnosis of GBS. "The sudden development of ascending paresis and, consequentially, the severe neurological deficit, the uncertainty concerning the future, and the often-prolonged absence from home confront close relatives with many emotional, social, and even financial problems" (Bernsen, Jager, Meche, & Suurmeijer, 2005, pg. 53). According to Bernsen, Jager, Meche, and Suurmeijer (2005), anxiety was scored as being at the highest point in the first month after diagnosis but decreased significantly throughout the year in caregivers. The researchers concluded patient support groups could be beneficial not only to the patient with GBS but also the family members and caregivers as well (Bernsen, Jager, Meche, & Suurmeijer, 2005).

Pharmaceutical

The recovery phase consists of pain management interventions as well as medications to relieve the symptoms of anxiety and depression. Plasmapheresis and IVIg are not often present in the recovery phase (Parry, 1998). Usually these treatment options are completed within the initial and plateau phases. Pain is often present within the recovery phase, but presents differently than the initial phase. The pain is localized in the lower part of the limbs, especially the feet and is described as more of a burning and stabbing sensation. The type of pain that the patient experiences in this phase is often referred to as neuropathic pain and does not respond well to analgesics. According to the Parry (1998), this pain responds best to anti-depressant and anti-convulsant medications in high doses, but may not show immediate pain relief. There is only a 50% pain reduction expected with treatment, so education for the patient is important to inform them that the pain may persist for months, years, or even permanently (Parry, 1998). The pharmaceutical approach was taken with depression and anxiety in the plateau phase and is continued on into the recovery phase until pharmaceutical therapy is no longer needed.

OT Intervention

Cost

The cost of GBS can be substantial not only for the patient, but also for the economy. When a patient is diagnosed with GBS, the average initial direct medical costs are \$45,301, with acute care inpatient costs of \$41,606 over the patient's lifespan (Frenzen, 2008). Tsai, Wang, Liu, Sheng, and Lee (2006), found that plasma exchange (PE) and intravenous immunoglobulin (IVIg) were the two common treatments for GBS. Plasma Exchange was shown to be more than double the cost in procedures and hospitalization compared to IVIG; IVIG was almost double the cost in pharmaceuticals. Community hospitals, inpatient rehabilitation facilities, and long term

care facilities have an average cost of \$32,000 each over a lifespan (Frenzen, 2008). Nursing home costs, if needed, average \$8,041 per patient (Frenzen, 2008). Outpatient services for each patient have an average of \$3,869 across their lifetime. The economic impact of a patient being diagnosed with GBS is shown with an average of \$186,416 in loss of productivity per patient and \$4,250,262 in premature death costs (Frenzen, 2008). Clearly, the cost of GBS is considerable for the individual and society.

Conclusion

In conclusion, GBS is a rare syndrome with an unknown cause. Although most patients find themselves recovering completely, many patients need to endure intense rehabilitation for physical disability, as well as psychosocial effects. The current literature presents causes of GBS, medical treatment, and general recovery. The literature is far less clear regarding the roles of members of the rehabilitation teams. Physical and speech therapists are part of the rehabilitation team, but little information is available on the treatment of GBS specifically. Similarly, there is limited information for therapists on interventions with GBS. The outcome of the scholarly project is to provide a reference tool for OT's to implement into a treatment plan and provide intervention ideas for patients with GBS.

CHAPTER III

METHOD

The methods used in creating this product involved reviewing the current literature, determining beneficial information and creating a detailed guide to the occupational therapy treatment of Guillain-Barre Syndrome. Literature was reviewed regarding the following topics: diagnosis, etiology, prevalence, and course of the syndrome; research regarding evidence-based occupational therapy practice was not available.

The literature was accessed through the University of North Dakota's Harley E. French Library using PubMed, CINAHL, OT textbooks, and the Internet. Articles were located and synopses were developed to gain an improved understanding of the selected topics. Additional searches of the literature were performed to supplement areas that were incomplete in the initial search, including use of textbooks and reliable medical Internet sources. The student authors prioritized the literature and selected information according to the following criteria: currency of the literature, relevance to occupational therapy practice, relevance to GBS, and the strength of the research findings.

Information was gathered and compiled into the literature review. The decision was made to develop a document to serve as a guide for occupational therapists' interventions for individuals diagnosed with GBS. Goals were developed to provide an example of typical goals for a patient with GBS. The goals were developed through personal experience with similar disabilities and current literature: the goals were determined as appropriate for each of the three phases of GBS. The assessments portion of the product was developed to provide the therapists

with recommended assessments to be used as part of the evaluation process for occupational therapy. Assessments were chosen through literature, professional experience, and compatibility to the Occupational Adaptation Model. The intervention section of the product was created using the Occupational Therapy Practice Framework: Domain and Process with special attention paid to the areas of occupation addressed in occupational therapy practice (American Occupational Therapy Association, 2008). The interventions were divided into categories as follows: activities of daily living, instrumental activities of daily living, rest and sleep, education, work, leisure, and social participation.

Based on the literature findings, a need was identified for patient/caregiver education materials to improve the understanding of the diagnosis and the typical progress from initial phase through the recovery phase. The patient/caregiver handout outlines diagnosis, etiology, incidence, prognosis and the course of medical intervention, including occupational therapy.

Chapter four presents background information on diagnosis, assessments, etiology, prognosis, and the course of GBS and medical interventions. This chapter offers ideas for assessments that may be used during evaluation, goals that may be used during the three phases of treatment, intervention ideas in all areas of occupation, and a patient/caregiver handout to educate them about GBS.

CHAPTER IV
PRODUCT

An Occupational Therapist's Guide
An Occupational Therapist's Guide
to Guillain-Barre Syndrome
to Guillain-Barre Syndrome



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Introduction

Each year approximately 2,720 people are diagnosed with Guillain-Barre Syndrome (GBS) in the United States (NIH, 2004). GBS is a significant cause of new long-term disability for at least 1000 persons per year in the United States. Approximately 40% of patients who are hospitalized with GBS will require admission to inpatient rehabilitation (Meythaler, 1997). Even though extensive research into the possible causes of GBS has been conducted, research on the actual treatment of the disorder by the rehabilitation team is limited.

Diagnosis

According to Porth (2005), “GBS is a sub acute polyneuropathy. The manifestations of the disease involve an infiltration of mononuclear cells around the capillaries of the peripheral neurons, edema of the endoneurial compartment, and demyelination of ventral spinal roots” (pg. 1204). Patients are clinically diagnosed after admission based on universal symptoms of the syndrome such as slow, progressive muscle weakness, tingling in distal portions of extremities, and in extreme cases respiratory failure and total paralysis. The clinical diagnosis is confirmed using a number of diagnostic methods including nerve conduction studies, lumbar punctures, and magnetic resonance imaging (MRI). Nerve conduction studies are able to measure how fast nerves can send electrical signals throughout the patient’s body. When these signals are blocked or take increased time to reach their destination, GBS can be a likely diagnosis. Another diagnostic method involves

a lumbar puncture for cerebral spinal fluid (CSF) to check for albuminocytologic dissociation which is elevated protein levels without increased white blood cell count. Magnetic resonance imaging of the lumbrosacral area two weeks after presentation of symptoms can be an effective way of diagnosing GBS in 83% of acute GBS and 95% of all typical cases (Tseng, 2008).

Assessments

There are three main assessments that can be used to assess the patient's functional status after the onset of GBS. One assessment that is commonly used with all GBS patients is the Hughes scale. This scale is rated as follows:

- 0 - Healthy state
- 1 - Minor symptoms and capable of running
- 2 - Able to walk 10 meters or more without assistance, but unable to run
- 3 - Able to walk 10 meters across an open space with help
- 4 - Bed ridden or chair bound
- 5 - Requiring assisted ventilation for at least part of the day
- 6 - Dead

(Koningsveld, Steyerberg, Hughes, Swan, van Doorn, & Jacobs, 2007).

Another scale used to assess GBS is the Medical Research Council (MRC) sum score. This assessment is rated as follows:

- 0 - No visible contraction
- 1 - Visible contraction without movement of the limb
- 2 - Active movement of the limb, but not against gravity
- 3 - Active movement against gravity over (almost) the full range
- 4 - Active movement against gravity and resistance
- 5 - Normal power

(Koningsveld et al., 2007).

This assessment is used to determine the muscle function that has been lost and provide a measurement for documentation. The Functional Independence Measure (FIM) is another assessment tool commonly used to determine the degree of dependency in the following areas: self-care activities, sphincter control, mobility, locomotion, communication, and social cognition. The scale rates the patient from 1-7, 1 being dependent and 7 being independent. This assessment tool can be used to document improvement in performance of functional tasks. The Hughes, MRC sum score, and the FIM have been helpful in determining and measuring functional abilities throughout the phases of GBS (El Mhandi, Calmels, Camdessanche, Gautheron, & Feasson, 2007).

Etiology

Radcliff and Thomas (2007), described the cause of GBS as an autoimmune response that is thought to be triggered by a viral or bacterial infection, but the true cause is unknown. The *Campylobacter jejuni* virus is the most frequently diagnosed bacterial cause of human gastroenteritis with an

occurrence rate of 2.1 to 2.4 million cases in the U.S. each year (Altekruse, Stern, Fields, & Swerdlow, 1999). *C. jejuni* is a food borne pathogen that is transmitted to humans through raw milk, raw or undercooked poultry, untreated water, traveling abroad, and contact with cats and dogs especially pets with diarrhea. *C. jejuni* is rarely passed from human to human. In one out of every 1000 cases GBS is a secondary diagnosis associated with *C. jejuni* infection. *C. jejuni* infection is prevalent in up to 40% of patients with a diagnosis of GBS (Altekruse, Stern, Fields, & Swerdlow, 1999). Another common link to a diagnosis of GBS is the cytomegalovirus (CMV). CMV is found in 50% to 80% of adults by the age of 40 and is the most common virus transmitted to a pregnant woman's unborn child. Once a person has been exposed to the virus it will stay with the person for life, but in most cases will not show any signs or symptoms in an infected person. Epstein-Barr virus (EBV) has also been associated with the cause of GBS. Upwards of 95% of U.S. citizens between the ages of 35 and 40 have been infected with EBV. Transmission of this virus requires intimate contact with the infected person's saliva; transmission through air and blood rarely occurs (CDC, 2008). According to Curtis, Barnes, and Dupiche (2008), GBS has been associated with EBV; by the time symptoms of GBS appear, the symptoms of EBV have usually resolved. A connection has been assumed between GBS and the influenza vaccine and has been a source of debate within the medical community. Juurlink et al. (2008) found that GBS is associated with the influenza vaccination and increases the risk for hospitalization. Each of the

infections is generated from different sources and has different physiological effects, but all have been known to precede a diagnosis of GBS.

Prognosis and Incidence

Prognosis of GBS patients can vary depending on numerous factors associated with the patient and the disease. Koningsveld et al. (2007) found a method of predicting a patient's prognosis based on clinical factors within the first two weeks of the patients diagnosis. The factors that were associated with prognosis were age, sex, diarrhea, upper respiratory tract infection, infection serology, anti-ganglioside antibodies, GBS disability score, Medical Research Council (MRC) sum score, weakness before entry, cranial nerve involvement, and sensory deficits. According to Khan (2004), "Most patients with GBS are discharged home with outpatient and home rehabilitation programs. However, 40% of all GBS patients require inpatient rehabilitation (especially those requiring ventilator support)" (pg. 1014). In approximately 5% of GBS cases recurrence may occur even years after the initial diagnosis (eMedicine, 2006). Throughout a 5 year study, 2.58% of the population died during hospitalization due to complications from GBS. According to Lawn, Eelco, and Wijdicks (1999), "In a specialized center, the primary event leading to death in GBS was ventilator-associated pulmonary infection, predominantly in elderly patients with significant co morbidity" (pg. 635).

Course of GBS and Medical Intervention

When a person is diagnosed with GBS, the course of the illness follows three phases. The first or initial phase of GBS is a rapid progression of symptoms that may take anywhere from 3-48 hours to reach the most severe symptoms and then continues for up to three weeks (Virtual Medical Centre, 2008). The plateau phase is the second phase of the disease. This phase involves no change with the patient's symptoms and may last an additional two-four weeks (Demir & Koseoglu, 2008). The third phase, the recovery phase, can extend over a one-two year time frame (Demir & Koseoglu, 2008).

Initial Phase

In the initial phase, patients could display any or all of the following symptoms: muscle weakness or paralysis, decreased sensation or numbness, tenderness, uncoordinated movements, blurred vision, muscle contractions, palpitations, blood pressure, respiratory difficulties, difficulty swallowing, fainting, drooling, difficulty moving facial muscles, or uncoordinated movements (Mayo Clinic, 2007b). Respiratory difficulty is a common symptom and if severe can lead to fatality. Treatment of respiratory failure is mechanical lung ventilation. Swallowing difficulties can range in severity from diminished swallow reflex to severe aspiration that could cause pneumonia which could lead to death.

The psychosocial area of treatment is often one that is overlooked with GBS patients. The physical demands of the GBS patients can often overwhelm the medical staff leaving the psychosocial areas untreated. The researchers

discovered that people diagnosed with GBS experienced a fear of dying when respiratory failure began. Feelings of abandonment have been described by patients who suffered from the loss of communication skills during the initial phase. The patients also felt feelings of insecurity when they were moved from ward to ward, leaving the people that they had become comfortable with. Patients who experienced a frightening onset of GBS longed for an explanation of why they contracted the disease.

Plasmapheresis is the treatment of choice when acute respiratory failure has occurred. “A total plasma exchange allows rapid elimination of auto-antibodies and pro-inflammatory cytokines giving hope for control over exacerbated autoimmune diseases, however, positive results have been obtained with only a few diseases, including GBS and myasthenic crisis” (Szczeklik, Jankowski, Wegrzyn, Krolikowski, Zwolinska & Mitka et al., 2008, pg. 240). Plasmapheresis is the separation of blood cells and the plasma fluid within the blood. This separation removes the anti-bodies within the blood that are attacking the body and replacing them with either donor plasma or a saline solution (Muscular Dystrophy Association [MDA], 2005). This treatment option can take up to several hours and three liters on average is replaced in one treatment session. The risk factors of plasmapheresis include allergic reaction to donor plasma, low blood pressure, bleeding secondary to the anti-coagulants, and excessive suppression of the immune system (MDA, 2005). The effects of this treatment can be seen anywhere from after one treatment to three to four treatments later.

Intravenous immunoglobulin (IVIg) therapy is another pharmaceutical treatment option for GBS. This form of treatment contains pooled immunoglobulin G (IgG), derived from blood donors, and is administered over two-five days in a series of treatments (Miller, Rodman, Sanders, Walker, Bromberg & Swenson, et al., 2003). The IVIg treatment consists of blood proteins being injected into the body in substitution of the body's natural antibodies (The Myositis Association, 2007). Side effects that are associated with IVIg treatment are fevers, headaches, and muscle aches. These side effects can often be treated before the IVIg therapy with ibuprofen and Benadryl (Miller, et al., 2003).

Pain, if severe enough, can cause dangerous heart irregularities and changes in blood pressure. Severe pain can be handled with analgesics such as morphine or steroids such as prednisone to decrease the pain. If the pain is not at a dangerous level, non-prescription drugs such as ibuprofen can be used (Parry, 1998).

Plateau Phase

During the plateau phase, severe cases are ventilated due to the weakness in the respiratory muscles. The main focus during the plateau phase is to provide maximum comfort and accessibility for the patient. The interventions may include development of communication tools; adapting hospital rooms to ensure access to the nurse call button, TV, light switches, and telephone; positioning; education about GBS; recommending support groups; and teaching anxiety reduction strategies. Due to the nature of the

plateau phase, the patient is still medically unstable, and functional rehabilitation begins in the recovery phase (Copperman, Forwell, & Hugos, 2002).

In addition to the emotional feelings the patients experience, mental status abnormalities have also been described. According to Cochen, Arnulf, Demeret, Neulat, Gourlet, and Drouot, et al. (2005), patients can experience vivid dreams, hallucinations, illusions, paranoid delusions, and abnormal rapid eye movement (REM) sleep. These mental status abnormalities appeared on average on the ninth day after disease onset and lasted on average of eight days. The vivid dreams that patients experienced often were strange, colorful, and highly emotional. Some patients reported dreaming they were leaving their bodies at the hospital while they went on vacation. Nightmares were experienced with themes of dying and of poor recovery. These dreams would occur several times a day and were remembered with detail months later (Cochen, et al. 2005).

Recovery Phase

The recovery phase can extend from one-two years and involve intense therapy from several disciplines. By the recovery phase, the average patient is being weaned from mechanical ventilation. According to Forsberg, Press, Einarsson, Pedro-Cuesta and Holmqvist, (2004) the average patient is weaned from ventilator support within a 20 day time frame. MacIntire, (2002) reported that “6 weeks of bed rest have been shown to reduce skeletal muscle mass by 10% and muscle strength by 25%. In addition...respiratory muscles can

atrophy after prolonged use of controlled (i.e., no spontaneous muscle activity) mechanical ventilation”. Usually patients regain their lost abilities within 12 months. Over half of patients diagnosed with GBS continue to improve after a 12 month time frame. Patients describe the frightening feeling of becoming dependent on other people for self care tasks. Some patients describe this as losing their identity and experience feelings of helplessness and shame associated with loss of basic body functions such as eating and toileting on their own (Forsberg, Ahlstrom, & Holmqvist, 2008). An area that is often overlooked by practitioners treating patients with GBS is the burden placed on the caregivers or family members after a diagnosis of GBS. “The sudden development of ascending paresis and, consequentially, the severe neurological deficit, the uncertainty concerning the future, and the often-prolonged absence from home confront close relatives with many emotional, social, and even financial problems” (Bernsen, Jager, Meche, & Suurmeijer, 2005, pg. 53). The recovery phase consists of pain management interventions as well as medications to relieve the symptoms of anxiety and depression. Plasmapheresis and IVIg are not often present in the recovery phase (Parry, 1998). The pain is localized in the lower part of the limbs, especially the feet and is described as more of a burning and stabbing sensation. The type of pain that the patient experiences in this phase is often referred to as neuropathic pain and does not respond well to analgesics. According to Parry (1998), this pain responds best to anti-depressant and anti-convulsant medications in high doses, but may not show immediate pain relief. There is only a 50% pain reduction expected with

treatment, so education for the patient is important to inform them that the pain may persist for months, years, or even permanently (Parry, 1998).

Referrals typically come from doctors who diagnose the patient with GBS and continue to treat the patient throughout the initial and plateau phases. The patient receives occupational therapy (OT) after being referred by their doctor and continues to be seen by OTs in various settings. The settings will include inpatient rehab, outpatient rehab and possibly home health. The patient is discharged from OT when he/she reaches expected goals or the patient does not continue to progress.

Conclusion

Current research identifies the possible causes of GBS and the phases. Research is scarce on OT and needs to include interventions and outcomes that provide evidence based practice for implementation of specific techniques. This handbook was developed as a guide for the occupational therapist providing interventions for the patient with GBS. In addition the handbook provides helpful information for the patient and caregiver by defining GBS and providing medical intervention for the patient and caregiver. One area that needs additional research is the psychosocial impact on the caregiver who is indirectly affected by GBS. The caregiver is one person who is impacted during this disease due to the debilitation that their loved one experiences. This handbook provides a supplemental handout for the patient and the caregiver, defining GBS and describing the typical course as well as medical interventions.

Assessments



Assessments in this section can be used to determine the patient's level of function as well as provide outcome measures for the therapist to develop a treatment plan. Most of these assessments are used in the plateau phase by the OT to evaluate the patient's functional abilities and determine the length of treatment required. All of these assessments in this section, excluding the role check list and the occupational questionnaire, are to determine the patient's biomechanical function and provide outcome measurements for the OT. The role checklist and the occupational questionnaire are designed to explore the patient's previous occupational and leisure roles as well as to determine future interests. These assessments are a starting point for OTs and further assessments can be completed if needed.

Dynamometer

Author: Mathiowetz V., Dove, M., Kashman, N., Rogers, S., Volland, G., Weber, K.

Purpose: To provide the therapist with an objective measurement of the patient's grip strength.

Time Required: 3-5 minutes

Description: The dynamometer is used to measure the power of grasp of the patient. The test is administered 3 times alternating sides with the patient's arm adducted, elbow at 90 degrees and wrist in neutral to perform the test.

Interpretation: The measurements are compared to a normative grip strength data chart. The norms are determined by sex, age, and left and right are separate. Refer to dynamometer owner's manual for details.

Reference:

Mathiowetz V., Dove, M., Kashman, N., Rogers, S., Volland, G., Weber, K. (1985). Grip and pinch strength: normative data for adults. *Archives of Physical Medical Rehabilitation*, 66,(1), 69-72.

Functional Independence Measure

Author: Initially prepared by the Center for Functional Assessment Research at State University of New York at Buffalo under the direction of Carl V. Granger, MD.

Purpose: The FIM is used as a measurement of functional status and reflects the impact of disability on the individual. It is designed for clinical evaluation of the individual and to determine outcomes of rehabilitation in terms of burden of care.

Description: This assessment includes 18 areas covering: Independence in self-care, sphincter control, mobility, locomotion, communication, and social cognition. The rating scale used includes 7 levels graded from dependence to independence in activities of daily living and degree of assistance required.

Interpretation: The scale is rated as follows:

- ✓ 0: Activity did not occur
- ✓ 1: Dependent
- ✓ 2: Max Assistance
- ✓ 3: Moderate Assistance
- ✓ 4: Minimal Assistance
- ✓ 5: Supervision
- ✓ 6: Modified Independence
- ✓ 7: Independent

Reference:

Asher, I.E. (Ed.). (2007). *Occupational therapy assessment tools: An annotated index (3rd ed.)*. Bethesda, MD: AOTA Press

Hughes Scale

Author: Refer to Reference

Purpose: To provide the medical team with a uniform outcome measure for patients with GBS.

Time Required: Approximately 5 minutes.

Description: The Hughes Scale rates the patient on 7 levels of physical function. The levels range from 0 being a healthy state to 6 being dead. This assessment allows the therapist to gauge recovery progress and set goals for therapy.

Interpretation: The scale is rated as follows:

- ✓ 0: Healthy state
- ✓ 1: Minor symptoms and capable of running
- ✓ 2: Able to walk 10 meters or more without assistance
- ✓ 3: Able to walk 10 meters across an open space with help
- ✓ 4: Bed ridden or chair bound
- ✓ 5: Requiring assisted ventilation for part/all of the day
- ✓ 6: Dead

Reference:

Koningsveld, R.V., Steyerberg, E.W., Hughes, R.A., Swan, A.V., van Doorn, P.A., & Jacobs, B.C. (2007). A clinical prognostic scoring system for Guillain-Barre syndrome. *Lancet Neurology*, 6(1), 589-594.

Motor Assessment Scale (MAS)

Author: Janet H. Carr, Roberta B. Shepherd

Purpose: This scale was designed to measure motor recovery using functional tasks.

Time Required: 15-30 minutes

Description: The MAS consists of one item that measures general muscle tone and 8 motor function items. Items are graded according to criteria on a 7 point scale from 0-6 (optimal).

Interpretations: Scores are recorded on a graph to identify weak areas of function, and progress which is easily compared with previous results.

- ✓ Supine to side lying
- ✓ Supine to sitting at side of bed
- ✓ Balanced sitting
- ✓ Sitting to standing
- ✓ Walking
- ✓ Upper-arm function
- ✓ Hand movements
- ✓ Advanced hand activities

Reference:

Asher, I.E. (Ed.). (2007). *Occupational therapy assessment tools: An annotated index (3rd ed.)*. Bethesda, MD: AOTA Press

Manual Muscle Test

Author: Hislop, H. M.

Purpose: To assess the motor function in specific muscle groups. This tool will provide a subjective measurement of the patient's strength and can guide the therapist during goal setting.

Time Required: 5-10 minutes

Description: The positioning of the patient will depend on whether the patient can move against gravity. If the patient is not able to move against gravity; gravity eliminated positions will need to be assumed.

Interpretation: This assessment is rated as follows:

- ✓ 0: No visible contraction
- ✓ 1: Visible contraction without movement of the limb
- ✓ 2: Active movement of the limb, but not against gravity
- ✓ 3: Active movement against gravity over (almost) the full range
- ✓ 4: Active movement against gravity and resistance
- ✓ 5: Normal power

Reference:

Hislop, H. M. (1995). *Daniels and Worthingham's muscle testing: techniques of manual examination*. Philadelphia: WB Saunders Company.

Pinch Test

Author: Mathiowetz V., Dove, M., Kashman, N., Rogers, S., Volland, G., Weber, K.

Purpose: This assessment will provide an objective measure for therapists to gage the process of recovery.

Time Requirement: 3-5 minutes

Description: The patient will use three different grasps to pinch the meter. This will measure the pinch strength in lateral pinch, three-jaw chuck pinch, and tip pinch.

Interpretation: The measurements are compared to a normative pinch strength data chart. The norms are determined by sex, age, and left and right are separate. Norms are also separated for the three pinch types.

Reference:

Mathiowetz V., Dove, M., Kashman, N., Rogers, S., Volland, G., Weber, K. (1985). Grip and pinch strength: normative data for adults. *Archives of Physical Medical Rehabilitation*, 66,(1), 69-72.

Role Checklist

Author: Frances Maag Oakley, MS, OTR/L

Purpose: The checklist assesses a client's perception of participation in past, present, and future roles.

Time Required: Approximately 15 minutes

Description: Ten roles are defined, and the respondent indicates whether he or she has, is, or anticipates being in each role and the degree to which the role is valued. Additional roles can be added by the respondent.

Interpretation: The Role Checklist helps identify roles that are significant to the client, the motivation to engage in tasks, and changes in perception regarding to roles. The following categories are assessed:

- ✓ Continuous roles
- ✓ Disrupted roles
- ✓ Role changes
- ✓ Past roles
- ✓ Present roles
- ✓ Future roles
- ✓ Not valuable
- ✓ Somewhat valuable
- ✓ Very Valuable

Reference:

Asher, I.E. (Ed.). (2007). *Occupational therapy assessment tools: An annotated index (3rd ed.)*. Bethesda, MD: AOTA Press

Occupational Questionnaire

Author: N. Riopel Smith with assistance from G. Kielhofner and Hawkins Watts.

Purpose: This questionnaire assess the patient's daily occupations and the value they place on them.

Time Required: 30-45 minutes

Description: This questionnaire involves the patient outlining their daily activities every 30 minutes. Then the patient will answer four questions for each half hour filled in.

Interpretation: The four questions are the following:

- I consider this activity to be:
Work, daily living work. Recreation, rest
- I think that I will do this:
Very well, well, about average, poorly, very poorly
- For me this activity is:
Extremely important, important, take it or leave it, rather not do it, total waste of time
- How much do you enjoy this activity:
Like it very much, like it, neither like it nor dislike it, dislike it, strongly dislike it.

Reference:

MOHO Clearing House. (2004). Occupational questionnaire. Retrieved November 17, 2008, from <http://www.moho.uic.edu/images/Occupational%20%20Questionnaire.pdf>

Goals for the Patient



Goals for the Patient

Initial Phase

The initial phase can be challenging for the patient as well as the medical team. At this point the patient has been admitted into an acute care hospital; the focus of treatment by the medical team is to stabilize the patient's decline in motor function. The patient's severity can range from weakness throughout the body to complete loss of function including respiratory muscles, requiring ventilator support. Occupational therapy treatment is limited in this phase due to the short time period of the phase and the declining status of the patient.

Plateau Phase

The plateau phase begins when the patient becomes stable and ceases to decline in function. Occupational therapy treatment begins in this phase with assessments to determine the patient's level of function. Goals and interventions are determined based on the patient's level of functioning. Due to the nature of the plateau phase, the patient does not experience an increase in function until the plateau phase is completed. When working with a patient who is experiencing overall weakness in the body, but is still able to perform daily tasks with minimal assistance, goals and interventions are directed towards adapting strategies to perform the patient's occupations, energy conservation, and active assisted range of motion (AAROM). Patients who experience more severe symptoms such as total loss of control of extremities, patients who are bed ridden, or on ventilator support, require more complex therapy. Goals for these patients include decreasing the risk of contractures through use of passive range of motion (PROM), sensory stimulation to alert the nervous system, and education to decrease the patient's fear and anxiety.

Recovery Phase

The recovery phase begins when the patient's functional abilities and strength start to increase. Occupational therapy treatment focuses on the areas of occupation such as self-care, productivity, leisure; performance skills are addressed through sensorimotor, cognition, and psychosocial.

Areas of Occupation

The goals for self-care include but are not limited to decreasing assistance required in activities of daily living (ADL's) and developing a routine to conserve energy. Patients who are experiencing severe symptoms may require assistive devices, such as slings or protective splints for a short period of time.

Productivity is an area that OTs can address with patients. The patients who have less severe symptoms may return to work or return home earlier than the more severe patients. The OT collaborates with patients on modification of the work or home setting to ensure their environments are safe. The goal for productivity is for the patient to return to home or work in a safe and effective way.

Patients with GBS may require OT services to address leisure activities. The OT can help the patient explore, modify or discover new interests to promote involvement in past occupations. Through use of a role checklist, the OT can assist the patient in exploring his/her interests and how they can be integrated into treatment. By integrating the patient's interests into therapy, the patient is motivated and more likely to achieve success. It is important to remember that the patient may not be able to complete leisure activities to their full ability until recovery is complete.

Performance Skills

Sensorimotor is another area that OTs address. Sensorimotor goals include increasing the person's passive range of motion, encouraging active

range of motion, maintaining proper positioning while sitting or lying in bed, and increasing muscle strength.

Another area that OTs address is psychosocial in nature. This can be a vital part of recovery with goals such as changing the patient's thinking about prognosis through education, providing relaxation techniques for the patient to use when stressed or anxious and providing social support information for the patient to reference after treatment.

Interventions



Interventions

The following interventions are examples of what a treatment session or activity may involve across areas of occupation. Not all patients will require assistance in every area and some may need more interventions than others. The handbook was developed to assist the OT in treatment planning and intervention. The OT is instructed to use these ideas to adapt his/her own individualized/client centered approaches to treatment.

Self-Care (ADLs)

Bathing: The patient can sit in bed and perform bathing activities such as using a wash cloth and applying soap to clean the body. The OT assists the patient in tasks that the patient is unable to perform independently. The OT modifies activities as needed throughout the task to promote success.

Showering: The patient transfers from wheelchair or walker to a shower chair. The patient performs showering tasks with decreased assistance as recovery continues. The OT may modify the environment using adaptive items such as a removable shower head, grab bars, or non slip grips on the bottom of the shower to promote independence in showering tasks.

Bowel and Bladder Management: Some patients are catheterized in the beginning of treatment. The OT can develop a bathroom schedule for the patient using a timer or writing bathroom times into the daily schedule of activities. The OT may recommend a new adaptive technique such as digital stimulation if the patient experiencing difficulties with producing regular bowel movements.

Dressing: The patient may experience decreased range of motion or decreased strength causing difficulty with dressing tasks. The patient is educated in modified dressing techniques that maximize efficiency. When dressing, the patient is instructed to put underwear and pants on while sitting, then pull

both up at the same time, eliminating extra steps. The OT recommends a dressing stick or sock aid, button hook, shoe horn, pants with an elastic waist band or elastic shoe laces to assist in dressing, if needed. The OT adapts a closet or dresser for the patient if he/she had difficulties with obtaining clothing.

Eating: The patient may experience difficulties in eating due to decreased muscular strength in the mouth. The patient can increase muscle strength in the mouth by practicing movements of the tongue and closing his/her mouth during food consumption. The OT may modify the task by introducing a bolus bag that can be used to help the patient practice chewing food without the risk of aspiration. The OT can recommend using thickened liquids and softened foods to prevent aspiration. If there is a speech pathologist available to the patient, this area may be co-treated with the OT to better serve the patient.

Feeding: The patient may experience difficulty in self feeding activities due to decreased muscle strength and coordination. The patient can complete feeding activities with the OT during meal times. The OT may recommend adapted eating utensils or plate guards to assist in retrieving the food from the plate and transferring it to the mouth.

Functional Mobility: The patient may have difficulty completing transfers due to muscle weakness and decreased coordination. The OT can modify the task by using various transfer methods during treatment. Transfers may include a two person transfer when the patient cannot bear weight. The patient can complete a sliding board transfer when he/she is able to bear weight or a pivot transfer. The OT also assists the patient in using their adaptive devices such as wheelchairs or walkers to ensure safety in mobility. The OT may modify the walker or wheelchair by attaching a basket/tray so the patient can transport items from one place to another. Physical therapists can also be involved in the treatment of this area.

Personal Device Care: The patient may require training on existing/modified adaptation methods to perform regular maintenance on personal devices such as hearing aids or glasses due to muscle weakness and decreased coordination. The OT can recommend places the patient can go to get these items repaired if needed. The OT introduces modified methods such as denture cups for cleaning dentures with ease.

Personal Hygiene and Grooming: This is an area that is especially important to the patient and family members. The patient usually strives to become independent in this area as soon as possible and the OT may start working on some of these activities early on in treatment. The OT can recommend that the patient use a toothbrush with a modified handle to assist with grip. The OT educates the patient and family members on how to adapt the grooming activities to maximize function. The OT may adapt the bathroom to increase independence by mounting the hair dryer on the wall so the patient does not have to hold it and attach nail clippers to a board to provide leverage needed to clip his/her nails. The OT can teach the patient to use electric razors instead of straight razors for removing unwanted body hair.

Sexual Activity: The patient may not be able to complete normal sexual activities due to muscle weakness and may require education from the OT on alternative positions to conserve energy and maximize satisfaction in sexual activities. The patient can also pleasure themselves sexually and require advice from the OT on how to modify the activity to meet their needs.

Toilet Hygiene: When the patient has gained enough trunk control to sit independently on the toilet, he/she may require some adaptive equipment to complete the task of using the toilet. The OT may recommend the adaptive equipment needed including grab bars, raised toilet seat, tongs for wiping, or a reacher to grab things that are not in arms reach around the bathroom. The OT can instruct the patient on how to change a catheter or colostomy bag if the patient still requires one to return home.

Productivity (IADLs, Work, Education)

Care of Others: The patient may experience difficulties with caring for others in their home due to decreased energy, decreased strength and obligation to outpatient services. The OT can educate the patient and family members on different solutions and assist the patient in modifying adaptive techniques to help the patient make arrangements for their dependents. The OT may recommend services that may assist the patient with caring for their family members. The OT can recommend various services such as daycare or a live-in nanny to assist in the care of their children.

Care of Pets: If the patient is unable to successfully care for his/her pets due to decreased energy, decreased strength, or is dependent on home health services, the OT can educate them about various services such as grooming and boarding until the patient is able to complete the task on his/her own. The patient may also have a pet door installed to let the animals in and out of the house if they wish.

Communication Management: The patient may have decreased muscle strength in the oral motor system and may require services to modify communication strategies. Speech pathologists (SP) may also be involved in modifying the patient's communication methods. The OT and the SP may work together to modify the patient's communication methods to meet the patient's needs. The OT can recommend writing boards or communication devices to the patient if he/she is unable to speak. The OT may recommend adaptive writing utensils or computers to assist with communication. The OT can also recommend modified telephones to the patient that may have enlarged buttons or a voice command option to allow the patient to call people with ease. The OT may mount the call light next to the bed to ensure the patient can reach it and receive assistance if needed from the nursing staff.

Community Mobility: The patient may experience difficulties in community mobility due to decreased muscle strength. If the patient drove a car before the onset of GBS, transportation may be an area of concern. This occupation can be addressed before the patient returns home. The OT can accompany the patient on the public transportation system to familiarize the patient with the bus schedule. The patient may also brainstorm with the OT to develop a list of people who may be able to assist him/her in transportation to and from therapy and other desired destinations if public transportation is not available.

Financial Management: The patient may be overwhelmed with the physical effects of the illness he/she experience during GBS and therefore may not think of financial management as a priority. The OT can help the patient to develop a budget and payment schedule for monthly bills. The OT may also recommend options to the patient such as hiring an accountant or educate the patient in paying bills electronically. Another option that the patient can pursue is designating a family member or friend to handle financial issues while the patient is recovering.

Health Management and Maintenance: The patient may become more aware of health issues after the onset of GBS and require assistance in developing a schedule for health management and maintenance. The OT may also help the patient to create medication routines to remember when to take his/her prescribed medications. The patient and the OT can collaborate and develop a health management schedule which can include creating a fitness routine, developing a weekly meal plan and decreasing health risk behaviors upon discharge.

Home Establishment and Management: The patient may require skilled OT services for home management tasks such as: cleaning, laundry, and yard work, due to decreased strength and endurance. The OT can help the patient to develop a home management schedule in which the patient can perform the tasks efficiently. The OT may recommend that the patient contact someone to

assist in household tasks such as a house keeper or a lawn service. The OT can introduce adaptive solutions such as modified household cleaning tools or assigning various household tasks to the patient's family members to relieve the burden of home management.

Meal Preparation and Cleanup: The patient may not be able to complete meal preparation and cleanup activities due to decreased coordination and endurance. The patient and the OT can discuss different ideas to assist in preparing healthy meals. The OT may assist in developing a meal schedule and planning weekly meals. The OT can recommend the patient use existing adaptation responses such as using the dishwasher to clean dishes, preparing meals ahead of time and freezing them for the week. The patient may assign cooking and cleaning tasks to different family members, if appropriate.

Religious Observance: The patient may not be able to attend regular religious services due to inpatient status or decreased endurance. The OT can recommend that a chaplain come in to see the patient, that a family member bring in the patient's bible, or that a family member take a video or a tape recorder to record the church services. If the patient is able to attend religious services, the OT and the patient can discuss modifying the task using energy conservation and stress reduction when attending a religious service. The patient can sit in the back of the church or remain seated when others are standing. The patient can have communion delivered to them if they desire. The OT and the patient may discuss exploring spirituality if the patient desires to incorporate a higher power into their life.

Safety and Emergency Maintenance: The patient may experience safety concerns when returning to an unmodified environment due to decreased muscle strength. The patient and the OT can talk about safety concerns and develop solutions to dangerous situations. The OT may recommend that the patient acquire a life line button in case of emergency or carry a cordless phone/cell phone with them at all times.

Shopping: The patient may not be able to complete the task of shopping due to decreased strength and endurance. The patient and the OT can complete a shopping list prior to going to the grocery store. A shopping trip can be completed by the patient with assistance from the OT in problem solving skills, and increasing efficiency during the activity. The OT can recommend that the patient use an electronic cart or a shopping cart to transport items. The patient may not have the endurance or the means to travel to the store, so another option that is available in some cities is the ability to shop online and have the item delivered to their home. In this process the patient will access the internet, select the desired items, and enter the time and date of delivery, and pay with a debit or credit card.

Education Participation: The patient may have to place education on hold due to physical effects associated with GBS. If the patient desires to return to school, accommodations may be needed for the patient to be successful. The OT can recommend that the patient or caregiver contact the school and inform them of ADA accommodations that may be needed upon the patient's return. The OT may recommend that the patient acquire a tutor if needed to familiarize him/her with the material, or contact a classmate to record class sessions to assist the patient in note taking throughout the class sessions. If the patient participated in extracurricular activities before the onset of GBS, the OT can suggest modifications to the tasks.

Employment Interests and Acquisition: The patient may need to explore alternative career options due to the length of GBS recovery and changes in the patient's functional abilities. The OT can assist the patient in exploring career interests and options that will maximize their success. The OT can assist the patient in preparing for interviews and completing applications.

Job Performance: The patient may experience difficulties with job performance due to physical effects. The OT can assist the patient in developing time

management skills or modify the work environment to provide a supportive structure for the patient.

Retirement Preparation and Adjustment: The patient may be older and thinking about retiring after completing recovery of GBS. The OT can assist the patient in leisure exploration or alternative occupations in which the patient may participate. The patient may have already retired and the OT can assist the patient in modifying the occupations that were fulfilled previously. Some of these activities may include: social outings, traveling, and volunteer opportunities.

Volunteer Exploration & Participation: The patient may have difficulties participating in the volunteer activities that he/she was previously involved in due to their weakness and disability. The patient may be interested in giving back to the community but may not know what services he/she can work for after recovery from GBS. The OT can assist the patient in exploration of volunteer activities or modify the activities to promote success.

Leisure (leisure, play)

Leisure Exploration & Participation: The patient may experience difficulties in participating in past leisure activities or finding new activities in which to participate that accommodate their needs after the recovery from GBS. The OT can assist the patient in exploration of leisure activities and modify the activities to promote success.

Performance Skills

Range of motion: The patient may have decreased range of motion (ROM) due to the lack of muscle strength and possible contractures from the patient being bedridden. The OT can start with passive range of motion (PROM) in the plateau phase to decrease the risk of contractures and keep the musculature stretched. If the patient still has some ROM the OT may recommend exercises

throughout the day to keep the patient active. In the recovery phase, the OT has many options with interventions through occupation based activities which can include ROM.

Muscle strength: The patient will have decreased muscle strength throughout the GBS recovery. The OT can recommend strengthening exercises through the use of weights, theraband, theraputty, or other occupation based activities. The OT may grade the activities from non-resistive through resistive as the patient regains normal muscle innervations.

Coordination: The patient may have difficulties with coordination due to the lack of muscle strength post onset. The patient's muscle strength may return unevenly causing decreased coordination with activity. The OT may work with the patient to increase strength and integration of the two sides of the body. The OT can increase hand manipulation and dexterity through the use of familiar occupations that require frequent grasp and release.

Energy conservation: The patient with GBS can be expected to have difficulties with energy conservation due to the lack of muscle strength and the decreased activity levels. The OT can promote energy conservation by recommending techniques that the patient can use throughout the participation in daily occupations. These techniques can include: sitting during grooming and household activities, prioritizing high energy activities first then completing low energy activities last. The OT may recommend that the patient separate an activity into steps, taking breaks in between to conserve energy.

Sensation: The patient may have difficulties with sensation due to disruption in the nerves from GBS. The patient can have problems with temperature, light touch, stereognosis, proprioception, and two-point discrimination. The OT may provide opportunities for sensory, tactile, and proprioception stimulation as sensory system function returns. These interventions could

include contrast baths, rice or bean buckets, vibrating massage tools with interchangeable heads, and position in space exercises.

Pain: The patient may experience pain related to their diagnosis of GBS. The OT can recommend relaxation techniques, distraction methods or over the counter medications to reduce pain. The OT may engage the patient in activities that he/she enjoys to promote distraction from pain.

Psychosocial (rest and sleep, social participation)

Rest: The patient may experience difficulty with resting due to worries/hallucinations involved with the diagnosis of GBS. The OT can promote rest activities by providing a list of relaxation techniques that will focus the patient's thoughts on relaxing. The OT may also recommend the patient set aside times to take brief naps.

Sleep: The patient may experience difficulty with sleeping due to pain, worries, and other disruptions. The OT can modify the room so the patient can sleep better. The OT may request that the door to the room stay closed during the afternoons and night times. The patient and OT together can set up a sleep schedule to promote healthy sleep cycles. The OT may recommend that the family members bring in items that are familiar to the patient to promote a familiar environment for comfort.

Community: The patient may experience problems in the community with buildings such as restaurants and public areas not conforming to ADA standards. The OT can recommend that the patient call ahead to a restaurant to ensure that the building can accommodate a wheelchair or walker.

Family: The patient may experience difficulties with filling familial roles due to the time the patient has spent away from home and the physical disabilities that the patient is experiencing. The OT can recommend that the family delegate responsibilities to decrease the tension. If the patient's family has

difficulties communicating, the OT may recommend family counseling to deal with the stress of the disability in a healthy manner.

Peer, Friend: The patient may experience difficulties with retaining friendships throughout the long recovery process of GBS. The OT can recommend that the patient or family members post updates on the internet to inform friends and family of recovery status. The OT may recommend that the patient attend support groups for GBS to promote socialization among a common group.

Course of GBS and Medical Intervention Continued...

Eventually the patient will regain muscle strength and be able to increase resistance (The Merck Manual Online Medical Library, 2007). Patients will receive occupational therapy along with physical therapy. This will involve the patient work on toileting, bathing, dressing, and feeding. Occupational therapy may also work on things such as their leisure activities, work environment, and home environment.

Outpatient Therapy

Outpatient services may be required if the patient does not recover fully before returning home. The patient will complete strengthening and range of motion exercises during this type of treatment to increase function in these areas and improve in occupational participation.

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Guillain-Barre Syndrome



An Information Guide for Patients and Family

▴ Etiology

Radcliff and Thomas (2007), described the cause of GBS as an autoimmune response that is thought to be triggered by a viral or bacterial infection, but the true cause is unknown. In addition, it was determined that in 60% of GBS cases, respiratory or stomach viruses preceded the GBS diagnosis. “The cause of GBS probably has an immune part. Studies have linked it to infection with *Campylobacter jejuni* in addition to other viruses, including Cytomegalovirus and Epstein-Barr virus” (Porth, 2005, pg.1204). Influenza vaccine has also been linked to the onset of GBS.

▴ Incidence and Prognosis

The incidence rate of GBS is between 1.65 and 1.79 per 100,000 people (Alsheklee, Hussain, Sultan, & Katirji, 2008). The outcome of GBS patients can vary depending on numerous factors associated with the patient and the disease. According to Khan (2004), “Most patients with GBS are discharged home with outpatient and home rehabilitation programs. However, 40% of all GBS patients require inpatient rehabilitation (especially those requiring ventilator support)” (pg. 1014). In approximately 5% of GBS cases recurrence may occur even years after the initial diagnosis (eMedicine, 2006).

▴ Diagnosis

According to Porth (2005), “GBS is a subacute polyneuropathy” (p. 1204). The process of GBS involves cells gaining access to the areas surrounding the capillaries of the peripheral nerves, swelling of the nerves, degeneration of the sheath around the spinal roots. Patients are clinically diagnosed after admission based on common symptoms of the syndrome such as slow, progressive muscle weakness, tingling in hands and feet, and in extreme cases respiratory failure and becoming totally paralyzed.

▴ Course of GBS and Medical Intervention

The initial phase presents with symptoms that occur within the first 48-72 hours of onset. Patients could display any or all of the following symptoms: muscle weakness or paralysis, decreased sensation or numbness, tenderness, uncoordinated movements, blurred vision, muscle contractions, fast heart beat, blood pressure difficulties, respiratory difficulties, difficulty swallowing, fainting, drooling, difficulty moving facial muscles, or uncoordinated movements (Mayo Clinic, 2007b). In severe cases of GBS, a catheter and aggressive bowel routine will be needed to assist the patient with toileting (Neurological Medicine Pocketbook, 2004).

The symptoms in the plateau phase become stable and remain in that state for 14-28 days. The treatment for the symptoms remains identical to the initial phase due to the weakness levels remaining the same. According to Morgan (1991), the longer the patient remains in this plateau phase with no improvement in their recovery the more extensive their recovery phase will be. During the plateau phase, severe cases will still be ventilated due to the weakness in the respiratory muscles. The other disciplines that may be included are physical therapy, occupational therapy and speech therapy depending on the level of rehabilitation required by the patient. The patient will also spend a significant amount of time with nursing staff due to the nature of the initial and plateau phases. The recovery phase can extend from one - two years and involve intense therapy from several disciplines. Muscular strengthening can be an important part of recovery and rehabilitation during this phase. In many situations, physical therapists will create a treatment plan to include muscular strengthening of the legs by developing an exercise program that for strengthening and movement. (Mayo Clinic, 2007). Often patients will be required to participate in activities which could involve moving the legs against gravity then adding a one pound ankle weight.

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CHAPTER V

SUMMARY

Guillain-Barre Syndrome is rare but can cause serious medical complications in severe cases. Approximately 40% of patients who are hospitalized with GBS will require admission to inpatient rehabilitation (Meythaler, 1997). Many of these patients will require services from multiple disciplines such as occupational therapy, physical therapy and speech therapy. GBS patients can also experience psychological abnormalities within the plateau phase and can have occurrences of depression, anxiety and stress throughout the recovery phase (Cochen, Arnulf, Demeret, Neulat, Gourlet, & Drouot, et al., 2005).

When a patient is diagnosed with GBS, there are various symptoms that the patient may display including weakness, paralysis, decreased sensation, difficulties with swallowing, respiratory difficulties leading to ventilator support and decreased coordination. These symptoms can have varying effects on patients causing problems in areas such as ADL's, IADL's, work, leisure and education. These patients will often have a sudden drop in functional ability, with one-two years of rehabilitation to follow. The occupational therapist can play a major role in the rehabilitation of a patient with GBS by helping the patient develop new adaptation methods throughout the recovery process and support their newly developing functional abilities. This project gives the therapist a resource about the syndrome and gives them options on assessments that could be beneficial, possible goals that could be applied to patient's treatment, and interventions that could be incorporated into treatment of a patient with GBS.

Limitations and Recommendations for Future Action

This scholarly project provides the therapist with recommendations to use in assessment, goal writing, and intervention planning, however is not meant to be a protocol to the treatment of GBS and should not be used in that manner. This guide is limited to GBS and focuses on the adult population throughout the course of treatment. When treating a pediatric patient it is recommended that the therapist use additional research to supplement missing information in the guide. The project was based on OA and addresses two of the main concepts of the model. While understanding of OA is believed to support use of the product, the therapist is not limited to OA alone and may consider other occupation-based models, as well.

While reviewing the occupational therapy literature, there were few articles in the area of treatment with patients with GBS. Most of the research that has been completed on GBS involves the possible causes of GBS, since the true cause is unknown. It is recommended that occupational therapy intervention techniques and the role of occupational therapy be researched to develop an evidence base for practice related to GBS.

Implementation of Project

This project provides a guide for occupational therapists to reference during the treatment of a patient with GBS. Implementation of the guide for in-patient, out-patient, acute and partial hospital settings is to be preceded by an in-service on the Occupational Adaptation Model and orientation to use of the guide. The guide is designed to provide the occupational therapist with a reliable source of information and education about interventions for GBS.

Conclusion

The effects of GBS on the physical and psychosocial areas of a patient's life can be overwhelming. It can affect how they perform the simplest tasks in daily life to the

endangerment of their lives. The occupational therapist and patient have unique opportunities to increase adaptive capacity within occupational performance to support maximum engagement in occupation as the patient progresses through recovery.

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