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AN INQUIRY INTO THE MEANING OF GUILLAIN-BARRÉ SYNDROME

by

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A thesis submitted in partial fulfillment of the
requirements for the degree of

Master of Arts

Massey University

2001

MASSEY UNIVERSITY**ABSTRACT****An Inquiry into the Meaning of Guillain-Barré Syndrome**

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Guillain-Barré Syndrome (GBS) is an autoimmune syndrome characterized by a severe and rapid onset of paralysis that ascends without warning. It has an unknown aetiology and is generally unknown by most people, including medical professionals. When a person who has had GBS is asked to speak about their experience, they are likely to talk about aspects of it that are personally meaningful. Their account can be likened to a story in that it collates seemingly unconnected facts, episodes of activity and emotional attributions into a sequence that provides knowledge and understanding. A story is a powerful form for expressing suffering and experiences and so is particularly suitable for the study of trauma and illness. The actual process of creating the story, plus its presentational and organisational forms, provides sources for uncovering the identities authors choose to create and present of themselves. Six people who have had GBS were interviewed about their experience, and their stories were analysed using a narrative inquiry to discern the meanings attributed to GBS from the participants' own understandings and perspectives. The intended focus of the research was holistic and content based. The result of the narrative inquiry was a plot common to all six narratives. Namely, GBS is an inexplicable condition, during which horrendous things happen, but people do recover with time and it is likely their life view will be changed in the process. Four fundamental issues, identity, meaning, making sense and meaningfulness were drawn from the stories and configured into a narrative of the researcher's making. What the participants chose to speak about became the meanings, or themes, major and minor, of their stories. No event has meaning in itself, however traumatic events can precipitate crises of meaning. When these crises are viewed within the context of other events, and are perceived to add value to life, then they have meaningfulness. In the telling of meanings and meaningfulness, the purpose for storying and the audience to whom the story is directed are the criteria for which the storylines are chosen. Both the story and the storying provide opportunities for the authors to create and offer images of themselves, that are then open to interpretation by an audience. As a traumatic experience, GBS enabled six people to tell their stories. In doing so they were able to make sense of important issues for themselves, and re-examine the way they saw themselves and the world.

ACKNOWLEDGEMENTS

Firstly, I would like to say a heartfelt thank you to the six people who humbled me by opening up their experience for others to share. I was truly honoured to hear your stories.

I would like to thank my supervisors, Associate Professor Kerry Chamberlain for his technical and theoretical guidance, and for the encouragement he gave me to interpret, not just describe, the data, and Dr. Robert Gregory for providing me with the desire to study GBS by sharing his own experience and for his wisdom and timely emotional support. Thank you also to Terrie Heron, who's transcribing was a marvel considering I didn't know how I wanted the interviews transcribed when she began the task.

My thanks are also extended to Dr. Gareth Parry, Professor of Neurology at the Universities of Auckland and Minnesota, for reviewing Chapter Two on the medical facts of GBS.

To my friends, especially Roger Walsh, Barbara Hay, Paul and Jennie McGuinness who had confidence in me and gave wholeheartedly of their listening ears, wise advice and morale boosts, I am truly grateful.

And to my husband James, mother Val, and children Hamish, Jack, Oliver and Sophie, who gave me unbelievable support and encouragement, I say forever thank you.

I dedicate this study to my father, Jack Gardiner, whose desire to see me go to university in the first place means I am where I am.

PREFACE

Imagine ...

One day you wake up and there's a strange numb, tingling feeling in your legs. You get up out of bed and feel a bit wobbly on your feet. Bit strange, you know you hadn't been drinking last night. You stagger back to bed and next time you want to get up to go to the toilet, you can't get up.

Alternatively, you are going about your daily business, and you feel extreme pain, so much so that it stops you from doing what you intended. Each day it gets worse, and so does the numbness around your middle. "This is ridiculous, really," you say. You go to the doctor, who repeats, "No, nothing is wrong." So one day you're in the kitchen and wham, the next minute you're "just laying there heaped up on the floor." You can't get up. Can't move, too weak. Your legs feel like jelly, or worse they don't even feel.

Or imagine this ...

You are a young woman and pregnant with your first baby. At 38 weeks you come out in hives. Within 24 hours you look like you have had a stroke. You are taken to an Intensive Care Unit (ICU) and placed on a ventilator because the paralysis that started with pins and needles in your feet has progressed up your body to your face and head. Your baby is delivered straight away, but this is just the beginning

This is Guillain-Barré Syndrome (pronounced Gee-lane Bah-ray). Paralysis, out of the blue, quick and possibly total, you are left unable even to breathe without mechanical assistance.

Your brain is unaffected, but the rest of your body is totally dependent on machines or other people for its basic requirements. You cannot speak to communicate your needs. You cannot feel the gentle touch of your loved ones, but you can jolly well feel the incredible pain deep within your body.

What would that be like? What does it mean? How would you make sense of that?

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1. INTRODUCTION

Guillain-Barré Syndrome (GBS) is a condition that arises as a result of an autoimmune reaction that disables the peripheral nervous system. It has an annual incidence in New Zealand and worldwide of only 1-2 per 100 000, but despite its rarity it is a leading cause of acute paralysis (Bolton, 1995). Weakness may develop in a matter of days, and sometimes with frightening rapidity and severity. Many people require treatment in intensive care units during the initial stages, but recovery proceeds for most people over six months to a year. It is known to occur in all age groups, in both genders and across ethnic groups.

The main feature of GBS is the rapid disorder of the peripheral nervous system that results in the onset of muscle weakness, which affects the ability to walk, write, breathe, swallow, talk, smile and so forth (Steinberg, 1995). In some cases sensory loss accompanies the muscle dysfunction and affects the ability to feel temperature and texture. Abnormal sensations like numbness, tingling, formications, electricity, and vibrations may be felt in the feet, hands or face. Some people experience pain. In severe cases the muscles in the thoracic region are damaged and within two to three days after onset the patient requires mechanical respiratory support to stay alive. A small number of patients may die.

Apart from a handful of studies (Bersen, Jacobs, de Jager, & van der Meché, 1997; Bourke, 2000; Lennon, Kobler, Hughes, Goeller, & Riser, 1993) research to date has centred on examining the aetiology, disease course, treatment, residual health status and epidemiological features of GBS in the hope of establishing prognostic indicators for recovery. Although research has comprehensively examined these physiological factors of GBS, studies have virtually ignored the concomitant psychological aspects. An extensive search of the research literature has found no references, apart from personal accounts (Baier & Schomaker, 1989; Bowes, 1984; Heller & Vogel, 1986) that explore the unique personal experience of GBS.

The purpose of the proposed study was to explore the storying and the storied account of people who have had GBS. My research examined this, as yet, uncharted domain, to provide an

interpreted account of what it means to have such a frightening disease. The method of investigation was narrative inquiry. This involved examining the stories told to me by six people who have had GBS, interpreting these stories, and analysing the process of their storytelling in order to find out what it means to have this syndrome, how people make sense of an adversity for which they were unprepared, and what images these people present to me as they speak about their experiences.

The value of listening to peoples' stories is that the stories give voice to suffering in a way that lies outside the biomedical domain (Hydén, 1997). It is hoped this research gives validation not only to the participants' experience of GBS, but to others who have had or are currently experiencing the syndrome. Also, that it will afford explanations to caregivers, and provide valuable and insightful information to medical, psychological and other professionals. It is hoped the study facilitated an opportunity for the participants to make sense out of their experience during their storytelling, thereby creating different possibilities for their futures.

This thesis is intended for an eclectic readership spanning medical professionals, social and health psychologists, people with GBS, interested lay readers and the participants who requested reading more than a summarised version of the research. The range of information provided covers many aspects of the GBS experience because the thesis attempts to be a more holistic offering than work previously published. It was for this eclectic readership that Chapter Two, with its extensive description of the medical meaning of GBS was included. The value of this chapter is in the detail it includes about the symptoms, prognosis, treatments, care and residual status that was likely to be associated with any one of the participants. Because this study's focus was on the experiencing of GBS, Chapter Two is intended to provide a medical context for the experience, especially as this information highlights the potential for misdiagnosis that accompanies this uncommon syndrome. Although providing generalisable statements about the conditions of GBS, however, the chapter says nothing about what it is like to actually have GBS and the experience is as much a part of GBS as the medical information. This chapter can be used by readers to orientate themselves to the interpretive findings provided in Chapter Five.

The way people speak about their experiences, and the various functions their telling serves,

are discussed in Chapter Three about stories, narratives and narrative inquiry. Explained in this chapter are the differences between stories and narratives, the assumptions of narrative, the two major types of narrative inquiry used in narrative research and how they were used in the current research, the usefulness of narrative techniques for examining traumatic illness, and the intentions of the present research.

A methods chapter follows in Chapter Four, in which details of demography, procedure and analytical method are outlined for the present study. There is a section on the reflexivity of the researcher, included to give readers more knowledge in judging the researcher's assumptions and interpretations about the stories and the storytellers. A section is also included on how the ethical issues of research were addressed for this study. Like the section on reflexivity it was intended as background information to assist readers' knowledge about the participants and to aid the assessment of the research findings.

Chapter Five presents these research findings. This chapter is written in the form of a narrative and was crafted by the researcher to provide readers with an interesting and meaningful account of the GBS experience. It provides readers with anecdotes and insights they can use to understand, or make sense of, the experience for themselves. The narrative begins with an analysis of the way the stories worked to create identities for the participants, while at the same time functioning as sense making mechanisms. Inextricable from the images the participants were weaving of themselves were the meanings the experience had for them. They spoke about their experiences as individuals, yet some of the meanings they distilled from the experience, and filtered through to me, were consistent with those of others in the group.

The final chapter, the Conclusion, provides readers with the main issues arising from the findings, plus thoughts about what the research did for me and for the participants, and what this thesis offers to interested readers. The chapter has suggestions for future research, and suggests that the outcome of the GBS experience is best caricatured in a remark made by one of the participants.

2. GUILLAIN BARRÉ-SYNDROME

Introduction

The aim of this chapter is to provide a background to the Guillain-Barré Syndrome. It provides a synopsis of the medical facts with which to orientate the reader to the general nature of this condition.

Guillain-Barré Syndrome is an autoimmune disorder that targets components of the peripheral nerves (Hahn, 1997). It is a leading cause of acute paralysis in people of all ages and of both sexes, and occurs irrespective of ethnicity (Bolton, 1995). Progression may occur for up to 4 weeks from the onset of weakness. Many people require admission to an intensive care unit (ICU) in the early stages. Patients should all be intensively monitored for the first 24-48 hours as about twenty five percent will go on to develop some degree of respiratory failure requiring support. The syndrome, so called because diagnosis is largely descriptive, is thought to have heterogeneous manifestations, each with different outcomes and possibly diverse underlying pathogenic mechanisms (The Italian Guillain-Barré Study Group, 1996). It is a self-limiting disorder, with the body spontaneously repairing itself after nadir (the lowest point of the disease). Depending on a number of factors, full recovery will typically occur over a period of between six and twelve months (Bolton, 1995). For some people full recovery is never achieved, and a small number of sufferers die.

History

The eponym Guillain-Barré Syndrome derives from two French army neurologists, Georges Guillain and Jean-Alexandre Barré, who were two of three men who described the condition in two soldiers in 1916. Although an illness of generalised weakness and distal paralysis progressing over several days had been noted by J. B. O. Landry in 1859, the 1916 paper highlighted an increased concentration of protein in cerebrospinal fluid in the absence of a high white blood cell count, as a laboratory marker (Ropper, 1992).

Clinical Spectrum

The Guillain-Barré Syndrome Support Group of the United Kingdom (2001) includes in its definition of GBS, a number of peripheral neuropathies caused by a dysfunction of the immune system. These include acute inflammatory demyelinating polyradiculoneuropathy (AIDP), acute motor axonal neuropathy (AMAN), acute motor-sensory axonal neuropathy (AMSAN), and chronic inflammatory demyelinating polyradiculoneuropathy (CIDP). The present chapter will discuss GBS as it pertains to the most common variant, AIDP, unless specifically stated. Participants in the present study experienced AIDP, AMSAN and CIDP.

Based on clinical observation, electrophysiology and pathology, it appears that the above conditions can be divided into predominately demyelinating and predominately axonal patterns (Ho et al., 1997). The distinction is important, since prognosis is dependent on the type of degeneration associated with GBS symptoms. Specifically, AIDP, the most prevalent form of GBS, is usually correlated, usually, with a quick and complete recovery (Hahn, 1998). Degeneration predominantly affects the nerve myelin as a result of inflammation from an aberrant immune response (Hahn, 1998).

AMSAN affects motor and sensory axons and has a poor prognosis for recovery because it is associated with severe degeneration of axons, but little demyelination (Feasby et al., 1986). Because axonal regeneration rarely exceeds 1mm/day in adults, recovery in this instance is very slow and incomplete (Feasby et al., 1993).

Another variant, AMAN, is similar to AMSAN but is restricted to motor axons and has less severe degeneration. It has a similar prognosis for recovery to AIDP (Asbury & McKhann, 1997)

CIDP resembles AIDP clinically, electrophysiologically and pathologically, but its course is progressive or relapsing and remitting. In this variant, nerves show evidence of demyelination and past remyelination, possibly as a result of the perpetuation of an immune response (Agius, Glag & Arnason, 1991). The majority of cases of CIDP are idiopathic and only a minority are associated with other diseases.

Clinical Features

The most common initial symptom of GBS is tingling and/or numbness in the fingers and toes (McLeod, 1995). Over the next few days, and over a period of up to four weeks, the arms and legs become progressively weaker. In mild cases, these symptoms progress no further, but in other cases the syndrome progresses to complete paralysis of the limbs. About half of the sufferers develop weakness in the facial and other cranial nerves controlling swallowing and talking (McLeod, 1995). This may cause the facial muscles to lose their signals, the expression to become lopsided, and food to get caught in the cheeks or at the back of the tongue (Steinberg, 1995). For twenty five percent of people experiencing GBS, paralysis progresses to the chest causing respiratory failure and necessitating respiratory support. This may be short term, but some need prolonged mechanical ventilation and a tracheotomy (Hughes, 2000).

Weakness in the legs is symmetrical, and in the face, bilateral. This latter point differentiates the condition from Bell's palsy. The legs are usually affected first and more severely; proximal and distal muscles are affected with equal frequency. Accompanying the weakness is a reduction in or loss of tendon reflexes (McLeod, 1995).

GBS affects not only motor nerves, causing weakness, but also the nerves that control sensation and the autonomic nerves that control the automatic functions of the body, such as heart beat, sweating, bowel control and bladder control. About twenty percent of patients have cardiac arrhythmia (Parry, 1999). Thus, depending on the extent of damage, a person in the acute stage of GBS may have decreased or abnormal sensations, and feel pain. The subject of abnormal sensations includes numbness, tingling, formications, electricity, vibrations, felt most often in the feet, hands, gums and face (Steinberg, 1995). Pain is a common early complaint, occurring in about fifty percent of patients; some estimates are that up to ninety percent of people with GBS have some pain (Hadden, 2000), and it is a major symptom for one third of these. This early pain is most commonly felt as aching or cramping in the back, flanks or thighs (Ropper, 1992). Later, neuropathic pain may develop, causing burning or stabbing sensations, mainly in the hands and feet. The skin is especially sensitive so that a light touch may be perceived as pain (G. Parry, personal communication,

September 18, 2001). Pain felt during the acute stage might be particularly severe for those people experiencing rapidly progressing and extensive paralysis.

Early pain probably results from inflammatory activation of normal pain nerve fibres in the nerve sheath; some of the muscle pain might result from loss of its normal nerve supply. The later, neuropathic, pain results from degeneration and regeneration of damaged pain fibres in the nerves. Pain also occurs as a result of being bedridden, from staying in one position too long, from lying on tubes and monitors and from hands digging into flesh when being repositioned.

Other symptoms, listed in Guillain-Barré Syndrome Support Group of the United Kingdom (2000b), include reduced or lost sense of taste and smell, visual disturbance, increased skin sensitivity, and hot and cold spells, while hallucinations, vivid daydreams and nightmares can be associated with ventilation or painkilling and sedating medication.

For people with CIDP the illness presents in a similar way but over a longer course, and usually without respiratory failure or facial weakness; sensory features are more prominent than in AIDP (Guillain-Barré Syndrome Support Group of the United Kingdom, 1995). Because the characteristics of fatigue and sensory disturbance are difficult to explain, the condition may be vague and confusing to both patient and doctor (Guillain-Barré Syndrome Support Group of the United Kingdom, 1995). As there is no typical CIDP, a general description and a certain prognosis are not possible, however there are some common symptoms among sufferers: tingling, numbness, loss of feeling, weakness in arms and legs, lost tendon reflexes, and aching in the muscles.

Clinical Course and Prognosis

McLeod's (1995) description of the clinical course of AIDP, the source for this section of the chapter, states that the interval from onset to nadir usually varies from hours to four weeks, with about thirty percent of people reaching maximum deficit within seven days, seventy percent in two weeks, ninety-two percent within three weeks and ninety four percent in four weeks. For about sixty percent of people this maximum deficit means they are unable to walk at the height of their illness, while twenty to thirty percent will require assisted ventilation to breathe.

Most people (seventy to eighty percent) make a full recovery with little or no disability. Recovery begins, spontaneously, about two to four weeks after nadir for two thirds of people. For the remaining one third, definite improvement may not be seen for several months. Sadly, for five percent of the people experiencing GBS, complications such as respiratory failure, pulmonary embolism, cardiac arrhythmias, autonomic failure and infections will lead to their death. There is little information on the prognosis for CIDP but it is usual for people to retain minor weakness and sensory residuals (Winer, 2000). Recovery from AMAN is generally slower and incomplete because the damage is to the axon of the motor nerve. Regeneration is approximately 1mm/day, thus months are needed to regenerate even a short distance. Also, some nerve fibres may lose their way as they re-grow along the longer nerves to the lower limbs (Ho, 1998).

Diagnosis

Diagnosis of GBS, especially in the initial stages, is difficult, not least because the presenting symptoms often resemble a viral syndrome rather than a neurological disease. A diagnosis for the rapid onset of weakness with symmetrical ascension, accompanying abnormal sensations and a loss in reflexes is generally made as a result of clinical acumen and experience (Ropper, 1992).

Electrodiagnostic tests of nerve conduction and muscle activity (with an electromyogram), and laboratory evidence (from a lumbar puncture) of elevated proteins in the cerebrospinal fluid can confirm the initial clinical diagnosis. A magnetic resonance imaging machine may be used to eliminate differential diagnoses. A suggested list of diagnostic criteria is given in Table 1, and the reader is referred to Parry (1993) for a more comprehensive list.

Early diagnosis is important since death can occur from rapidly developing respiratory failure and autonomic instability, and because a range of specific treatments - if given early - help speed recovery, reduce disability and prevent complications (McLeod, 1995). Diagnosis of CIDP includes a similar cluster of symptoms, but these occur over a period of more than eight weeks.

Table 1

Diagnostic Criteria for Typical Guillain-Barré Syndrome (Asbury & Cornblath, 1999)

Feature required for diagnosis

Progressive weakness in both arms and both legs

Areflexia

Features strongly supporting the diagnosis

Progression of symptoms over days to 4 weeks

Relative symmetry of symptoms

Mild sensory symptoms or signs

Cranial-nerve involvement, especially bilateral weakness of facial muscles

Recovery beginning 2 to 4 weeks after progression ceases

Autonomic dysfunction

Absence of fever at onset

Elevated concentration of protein in cerebrospinal fluid, with fewer than 10 cells per cubic millimetre

Typical electrodiagnostic features

Features making the diagnosis doubtful

Sensory level

Marked, persistent asymmetry of symptoms or signs

Severe and persistent bladder or bowel dysfunction

More than 50 cells per cubic millimeter in cerebrospinal fluid

Features excluding the diagnosis

Diagnosis of botulism, myasthenia, poliomyelitis, or toxic neuropathy

Abnormal porphyrin metabolism

Purely sensory syndrome, without weakness

Epidemiology

GBS is the most common cause of acute generalised paralysis, with an annual incidence of 0.75 to 2 cases per 100 000 population. This means there are approximately 1500 cases per year in the UK (Guillain-Barré Syndrome Support Group of the United Kingdom, 2000a). Based on European, Australian, North and Latin American population-based surveys, GBS is known to occur throughout the western hemisphere without clustering and with minor seasonal variation (Hahn,

1998). It can affect people of any age, but is rare in infancy and does increase with advancing age; the highest incidence being in the 50 to 74 year age group (McLeod, 1995). It may be more common in men than women with Meythaler (2000) claiming a ratio of 2:1. However, a recent New Zealand survey conducted by Renaud (2000) found an equivalent ratio of men to women.

Generally 75% of people recover completely in 6 to 12 months (Bolton, 1995), less than five percent die (Guillain-Barré Syndrome Foundation International, n. d.), and three percent have GBS recur (Steinberg, 2001). CIDP is less common than AIDP (ratio 1:10) (GBS Support Group of New Zealand, n. d.), and death resulting from this variant is highly unlikely (Guillain-Barré Syndrome Support Group of the United Kingdom, 2000c).

GBS is a significant cause of new long-term disability for at least 1000 people per year in the USA, and it is expected that between 25 000 and perhaps 50 000 people in the USA experience at least some residual effects of GBS (Meythaler, DeVivo & Braswell, 1997). In New Zealand eighty seven percent of the 119 GBS participants in Renaud's (2000) survey had AIDP, and of these eighty-one percent experienced long-term deficits. Most of the eight people who had CIDP were left with permanent damage, while those who had AMSAN made an incomplete recovery.

GBS can occur in pregnancy, but the risk of developing GBS is not increased by pregnancy, and recurrence in future pregnancies is not indicated (Steinberg, 1998).

Aetiology

The physical symptoms of GBS arise from an immune response directed against the body's own cells. For approximately two thirds of patients, onset followed a viral or bacterial infection (Hahn, 1998). Some vaccines have been implicated in precipitating the syndrome (Koski & Laskey, 1998). Many other antecedent events have been described but with insufficient consistency to prove an aetiological association.

Literally millions of people are exposed to the triggering agents mentioned above, but only a few go on to develop GBS (Steinberg, 1995). A number of specific infections have been implicated in the onset of GBS (Jacobs et al., 1998). In order of frequency they are: *Campylobacter jejuni*

which causes gastroenteritis, *Mycoplasma pneumonia* which causes pneumonia, *Cytomegalovirus* experienced clinically as upper respiratory infection, and the Epstein-Barr virus, which causes glandular fever.

Because of the high number of people reporting an antecedent infection one to four weeks before an onset of GBS, Jacobs et al. (1998) have suggested an immune-mediated response against peripheral nerve antigens. In a study with case-matched controls, they found that the variety of reported infectious agents associated with GBS might be the cause of the syndrome's immunologic and clinical heterogeneity. This study found anti-GM2 antibodies were associated with CMV, antibodies against galatocerebroside with *M. pneumoni*, and anti-GM1 antibodies with *C. jejuni* infections. Evidence from another study (Hughes & Hadden, 1999), suggested antibodies to ganglioside GM1 and preceding diarrhoeal illness in AMAN.

Supporting their hypothesis that variants of GBS are associated with different antibodies, Jacobs et al. found CMV-associated GBS patients had a higher frequency of sensory and cranial nerve involvement. Further support came from Jacobs et al. (1998) who found certain strains of *C. jejuni* were the most frequent triggers of MFS, and Ho et al. (1995), who found these strains to be strongly associated with the incidence of AMAN in northern China.

It seems the response of the body to *C. jejuni* could be one of molecular mimicry. By way of explanation, Griffin and Ho (1993) postulated that peripheral nerves may share antigenic sites with *C. jejuni*, and that an immune attack initially mounted against *C. jejuni* may be misdirected toward the myelin of the peripheral nerves. Although protected for much of their length against the immune system by tight capillary endothelial junctions and perineurium, the protection is only relative (Pleasure, 1999). Peripheral nerves not only allow access to lymphocytes, immunoglobulins, complement components, viruses and toxins via the terminal in the motor nerves and the dorsal root ganglion in the sensory nerves, but they contain molecules that serve as suitable antigens to lymphocytes (Pleasure, 1999).

A further explanation for the initiation of the different GBS variants by different physiological processes was outlined by Ropper (1992). He distinguished between those cases that

could be caused by early antibody attacks and those occurring as a result of the inflammatory process. The blood-nerve barrier, which is usually a tight seal around blood vessels, becomes leaky when GBS weakness begins and closes again as weakness subsides, while T cells causing inflammation and the attraction of neutrophils and macrophages have been shown to open the blood-nerve barrier in rats (Hadden, 2000). The different routes of injury to the nerves may explain the varying severity of illness in patients, and why some develop a mild case and others a prolonged paralysis with concomitant axon damage (Steinberg, 1995). Both processes however, lead to a macrophage response that causes myelin destruction. As both arms of the immune system are known to participate in macrophage-induced demyelination, it is concluded that the humoral response may occur early and continue in a sub set of patients, but that inflammation eventually dominates the pathogenesis in most cases.

Management

Immediate – General Practitioner (GP)

Because of the rapidity, variability and severity of GBS, an initial diagnosis by a GP requires that a patient be admitted to hospital as soon as possible, because intubation and mechanical ventilation may be required within 24 - 48 hours of onset (McLeod, 1995).

Intensive Care Unit (ICU)

All patients with GBS need to be closely monitored for 24 - 48 hours after onset of their weaknesses, and around thirty percent of those with GBS will need to be admitted to an ICU (Bolton, 1995; Ng et al., 1995). Connection to a ventilation unit via the nose, mouth or through an incision in the neck (tracheotomy) may be required for many of these people (McLeod, 1995). The heart, temperature and other vital signs are also monitored, and a catheter may be inserted to drain urine from the bladder.

Hospital

Careful and attentive nursing is extremely important to prevent infection, to avoid thromboembolic problems resulting from lack of mobility and prone positioning, to aid feeding, to prevent or clear blockages in the nasogastric tube or ventilation tube, for online cardiac monitoring, for bowel care and for pain management (McLeod, 1995). Subcutaneous heparin may be given to patients to reduce the risk of deep venous thrombosis, which is common in GBS (Meythaler, 2000).

Treatment

Specific

The most effective treatments for GBS are plasma exchange (plasmapheresis), if commenced within the first two weeks and high doses of intravenous human immunoglobulin (McLeod, 2000). Pain relief is available for the numerous types of pain accompanying GBS, and the reader is referred to Nurmikko (2000) for a comprehensive list of these treatments.

Physical

Splints may be required to prevent foot and wrist drop. Hydrotherapy and physiotherapy are employed to maintain and increase muscle strength and relieve discomfort. Occupational therapy may be required to assist in the strengthening or retraining of basic fine motor movements required for everyday functioning. Speech therapy may be incorporated if the person has been unable to speak because of a tracheotomy. While the ventilator tube is in place, a communication board may be used to communicate.

Psychological

Because of its dramatic nature, a person experiencing Guillain-Barré Syndrome may experience psychological problems. Acute tetraparesis with resulting dependency and lack of communication were reported to have great mental impact during the first months of GBS (Powell, 2000). Inability to move or speak does not prevent the brain from functioning, and it is possible that

psychological adjustment to one's physical state, the change in role and identity, and the adjustments required for everyday interactions with medical professionals, relatives and friends, will be required (R. Gregory, personal communication, July 28, 2000). Fear, worry, panic, boredom, frustration, and anger are co-morbid possibilities.

The rarity and inexplicable nature of the disorder, even among medical professionals, creates potential for misdiagnoses of conversion disorder (Wherry, McMillan & Hutchenon, 1991) or depression (R. Coleman, personal communication, July, 2001). These are dangerous because it may mean vital life-maintaining services are not provided for the patient.

Involvement by family and friends during the hospital stay helps reduce a sense of isolation and helplessness, while explanations of care management by medical staff help alleviate anxiety (Steinberg, 1995).

Counselling and affiliation with peer group members may be helpful to allay fears and encourage the person experiencing GBS to look forward to recovery (Gregory, 2002). Talking therapies are redundant when the patient is unable to speak. What is important is that the person with GBS is given an explanation of the disease, and advised that they have a relatively good prospect of recovery (Steinberg, 1995).

In many patients with GBS, psychosocial functioning, as defined and measured on a psychosocial score in the Sickness Impact Profile (SIP), is still seriously affected, even when they have physically recovered, or show only mild residual signs (Bernsen, Jacobs, de Jager & van der Meché, 1997). Physical recovery may continue for anywhere from six months to two or more years, (Steinberg, 1998).

Recurrence

GBS is thought to be a one-time disease, but relapses and chronic recurrent forms can occur. AIDP can recur following a similar preceding illness, but this is rare. The same treatment is appropriate for a recurrence as it is for the initial episode (Kleopa & Brown, 2000).

Outcome

About seventy five percent of patients experience a good recovery, fifteen to twenty percent have moderate residual signs, and some five to ten percent are left with a severely disabling physical condition (Bernsen et al., 1997), although Renaud's (2000) statistics for a New Zealand sample suggest over eighty percent of patients experience residual symptoms. Time from onset to nadir and the duration of ventilation assistance has been correlated with outcome at three and six months (Ng et al., 1995).

Based on a study reported by McKhann (1988) the patient characteristics suited to a ninety-five percent chance of good recovery, in declining order are: relatively normal muscle electrical activity; received plasmapheresis within four weeks of symptom onset; did not require a respirator for breathing; the disease progressed at a slower rate over weeks rather than days; the person is closer to thirty than sixty years of age. From the same study, Cornblath et al. (1998) noted that a mean distal compound muscle activity potential (CMAP) amplitude of less than twenty percent of the lower limit of the normal range increased the probability of a poor prognosis, but this could be improved with plasmapheresis therapy. Patients who did not fulfil the characteristics listed above were predisposed to a longer recovery period (Steinberg, 1995).

A later study of a large number of patients by The Italian Guillain-Barré Study Group (1996) concluded that a poorer chance of recovery was linked to older age, antecedent gastroenteritis and electrophysiological evidence of axonopathy.

Residual Symptoms

Physical

Minor neurologic abnormalities resulting in annoying parasthesias and vague aching pain, especially in the feet, are common residual symptoms (Parry, 2000). In a study of ten people with GBS assessed between eleven and thirty-five months after onset, all patients showed persistent limb weakness on a number of impairment, disability and handicap scales, nerve conduction studies and on a standard neurological examination (Lennon et al., 1993).

Psychosocial

In a study using the SIP and a modified functional assessment scale, Bernsen et al., (1999) concluded that for many patients, psychosocial functioning (as defined above) was still seriously affected three to six years afterwards. This was so even if physical recovery was complete or residual signs were mild.

Supposition

It is while living with these residuals that a large number of people recall and speak about their GBS experiences. They probably include much of the information presented in this chapter not as isolated pieces of information, however, but as information contingent to its importance or significance in being connected with and shared, in some cases many years later. The original thoughts about an experience are likely be modified and replaced as either a consequence of exposure to new information, reflections upon old information, or the distortion of what was thought to be the experience in a way similar to what happens to information passed around in the game of Chinese Whispers. “Events have no meaning in and of themselves” (Emmons, Colby & Kaiser, 1998, p. 164), because meaning is made and imposed by each person according to the type and intensity of feeling associated with the events and the reason they were later recalled. How people, in general, choose to present and speak about past events and experiences is the subject of the next chapter.

3. STORIES, NARRATIVES AND NARRATIVE INQUIRY

Introduction

When one of the participants of this study said, “But anyway, I’m just trying to think what are the other significant things”^{D393},¹ she was referring to anything else about her GBS experience that was important enough to tell me about. The malleable nature of her memory of the experience implies a dynamic phenomenon rather than engram. Memories are considered to change over time as the individual, events, and the contexts within which events occur, change (Fife, 1994). Each time the participant quoted above, thinks or speaks about any aspect of the experience an opportunity is provided for her memory of it to be reconfigured. An analogy is what happens in medicine when information and theory accepted by the medical profession as fact is changed in the light of new evidence. Thus the summary of ‘facts’, presented in Chapter 2, is open to evolution, as is the meaning it has for the people informed by this knowledge for their professional integrity.

This scenario also happens when people look back on an illness and review it in light of recent medical knowledge and present day research that links stressful events with a physiological specificity response (Taylor, 1990), particularly human immune functioning (O’Leary, 1990). People are now as likely to examine factors in their lives or life-styles that could contribute to the onset or prognosis of illnesses, as they are to search for exogenetic causes. Reciprocally, they are as likely to explore the psychological impact of an illness on themselves and their relationships with others. Based on some of the personal stories I have read in various print media², comments from people who have had GBS, in particular, are likely to contain psychological seeds of destruction and metamorphosis. Their words became woven into stories containing themes of tragedy and heroism.

¹ The superscript text at the end of each participant’s quote contains the identifying letter of the participant described on page 38 and the transcript line number on which the quotation begins.

² Contact Janet-Lee Mace at jlm@macecompany.com for the reference sources of these magazines and newspaper articles.

Stories

The stories that I read in these newspapers and magazines, were the authors' attempts to redefine the meanings they assumed as part of their routine living before they were afflicted with GBS. They wrote first of being blighted with the syndrome and then of having their taken-for-granted existence consumed by it.

Throughout, they offered or inferred their opinions of what was happening. The process of formulating these opinions became an activity of making sense. This was because,

[t]he occurrence of critical events requires that we reconstruct and transform the meaning upon which we based our lives..... the meanings which are formulated are likely to change in crisis situations, sometimes very rapidly, as the individual engages in the coping process and actively struggles to arrive at a meaning that is not devastating to his/her self-perception. Within this context of a highly threatening event, such as serious illness, the process of defining meaning involves effort to understand and put in perspective the occurrence of the event, and to comprehend its significance for one's self and one's future life" (Fife, 1994, p. 311).

Their storying was thus, a fundamental way of organising their experiences (Andrews, 2000) in order to make sense of them, and hence the story can be considered a very natural format for passing and receiving information. People listen to stories; they understand the rules of stories and this naturalness in the activity of sense making through storytelling is from "...narrative imitate[ing] experience because experience already has in it the seeds of narrative" (Mattingly, 1998, p. 45). Thus, if experience is to be spoken about and understood, as far as it can be by someone standing outside the reality of that experience, then a perfect medium for this passing of understanding is the story. The appropriate method for deciphering the meaning of experience is one that encompasses the everyday processes for reaching understanding; one that uses the rules for storytelling and story structuring, but at the same time stays faithful to the storyteller's intentions about the experience.

Narratives

As we go about our daily lives we are constantly constructing purposeful stories to answer questions about who we are, how we exert control, enhance our self worth, how we assimilate or accommodate new information, how we justify our actions, obtain rewards, pass along information, and present ourselves to others (Baumeister & Newman, 1994). Basically, this process is how we come to understand the world and our role within it.

By its very nature, this process of acquiring understanding is retrospective. Past events are remembered and highlighted as to the significant role they play as contributors to an end event. Other happenings considered as historical truths may be omitted by the author from the story (Carr, 1986), or included only to provide background information. Likewise, a story may include inferences which fill in any detail, thereby adding to the coherence of the tale (Baumeister, 1994). The fundamental consideration is that meanings attributed to experiences are important. “The order of understanding has been inverted: the past is now understood as meaningful because of the present, and the concept of cause appears as a rhetorical imposition. The narrative [story] operates to find causes for present conditions....” (Polkinghorne, 1988, p. 121).

These everyday stories for providing explanation are made up of the principal features of a narrative. These include a setting (the context of the present telling, the context of the original experience, background information and anecdotes to provide humour and interest), characters (the narrator and the people spoken of), a plot (interrelated episodes that mean something), happenings (actions), a beginning, middle and end (temporal sequence), a medium through which the experience can be interpreted (language), and possibly a moral (message). They also require a process of authorship. Emplotment is the term coined by Sarbin (1986) as the process of giving shape or synthesizing heterogeneous elements into a coherent whole. The storying is ongoing and iterative. New information requires a configuring, or later reconfiguring, of the original experience to create an understanding that is meaningful and cogent.

The efficacy of this technique for assembling a large amount of information into a cogent form was metaphorised by Sarbin (1986) when he defined narrative [story] as the organizing

principle for human action, a way in which humans impose structure on the flow of their experiences. By taking account of actions across time, Sarbin has claimed storying as being a root metaphor, or framework, for construing the world. Unlike the root metaphors for other ontological positions in psychology, and because of their transmutability capacity, stories and storying are the most suited for encompassing the idea of constant change in the structuring and positioning that occurs during peoples' day to day lives. The figuration of this structuring and positioning becomes the way people make sense and come to understand their existence in the world.

Spink (1999) defines making sense as a powerful and possibly inevitable force for active shaping of our daily lives into a continuous production of meaning. Storying can thus be viewed as a 'living' epistemology for finding meaning in everyday occurrences. This knowledge is not factual, objective knowledge, but subjunctive knowledge from the expressive domain, the type of knowledge that can only be anticipated and not predicted in advance (K. D. Murray, 1995). It encompasses emotional attributions as well as the accounting of events, and is revealed through the structural elements that form stories.

In general terms, stories are a way of meaningfully communicating to ourselves and to others what is happening in our lives. It is a method of connecting separate, seemingly unconnected events or episodes of activity into a sequence that provides understanding. As such it is not just a string of words or sentences in the form of discourse. It is a process, the creation of a story that informs. It is a natural activity that humans perform from their earliest years, and have been performing as a species for centuries and across cultures.

The stories in our lives are flexible in that they change according to where, when and to whom we are telling them. A single story is configured and reconfigured following the principle features of narratives and with reference to changes in context or new information. Thus for narrative psychologists, narrating characterises the process of authoring and telling that the participant and researcher, client and therapist, are involved in together. The same occurs in everyday life when a person is making sense and finding the meaning of their actions and interactions in the world. For,

[i]t is not the case that we first live and act and then afterward, seated around the fire as it were, tell about what we have done.... It is the attempt to dominate the flow of events by gathering them together in a forward-backward grasp of the narrative act.... Narration constitutes something, creates meaning rather than just reflecting or imitating something that exists independently of it. But narration, intertwined as it is with action, does this in the course of life itself, not merely after the fact, at the hands of authors, in the pages of books. (Carr, 1986, p. 61)

However in real life people tell stories, not narratives (Frank, 2000). To make clear the semantic distinction between story and narrative, the present research uses the term 'narrative' for the specific way it describes the kind of organisational structure expressed in story form, narratising for the process of creating that story form, and narratology for the study of these story forms. The storytellers may not be aware of the structures and structuring that goes into forming their stories, but it is these aspects of the story that are homed in on as part of a narrative inquiry. By referring to the participants' accounts as stories and not narratives, the researcher honours the gestalt and thus privileges what is important to the storytellers themselves. In Chapter Six, the section headed The Meaning of GBS is referred to as a narrative not a story, because even though it is the researcher's story it is one created out of a narrative analysis.

Assumptions of Narratives

There are various assumptions associated with narratives as they are defined above. These assumptions underpin the methodology and thus the findings of the present research. These assumptions are,

Our world and ourselves are social constructions

The authorship of personal stories through the process of configuring and reconfiguring is not one that occurs in isolation. The ontological position of this study is that knowledge is constructed as part of our interactions in a social world. The world as known by each person is created through these interactions, and afterwards during our personal reflection on them. In an anthropological way

we think and act according to the values and morals we accept from our culture's stories, in a sociological way we base our future actions on what we learn from our personal encounters, and in a psychological way we choose to think on and act out behaviours based on our understanding of what reaction these behaviours will elicit.

From the end result of these exchanges we develop a repertoire that enables us to present an image of ourselves and/or the experience that we wish to present in any given context. The story we judge worthy of telling about ourselves and our experiences is conditional on this choice of presentation, and differs according to when, why or to whom the story is being told. The story has a purpose, and we have the audience in mind when we are telling it. David Carr (1986) summed this up elegantly when he wrote, "Sometimes we must change the story to accommodate the events, sometimes we change the events to accommodate the story" (p. 61).

The story is, then, offered as a mega-metaphor for an audience who act as the final interpreter of the experience. Because of their subjectivity, the meanings within this story need to be comprehensible for the audience to understand them in the way the speaker intended. The analogy is an effective technique, for example, that enhances this comprehension.

The validity of a story does not come, therefore, from its use as a passive explanation, but from its ability to be appropriated by the audience; its ability to make one's own what was initially alien (Ricoeur, 1972, cited by M. Murray, 1999). In being able to do this, the story has the illocutionary power to effect changes in people's lives, much the same way we are drawn into a quality novel and emerge with different possibilities for our future actions. For this to happen there needs to be a conduit for the necessary understandings to be filtered through. This conduit is a language accessible and comprehensible to both giver and receiver.

Our world creates language but it is also defined by language.

If the nature of this world is viewed as a constructed reality then the means of comprehending the nature and meaning of our existence in this reality would be with a tool crafted for and from this construction. That tool is language, and it is used by humans to extrapolate an interpretation (or

hermeneutic) of existence. Enmeshed as it is within historical, situational and sociological contexts, narrative is the methodology, narratologists claim, through which language crafts our lives. By examining spoken accounts as narratives and working backwards through the process of story making, while simultaneously accommodating the contextual elements of culture and language, they seek to elucidate the meanings attributed by a speaker to a particular experience. For narratologists, language plays a pivotal role in the understanding of experience and by extension, of constructed reality.

The genesis of an historical philosophical debate about the role language plays in understanding reality culminates in the view recently presented by Polkinghorne (1988) and is the view with which the present study aligns itself,

... namely, that language takes up the contingencies of existence and the perceptual openness of life to the natural and inter-subjective worlds, and moulds them into a meaningfulness greater than the meaningfulness they originally hold. One of the ways language does this is to configure these givens into a narrative form in which desires and aspirations are used to transform the passing of life into an adventure of significance and drama. (p. 31)

Language is thus the meaning-maker, and the story a creator and definer of our human lives. Our existence is a gestalt to the chaotic assemblage of activity, identity and temporality characteristics inherent in our daily lives. We know of our existence because we are constantly forming and reforming the concept of it through our attributions of significance. Our perception of what is real is not static or confined to an objective reality as conceived by those espousing a realist perspective. Our perception is a continual interpretation and thus our conception of what existence is, and who we are in this existence is a process of construction under construction.

Selves are constructed within a social world.

The basic assumption of social constructionism is that the essence of who one is arises from whom one is in a body as one moves in a corporeal and interactive social world. As we move around in this world we make up identities of ourselves that are a reflection of this activity. Our identities,

our 'us', is constructed from our actions in the world, what image we are at any particular time or place, and what images we think we portray to other people. We are an existence, but one that we are constantly creating and changing, and in this respect our identity is multitudinous, inconsistent and unpredictable.

As well as being an existence, we also live within an existence. This is the world we classify as 'not us', and as with the notion of our selves, it is also a construction, and something we continually reconstruct throughout our life. So much so that when G. W. Bush (2001) said, "Every death extinguished a world" in his speech at the three-month anniversary of the September 11 attacks, he perfectly metaphorised the concept of the constructed selves in a constructed world. We create the world, as we know it, from the accumulated knowledge of our culture. Because culture is ever changing in response to new information, our world and our selves are an ongoing construction project. One way of conceptualising our selves as human beings would be through the ordering of our experiences based on the significance they have in determining that part of our identity under construction. The question of "Who am I?" may be answered through a making sense and figuring of the experiences that the 'I' is involved in. This figuring *cum* sense making activity gives coherence and shape to the storyteller's view of his or her world as much as the telling of it present this person's inner thoughts to the outside (Lieblich, Tuval-Mashiach & Zilber, 1998).

The figuring, configuring and subsequent reconfiguring - narratology terms analogous to the constructionism lexicons of construction and reconstruction - are by nature retrospective, as they involve examining past interactions and assigning them meaning in light of a known outcome. The past is continually configured in the present to offer a different perspective or possibility for different action (thought or behaviour) in the future. The process of meaning making and thus identity formation becomes bounded in time. Because the outcome of these two processes is for comprehension and communication, people will story their experiences by ignoring chronological time using narrative time instead. This narrative time is time without linearity, and is the time that a sequence of episodes in a story creates when it leads an audience toward a dénouement.

Activities occur in time

A personal history is a reflection of the chronological progression from birth. However, when people review their lives they are unlikely to remember every detail of every event that occurs, one after another, in this progression. The lives they create and speak about are actually interpretations of an agglomeration of experiences, dispersed or tightly connected, with known sequela, selected for telling depending on the purpose of the telling and the images the speakers wish to present of themselves during the occasions of telling. The potential for complexity amidst this is immense, so much so that a number of meanings may arise from one single experience.

It is an assumption of the present research that each experience in a story has a relational connection of significance to life as a person chooses to think about it. This is the same as the episodes of a novel having significance to the plot and towards the final unravelling of the complications of this plot. Time features in life storying as it moves architecturally from a beginning to an end and in this way it sets the boundaries of a story. However, in describing temporaneousness in its relevance to life storying, time is not merely the common idea of numbered points on a clock. It is the ordering of events based on their temporal sequence, but it is also an ordering of events based on their significance.

Riceour's hypothesis, outlined in his book *Time and Narrative* (cited in Polkinghorne, 1988), was that the temporal character of experience and the activity of storying are not a correlation of accident. Plots and sub-plots arise from the polysemous aspects of experience and are inclusive of the multiplicity of ways that time is experienced. "A narrative can ... present events occurring at the same time and in the same space, or at different times and in different spaces ..." (Prince, 1982, p. 66). Because of this a story is also able to capture that broad moment of time where awareness is thick and complete. That moment outside the duality of time and space that Joseph Campbell (1988) claims is "...innocent of time, innocent of opposites..." (p. 50). This conceptualisation of events in time was regarded by William James (cited in Polkinghorne, 1988) as being so agreeable that he described it as the specious present. There was a sense that the future could be represented and reflected by the past that occurred during a single moment of reflection. Time was thus envisioned as

incorporating, ignoring, or manipulating chronological time, depending how authors chose to play their stories.

A narrative contains action seen through the eyes of the narrator

As with the episodes in a novel, the events in a life story are comprised of actions. These actions are likened to the words on a page in the way they display the author's intent; the author of a story being the person thinking or relating the story. The actions of the characters, and the interactions of the author/narrator with scene elements in any particular episode, are included in a way that carries the audience toward a goal. As noted above, these episodes are neither serial nor independent, but are included because of their meaningful contribution towards that goal (Polkinghorne, 1988). The author composes a story comprising the past actions he or she considers meaningful and new information he or she has about the present. This is an ongoing and ever-evolving process since new meanings arise from the assimilation or accommodation of new information with old. Present and future actions may be instigated based on previous stories, while at the same time they remain open to the unique elements arising from reconfigured stories.

Narrative Inquiry

Narrative inquiry is a qualitative research methodology for sourcing knowledge, but is not a method *per se* (Chamberlain, Stephens & Lyons, 1997). It differs from other qualitative methods in that the data with which it concerns itself are diachronic data. These data contain information about the sequential relationship of events (Polkinghorne, 1995). Unlike studies that rely on synchronic data - the data that answers the questions put by interviewers to provide information about the present situation or belief of a research participant – narrative inquiry relies on data about personal episodes where things that happened resulted in other things that happened and so on. The data collected is assumed to be delivered in a story format, with the process of storying providing the storyteller the lenitive of creating coherence and meaning to what may otherwise be considered a discombobulation of isolated impressions.

As the present research is bedded on social constructionism, the stories told are co-created

ones rather than "... a neutral account of a pre-existing reality" (Hollway & Jefferson, 2000, p. 31). In stories authored for academic purposes the audience is very much in the mind of the participants as well as the researcher. The eclectic assemblage of information acquired in interviews will be offered thus with agendas. The words and images offered by the participants about the phenomenon under study have manipulability and are open to development and change as the storying or the analysis of the stories proceeds.

As Michael Murray (1997) stated,

[i]n the research interview the interviewee does not tell a standard story but a particular story which is designed to present a particular image to the interviewer. Similarly, in analysing the story told, the researcher begins to construct a new story which is acceptable to his or her audience (p. 299).

Thus the participants' stories will depend on what has gone on for each before their interview, what each person knows about the other as they begin the interview, what each expects from the research and the interview, and what each thinks will happen to the collected data in the future. Likewise, participants may change the descriptions or emphasis of their stories when the audio-tape is switched off, or the meanings comprehended by the researcher may change with the addition of other information later acquired about the participants. The choice and quality of information provided from the interviews will also depend on the rapport between participant and researcher, the listening skills of the researcher, and the ability of the participant to make understood what he or she wants to convey. The skill and insightfulness of both in elucidating the dramaturgical elements of the experience into a narrative will be further influences on the choice and quality of the data. The outcome of a narrative inquiry, then, is a joint product of the participant, the audience and the research that facilitated the sharing of stories (Bamberg, 1997).

The interview is one component of the narrative inquiry only. A method for analysing the stories sourced in the interviews is also a necessity. There are a number of methods located under the methodological umbrella of narrative inquiry. Polkinghorne (1995) mentions two major pathways for methods in narrative inquiry, namely, analysis of narratives and narrative analysis. One procedure

requires a separation of data, the other a synthesis.

The first pathway employs a paradigmatic process of analysis in that it seeks to locate common themes or conceptual manifestations across several stories collected as data (Polkinghorne, 1995). These data are generally gathered as stories about an event and told by participants in an interview situation. Within this approach the researcher performs either a deductive search in which instances of concepts are found to support a theory, or an inductive search in which the concepts arise from the data itself.

The other pathway for a narrative inquiry, narrative analysis, contains a narrative process in which the researcher collects information about an event from a variety of data sets. This information is then collated and configured by means of a plot into a narrative of the researcher's creation.

Both these pathways are premised on the assumption that stories work to provide information, and that the data contained within them work in the diachronic fashion to show the consequential relationship of one event affecting another. It is the processes of finding and presenting this information that differentiate them. The choice of pathway is contingent on the requirements of the research and the conceptual focus of the researcher.

For the present research into the experience of GBS, both types of narrative inquiry were used but for different purposes. An analysis of narrative with an inductive subtype was chosen in the initial stages because it was assumed the interviews would contain autobiographical data about cause and effect relationships, temporally sequenced around the experience of GBS. The data were storied narratives suitable for categorisation into common themes from which a nomological meaning of GBS could be discerned. As the research proceeded the deconstructed themes were transferred into a narrative analysis whereby all information gathered from and about the participants was gathered into a new narrative. Both types of narrative inquiry, and the way they were used in the present research, are discussed in more detail during the following two sections of this chapter.

Analysis of Narratives

As noted above, the methods employed for an analysis of narratives involve the researcher collecting a group of stories and processing the information within them in a paradigmatic way. It is the participants' words rather than the researcher's configuration of them that is considered the object of analysis. Based on the ontological and epistemological assumptions previously discussed in this chapter, this pathway privileges the participant's account as a narrative, albeit one that is co-created by researcher and participant for the present context.

The researcher uses the rules and structures of language and narrative – for example, grammatical and syntactic information - while examining the stories to see which elements are shared across them. As a result of moving back and forth between information contained in the stories and the emerging categories posited by the researcher, these elements are sorted and appropriated into categories based on family resemblances (Smyth, Collins, Morris & Levy, 1995). Categorisation is a useful strategy for bringing order to a large amount of data, but can be used as a method in narrative inquiry despite its partisan association with the methods of cognitive inquiry. Even though the research is guided by a set of objectives or questions, when an inductive method is employed the categories are still not overtly driven by pre-existing theory, nor do they mirror the questions asked of participants in a structured interview. They emerge out of an immersion in the audio recordings and the written transcripts of stories.

Paradigmatic research is not confined to discovering or describing the categories of particular elements, but is also used to note the relationships among categories (Polkinghorne, 1995). What the categorisation does is provide a means for the researcher to examine a number of stories at once in order to discern common and differing meanings.

By systematising the data, categorisation also helps in the observation of patterns and groupings, however the temptation to fragment stories into ever more detailed categories and subcategories means the wholeness of the tales could be lost. The non-obvious links between statements, the contradictions, pauses and sighs and utterances that are omitted when only a categorisation strategy is employed, are what adds to the tale's meaning. For this reason, the present

research did not limit itself to merely interpreting the various categories and their connections.

The desire of this researcher to hear the participants tell their own stories means the interviews were unstructured. This format allows the tales to meander wherever the storytellers take them, and thus precipitates the spontaneous associations that could provide information "... offering richer and deeper insights into a person's unique meanings" (Hollway & Jefferson, 2000, p. 152). The format also allows the focus of the study to be centred on the people telling the stories, as well as the stories being told in the specific context. It is through a free association-type story that the researcher seeks to identify how the participants view of themselves through, and as a result of, an experience.

Once the story is underway, of course, there is no guarantee that the storyteller and the listener will share meanings. The problem with the co-creation aspect of stories is that the participant and researcher are entwined in the act of creation during the interview. Can the meanings revealed by the participant be taken at face value, especially since language is not transparent? No, they require interpretation, and to interpret then classify the meanings given by the storyteller, the researcher selects from a number of resources. These include, as well as the theoretical and professional skills of the researcher, a knowledge of the contextual elements (cultural, social, historical, geographical and demographic), knowledge of the phenomenon under study, the courage on the part of the researcher to use insight and creativity in reading the emotional as well as the cognitive clues hidden in the narratives, the checking out of meanings through questions to the participant once the free association section of the interview is completed, and the use of field notes about the interview procedure, setting, interactions and interviewer's feelings written immediately after the interview is finished. Once cataloguing has taken place, the researcher uses these categorisations to guide the next stage of the inquiry, when a narrative analysis is undertaken.

Narrative Analysis

In a narrative analysis, the researcher uses all available information to create a narrative about the object of study. The same essential elements used in stories are employed to make this narrative –

boundaries, characters, background, scene setting, style and plot. The aim is to provide a uniting and meaningful account that serves the purpose for which it is intended. The researcher uses narrative rather than paradigmatic reasoning to configure a synthesis. Thus the narrative comprises the significant events, thoughts or behaviours that contribute to the emplotment and its outcome. As with analysis of narratives, the data are diachronic even though they come from many sources – participants' account, field notes, answers to questions posed both in and out of the interview, comments by friends or family, newspapers or magazines – and the researcher selects contributions from these during the

... recursive movement from the data to an emerging thematic plot.... The development of a plot follows the same principles of understanding that are described by the notion of hermeneutic circle. The creation of a text involves the to-and-fro movement from parts to whole that is involved in comprehending finished text (Polkinghorne, 1995, p. 16).

This narrative analysis method is used by biographers, researchers and storytellers such as Oliver Sacks (1986, 1989, 1991, 1995, and 1996) to join previously disparate facts together within a structure to provide a coherent tale that is interesting, insightful and explanatory. Sacks' tales about his patients or anthropological subjects are more interesting and meaningful to many readers than would textbook accounts of their neurological conditions.

The appeal of this method of narrative inquiry is that individual cases can be incorporated and not excluded as they are through aggregation. All the elements of a story go into this narrative. The character may be a specific individual or the conglomerate of many individuals in the form of a generic character. When this method is used in conjunction with the analysis of narratives method, the combined attributes of both can be very advantageous for interpreting and explaining the meaning of an illness experienced by many people, but in their own idiosyncratic way.

Narrative Inquiry and Illness Research

The value of a narrative inquiry is that information can be analysed and presented about topics not generally conducive to other methods of data analysis. This is particularly so for the study

of meaning in trauma and illness. Each of these concepts by itself offers wide scope for the examination of subjective experience. In combination, as they are assumed to be in Guillain-Barré Syndrome, even more so. Antony Broyard (1992, cited by M. Murray, 1999) wrote of the initial experience of his cancer diagnosis as being one of disconnected shocks, and how of he had an instinct to control and confine the catastrophe by turning it into a narrative. Robert Murphy (1987) and Arthur Frank (1991, 1993) likewise took pen to paper as a way of sorting out what their respective illnesses meant, and offered insights for others to read. Several researchers (Crossley, 1999; del Veccio-Good et al., 1994; Frank, 1997; Garro, 1994; Good & del Veccio-Good, 1994; Mathieson & Barrie, 1998; Mathieson & Stam, 1995; Robinson, 1990) have taken the accounts of people with life threatening, chronic or debilitating illnesses and used a narrative inquiry to expose different aspects of the illness experience.

Narrative inquiries, like the examples above, are not the only ways illness can be researched, however they do demonstrate the value and utility of narrative inquiry in this field. By incorporating biographical and experiential contexts, Garro (1994) wrote, along with shared cultural knowledge into account, illness stories help people make sense of what happened because they provide an arena with which to negotiate reality. As previously argued, stories have this coherence and reconstructive (reconfigurative) function (Mathieson & Barrie, 1998), and this is especially useful for identity formations and presentations after an illness has shattered previous illusions of established self-identities. What is interesting about the study of chronic and life threatening illness says Crossley (2000, p. 528), is that in upsetting the “routine and taken-for-granted of life expectations” which give coherence, unity and meaning in life, these illnesses trigger the individual’s attempts to “reconfigure a sense of order, meaningfulness and coherent identity”. One way to grasp the meaning of an illness is by authoring a story about it.

Emmons et al., (1998) wrote that traumatic events precipitate meaning crises and can serve as wake-up calls for people to examine their priorities and possibly change their life view. What is the meaning of life for a person who becomes suddenly and severely disabled, asked Gregory (1999)? The crunch point for some disabilities and illnesses offers an opportunity, as Frank (1991) suggests,

... of being taken to the threshold of life, from which you can see where your life could end. From that vantage point you are both forced and allowed to thinking new ways about the value of your life. Alive but detached from everyday living, you can finally stop to consider why you live as long as you have and what future you would like, if any is possible. Illness takes away parts of your life, but in doing so gives you the opportunity to choose the life you will lead, as opposed to living out the one you have simply accumulated over the years (p. 1).

The Present Research

The aim of the present research was to provide insights into the experience of people who have had GBS, using a narrative inquiry. Although, as noted above, traumatic illnesses have been researched and written about from a narrative perspective, this researcher has found no published studies, to date, that have done this for GBS. After an extensive examination and reflection upon the findings in the aforementioned articles about illness narratives, this researcher chose the following objective: To examine a group of stories about the experience of GBS using a narrative inquiry to uncover what it means to have Guillain-Barré Syndrome, how people make sense of their experience, how people present themselves through the telling of the experience, and whether the experience was meaningful.

Summary

The process the participant and the researcher go through to make sense of an experience, the story about this experience, and the resultant interpretation of it are illustrative of what occurs as part of the figuring and reconfiguring we do when constructing our selves and our world. The process of storying draws together a myriad of events and actions into a storied account. This story has a theme or plot that begins at a chosen point in a person's experience. Events and identities are gathered together based on their contribution towards a plot. As the conclusion is already known, the author of the story is able to retrospectively select the "...temporal sequence, human motivation, chance happenings, and changing interpersonal and environmental contexts,"

(Polkinghorne, 1995, p. 7) that go into making the plot. The things they select can be regarded as narrative structures and examined in a narrative inquiry to see what is considered important enough to want to tell as the account of an experience.

All stories, whether created for personal or academic reasons have a purpose, namely, to describe and understand events. The present research was instigated to analyse a set of stories in order to understand what the participants said about their experience of GBS with reference to meaning, comprehension, identity and meaningfulness.

4. METHOD

Introduction

This research was based on the ontological and epistemological assumptions associated with the constructionist-interpretive style of research, which emphasises purposive sampling, inductive data analysis – obliquely influenced by the research questions and the researcher’s perspective - and contextual interpretations (Denzin, 1994). The methods of inquiry used to find the meanings associated with having GBS were developed by the researcher during the research process itself. This seemingly hit-and-miss procedure, however, was always prenoted by a holistic-content perspective, as distinguished by Lieblich et al. (1998) in their typology of narrative inquiries. Other methods of narrative inquiry examined by the researcher have used semi-structured interviews as opposed to unstructured, and focused on either the form or the content.

The free flow of the interview format used in the present research, the punctuating of sections only to delineate meaning, and the maintenance of the whole story rather than the sectioning of it into small structural parts like the poetic stanzas Riessman (1993) recommended, meant not only does the power of the story stay with the participant as much as possible, but the free associations made by the participant as a consequence could be used in the analysis.

Unprepared speaking is not always overtly purposeful. When relaxed, people will meander over a wide range of topics with each topic often being prompted by some association with another. Psychoanalysts call this free association and use it to tap the unconscious motivations of a client’s stories. It allows the analyst to uncover meanings that may have been hidden even from the analysand. Although not integral to the creation of a story, an unstructured interview method allowed these meanderings to occur, without undue direction from the researcher or the agenda of research objectives. Although aware of power issues inherent in any interview situation and during the selection of elements for analysis, the intent of the researcher was always to have interpretive voice only later, during the analysis.

Participants

Six people who had had Guillain-Barré Syndrome were selected because of their geographical proximity to the researcher. Each was approached individually, by either a mutual acquaintance or by the local representative of the New Zealand GBS Support Group. The group comprised three women and three men who had had GBS between four and twenty-seven years ago. Their ages at time of interview (May - July, 2001) ranged from mid-twenties to mid-seventies. One man had had AIDP twice, one woman and one man had had AIDP once, one man had had CIDP, and one woman had possibly had AMAN. Demographics of the participant group were: Participant A: Female, married, AIDP onset 1974; Participant B: Male, married, AIDP onset 1976; Participant C: Male, married, CIDP onset 1996; Participant D: Female, married and pregnant at time, AIDP onset 1985; Participant E: Female, married and pregnant at time, AIDP but possibly AMAN onset 1998; Participant F: Male, married, AIDP twice, once in 1971 and again in 1991.

Procedure

A number of people who had had GBS were suggested for possible contact from the local GBS Support Group representative, and from friends and acquaintances of the researcher. After initial contact by an intermediary, prospective participants were phoned by the researcher and asked if they wished to participate. If so, they were asked to read the information sheet that would be posted out, ask any questions, sign the consent form and return it to the researcher, who would then phone for a suitable interview time.

All interviews were held in the participants' own homes and were conducted by the researcher. The interviews began with general introductions and a cup of tea or coffee offered by the participants. Participants were asked to talk about their experience of GBS, and this was recorded on a digital recorder. The interviews were unstructured in the manner suggested by Minichiello, Aroni, Timewell and Alexander (1990), with the interviewer interrupting as little as possible to allow the stories to be of the participants' own creation. It was their own story that the interviewer wanted to hear and analyse, and in fact no participant required any prompting or encouragement to tell their

story. When the participants indicated they had finished, the interviewer asked about any issues that had arisen for her during the non structured phase of the interview. These questions were left until the end of the interviews so as not to break the flow of the participants' speaking. This was important because an objective of the analysis was to examine elements of the narrative structure that the participants chose to include. The choice of narrative constituents was the key to unlocking the meaning of the experience. The interviews were concluded with most interviews lasting one and three quarter hours.

A transcriber was given the downloaded voice files to type a transcript for each interview. The researcher used a combination of the typed transcripts and participants' voices stored as voice files to edit the transcripts, using punctuation only to define semantemes - groups of words which belonged together to provide meaningful images or ideas in the stories.

Analysis

For analytic purposes, once the stories were transcribed they were reclassified as narratives and the structures used in forming these narratives deconstructed and critically examined using the following questions:

The beginning: At what temporal point in the experience did the participants choose as the starting point? What aspect did they start with (people, onset symptoms, background information)? How does this set the tone of the story and if it does, how does it relate to the rest of the story?

The ending: What does this say about how the person thinks about the experience and themselves now, if in their choice of ending they are making a bridge between the remembered experience and their life as it is in the present? Does it link in with how they started the narrative? The ending provides a clue to what they think the experience is and what it means to them now. They may choose to summarise the experience, say how they are in their physical or mental state right now, or how the experience influenced these present states.

The characters: The people they mention are significant. Who are they in relation to the participant (him or herself, medic, family member, and friend)? What role did they play in the

experience? What judgements did the participant make about them to define them as a character type, and what messages is the participant giving about and to these people?

The themes: These are the incidents and episodes the participants talked about. What are they? Do they fit into a system of categories, and if so what are the major and minor categories? What factors could be used to discriminate placement of a theme into a category: the intensity of the experience, a gut feeling rather than a pedantic counting on my part, or the adverbs/adjectives associated with the theme?

The scene: What other information is given as anecdotes, background information, setting, political or social comment that form the context the narrative is set in?

The style: What sort of emotional words are they using? What is the general impression of the interviewer, and are the participants telling aspects of their story in an overt, covert or unconscious way? Information gleaned from field notes is used for this.

The tone: Were laughing, crying, long pauses for effect, or other activities like speeding up, lowering voice, sighs of disgust or banging hands during an emotional section used for effect? Also, what and how were adverbs and adjectives incorporated? These grammatical structures express the significance of emotion that the participants attribute to the experience as a whole, as well as to each particular theme or character/s. One can look at these to judge and interpret the intensity of feelings within the narratives.

The moral: What are the messages the participants wish to impart? Are they hidden, either deliberately or unconsciously, but in the speakers' agenda? Are these messages for me or are they meant for someone else with me as the intermediary and interpreter?

The genre: This arises from the feelings participants express through the words they use to elucidate the tone. For the purposes of illness narratives, this means were the stories representative of the cultural stories Crossley (1999) defined as normalising or conversion/growth, and that Frank (1997) defined as restitution, heroic or chaos?

All of these narrative structures were examined in the present research to see what the experience meant to each participant. They became the issues, or the elements that described the

meanings. After reading all transcripts and listening to the voice files many times, noting exceptions and unusual features, which inform as much about the stories as consistencies can (Lieblich et al., 1998), some elements stood out as being significant. These significant factors were the ones with possibly more space, more intense or descriptive language, and more details devoted to them, or they may be the ones that intuitively ‘spoke’ to the researcher as being important. Initial categorisation was made using marginal notes on the typed transcripts, much as Mathieson and Stam (1995) did for their narrative inquiry about the articulation of threats to identity. Once selected, they were collated into a single list, and classified into categories based on family resemblance.

A superimposed ordering then followed this classification, when a matrix was created with significant factors listed under the category headings. Alongside this list were columns to comprise the participants who spoke about these factors, those who did not speak about them, and the supporting transcript sections for those who did. By initially employing a categorisation technique and later moving out of the deconstruction matrix to look at contributions toward the whole picture – complete narratives, answers to interviewer questions, field notes and the voice files from the interviews – after the main themes were isolated, a guided approach was used to discern individual plots. Polkinghorne (1995) described the plot as the narrative structure through which people understand and describe the relationship among events and choices in their lives. Further, one of the ways the plot functions to compose these elements into a story is by clarifying or making explicit the meaning events have as contributors to the story as a unified whole. The above method enabled the meaning events to be unravelled and compared to identify the plots shared by all stories.

The outcome of the analytical process was a narrative created out of the stories of others, in which the shared themes were described and explained using the researcher’s voice interspersed with the voices of the participants. Specifically, the voice airing the ideas in this narrative is the researcher’s own, but the words used to describe these ideas are often those of the participants. The explanation of the description also belongs to the researcher. Presented in Chapter Five under Findings, this narrative revivifies the deconstructed themes that took place as part of the paradigmatic analysis, and weaves them into a narrative of Polkinghorne’s (1995) narrative analysis

type of narrative inquiry.

As it was the goal of the present research to provide an experiential account of the GBS phenomenon, the words and phrases of the participants, as I mentioned above, were assimilated into the writing of this narrative. This means the report of findings is not only not presented in a traditional scientific report format, but may have an incongruent feel to it as well. This is because the narrative combines past and present tenses depending on whose voice is being used – the researcher’s or any participant’s. The narrative also appears incongruent because in not presenting aggregated or generalised statements about the GBS experience, the findings are juxtaposed in a sometimes idiosyncratic manner. These idiosyncrasies blossom as contradictions, but a garden that is speciose is available for appreciation by a wider range of people than a homogeneous one.

To ease the flow of the narrative, I used a non-intrusive but non-traditional grammatical format, with participants’ comments reported verbatim apart from repetitions of words, utterances and the ubiquitous “y’know” and “yeah”. The quotations are separated from my text only by quotation marks and not by indentation, full-stops, commas or capitals, as is usual for American Psychological Association (1996) referencing. Any questions posed by myself during the interview were included in italics. I chose a crisp and perhaps dense style of presentation. This was because there was a lot of detail and a wide range of relevant topics in the stories, and because I did not want to author an ‘aeroplane novel’. I wanted to create an absorbing and fascinating story that the reader wishes to read several times, or at least slowly, in order to find a multiplicity of understandings and possibilities.

Reflexivity

A narrative inquiry requires the researcher to use intuition and judgements when analysing the research data. The ontological beliefs and the epistemological assumptions underpinning the discovery of this knowledge inform the research questions she asks, the methodology and method she selects to answer these questions, and the way she interprets and writes about the findings. Readers of her narrative, like any recipients of created works, need to understand the meanings in the

way she intends them to be understood. By providing a synopsis of what she brings to the research, this researcher offers a perspective of relativity within which her work is framed.

I arrived at the present research after completing a Bachelors degree in History in the 1970s, and after teaching, marriage and raising four children, I chose to re-enter the academic world with a postgraduate Diploma of Social Science, which then progressed to the present Master of Arts in Psychology. A large part of my psychology training was in biopsychology, neuropsychology and cognitive psychology, and it was not until I enrolled in graduate papers for research methods and health psychology that I discovered the value of qualitative methods for answering certain kinds of questions. My interest in the experiencing of illness arose from my own illness, which in its own insipid and unique way tipped my life upside down. As a consequence of this I re-evaluated my priorities, identities and life views.

I was also part of a generation, which grew up during the post-modern era, and thus come to this inquiry with the belief that experience is one hundred percent subjective. Despite my gestation within this philosophy, my criticism is that in seeking truth through intellectualism, the recipients of artificers' creative works cannot find meaning in them if they cannot bring coherence to the pieces. Experiencing **is** subjective, but at the same time developing an exposure needs to be done within a frame. Without providing a structure and some clues it is difficult for a recipient to be enlightened about the medium's message, or at least our interpretation of it. It's a bit like trying to pass on values to my children. If the post-modern principles were the only rule in my family then I would end up a very hen-pecked mother. To create and maintain order, my family needs structures, rules and boundaries. Stories have a similar goal in bringing order via structure, rules and boundaries to the chaotic assemblage of activity, identity and temporality characteristics inherent in our lives.

Meanings are what we perceive as we make sense of events in our lives. When we want to share these 'truths', we create stories to tell other people. One of the techniques used to facilitate this is to express what we want to say in such a way that it is 'felt' by the receiver. We use stories with emotional language and graphic word pictures to 'kick 'em in the guts', so to speak. Just as this slang expression has a meaning beyond the obvious physical wince, the narrative I present from my study

had a purpose. This was to provide an account with which readers have an opportunity to feel what it is like to have GBS, and to do this by drawing on their own life experiences as metaphors to understand what happened to the participants in this study.

My own life experiences acted as metaphors to create a perspective from which I interpreted and conveyed the meanings of the GBS stories to my audience. Because of the multifarious nature of understanding, extra information that aided the meanings the storytellers wished communicated was an advantage. It was to enhance the understanding of meanings during the reading and interpretation of my narrative of findings, that this section on reflexivity was included.

I wanted the study findings to be presented in a more naturalistic mode, with myself as the narrator. This was largely because as Baumeister and Newman (1995) write, "Narrative is the mode of thought that best captures the experiential particularity of human action and intentionality, and it involves reasons, intentions, beliefs, and goals" (p. 677). My idea was to provide readers with knowledge about GBS, and myself, in the initial chapters to assist them to make honourable inferences about information presented during the interpretation. Based on the information I have presented, it is up to the reader to perform what Baumeister and Newman (1994) say is the

... additional cognitive work of drawing the abstract and general conclusions. As the [reader] does make such generalizations, however, these become a useful resource for interpreting subsequent events, because general principles and broad assumptions provide useful frameworks for making future stories (p. 679).

Such an activity occurred for me while I was writing this section, as it happened on the day American Airlines 857 crashed into Queens (NY) on November 12th, 2001. On first hearing the news, I immediately leapt to the conclusion that terrorists had sabotaged the plane. My thoughts extended to thinking how people try to make sense of unknown things, and that is by placing them within a cultural story already known about them. This story contains information to neutralise any danger, because by knowing the unknown and future probabilities of an encounter with this unknown, we feel safe. When there is no cultural story, we try first to explore and enlarge our field of knowledge, finding actions that are serviceable and salutary, or we stay caught in a story of chaos

(Sheets-Johnstone, 2000).

A similar thinking process happened when I followed this train of thought and formulated the idea that people make sense by looking for links or relationships of causality, and to do this they seek information. The media attempted a global sense-making by providing us with information about Osama Bin Laden, the Taleban, and the Muslim faith. It was this organisation's way of seeking understanding but one that acted as a metaphor what for we do as individuals when incongruence occurs. As was the case for the people with GBS trying to find out what caused their affliction.

In a similar way, my conceptualisation of making sense by ruminating about a traumatic scene over and over, occurred while I was trying to make sense of the recent terrorist attack against the United States. The visual media attempted a public sense making action once again, by repeatedly replaying graphic footage of the planes going into the World Trade Centre Towers in New York on September 11th, 2001. This tragic scenario, the anthrax scares and the war in Afghanistan was running in the background during the final stages of my analysis, and in doing so provided another example of how these events were informing my thinking. How bizarre it was that I felt relief with the plane crash in Queens, and yet it killed 365 people! I should have felt horror and grief, instead I felt relief. Why? Because like the participants in my study, who spoke with relief and gratitude that they had GBS, I did so because I viewed the experience within a context. And like having GBS, it could have been a lot worse.

One significant excogitation I would like to include, at this point, is about what happened when I was editing a draft of the findings chapter. I initially wrote this chapter framed within the structure of my research questions. The questions were converted to headings of separate sections and then further subdivided into descriptive and interpretive sections. On re-reading the narrative, however, this formal approach looked erratic, disjointed and was not a clear reflection of either the assumptions of narrative or what I wanted to say about the GBS experience. What I had assumed were separate issues of meaning, identity, making sense and meaningfulness, each to be discussed in isolation, were in fact inexplicably bound together. I realised the stories were not just simple descriptions of what happened to the participants but were stories authored by them, for me, so that I

could understand what it was like to have GBS.

As I said, I had initially summarised these stories and re-organised them into a narrative, however in many places this narrative read as if I accepted the participants' talk as an accurate reflection of what had happened. After a reworking, the findings narrative became **my** story and included, not only descriptions from the original stories, but my interpretations of how these were presented and what work they were doing to help the participants make sense. It was as if I was acting the role of myself in a play I was writing, for in the storying of my story I was making sense of the meaning of GBS for others to make sense of.

It was important to make the changes, and now to mention them in this section on reflexivity, because they show the circle of understanding that occurred not only between myself and the data, but also between myself and my maturing knowledge of how stories and narratives work.

Along with the value of having my reflexivity to aid the understanding of the research, the historical, geographical, social and cultural contexts within which the participants set their stories were also important. Medicalisation in New Zealand from the nineteen-seventies until the present has been metamorphosing from a paternalistic to a more patient-centred approach. Lay health beliefs have also undergone permutation as the responsibility for disease moves away from exogenetic to individual responsibility in the creation and maintenance of wellness and illness (Herzlich & Pierret, 1985). The participants, who were admitted to New Zealand hospitals some time during this period of change, were all middle class, New Zealand-born and either rural or small town residents.

Finally for me, as Frank (2000) says his study did for him, this study provided me with an opportunity to listen to six stories about GBS. I hope my research gives the stories greater currency, and helps others with GBS and those who do not have it to hear the wisdom of these stories. The reader of my narrative is encouraged to engage with it in an experiential and not just an analytical, manner. It is also my hope, and the criteria I wish readers to evaluate my work on, that my narrative has drawn others into the world of GBS far enough so that the people's actions in that world seem reasonable ones for that world.

Ethical Issues

My goal was to respect the ethical principles that guide psychosocial research. This held true for any procedure performed during the progression of the research, whether it was during the formulation of the research objectives and aims or anywhere in the process from contacting the participants to the final word of the written analysis. Hollway and Jefferson (2000) have guided me in acknowledging each of the following ethical principles and respecting each of the values desirable for researchers of human subjects.

Power

A power discrepancy is noted between myself and the participants because I am university educated, identified myself as doing a Master of Arts degree in psychology and thus could have a certain perceived social and cultural status. This may have added an ethical dilemma. However because the interviews were conducted in the participants' own homes, I depended on the co-operation and hospitality of my hosts, so that they had a territorial advantage. The relationship between any two of us may have been educationally unequal but my understanding and knowledge of GBS and illness allowed me to show understanding and respect. These two attributes, "which [draw] on the deep pool of human characteristics, [do] not equalise power, but [they] make it negotiable, rather than an inevitable effect of status difference" (Hollway & Jefferson, 2000, p. 85).

Informed consent

Participants' initiation into the research was via an information sheet. This sheet introduced me, my affiliation, outlined the nature and purpose of the study, the role for them as participants, the future uses of information, their rights as participants, and the acknowledgement of confidentiality and anonymity. A consent form was included in the mail out to be signed and returned. When the interview began, I left it to them to decide what to say, saying I did not have any set questions but may ask some later if any arose out of the interview. I chose this generalised request rather than restating my research questions because I did not want to impose my expectations onto the

participants' stories. I did not refer to the interview data as a story at this stage. However I did say on the information sheet that I was doing a narrative analysis and I would gladly have answered any questions on this method if asked.

Anonymity and Confidentiality

The dilemma in maintaining confidentiality, while preserving the idiosyncratic attributes of some participants, plus the difficulty of disguising identifiable characteristics about family, friends and members of the same small community was problematic for me. Career, community status, speaking style and sometimes gender were important 'fingerprints' to cover. Every endeavour was made to fulfil the criterion of anonymity. Most participants offered to have their real names included. However as I did not have permission from other characters in their stories, I preferred to keep anonymity as much as possible. One participant, Tania, has names included with her and her husband's written permission, because I chose to honour her generosity in allowing her photos to be included. In wanting to use their real names the participants asserted their power in claiming their identities for publication.

Confidentiality was maintained by my going alone to the interviews. The transcriber signed a confidentiality agreement and no-one else knew the identities of the participants.

Deception

The participants were not deceived about the nature and purpose of the research. Any deception that may have arisen was inadvertent on my part in that I may have failed to attend to the participant's story or did not have enough information with which to make wise interpretive judgements.

Avoidance of potential harm to participants

Some people can become distressed when speaking about traumatic experiences, as they remember pain, fear, humiliation or other difficulties. Distress does not imply harm however, and must be evaluated independently. Some participants did show emotion, and I certainly had some

tears in my eyes during the recounting of some episodes, but I could see no obvious signs that any were harmed by their telling. One participant still had a lot of anger, but said she was going into therapy for it. The interviews provided more of an opportunity for sense making, catharsis and/or healing in the busy lives of the participants, than observable harm. Most participants were happy, even affectionate, when I left and all were happy for me to visit them again.

My concern was that in interpreting I may have harmed the integrity of the story or the personality of the storyteller, by proxy. For this reason I have included, at this stage, some information from my field notes to provide an audit of any bias that may have occurred as part of the analytical process. All participants were interviewed in their own homes; all offered and shared a hot drink with me before we started. Every interview closed with my request to call them again if I needed some clarification and all participants said they would oblige me. I did not need to call them about what they said, in the end, because I accepted what they said in their stories as what they wanted to tell me, when and how they did, at the time.

The first interview was characterised by technical difficulties with the digital recorder, causing interruptions and delays. Also, my preamble about myself popped up later when she compared herself unfavourably. Both actions of my naiveté may have unsettled the participant or underscored a power relationship. She was a very friendly person and went out of her way to make me feel comfortable and for this I was grateful she had been my first interviewee. She said she was guided by strong personal role models for her recovery as well as Christian teachings. She had an infectious laugh and possibly used humour to manage her self-image in the way Michael Murray (2000) defines as positional. She said she is a hard worker and a great deal of her story was devoted to her social responsibility, with the overt and covert distinction between selfishness and selflessness being revealed in many of her anecdotes. She still has some arm weakness.

The second participant's story was hesitant and transilient. During his interview, he was either choosing to be deliberate in his choice of words, making sense as he went, speaking in his natural way, or all of these. This man presented as strongly valuing his role as a traditional rural New Zealand male – strong, self-reliant, disciplined, proud, stubborn, responsible to family and society, a

sense of humour and mischief but sincere when speaking about serious topics, a bloke's bloke who judges people on their integrity. But also a spiritual person who feels deeply and who disclosed "... there's greater forces than human beings on this world."^{B305} He was very appreciative of having this time to bring thoughts about his experience to the surface as he had never been given an opportunity to speak in this manner, despite having GBS over twenty years ago. He said "nobody had ever done that before" and his talk with me "blew away a lot of sand". He was quite emotional at times. He values family and friends and has long, loyal relationships. He still has major residuals in one eye and both feet.

The third interview was short and sharp, with the participant speaking decisively. He knew what he wanted to say and did so with no pausing, no distracting mannerisms, body language, utterances or meanderings. He presented as determined, focused, strong willed, successful professionally and athletically, as loving his family and as very appreciative of their help, admiring of his specialist, and blessed with good friends. As his wife said, he is a man not given to verbosity, is very sensible and has an incredible ability to bounce back. She said the experience, for them, was life changing and humbling in that she thought he would not recover to lead the kind of full life he now has. Their changed view of life – that other things are more important than the material – she said is still pre-eminent. She also said that he made sense of the experience because he had a "bloody good wife!" He independently agreed, so the experience of GBS was a shared one for them. He is willing to search and share any knowledge he can about GBS. He has residual fatigue, leg weakness and foot drag.

The fourth interview was extremely long and could have gone for much longer except that we both had other commitments. This participant spoke in a fluent and prolific manner about the abuse she had from medical staff and the system, categorising her experience as traumatic. In fact I restarted the digital recorder several times after I thought the interview was over, which indicates she still had a lot more to say about her attitude to her hospital care. This abuse included the staff insisting she come off the ventilator when she said she could not breathe. It was later found her lung had collapsed and what remained was squashed by her unborn baby so her inability to get enough

oxygen was critically dangerous to both her and her baby. She was unsettled at the time of the interview by some current emotional entanglements that were bringing up painful feelings from her past. She presented as articulate, hard working, strong willed, and as a fighter for her rights. She was knowledgeable and interested in the medical and psychological aspects of GBS, and as such had prepared notes so as to give me all she could about her experience. A lot of her story was spent providing background information to her personal history, beliefs, onset and acute symptoms, and to her treatment by medical staff. I found her tale fascinating and somehow exciting. I felt emotional several times as she spoke of the trauma she felt and the horrendous things that happened to her. She has no physical residuals that she mentioned, but does have psychological residuals.

The fifth participant was very honest in her portrayal of herself and her foibles during her interview. She felt free to include into her story her own misbehaviour as a patient, the psychological concomitants during her recovery phase and her initial ambivalence towards her newborn baby, despite the New Zealand culture's negative attitude toward anyone telling about these attitudes. She was also honest in her appraisal of how the experience shaped her maturation and her marital relationship. Two other people spoke of her as being a super girl who despite her disability would never mention it, and she didn't. She said the whole drama for her, her husband, father and step mother "hasn't affected her one iota"^{C596}. She specifically asked for her name to be included in the presentation of the research. She has obvious physical disabilities in her hands and gait which prevent her walking on uneven ground, but believes the nerves will heal.

During the sixth interview, and afterwards, the participant banged the table to show his anger at some aspects of his hospital care, particularly his perception that he was treated as a body and not a person. He wants research to be done on this idea of the patient as a non person - one who is totally incapacitated, cannot speak and therefore is reliant on staff for everything. The psychological aspects of being paralysed **and** unable to communicate can be compared to those written about for Morrie Schwartz (Albom, 1997) and Robert Murphy (1987) with their amyotrophic lateral sclerosis, who were paralysed but were able to speak. The repercussions of the mind activity, while mute, occurring for the participant in the sixth interview are still present in his consciousness, and he spoke a lot

about the power of the mind, and at one time the Zen of mind-body healing. His message is as much to the medical professionals as to me, and I noticed he was very pointed in his story to me, the psychologist. He was explicit and adamant having this message actioned. He had had GBS twice so had a bench mark from his first experience with which to judge the mishandling and treatment he said he had in the second. He is intelligent and extremely reflective. He complained that the lack of contact with the outside world was a major limitation because he needed the familiar to give perspective and feel less dehumanised in hospital. He tended to deflect away from talking about himself, but reveals his identities through his work medium and his opinions of other people. Despite his complexity, intensity and earnestness to get his message across, he laughed a lot in the interview and mentioned that his wife considers him a very amusing man. He has residual wastage in his left hand and a heavy gait.

Principles for researchers of psychosocial research

Honesty: I approached the research with openness and inquisitiveness. I strove to keep equanimity and to be judicious not biased. I attempted to support my interpretations and judgements with evidence from the stories and in some cases from established research. The limitations of working alone as I did were that I did not have anyone challenging me on these judgements, and lack of time prevented me referring the final analysis back to the participants to check the meanings of their stories. However, I have stated clearly these limitations and the result must be critiqued with this in mind.

Empathy: My knowledge of GBS from an academic perspective plus my own experience of chronic illness meant I approached the stories with empathy. In some instances – as I have previously confessed - I identified with the pain, humiliation or anger they were expressing. This is the reward in listening to a story rather than just obtaining answers to a set of pre-determined research questions. The interview data resonated with me and I had an opportunity to show empathy. This, combined with an active listening technique of not filling in any silences, opened the way for revelations such that some participants said they had never spoken like this about these things to anyone before.

Respect: I approached the participants with dignity and respect. I was genuinely honoured they agreed to participate and thanked them all, verbally and with a mailed handwritten card, for helping me with my research after the interview was finished. I wanted to show respect by listening attentively and observing carefully, and I hopefully showed this when asking questions that arose from what they had said during the initial free-flowing part of the interview. I hope my comments during the analysis and discussion were not disrespectful and if so they arose from my naiveté. I am truly grateful to the six people who opened up and shared their experience with me in such a personally revealing way.

5. FINDINGS

Introduction

Guillain-Barré Syndrome is an inexplicable syndrome, in which horrendous things can happen to you, but you do recover with time and as a result of the experience you are likely to say that in making sense of it you changed your views about life.

This one sentence incorporates the most significant themes about the GBS experience storied by the research participants, and distilled by the researcher during an analysis of narratives. The themes are consistent with the focus of the research in that they reflect the fundamental issues of identity, meaning, making sense and meaningfulness, which the researcher chose to explore at the outset of this study.

This chapter presents the description and interpretation of these major themes woven into a narrative of the researcher's own making. By assuming the participants' words were crafted as stories, the researcher used the tangible choices these authors made to structure their stories, to write a narrative for others to read. This narrative begins by presenting what the stories did for the participants as storytellers. These people gave me information in a certain way and in doing so revealed their overt or recondite agendas for me to interpret. As the introductory section for this narrative, the extrapolation of identity discloses what I as the researcher got from my interaction with the storytellers and their stories, and thus works to shape and mould the whole narrative about this research's findings.

Incorporated into the descriptions and interpretations is a discussion of the ways various participants made sense of their predicament. The analysis of this comprehension building process covered what they said had happened at the time and what they said they had been thinking about, in hindsight, with respect to their GBS experience. The strategies or structures used by the authors to make sense are commandeered by the researcher in elucidating the archetypal roles storytellers chose for themselves to play as their main character, and in distilling the overall genre common to all stories when the meaningfulness of the experience was revealed. This was the genre of heroism.

The Meaning of GBS

Identities revealed through the GBS stories

The overt function of the participants' stories was to speak about their illnesses. The recondite - covert or obscure - function was to tell me, the listener, that they were people damaged by something they were not responsible for and from which they incurred horrendous things as a consequence, and for which they were also not responsible. However they also wanted me to know that despite debasement by this syndrome they were eventually victorious in their recovery. It was by drawing on function that the identities of the participants were revealed.

Why did they speak about these things to me? I have argued that stories are spoken with a purpose, and the stories in this study about GBS had as their main function the conveyance of GBS being imposed upon them. They were not responsible for the illness because the cause of GBS is unknown, and even if one is eventually found by scientists, some participants had already assumed an exogenetic virus or chemical poisoning as the causal agent. Other participants had no idea what caused their affliction.

A further function was to let me know how devastating degrading, humiliating, boring, frustrating, depressing or traumatic the experience was. Yet despite all of the above, and the losses incurred, these participants spoke as if they were proactive actors in their recovery. Two chose to let go, and allow their bodies to heal themselves. One acted by co-operating and doing everything the staff asked, while another set goals, developed a strategy and set about through sheer will to accomplish them. As Emmons et al. (1998) wrote, some people find meaning through action. Goals for this latter participant had always been an important source of personal meaning because as a top New Zealand sports person, goals had provided structure, unity, and purpose to his life. A further participant was determined to get what was desired by whatever means possible, including drawing family members into the subterfuge, while another used a strong sense of pride and a very determined nature to exert control over a weakened body once it finally began to co-operate.

The participants wanted me to know that their minds were healthy and active despite their

inability to communicate. Not only that, but in lying paralysed and on a ventilator for months with nothing to do, they had an opportunity for their minds to explore in new directions. An example of this was one man's relative engagement with the possibilities for his creative work, and the later manifestation of this into a tangible form advantageous to his financial position.

They also used the opportunity to let me know that they were good persons who were fair in their judgements of other people, were less judgemental and less abrasive than they used to be, or alternatively more discerning in not suffering fools gladly. They wanted me to see they were not at all dour in themselves, despite the experience being horrid and their tales being full of very serious matters. They made me laugh when they popped out with things like, "back in seventy eight the regeneration was so slow. They said it might take years, you might never get full control and that's why, on this side of my face, it's never come right. And when I get tired this eye, my right eye, just drops down, and I get quite a leer on. Some blokes think I'm a squint eye bugger, and I say, "Yes. [pause for effect] At least I can see through it."^{B488} Through the tales they storied most of these people told me they were better people, and that their lives or careers had changed in a positive way, because of their experience.

These messages were aimed directly at me. Others were directed through me to other people. The participants wished to inform the medical profession what they should and should not be doing in the treatment and care of people with GBS. They wanted to show to this group as well as other interested people, the importance of family, friends and the continuity of care, for the preservation of selves during the times they said they were diminished by paralysis or expanded by the hallucinatory experiences of drugs. The interview was the first opportunity some participants had had to speak about their experience, and they used it to reveal their sense of guilt over being a burden to family, or the gratitude they felt for the super human support they received from close family.

All the above functions were fulfilled through the stories. In pursuing them, the participants revealed, consciously or not, particular images of themselves for the researcher to interpret. The discernment of these, plus some of the structural aspects of narrative, was used to deduce and formulate a main identity for each participant. In authoring a particular characterisation, the

participants were fulfilling a purpose: to let me know the type person they wanted me to see them as in connection with their GBS experience. The types of people they portrayed themselves as determined the style and tone of their stories. Thus the audience for the stories had more information with which to interpret and understand the meanings the storytellers wished to convey. If I were to limit my interpretation of each participant's portrayal of him or herself through the experience, the descriptive nomenclatures below would portray each one.

Participant A: The Self-Sacrificing

Participant B: The Resolute

Participant C: The Strategic

Participant D: The Contendent

Participant E: The Burgeoning Rose

Participant F: The Intricate

Returning to the stories about GBS, the purposes and identities revealed by the storytellers were drawn out of the stories, and the way these stories were told during the interviews. The same elements were also used to find the storyline for each tale. Although all participants were asked to speak about their GBS experience, each did so in a way peculiar to his or her experience. The plots thus contained much personal information relevant to the individual telling the story, but they also contained many elements shared by other storytellers in the research group.

As elaborated in Chapter Three, the stories people author serve the purpose of organising and making sense of an experience, while at the same time communicating this experience in a meaningful way to others. The stories told during the interviews were configured by each participant about his or her own experience of GBS. The participants selected those aspects of the experience they considered important, needed to make sense of, and/or wanted me to know about. What they said became the meanings of GBS for them on the occasion of the interview, and the meanings for me to later analyse and write about as my understanding of having GBS.

A major part of the meaning of GBS across all stories was the cluster of characteristics arising from the nature of the syndrome and the horrendousness associated with the symptoms,

treatments imposed or lack of care by medical professionals. The medical factors, as presented in Chapter Two, were not spoken about in isolation however, for the participants also authored their feelings and judgements about these factors into their stories. It is these feelings and judgements that provide the foci for the following descriptions of meaning. These are crafted in the narrative as two parts, the nature of GBS and the horrendousness of the GBS experience.

An interpretation of how the participants came to understand, or make sense of these meanings is included at the end of each part.

The nature of GBS

Guillain-Barré Syndrome was described as an inexplicable syndrome largely because of its severity and its rapid onset, the difficulty medical staff had in diagnosing a set of symptoms that had no connection with anything that had previously happened to the participants, and because the condition is not generally known about in the general illness knowledge of most people - including medical professionals. Medial information about the nature of GBS is the result of epidemiological, experimental and clinical case research, and is available in written and electronic format for academic perusal. To inform about having this condition, however, was to speak about the experience as “frightening and horrible”^{D233}, and “really, really worrying”^{E30}. Because the “body deterioration is very rapid”^{B30}, overnight in one participant’s case - the confusion and fear it elicited meant people wanted answers from those who are supposed to know. While stumbling about, maybe with pins and needles, no limb proprioception, or inexplicable and incapacitating pain, the family became indispensable for assisting basic movements, and so shared the confusion and worry of the newly afflicted. This was even more so when the person suffering the progressive weakness was pregnant, could not speak and looked like she had had a stroke.

Crashing to the floor prompted a call to the doctor, if preliminary symptoms hadn’t precipitated this already. The confusion and worry continued, and for some of those involved feelings would escalate into trauma. For the participants fortunate enough to be diagnosed straight away, the fear was lessened or dissolved at this stage because the cultural assumption that being in

hospital and cared for by the experts outweighed the seriousness of the symptoms. To some extent, the patient was also encouraged by the advice that recovery is ninety-five percent certain.

Unfortunately this did not happen for all participants. Two exhausting aeroplane trips to diagnostic services outside his geographical area meant one man “got very upset in the end ... [he] was so frustrated that [he] didn’t know what [he] had. They couldn’t tell [him] and ... when you’re getting weaker and weaker every day and you don’t know what you’ve got. Well it’s just so frustrating.... [He] thought [he] had cancer `cause [he] was fading away to nothing and getting worse and worse, but they couldn’t find anything. They just couldn’t, they were dumbfounded”^{C461}. It took a lumbar puncture four and a half months later by a practitioner whom he regards saved his life, to produce the diagnosis of Chronic Inflammatory Demyelinating Polyneuropathy.

An inability to diagnose GBS, sadly, is not the only scenario possible. There is also the potential for misdiagnosis. Incomprehension about the nature of GBS was heightened for one participant when she said, “I didn’t understand what was happening ... no idea ... you just knew that things just weren’t working. I looked fine, everything looked fine, although the problem with my hands, I didn’t feel sick or anything ... didn’t feel hungry, there was a lot I didn’t feel that you don’t account for `cause you’re just not getting signals.”^{D161} How easy it was to misdiagnose this woman’s condition, not only because of her confusion but because her high level of fitness and strength meant she could still lift her legs. She was diagnosed with depression. She said the next two weeks for her were “horrendous”, and “traumatic”. Despite having no reflexes at the time she was diagnosed and losing more and more of her physical abilities, “just like ... somebody was switching off something in my brain, where my legs were going, my hands and arms were going and I just knew that I was losing, losing more and more function and just felt like these little switches were going off. Everyday there’d be something else that’s gone”^{D177}, the staff of the hospital were instructed to make her fend for herself. The outcome for this seven-month pregnant woman was to be left lying on the floor in the lounge all night because she could not get up, she could not call out, her lips were blue from the lack of oxygen, but she “wouldn’t have known that `cause [she] couldn’t feel.”^{D277}

The participants spoke about these situations, and others, in their experience at different times

during their experience. The nature of GBS was most commonly described during what could be labelled as the initial stage. It was here that the stories contained many expressions of fear. This fear arose from personal confusion, but also from the inexplicable nature of the symptoms, the inability of trained professionals to recognise and distinguish rapid incapacitation from physiological as opposed to psychological origin, the possibility of a disease like cancer or multiple sclerosis - illnesses that are known in lay stories to cause a severe array of debilitating symptoms - the fear that “oh well, this time I won’t make it through ... because the feeling of somehow making your body fight this disease [is] a truly exhausting process, even though you can’t speak or anything else.”^{F93}, and from the worry a mother would have that her small child be cared for while she was away in hospital.

Why the fear? Fear presented because the progressive speed of the symptoms reduced a fit and healthy human being to “virtually a cabbage”^{F347}. It was difficult to feel safe with something that happened so quickly that you “didn’t understand what that was.”^{D76} Fear, because the deterioration had become so bad that there was no way the patient thought recovery was possible. Fear, because while it may have been possible to recover a first time at a younger age, it may not be for a second attack later. Fear, because an inability of professionals to provide a diagnosis meant one of the diseases known in society for their progressively incapacitating and fatal prognosis was presumed, and also fear that family members would not be able to cope without the patient fulfilling filial responsibility.

However, because illness is experienced in an idiosyncratic way fear was not necessarily present during the initial stage. Until recently - the 1990’s - in New Zealand, and before the decline in public trust prompted by the high profile medical misadventure cases of Drs. Green (with the National Women’s Hospital cervical cancer experiments) and Botterill (with the Gisborne cervical smear misdiagnoses) or the change in the image of medicine, the average lay person had a particular belief about medical expertise that was constructed out of the ideology of western society (Wright & Treacher, 1982). This was that the doctors and the medical system were the only ones able to provide effective treatment, care and recovery during illness. Locus of control was freely and trustingly given over to the system and the people in the system. Thus, when one participant was told by the

physician her recovery was assured, there was no need for her to panic, she said she was not afraid and believed in hindsight she had recovered from her predicament because she he did not worry. As she said, she “had faith in the doctors, I didn’t think the doctor could be wrong about [her recovery].”^{A561}

What did the participants say about how they made sense of all that was going on for them and what did they say they were feeling during these initial stages? At the time, most said they made sense by thinking only of themselves. Everything they had went into dealing with the physical, psychological and environmental conditions and “at the time I was just focused, I was going to stay alive, and I didn’t care how.”^{A1363} This is much the same as the heightened attention people say occurs for them in other traumatic events, for example the train driver who scrambled for his life after his train ploughed into the flooded Rangitata River in New Zealand (New Zealand Press Association, 2002). He said it was not until after the immediate experiencing of the traumatic event receded that he reflected upon what he had lived through, and what could have happened if he had not been so alert in getting away.

At the individual level one woman participant implied her way of making sense during the early days was “to lie here and put up with it. I’m going to get better, so I never worried about it after that.”^{A131} For this woman, when the crunch came she said, “I just thought you know this just can’t be happening, I must be imagining this. This couldn’t be happening to anybody that you feel like this. I wasn’t in any pain. I didn’t have pain but just this terrible pins and needles in my legs and arms. Anyway during the night I deteriorated as far as my lungs were going. I could feel, and it was the only time when I really felt a little bit panicky, that I was starting to not be able to breathe. Before that I hadn’t panicked. I thought well, what ever it is you know I’m going to get better. At 29 you don’t die when you’ve got a young husband and a little girl and a business to run, you just don’t die, you know you can’t do. So I’ve just gotta lie here and get better”^{A86}. She rationalised her way out of the panic because she believed in God, people and the medical system. “Oh well, they say I’ll breathe, I suppose I will”^{A214}.

Contrary to this woman’s choice of giving her locus of control away, another woman spoke

as if she drew control into herself. In doing so, she gave herself the power to get angry and the impetus to make a pact with herself to fight the system. When asked how she got through it, she said, “I just, when my back’s to the wall I think I go well ...”^{D1361} as she made a fighting action with her hands.

One participant claimed to have made sense by accepting what two medics said “you’ll be in hospital and you’ll be on your back for a while but you’re young and fit, you’ll recover”^{F18}, whereas another participant indicated he made sense of his symptoms by attributing them to cancer.

During the later stages of the experience, people tried to find meaning by searching for a cause. This approach of making sense by searching for a medical cause to the illness arises because people like to find relationships or connections between things. Like storytelling, this connecting is a way of bringing order to the world. Even though GBS happened many years ago, the participants spoke of the answer to the causation puzzle as still being elusive. Latterly, however, because of changes toward individuals’ responsibility for health and illness, and because people are generally more aware now of the role psychological factors have in illness, some of the participants had explored a number of factors in their lives prior to the GBS. One participant spoke about the number of stressful incidents that preceded her GBS, another said he could not explain why he had GBS because he had never been sick in his life and he had no stress.

The alternative for some participants was to not make sense of it. One woman said she thought she was going “funny in the head ...just being stupid”^{E43}. She became depressed about her condition, and was “really, really gutted actually”^{E65}. As the “neurotic”^{E333} woman she described herself as, she did not believe the medical advice that said she would live. Another participant authored a similar chaos story about his depressive state, because as a second timer he already knew what he was in for during the months ahead.

Participant D storied at one point that she was unable to make sense of what was happening at the time because she was insensate. For her the whole experience was “horrendous, horrendous, horrendous”^{D170} and so stupefying that “I didn’t remember most of what happened to me there.”^{D170} This woman’s reaction emerged during the telling of her story in response to her attempts at

remembering and then systematically organising her thoughts around a set of topics she had selected to discuss before the interview. This process elicited a cataract of remembered events, which flowed so prolifically that she was unable to recall all the details. It was also her response to the state she said she was reduced to during her living the experience - the attenuation of the emotional trauma by the callousness of by her diagnostic and treatment professionals. For her, speaking about the emotions she had at that time was important and it was this aspect she wanted to share with me. By way of an analogy, it is much the same as trying to speak about something someone told you when you were scared or angry. No matter how logical or reasonable the statements they verbalise, all you hear is a cacophony of sounds. When you think about this exchange later, what you think about is the escalation of your emotional state, not any of the other person's logic. For some, like the participant I mentioned above, the significance or meaning was the emotional tag, not the precise details, of the statements or events. These latter details became subsumed within an emotion rather than having primary importance in and of themselves. There was an appearance of not making sense to her, because the statements and events were considered more significant and the emotions less so for the purposes of the research interview.

The horrendousness of the GBS experience

Once in hospital and with a diagnosis made, the participants said their condition deteriorated before they began a spontaneous travail towards recovery. What was glimpsed at before, now set in as the reality. You weren't going to be given "some drugs ... be right by tomorrow, up in a normal ward and [be going] home."^{E59} "It is a nightmare of a disease as far as I'm concerned because you're completely dependent on other people and you're reduced to a baby status. It's very humiliating apart from anything else to have all your functions, as it were, sort of all taped up and joined to catheters and things through your nose and being suctioned and turned as it were."^{F51} Add to this combination the incompetence or negativity of staff, and you had a very unpleasant but inescapable situation.

The most pervasive experiences across all stories, aside from the story about CIDP, were

those associated with breathing, the ventilator and the tracheotomy. It was here they said their fear escalated into panic. When breathing was inhibited, fear for the patient was so all-consuming that common sense appeared to be suspended. This situation was relayed when the participants' stories focused particularly on the ventilator. For example, "the ventilator was really hard. I was really scared of dying when I went to sleep. It sounds really stupid but I didn't sleep much at night, I couldn't sleep because I was scared that something might happen while I was asleep. I didn't really understand that the ventilator would just kick in no matter what and keep going."^{E130} And later, for example, when, "I was frightened when they took the tubes out. I said, 'but what if I don't breathe when I'm asleep?'"^{A214}

Although an accepted necessity and one you "become so reliant on"^{E564}, one unpleasant side effect of being attached to a ventilator was said to be the pain - "like a red hot poker in your brain"^{D460} - during intubation or extubation, and the "sucking you out, that really hurt, that was really uncomfortable all the time."^{D461} It was unfortunate that such a life saving device could be so unpleasant.

It was when speaking about breathing and ventilation procedures that staff incompetence in not fixing a broken machine, in not bagging (manually oxygenating) fast enough when there was a power failure, in deliberately inhibiting the inflow of oxygen facilitating one resilient woman's descent into a "distressed state"^{F103}, in allowing a build up of carbon dioxide to cause excruciating headaches in another, and in allowing training nurses to attach the wrong nozzle to the wrong place when "your condition is fairly fragile there"^{F173}, was most grievously commented on. Three people complained their recovery was prolonged because mechanical breathing assistance had been inadequate or insufficient.

It was also during the telling of ventilating experiences that staff members were condemned for their dehumanising attitude towards the participants as patients. "They treated me like I was a dead body 'cause that's all they usually deal with in intensive care, a body, they attend to the body. They don't attend to the person."^{D642} At this point you are "sort of being a cabbage"^{B218} and the most degrading thing for you to be called is a "hulk"^{B141}, especially by a group of nurses who thought you

were “swing[ing] the lead”^{B150}. Didn’t they realise that you had been doing everything you could to beat it, but you were paralysed “one hundred percent from the waist down and ninety five percent from the waist up”^{B102}.

One difficulty in being totally paralysed like this was that you couldn’t speak up for yourself and, “the one terrible thing, I was so annoyed because I heard doctors discussing my case and whether I was making an effort or not. I got furious and tapped out to them because I used to, no, not tap out, but I used to flick my eyes as they held a chart of letters to my face, ‘A ... patient is a patient and a doctor is a doctor.’ And sometimes one of the things that’s very difficult about the disease is although you feel furious, you can never express yourself in the sense that you’ve got no means of expressing it, and to do so is such a laborious process. To get a message through to anybody, took a very long time.”^{F107} You couldn’t speak, couldn’t move your fingers to write, so you had to blink off one letter at a time on an alphabet board, if you had one.

How much worse would this be if “you would have that pain and it wouldn’t go anywhere, it would be in your head and you couldn’t yell or do anything to express it?”^{D1454} “In fact I always remember the monitors on my wrist, it felt like I had broken wrists, the pain of lying on those lumpy thermometers on my chest, and they hurt for years afterwards. My ribs still hurt, even just thinking about it, my ribs hurt ...it was the most horrific pain and because you couldn’t shout out.”^{D568} And then “they got the bed up to a certain height and the pain was just so bad, I must have blacked out or something and so they got a hell of a fright I think.”^{D961} For this woman “the pain would be the worst thing of the whole experience”^{D1480}.

Aside from the pain incurred during treatment, handling and care, GBS symptoms caused pain “like that worst stage of pins and needles why you don’t feel the pins and needles, you just felt the pain. And you imagine if you had that all the time.”^{D1465} The meaning in this is that “the pain I had then, I never experienced it again and I don’t want to”^{B171}.

To alleviate the pain, some of the patients were given drugs. This meant that one of their GBS experiences was a psychedelic one. “The drugs tended to distort, there were amazing surrealist dreams and sometimes absolute nightmares that happened”^{F135}. “They were very vivid and I couldn’t

speak them. My sister could see, like there'd be tears in my eyes and she knew I was getting quite disturbed"^{D1432}.

Also "they give you amnesic drugs so that you don't remember it and it's just like a nightmare."^{D1427} This feeling of "horrendous, horrendous, horrendous, I didn't remember most of what happened to me there"^{D170} infers the experience had a strong negative emotional attachment despite her saying the specific details of it were lost to her.

It was also likely that these hallucinations and blank patches were part of the being "burnt, burnt up"^{B33} from fever effect. The terrible, fearful and so very real experience of being "inside a stone and the stone was crushing in on me all the time and yet I had to fight to get out of it."^{B64} "It was at that stage now as I can recall it for some reason or other, I felt that the difference between life and death was just a vibration, the experience I had."^{B60}

Near death experiences, "those sort of experiences and people say it's very peaceful when you die"^{F539}, and the weighing up between life and death is what it meant to have GBS. Although only five percent of people with GBS die, the bodily deterioration can be so severe that some participants said it felt like they were dying. If not, then one person wished she was because "the pain was so bad I wanted to die, I just wanted to die"^{D1038}. This fragile situation also brought with it a fear of dying. This was so for one man who had another patient with GBS in the hospital with him. When he asked staff members how this other patient was, he was told the man hadn't made it. The reality is that some people with GBS do die. The solution to allay this participant's fear was the same one he used to get back on his own feet in time for his daughter's wedding.

Life was the "luckiest"^{C323}, the "ultimate choice"^{F187} when a "weighing up my own life and death"^{F186} occurred during the vibrant dreams and "somebody was arguing for my recovery and it seemed that somebody was arguing to let me die"^{F187}. This meant either the "voice of reason came through with that I should live"^{F562}, the fight was won, or "I was at the gates or something and they were full up. One day I was that close. They sent me back down again, they were full up"^{C24}, and these participants did pull through.

Interspersed through these occasions of trauma, other significant factors in the GBS

experience were problems with sleep and fatigue arising from any physical exertion. “To give you an idea of my personal condition ... a frame, I more or less pulled myself up with my hands rather than my legs. But I was only up about five seconds and I fell back, on the bed and I slept for twenty-three hours”^{B109} and “squeezing someone’s hands, exhausting just exhausting to do that when you haven’t done it for a long time.”^{D1331} Even without exertion, systemic fatigue meant “you’re so tired, you just couldn’t be bothered to do anything, couldn’t eat, or even though I could probably hold a book I couldn’t be bothered to read it.”^{C621} Or paradoxically, “I had tremendous pain, to the extent where [for] five days I didn’t sleep.”^{B71}

Sometimes GBS meant boredom because “if the staff didn’t come and talk to you for a while, you sort of thought, oh no, this is real boring. You couldn’t sing out and you couldn’t do anything ... it’s just a sort of a long experience of lying there with nothing to do I suppose, and just hoping that you were getting better.”^{A183} Some participants even laughed at themselves when they mentioned how the condition and patterning of the ceiling became very significant during the ennui of lying immobile on their backs for months at a stretch.

A further problem with this prone and captive position appeared when some of the participants spoke about the activity of their mind at this time. One said, “I just think that the mind is the one thing that’s left working. I mean, your normal activities every day, you think about the things that you’re doing, but you can’t do anything so your mind wanders and it can equally go into the dark side of nature or the light side, and it tends to. I do think that you’re obviously more pre-occupied with yourself because of your situation. Yeah, I’m sure there’s an exaggeration away from your usual. I mean maybe you’re pre-occupied with yourself anyway, but I mean I actually think you have more chances of diverting that pre-occupation as you live. You have very little chance there.”^{F420} So how did they fill their time? “Just lay there, looking at the bottle drip going into my arm. Sick of needles, these big needles into you, all the stuff they were pumping into me, that’s why I got fed up I’ll tell you ... because it wasn’t making any difference to me. I wasn’t feeling any better one iota, for week after week and that’s what frustrated me. I said, ‘Why am I getting all this stuff and not even getting any better?’ which I wasn’t”^{C625}.

Not surprisingly the above aspects of the experience were associated with frustration, fear, helplessness and depression. For “one of the facts of a long term illness is the depression side of it, you know the trying to fight all the time and not seeming to get anywhere which is very debilitating.”^{F271} Likewise to be so dependent on others for some very basic functions like personal hygiene. “When I say give up, I was just so down and I was so weak and the thing that frustrated me most of all I think was that I couldn’t look after myself from any way. Like you can’t wipe your bottom when you go to the toilet and that’s what really frustrated me. Like getting someone to do the dirty work, and which my wife didn’t mind, she didn’t mind but I thought hell, I’d hate to be doing that to you. And that’s what really hurt me, I think, like making people, because I couldn’t do anything and when you can’t even do that sort of thing. Very frustrated really.”^{C311}

Why, apart from the obvious physical symptoms, did these experiences mean it was remembered and recounted as a “whole bloody nightmare”^{D217}? Largely, because the participants no longer had control of the bodily functions they had always taken for granted. They also lost the control they had of what was done to their bodies. Once control was delegated to the medical profession they tended to lose it to this culture. The disregard, depersonalisation, humiliation and abuse by medical professionals, that some of the participants spoke about, was perfectly captured by the following metaphor. “They took me out and they got me down and I saw the River [Name], and the ducks were there and the sun was shining, and then there was, oh no, there’s all these ducks going for one duck and it was all the back of it’s neck was raw. It was the one that got pecked on the most and I felt exactly like that duck. Yeah, it was awful, you know there you are and that, you know nature and it seems, you know ducks seem such friendly things, but there you are.”^{F470}

The feelings about staff and the system were largely intensified by the captivity the participants felt, of being reduced to “a bloody vegetable”^{C321}, “cabbage”^{B467} or “baby status”^{F170}, and by their irritability from the extreme and sustained discomfort of their predicament. Feelings also arose from being frightened about not only what **was** happening but also what **could** happen. For example: being unable to breathe after extubation, going outside, going home, being sexually undesirable, or being unable to look after family.

To say the losses incurred by this condition and the treatments received were all bad, would be dishonest to the stories. The quirk is that some participants said they enjoyed their experience in hospital and had some fun while they were there. Their stories are full of humorous anecdotes about physical states, the hospital routines and the goings on in staff relationships that they were able to observe silently and voyeuristically. Humour was a powerful device used by the participants to make sense in retrospect of the horrific aspects of the experience and for some, to make sense *in situ*. They either related things to me in a humorous way, or they spoke of how they saw the funny side of situations at the time, some even said they became involved in humorous pranks.



Figure 1. Tania with her four-day-old baby girl, Taylor, delivered while she had GBS. Photo reprinted with Tania's generous permission.

Some stories told of making sense by transcending a scene similar to that in Figure 1, in that “this might sound stretched, but this is what I actually had to do. My mind, I wouldn’t accept the hulk that was lying there, you know, absent, inert and so on. And with the pain, I would lift myself above my body, put myself in a position where I could then sleep. *You left your body, so you could sleep?* Yes. Left the pain? And you could sleep then? Yes. It took a tremendous amount. Were you consciously putting yourself in that phase so you could sleep? Yeah. Yet it took a lot of strength, mental willpower Yeah, but I would, just be above. As I say, the thing was, I wouldn’t accept that that was me.”^{B74} This segment of a story told how one man detested his dehumanised condition so much that he chose to leave his physical body. By storying this he was saying that the essence of who he is – his selves - were not embodied. Recent evidence of this idea comes from research (Gallagher, Allen & MacLachlan, 2001) suggesting psychosocial factors have a significant role in phantom embodiments, and from interpretations of experimental procedures (MacLachlan, 2001) which reliably induce anomalous ‘phantom’ sensations in terms of a more socially constructed ‘body plasticity’.

Other participants also spoke of making sense by absenting their selves completely from the terrestrial aspect of the experience at different times. One man said, “You know, I probably have a fairly active imagination anyway, and I would just go off thinking in my own areas really. My mind would move out of there sometimes, you know it would be elsewhere. Yeah, you disassociate from the experience. Your mind, you think of something else and to a degree you’re moving out from all these things that are happening or not happening or whatever it was. Yes, I think you’re not given a lot of choices, are you. I mean you can’t move, you’re dependent on other people, your mind has to be active and in other areas, thinking of different things, and so you do”^{F390}.

Some spoke of transforming their affliction into one that made them think, “I’m pretty lucky in a way to have what I’ve got instead of having what he’s got. And it puts a different aspect on life. I thought, oh well, I’m really lucky in a way because I could have had motor neuron disease and you know you’re going to die.”^{C139}

Transformation also occurred when someone decided to attribute a new meaning to an

experience, usually by taking, as one participant claimed, “an unfashionably sunny point of view”^{F889}. That, “yeah I think that any near death experience, you know that especially after the Guillain-Barré, the getting better and the enjoyment of life, suddenly, after being denied it, makes you focus. You realise that life is a much shorter thing than you thought before. That you are destructible and like any near death thing you do change in your attitude, you do mellow, I think in many ways from the way that you used to think. And I think that happened to me. I think that one of the results of the illness, is that I used to sort of be hyper-critical about prettiness, which doesn’t seem a very important thing to a lot of people, but you know I’m far more accepting of less aggressive areas, and possibly more inclined to be tender hearted about things if you got to put a word to it.”^{F843}

In hindsight, some participants considered it was also possible to transmogrify their feelings into another form. One had done so by changing his representation in artistic pieces. Before GBS this participant’s creative objects had presented the intellectualisation of his feelings, but now they were more of a spiritual reflection. “I think it was hurried on by the Guillain-Barré, changing my viewpoint, allowing sun to come into things. Because I guess there’s too much that can be difficult and harsh and depressing in the world, there seems little point of just adding yourself into the same sort of equation. I mean, I quite like bleak things as well and being alone, I walk alone, but I do find that I tend take an unfashionably sunny point of view sometimes.”^{F844}

Another spoke of her fear by translating it into worrying about her future descendents. “I do worry that maybe when they find out what it is, that maybe if it’s a thing that’s in the genes or something like that, that it could pass on through the family”^{A1091}.

While another participant channelled her feelings into family. “I don’t know if I would’ve been like this now if I hadn’t got sick, I don’t know, but I just really, really love Jim and Taylor and, yeah I think that’s got a lot to do with the fact that I thought I would never have them”^{E707}.

Another way of making sense was by having information. When told that the excruciating pain they were having occurred because the nerves were regenerating, some participants said they were able to rationalise that the pain was okay because recovery was on its way. “And the pain

would be the worst thing of the whole experience. But as I learnt that that meant things were coming back at one stage and once I knew that I could tolerate that.”^{F1480} Recent Internet searches for information on GBS helped some participants to make sense in retrospect. These people were also more likely to join a GBS support group so that they could share their understandings.

Information about GBS provided a reassuring comparison with other GBS sub-types or neurological disease. “I think, well if you look through even all the different Guillain-Barré, you go, well heck, well I did choose the best one. I mean it might mean that I’ve had to learn to pace myself now. It might mean that my feet get a bit colder and my hands or something, and I need to take extra care or whatever but you can’t compare that to a person who’s got permanent brain damage or all those people that were dying of strokes around me all the time.”^{D1404}

As mentioned at the beginning of this narrative, making sense was said to occur by thinking only of oneself, of being totally focused during the acute stage. It was only later when they were further along in recovery that they thought of the burden on others. “It was about ten weeks that I was down there and you just start realising, once you start getting better you realise how hard it is for everyone else. At the time you don’t think about it, you’re just, you’re trying to get better but when you start getting a bit better yourself, you think, oh how awkward it’s been for them”^{E255}. “But no, the trauma for my family was just amazing. I just hadn’t realised for them what it was like. My sister wrote in her diary, well do you think she will want to be switched off? You know they were the sort of questions that they’d been dealing with, and that I as a patient was dealing with keeping myself alive day after day, just that immediate survival, yeah.”^{D20}

Others, however, chose not to consider the needs and feelings of others. One man said, “I took it out on lots of people then. Yeah, I started being angry with people”^{E555}, sometimes the people most close to them. Another participant presented as more than just angry, but actively blamed others, in particular those professionals caring for them. Her anger against the staff may have been transference of anger at her condition. This could have happened, because the world she was in was narrowed to an ICU or hospital ward, and these professionals were the people who largely inhabited and controlled this world. “There were mistakes I think in the nursing. Rather than say at this point

that everything was bad or whatever, I think you need to bear in mind that patients are complex creatures and so are nurses, there's human factors in it, and personalities actually in it"^{F103}. In his judgement he was inferring a lot of what happened might not have been the fault of medics. Certainly ICU nurses were trained to deal with short-term critical care patients and not those paralysed but aware, and certainly medicalisation was different before the 1990s - possibly as evidenced by the stories of the two participants whose experience happened after this date - and these could account for some of the perceived abuses.

A way of making sense used in professional psychotherapy, is talking. Sometimes hospitals employ psychologists to help patients, when they can speak that is. This service was provided for some of the participants, with what can only be described as mixed results. Generally the most likely person to hear the patient's tale was not a trained professional but anyone who just happened to be there at the time. This happened to be a young female house surgeon soon after one patient's trachee came out. "You know you've got no room to reflect, so obviously you're just going through whatever's happening to you. And later on when you recover you can think back and think about them. My first immediate response was enormous anger, directly after it, and because everything, all the little insults or whatever it is that happened during the time, was still very alive and made me furious. Because you haven't had the means to express it, and then suddenly you know you're talking and expressing it"^{F681}. The sense of relief he had from this cathartic session was part of this man's story.

There was no cathartic release through talking, however, for the participant who declared several times during the interview what a talker she was. She found visiting times with her husband, dissatisfying "because he's so quiet. 'Cause I was paralysed except for one eye moving, I couldn't talk to him. He doesn't talk anyway, so he just sat there. And I used to think to myself, please [husband] talk to me and say something. 'Cause he didn't know what to say because I wasn't talking, so he just sat there. He would go again and I'd think well that was useless, he didn't say much to me. I don't know what's happening outside this hospital because he's not telling me."^{A146} The absence of her enjoyable pastime, talking, was probably why she considered the experience such a boring one.

Alternatively, given it was her husband, her frustration at not being allowed to converse with him may have had a deeper meaning. Similarly by including this aspect of the experience, she may have been alluding to feelings of fear or her need to have normalcy reinstated into her life.

This participant said she loves to talk and loves to be socially connected. Her professed acceptance of her paralysis was probably sustained by her faith and fellowships. Recent literature (Emmons et al., 1998) asserted religiosity has an effective role in determining the recovery of meaning from pain and suffering because it connects the individual horizontally with others and vertically to a higher power, and as she said, “I have a faith in God ... I’m a Methodist, and that helped. I had people from the church that came to visit me. And, I think that faith helped”^{A403}.

More than a blind acceptance through faith, spirituality may provide an integrating, interpreting and stabilising force that creates a unifying philosophy of life with which to resolve the challenges thrown at you (Emmons, et al., 1998). So when one participant said, “Well how should I put it? Well when I was really ill I felt somehow a presence. Hard to explain really, but I know it’s [the] only way to put it. Different things that have happened under stress and so on, I always feel that there’s something there. It might sound strange. It’s still there”^{B541}, he was referring to the way he framed his experience within the context of his beliefs about a spiritual force and the revelations it gave for him.

If you did not want to do any of these, they could have chosen not to make sense by blocking the experiences and the drugs helped with this; “yeah there was lots of drugs and they really played tricks on your mind, but then again they were really good because they blanked out lots of parts.”^{E143}

Unfortunately, there were some participants who have yet to make sense. For “I don’t think I have made meaning of it in my life”^{D1555}. “I do still feel angry about it and that’s when I said I was going to take it to therapy, but I still haven’t done that in all this time I’ve had to do it. Yeah, I just don’t know how to resolve it I think. So I think in some way I’ve come to some sort of degree of peace over it, but I’m not really that happy about it”^{D1357} Although this woman said she used her anger at the time of her experience to make sense by battling for her life and dignity, it was apparent in her presentation during the interview that she was still holding onto some anger. She still

identified with the pictures and feelings she told me were there before she blacked out, when “my heart stopped and all sorts of things. They didn’t bother trying it again after that, but it was like they wouldn’t listen. I was treated like a body. I wasn’t treated like a person. There was a lot that was very abusive. They just wouldn’t listen to me. I begged them not to do it again.”^{D964} This woman has said she **will** make sense of this aspect of her experience, and the anger it generated, by working through it with a therapist at some later date.

Despite her condemnation of the treatment by medical staff, she and all other participants did not want to appear exclusively negative in their judgements. The behaviour and attitude of people they came into contact with became very important. The patients had abdicated control and the unwritten agreement in this situation is that both sides have a role to play and the bargain must be kept; I will relinquish control, you will be nice and do a good job and I will co-operate. This was a contingent arrangement, with the participants saying they moderated their behaviour depending on who was looking after them. For example, compare one man’s reactions to an occupational therapist “this person. She grabbed me by the side of the face and twisted it. She said, “Oh, nothing wrong, at all,” and I won’t say what I said, but I never ever went back, again. Ah, I had no faith in her at all”^{B98}, with how hard he worked for another person, the physiotherapist who said, “ ‘you know, I never ever knew whether your knee was moving at all.’ *Was it?* No, but she convinced me that it was. *And you believed her?* Well I had complete confidence in her. Yeah, so she was a marvellous woman, really.”^{B114}

The personalities in hospital were very important, and for one participant “the nurses, and everybody in intensive care were absolutely marvellous. I would never have a complaint about any of them; they were just absolutely fabulous in there. They did everything they possibly could to make me comfortable. They came and talked to me, they were wonderful”^{A156}. Such confidence in her carers came from her beliefs. For a person able to shelve understanding like she said she had in another part of her story, and to trust the professionals so wholeheartedly, then it was likely the faith she professed had a huge role in underpinning her beliefs about her treatment and her recovery, as well as the interactions she had as part of these processes.

Such admiration, as she expressed in the above statements, was ironically suggested by all the participants at some point - usually the end - of their stories. They all had good things to say about staff members. They realised that theirs was an extremely unusual condition and although they may have been treated like a “guinea pig”^{D1328}, on the whole, the staff did their professional and personal best. For example, “Mad at my condition? I was never angry at the nurses because they were all really great. And the system, well I’ve heard so many bad stories about the health system but Jim and I were just looked after so well. Like they looked after Jim”^{E527}. When speaking about their relationships with others, these people did not want to appear overly critical. Generally, they wanted to make an impression that they were good people and balanced enough to look at all sides of the picture. The participants offered an identity of themselves that was based on this motivation for impression management.

One final and particularly ubiquitous way of making sense is to bring the inexplicable up again and again. Perhaps this is why the hyper-accessibility of unwanted thoughts in post-traumatic stress disorder from techniques of thought suppression forces some people to work through trauma repeatedly until they find meaning (Greenburg, 1995). During the stories some participants spoke a lot about other people. Were they trying to make sense of the relationships in the process of speaking to me? Perhaps, but in examining who spoke a lot about staff and who did not, and what was said, it made me wonder whether the different experiences people had were created by their own personalities. Was attitude the reason some had better experiences? Participant A, who presented the most positive story, was not told that her condition could be fatal. Although reflective about the psychological cause of GBS in later years, she was a self confessed non-worrier. Her story was full of humorous anecdotes, positive things to say about everyone and her presentation during the interview was one of good cheer. Her story also covered lots of personal examples about the fundamental importance of self-sacrifice in a good Christian life. Conversely, two participants who declared their neuroticism, had experiences characterised by anxiety and depression. One of these admitted to being complex as well as neurotic, so the episodes were experienced then scrutinised from many different angles. Both of these participants, plus the preceding one, spoke a great deal

about the characters in their stories, either positively or negatively depending on the value of the relationship. Add to a thinking mind a high degree of natural feistiness, presented as a family trait, then the experience was also likely to contain a highly critical commentary of the system and the people working within it. It is little wonder that this last participant loaded her story with strong negative words.

The archetypal roles in GBS stories of the heroic genre

Everything discussed in the proceeding sections were drawn from the stories and from an observation of their storying. As previously explained, the things that have significance or meanings for people are the things they choose to include in their story. When adversity hits, people often choose to author behaviours consistent with one of the archetypal characters or roles of their society. The stories for the present study revealed that one participant took on the role of the victim when she said she become sulky and had tantrums. Another became the martyr, because she subsumed her own needs under the guise of responsibility and duty. The remaining woman became the warrior when she called in all her resources and said, “I had to fight for that every day”^{D1353}. People like her could become the patients from hell because “they were always annoyed with me for calling and getting attention and asking for things.”^{D1364} One of the participants felt he had no control and withdrew into depression. He emerged later like a phoenix from a fire, but as the tortured hero. Then there was the participant who said he saw what his problem was and got on with fixing it. He assumed the role of the wayward prince. He had wealth and power, but needed to appreciate the intangibles in life to claim his kingdom of family. The final role was taken up by the participant who became the wise man. He said he was able to look back at his experience and view it now with peace.

Unlike the characters in a novel or play, the roles people assume in real life are actually multifarious. These roles are social constructions, sometimes played simultaneously as with the mother, wife, daughter, friend, athlete, colleague, student, teacher, and company director roles, and sometimes assumed at different times or for different occasions. The roles or identities the participants presented in their stories were thus re-crafted for another purpose when they spoke about

their attitudes and behaviours towards recovery. What was their ultimate motivation for getting better? The stories did not contain evidence of a crystallisation from the ethereal into the corporeal. Even if the participants did say they believed in destiny, the hand of God or the veracity of the judgements made during out of body experiences, they also said, in the way people have of being able to hold several contradictory meanings at once (Reker, 2000), they became better because they had a motivation to achieve a goal. In this respect their stories epitomised the heroic characters in Frank's (1997) story genres.

The hero figure was developed by the storytellers as part of their plots and emerged in response to their personal reasons for getting better. The structures of narrative - major, minor and peripheral characters, scene setting, sequencing, style and tone – were authored to accomplish the regressive and progressive storylines claimed by Gergen and Gergen (1986) to provide dramatic tension. Would the main characters rally their forces, face their affliction and emerge the victors?

All the stories began with scene setting, either as background information or as a description of the onset stage and symptoms. The storytellers then carried their audience along on an illustrative and metaphoric journey from initial deterioration to recuperation and recovery. The dénouements revealed the heroic nature of the characters because it was here that participants commented on the experience from the perspective of the present. It was from filtering their experiences through hindsight, as well their need to paint themselves in a good light to impress me that they presented themselves as the hero.

For Participant C the hero role was prompted by his desire to walk his daughter down the aisle at her wedding. He went out of his way to organise physiotherapy, and later home-made exercise equipment, to speed and enhance his mobility. For Participant F, the goal was to see his old cat again, to walk around his garden and taste butter or a nice steak. For Tania, the young woman in the photo (Figure 2), whose baby was delivered the day after she was admitted to ICU, the goal was the enjoyment of staying home, sitting on the couch with her husband and playing with their baby. Likewise, her determination to come off the ventilator was prompted by her desire to ease the responsibility for her baby away from her family to herself.



Figure 2. Taylor with her still paralysed mother now four months later.

Photo reprinted with Tania's generous permission.

A sense of duty in worrying about family and earning an income prompted Participants A and B to get out of hospital and back to work as soon as possible. To the extent that one of these participants “had to crawl to his horse, to feed the dog or crawl to his dog, to his horse, to feed them.”^{B570} As a husband and father, he felt his family did not deserve the weight placed upon them as a result of his incapacity to fulfil his traditional financial and household responsibilities. The other participant wanted to get back to the business she co-owned so her husband didn't have to manage on his own any more. Characteristically proactive, Participant D hurried herself out of hospital, even though she could not sit up and had not done so for four months. Her family was tired, financial resources were being drained and she wanted to return to her hometown so her husband could go back to work and give up the rented second house near the hospital. This fighter ran a half marathon a year later. And like the man with an aisle to walk, she worked through fatigue to convert a typical GBS gait, a “walk, [that's] pretty funny, very flat, no spring and [that's] a really weird sort of a walk^{D1516}, into a normal one.

For her, the return to full function was achieved. For the others in the study, however, the physical legacies of the condition remain to varying degrees. What makes their residual status particularly interesting is that none of them accept an identity of disablement. Consistent with the polysemous nature of narratives, then, some of the stories had a restitution or normalising genre as well as a heroic one. The participant with the most visible disability, Tania, barely mentioned her present physical status. Others spoke of their residual symptoms but generally moderated or negated them with statements like, “probably still haven’t grown back a hundred percent but anyway that’s only pretty minor really isn’t it? I can walk as good as gold now. You wouldn’t know I had it really. Except I might drag my right foot a wee bit still, but not much or hardly noticeable really.”^{C196} Likewise, “but I could do pretty well everything else, and my arms strengthened up. And in 1980 when I went to work in the rest home kitchen my arms really strengthened up with that work there, and although I’m probably a little bit weak in the arms, I don’t have much bother with that today. I would say that I don’t really have any problems from Guillain-Barré Syndrome ... Maybe a little bit that I had this terrible thing that’s left me a little bit weak, but other than that I don’t think I have had any problems.”^{A392}

What does this mean? Possibly, that these people have a physical disability or limitation, but they do not claim a disabled identity. They identify with normalness and thus their stories incorporated a genre of normalness. It is their view and their desire, they inferred, to get back to life as it was for everyone else. To have “been [there], done that, got through, so it’s history.”^{C651}

Unfortunately, the only person to have no physical residuals has not been able to put the damage behind her. Her overt demonstration with body language of the residual anger she was speaking about, gave Participant D’s story an echo of chaos. Based on the contextual assumption for narratives – in this case the temporal and emotional events leading up to the interview – her story however, may have been bleak for her only on this particular occasion, or only to me as I interpreted it. I am open to believe, because the participant said, “and while I say I’m angry at that and I haven’t resolved it and all that too, I did learn a lot. As I said there were some gifts out of it, but maybe I’m angry and I’m not seeing those”^{D1553}, that her experience, like the others, was not all bad and

probably did provide her with meaningful gifts – such as her comfortableness in discussing death with a dying woman, when no-one else around seemed able to.

Although this participant did not author elsewhere, the idea that she had gained from her experience, the others did. Their meanings moved to a different level when they spoke about the changes they made as a result of GBS. Michelle Crossley (1999) wrote that

... stories framed by the threat of death and human finiteness tend to highlight and exacerbate the importance of moral and existential concerns.... [These stories] are able to painfully bring forth questions of meaning and concern; questions about our relationships with others; questions about how we have lived our lives; questions about values and priorities; questions in short, about the meaning of life (p.1688).

The lexicon for this level of meaning is meaningfulness. Whereas the meanings any event has are revealed in the significant things people say about it, the meaningfulness of these events is in the events ability to facilitate the questioning, and possible change, in the beliefs and actions of the people involved.

The meaningfulness of GBS

Was the GBS experience a meaningful one for the participants in this study? I would say, definitely yes. Even though it was something they wouldn't ever want again, nor would they wish it on anyone else, they claimed there were some positive aspects that came out of it. "Yeah, I suppose even though it was the worst thing that ever happened to me, looking back now it wasn't all bad. Some of the things were really, really terrible but then looking back there were some really good things. Like I got to meet people that I would never have met otherwise and you get to see people so differently. And you just learn not to take people for granted. Jim and I have probably got, well the best relationship I can ever think of. I look around at people and I think, gosh Jim would never do that to me and Jim wouldn't. And I think because we were there together, and I know that Jim'll always be there. It was horrible and I'd hate it to happen again but it wasn't as dreadful as it seemed at the time, in hindsight, yeah." "*Because of the things you've said that are positive?*" "Yeah. Yeah,

I don't know if I would've been like this now if I hadn't got sick, I don't know. But I just really, really love Jim and Taylor and I think that's got a lot to do with the fact that I thought I would never have them. And having something like that really makes you feel good about every day, it really does"^{E696}. In some ways what Tania was alluding to was the moral of her story. The idea that in passing through adversity, the heroine of her story appreciated the intangible things of life.

As it was by Tania, this bringing together of families to a state closer than they were before, was moralised as rewarding and meaningful for many of the participants. One person said of her family that "to have me dying was a huge thing, and in fact I brought them all together, and the relationships that had never existed before happened because of that"^{D17}, "so I think they were lucky that they were supporting each other"^{D707}. She also appreciated the bond created with her father who performed a monumental act to be by her bedside every night, largely because "we hadn't had that close a relationship always before then"^{D799}.

Respect, love, humility and extreme gratitude were feelings expressed towards sons, husbands, wives, sisters, fathers, and stepmothers. For the devotion the participants said was provided by their family members, to be so consistent and long standing, often for many weeks or months, I assume the feelings must have been reciprocal. To support this interpretation one participant said, "And funnily enough the marriage thing was more cemented by the actual experience, which is weird but there you are. Because I think [spouse] realised that maybe I was more important than [spouse] thought I was, apart from all [the] annoying things that I do."^{F102} This person's marriage had been going through a difficult patch pre-GBS, so for the participant to regard the experience as a cementing one largely due to the spouses reappraisal, meant the participant was grateful for the long-term outcome of their marriage as a fulfilling, fun and rewarding relationship.

One participant mentioned that it was the people closest to her who noticed when she changed. She said, "I have changed, and people that know me have said I've changed. I've grown up a lot. I really, really honestly think that your health is the most important thing now, I didn't used to think about my body and health"^{E658}. For her, the meaningfulness of her experience was that she, and probably her family as well, would never take wellness for granted again. This aspect of the

experience was meaningful for her, and other participants, because GBS provided the opportunity to think about their bodies and health in a way they had not done so before. Some also said they were pretty thankful, or even lucky that what they had was GBS and not some other medical or neurological condition. Somehow, “what for me they were about was that I was very ill but I had something I would recover from. It’s like a person with multiple sclerosis, there’s gradual progression and they get worse”^{D1247} and also “I think well if you look through the, even all the different Guillain-Barrés, you go, well heck, well I did choose the best one”^{D1404}. These comments put a syndrome with nightmarish characteristics into a context of relativity. GBS was the best syndrome to have because they would get better and they could avoid the identities of illness and remission associated with progressive neurological conditions.

From this angle it is not difficult to surmise that the experience has definitely made some participants more understanding of others’ health conditions and other people in general. “It’s made me realise that there are these things out there that can happen to people. And I probably take more notice of people that aren’t well now that I feel differently towards them. Instead of thinking, oh, they’re always sick or something like that, I think well they have may have something that’s really bad troubling them. And I think I look on people a bit differently. It’s probably made me more aware of what people can go through.”^{A1072}

“It’s also made me understand people that have got things like MS [multiple sclerosis] and motor neuron because I think how lucky I have been that I didn’t get them, that I had a short time where I was like them. Yes, so I think that I’m more thoughtful about people that have got those conditions, whereas beforehand I used to hear of someone that was in a wheelchair and I just sort of think, oh poor things, oh it must be hard, I’m glad it’s not me ... it has changed the way I feel about lots of people. I think I look at people a bit more now too and see what they’re really like, not just take them at face value”^{E671}.

An extension of walking in another’s shoes is to bring understanding to existential questions by looking outside oneself, to find answers to the big questions in life. Several participants said they believed in destiny. That “one thing where [GBS] did make some meaning was something about

when [spouse] got sick and he was dying and I was nursing him. It was like there was, it was kinda like meant to happen. Like [spouse] looked after me, waiting on me hand and foot and then it was only a few years later and the positions were reversed. And I don't know what, it was just something about that that made me think, oh this was always just going to happen, how it all happened." "*Like destiny do you mean?*" "Mm" "*That the Guillain-Barré was destiny*" "Mm" "*and [spouse's]*" "Mm" "*cancer was destiny?*" "Mm."^{D1547} Expressions of belief, such as this, show the experience was put into the context of a whole life. This landscaped view is what Reker (2000) defined as "depth of meaning" (p. 44). He wrote that experiencing meaning at the higher levels of the "depth of meaning" means more fulfilment and satisfaction in life.

Another participant spoke at this level of meaning when he included in his story the anger he released at the unsuspecting house surgeon – whom I wrote about before - when his trachee was taken out. "You know now it seems relatively unimportant because other things are important. You can't sort of just go back to that experience. It's just an unfortunate experience really, Guillain-Barré."^{F733} He was looking back and reflecting on the significance of his experience in the light of his present daily activities, and in doing so he implied that although the experience was unfortunate it was not relevant to what he was doing now, suggesting there was no point dwelling on something that was in the past. Although his statement gave the appearance that GBS was not meaningful for him, because he said it did not influence his present beliefs and activities, I believe it was. In sharing his musings about the past influencing the present, he was saying he was engaged with an existential concern as much about temporality and existentialism as the role of the divine in guiding the lives of mankind.

For the participant quoted above and for several others belief in God was not authored. They chose to speak more in existential terms of what they should do with the opportunities life threw their way. They stated quite clearly that they did not relinquish control and wait for things to happen, they acted. One man said, "It also makes you realise what you can do when you want to. Like you never want to give up. It's all very well to say that, but it's a fact if you give up, you give up all right. You just can't afford to give up when you've got something like this."^{C537} The big picture for him was

that anyone can do what they want to when they put your mind to it, and when they are prompted to act they can change much.

Life crises, such as an encounter with GBS could provoke, may serve as a wake-up call, leading people to re-examine their priorities (Emmons et al., 1998). So much so that when asked if he looked at life differently now, one participant replied, “Yes. You do. I do think about that, like you take every day for granted when you’re a hundred percent. Like, oh I’m good as gold. I can do what I wanna do. But when this sort of thing happens you certainly do get a new look on life; you appreciate things a lot more. Appreciate what you’ve got and you appreciate your wife and your children and grandchildren and yeah, you do. You get a different perspective on life all right. Every day’s a bonus now. Like when you wake up in the morning, it’s great to be alive really now, whereas before you probably took it for granted or something. Mm, yes it makes you change your outlook on life.”^{C390} In saying this he shared what Albert Schweitzer termed his reverence for life.

When a participant was open to change, he or she was also open to seizing opportunities to make change happen, the possibility to have a second chance in life. One man “was grateful for another chance to live and I think that that was, both times it’s like being born again. I mean the actual nightmare of the disease is a nightmare, and it’s very hard to explain to anybody what it’s like, but the recovery from it is like being born again. You can, you know just tasting things again for the first time. Having a glass of wine or just being able to move, to walk, all those things. And you have to learn to walk and do all those things too with the physio. All that is magical, absolutely magical. You know to actually get back those things, which you’d been denied and lost use of, it’s just fabulous. So, I don’t recommend it, but it’s interesting.”^{F484}

A new outlook and a new attitude like this were two of the gifts that made the GBS experience meaningful for some of the participants, as well. One gained a new skill, another realised a natural ability. This discovered ability was the potential to counsel, and this later lead into a new career path. “When I came back to [City] Hospital, there’s a woman there dying of cancer and I wasn’t scared of death after my experience. I could just go and talk to her and nobody would talk to her about death. I just went in to her and she was able to talk to me about what she was afraid of and

I wasn't afraid. I wasn't afraid of death. Yeah it felt like that was a gift I got from it. Yeah, that was just like, oh! No, it's just good things. It's okay."^{D1417} The skill was learned because the participant experienced a change in his attitude. He said, "I think, the actual terribleness of the disease actually allowed me to relax and bring in more light and stuff into my work and funnily enough everybody else tended to like it. There was no longer that sense of desolation in the [pieces]"^{F604}. The change in this person's creative pieces emerged with more light, some sun, and dare I say more beauty.

All these wonderful comments about the meaningfulness of the experience are inspiring. However not everyone felt the experience was meaningful. The person having only positive things to say about others and the episode of GBS actually negated her whole experience when she replied to the question, "*So looking back on life now, do you think it was good thing for you to have?*" with, "Oh, I don't think it was a good thing to have. I wouldn't have it by choice. If somebody came along and said would you like to have it, even though I've just said that it would be a good rest now. But, no I wouldn't. I wouldn't think it was a good thing. I don't think it's done anything marvellous to me that I would think."^{A1081} The experience was not a meaningful one for her because her life, "no it didn't change. It just carried on the same." "*So it went back to what it was like beforehand, carried on the same?*" "Yes it did. Yes it carried on the same. Yes in about five months I was back doing exactly the same as I had been before. It was just the same... no, nothing really changed."^{A651}

Perhaps the best way to decide whether the participants' experience was meaningful or not, is to look at the words with which they ended their stories. These were the words chosen at the end to sum the retrospective view they had of their experience within the context of the present, and it was in these retrospective reflections that meaningfulness was most often considered. The dénouement of this narrative is devoted to the conclusion of each participant's story, in turn.

Participant A: It was difficult to select this person's ending because as a neophyte I had not allowed her story to flow freely. This meant that the words to best sum up her experience were selected by me. Although not the actual end, her natural ending, before she ran on with the story again, appeared to be that "it was, it was a part of your life that, you could've done without it but it happened so ... you know you just get on with the rest of it then. Nothing really, really negative, I

didn't feel about it, and don't feel about it. No."^{A1077} However, she did slow down at the conclusion to her story and say, while talking about another person's trials and tribulations through life, "I think it would make an interesting story sometimes. I think I should write a book"^{A1063}. I feel these words actually summed up her experience as well, because her story about GBS was littered with interesting anecdotes and testimonials about events and people from many episodes in her life.

Participant B: This person experienced a lot of pain and enough residual symptoms to restrict his career opportunities. However, now that many years have passed and he is an older man looking back on the experience in the context of a long life, he told me a story in which extended family and loyal friends figured prominently. It was within the context of his post-GBS life and his near death experience that he feels he was given another shot at having the kind of life that will allow him to die a peaceful man, when the time comes. "As to whether I might pop off next week or not, I don't know. Wouldn't worry me because I feel I've had a reprieve, really. *You mean you've had a second chance?* Yeah, definitely ... So that's that, but I'm here, you know at peace, mm. So that's about it. All right?"^{B320}

Participant C: This person ended with, "like I say I was lucky really. So that was my last four years or something, four and a half years. But I'm good now ... so that's about all I can tell you I think really"^{C231}. However, the core of his story was not really about luck, it was about desire, dedication and discipline. A better example of his storyline would be, "I think it's your will to live I suppose. And if you've got an incentive to live, which I have, a great family and I have no worries. It's not as though I was upset about anything and I had everything to live for."^{C384} A desire to be with his family, and live a bit longer, drove his dedication and discipline to be walking at his daughter's wedding.

Participant D: This story ended when she was talking about someone who had made a comment about the baby boy in her womb at the time of her experience, and I think it aptly describes her experience as well. "I was just remembering he lived in [Town] and he promised [Son] a horse when he grew up a bit. Yeah, [he said] 'Oh that little chap, you know he's a bit of a battler that he survived all of that.' Yeah."^{D1537} This woman was a battler who fought an amazing series of

indignities directed against her by the professionals with power over her life or death. She depicted herself as a battler when describing the conditions she was subjected to and in her responses to these.

Participant E: For her, “[t]here’s so many horrible things that can happen to you but this is nothing, it’s a breeze actually. Looking back now it was ...” “*Okay.*” Yeah, if I had to I could do it again, I wouldn’t want to, but yeah.... I don’t think I’ve kept anything that’s got Guillain-Barré on it because one day I just got really crappy and threw it all out and just didn’t want it any more. So it’s all gone, I haven’t got anything.” “*And why was that?*” “Because it was done! I just wanted to start again. It was like that was my old life. I didn’t need it.”^{E748} Tania inferred overall her experience had been a formative one. Her tale can be perfectly metaphorised by a part of the song serendipitously playing on the radio as I hopped into my car after our interview. That song was *The Rose*:

When the night has been too lonely
 And the road has been too long
 And you think that love is only
 For the lucky and the strong
 Just remember in the winter
 Just beneath the bitter snows
 Lies the seed that with the sun’s love
 In the spring becomes the rose. (McBroom, 1997).

Participant F: “It’s very difficult, even after all this time to come to terms with it, and I do think it’s probably had an impact on me psychologically, definitely some of the factors in it, and you know probably exaggerated too by the use of drugs at the time. But as I say you’ve got to go on living and I’m enjoying my work and you know things actually, apart from some personal sort of psychological problems, things have been very good for me”^{F477}. The implication of this man’s concluding statement is that it demonstrates how he was “... able to integrate the contradictions, conflicts, and absurdities of life by rising above them and view them in the context of more comprehensive horizons” (Reker, 2000, p. 44).

Gary Reker (2000) wrote “Contemporary psychological research has shown that existential meaning is an important psychological construct in the successful adaptation to life’s changing circumstance (p. 39).” What does this mean for the participants in this study? All but one said they had reviewed existential meaning and changed what it meant for them as a result of their GBS experience. Perhaps the out-of-step participant’s desire to be liked and be a good person precluded her from thinking too deeply about her situation. At the time, she was too busy looking after everyone else, but now she has more time and perhaps more inclination because of her age to be reflective. Deterioration in recent health status and the death of a neighbour have prompted her to revisit her GBS experience.

For the rest of the participants, something positive did come out of the experience. Mahatma Gandhi once said, “As human beings our greatness lies not so much in being able to remake the world as in being able to remake ourselves.” The greatness for these people came because they remade their experience into a meaningful one. They chose to gather from their experiences a new outlook, attitude, or skill. Apart from the participant who still has some anger issues to deal with – and I believe because of the way she portrayed herself, she will deal with them – these people were able to adapt to life’s changing circumstance by changing existential meaning.

Perhaps Victor Frankl (1984) was correct when he wrote,

The way in which a man accepts his fate and all the suffering it entails, the way in which he takes up his cross, gives him ample opportunity – even in the most difficult circumstances – to add a deeper meaning to his life (p. 76).

Epilogue

The above narrative concludes with a strong emphasis on meaning, and although it also refers to change and revision, it does not place identity in a strong way. This was probably because I wanted to end with the profundity of the GBS experience. However, the identities the participants authored for me were as much a part of my experiencing of GBS as the meanings they gave me. The participants created the main characters and the changing roles these characters had in their stories,

and thus aided my discrimination of the stories into genres. Consciously or unconsciously, the characters served a function for the participants - one they wanted me to know about. It was through their choices that I perceived their experiences to have many meanings and, ultimately, to have meaningfulness.

6. CONCLUSION

This research has provided some valuable insights into the experiencing of Guillain-Barré Syndrome. As the outcome for an originitive analysis about GBS, these insights are unique additions to the knowledge trove of GBS. They are offered as seeds for germinating new ways of looking at a syndrome that has previously been documented only as medical discourse or as individual accounts.

Their eventual presentation in a narrative form was a mimesis of the presentation used by participants during an interview with the researcher. This presentation was considered by the researcher as the way people organise disparate information into a coherent whole. The accounts as stories were analysed through an analysis of narrative, with the results of this analysis centring on the four main elements: identity, meaning, making sense and meaningfulness. These elements were subsequently revived during a narrative analysis and presented in Chapter Five as a narrative. This narrative, headed *The Meaning of Guillain-Barré*, is an exposition of what the researcher discerned about GBS. Her insights about the experience and the people who did the experiencing, are available to readers because she examined the stories, and their storying, in depth, and made perceptive judgements about what she found.

The first set of insights revolved around the functions their storytelling served for the participants. These functions were sometimes overt, for example when they spoke of being afflicted by the syndrome and not responsible for its arrival. They also stated, quite candidly at times, that despite the humbling or exinanition of the experience, they were proactive in effecting the extent of their recovery. This concern to let me know they held control, aside from some initial episodes of chaos, carried over to their descriptions of their mental and emotional states. At other times the storytellers were not aware of the hidden messages they were conveying. It was in interpreting their storying that inferences were made about the nature of the messages. These included, for example, letting me know what good people they were, how important friends and family were, and how grateful they were for what their families had done for them.

The second set of insights was inspired by the characters or identities the storytellers chose as

their main characters. These characters were, of course, themselves, and these characters were re-authored into many different roles throughout the stories. Mostly, the elucidation of these roles came from the way the participants spoke about themselves with respect to events and other people. They composed a picture of themselves with the words they used and the styles they chose to present their stories in. There may have been a deliberate purpose to their characterisations within the context of this study; alternatively these characteristics may have been the way they figured themselves through their GBS experience.

The insights concerned with the meaning of GBS, were organised into two parts, the inexplicable nature of the syndrome and the horrendousness of the experience. Both aspects of having GBS facilitated a wide range of different emotional states of varying intensities. The participants made sense of GBS by storying what they did at the time of their experience and what they thought of the experience in hindsight. Some of their making sense strategies included taking control for themselves or antithetically abdicating it elsewhere, comparing their condition to other illnesses, thinking of the pain as part of the body's healing process, and devising ways to gain from the experience.

An examination of the narrative structures used to author these and other parts of the stories revealed that when adversity featured, each story portrayed the main character as one of our culture's archetypal narrative figures. There was the victim, the martyr, the tortured hero, the warrior, the prince, and the wise man. However, when the whole of each story was considered, the character common to all stories was the hero; the story genre of the tragedy befalling the innocent who overcomes adversity by rallying resources to his or her ultimate victory.

As they made their way from the beginning to the end of their stories, the participants were able to make sense of their experiences and see how meaningful they were. As meaningful experiences, all participants except one said they had thought about existential questions and/or effected a change in their outlook to life. These, as Garro (1994) wrote, included thoughts about themselves, their present, their future as well as their past.

The research has been meaningful, if challenging, for me as well. As I near the end of a

performance, that all involved in this research have played in, I realise how much I now take for granted about GBS and the experience of GBS, that I did not know when I began. Not only that, I have accumulated and developed knowledge about the research process and the method I propagated. I hope a similar enlightenment has happened for the readers of my thesis, for when planning the writing I did not want to give them a generic and sterile version of just any traumatic illness. By weaving a series of quoted vignettes into my narrative, I wanted to offer an experiential glimpse into what it means to have GBS.

I appreciate the generosity of the six people who gave of their time and their selves to inform me about GBS. This research offers insights into the meaning of GBS and the processes people go through for finding meaning. At the same time, as suggested by Sommer and Baumeister (1998) the process of organising and describing episodes in narrative form facilitated the development of meanings for them. It is hoped that the present research will contribute to this evolution, by enabling the research participants to perceive or create connections between previously random events, conceived both during the authoring of their stories and the reading of mine.

It was my intention that the insights provided here about GBS would be useful for other people who have had GBS or who are experiencing it right now. Likewise, for the caregivers and people involved with GBS from other perspectives – family, friends, general practitioners, physicians, nurses and so on – to aid in their sense making of this inexplicable and traumatic illness.

Where to from here? A number of questions arose for me during the development and writing of this thesis, the answers to which would add value to the existing knowledge about GBS. For example, what are the words that best describe the neurological sensations felt by people with GBS, and how can the experience of these sensations be explained to others? Nerve pain is profoundly different to muscle pain, and as most lay people and professionals experience muscle pain, they tend to generalise from that to nerve pain. Another question was, that if scientific evidence points to GBS arising from an auto-immune attack on the peripheral nerves only, why is that several of the participants said they were depressed, anxious or had panic attacks? Were these a result of endogenetic or exogenetic influences? Emotional and personality effects could be compared to those

for people with MS or minor brain injuries, who have damage to the central rather than peripheral nervous system. Zeldou and Pavlou (1984) found, in the meta-analysis they performed with MS studies, that physical health status was a major influence on personal efficiency and well-being, capacity for independent thought and action, self-confidence, self-reliance and number of meaningful social contacts. If health status influences psychological well-being so much, could the well-being of GBS sufferers be compromised because of their residual status? Zika (1996) found that people with MS who have a weaker sense of personal control were more likely to display psychological distress. Does this translate to people with GBS? This is an area worthy of investigation, as is the cognitive functioning of people post-GBS. The repertoire of conceptualisation and action for living in the world after GBS may be quite different to that used before its arrival. Changes are possible as the syndrome shuts down certain abilities, caregivers respond in varied ways and people try to function using previous strategies. Limited success may mean they have to configure new strategies to accommodate lessened abilities and a changed social or employment status. Relevant and valid neuropsychology batteries could be used to measure cognitive abilities post-GBS, and although baseline measurements may be absent, the scores in their tests could be compared to the person's reported abilities in education, employment and general functioning.

The present study was about identities, meanings, making sense and meaningfulness. The participants storied these for me in retrospect. I wonder how, and if, these change while living through GBS. Would a prospective, longitudinal design employing narrative techniques show this?

Also, what insights would be garnered with respect to identity, meaning, making sense and meaningfulness from the stories of people who have another type of sudden and traumatic illness or injury? For example, traumatic brain injury, paraplegia or limb amputation.

A question I considered was, what is this syndrome like for the loved ones and caregivers, and how do they make sense of something that is likely to disrupt their lives as well? They would be in the situation most of us were in before we heard of this condition, complete bafflement probably. Based on what the participants in this study said about these people, they are likely to devote many days, weeks and months to hospital visiting, to running a household and family without spousal help,

to allaying the fears and bolstering the sagging confidence of the patient in hospital, as well as dealing with their own conflicting emotions as the cared one moves progressively, but slowly towards recovery. For even though the patients may say their recovery is complete, the loved ones may not be so confident, nor necessarily accepting of the changes made by the patients' existential ponderings as a result of their exinanition from GBS.

Two further areas to research could be the educational needs of general practitioners and neurologists from the point of view of the patient, and the financial costings and economics relating to the health care for GBS. Both these issues would be of value to future patients, caregivers, people in the medical world, and government funding agencies.

In conclusion this research proposes, as Ryff & Singer (1998) did, that investment in significant life pursuits, the perception that life has meaning, and experiences of self-realisation and growth are amongst the defining features of good mental health. Korotkov (1998) noted that the people Victor Frankl observed as having purpose or meaning in life were the ones who adapted to, and survived, the odious conditions of concentration camps in Nazi Germany during WW2. Coined by Frankl (1984) as the "will to meaning" (p. 105), the motivations presented above were present in all the stories. The participants had survived. Post-GBS they had transcended the suffering they experienced by finding new meaning and new possibilities in their lives. As Tania quoted her taxi driver saying as he drove her to the hospital for her daily post-GBS physio session, "Isn't it a beautiful day?" he said, 'I wouldn't be dead for quids,' you know that old saying, and you just think you wouldn't, it's true."^{E713}

REFERENCES

- Agius, M. A., Glasg, F. R. C. P., & Arnason, B. G. W. (1991). Autoimmune neurological diseases and their potential relevance to psychiatric diseases. In J. M. Gorman & R. M. Kertzner (Eds.), *Psychoimmunology update* (pp. 9-29). Washington, DC: American Psychiatric Press Inc.
- Albom, M. (1997). *Tuesdays with Morrie*. Rydalmere, NSW: Hodder.
- Andrews, M. (2000). Narrative and life history: Introduction. In M. Andrews, S. Day Sclater, C. Squire & A Treacher (Eds.), *Lines of narrative: Psychosocial perspectives*. London: Routledge.
- American Psychological Association (1996). *Publication manual of the American Psychological Association* (4th ed.). Washington, DC: American Psychological Association.
- Asbury, A. K., & McKhann, G. M. (1997). Changing views of Guillain-Barré Syndrome. *Annals of Neurology*, *41*, 287-288.
- Asbury, A. K., Cornblath, D. R. (1990). Assessment of current diagnostic criteria for GBS. *Annals of Neurology*, *27*, S21-24.
- Baier, S., & Schomaker, M. Z. (1989). *Woman in bed number ten*. Boca Raton, FL: CRC Press.
- Bamberg, M. (1997). A constructivist approach to narrative development. In M. Bamberg (Ed.), *Narrative development: Six approaches*. London: Lawrence Erlbaum Associates.
- Baumeister, R. F., & Newman, L. S. (1994). How stories make sense of personal experiences: Motives that shape autobiographical narratives. *Personality and Social Psychology Bulletin*, *20*, 676-690.
- Bernsen, R. A. J. A. M., Jacobs, H. M., de Jager, A. E. J., & van der Meché, F. G. A. (1997). Residual health status after Guillain-Barré syndrome. *Journal of Neurology, Neurosurgery, and Psychiatry*, *62*, 637-640.
- Bernsen, R. A. J. A. M., de Jager, A. E. J., Schmitz, P. I. M., & van der Meché, F. G. A. (1999). Residual physical outcome and daily living 3 to 6 years after Guillain-Barré syndrome. *Neurology*, *53*, 409-410.

- Bolton, C. F. (1995). The changing concepts of Guillain-Barré Syndrome. *The New England Journal of Medicine*, 333, 1415-1417.
- Bourke, C. (2001). Recovery from Guillain-Barré Syndrome: Relationship between degree of severity and mental status in a New Zealand sample. Unpublished master's thesis, Massey University, Palmerston North, New Zealand.
- Bowes, D. (1984). The doctor as patient: An encounter with Guillain-Barré Syndrome. *Journal of the Canadian Medical Association*, 131, 1348.
- Campbell, J. (1988). *The power of the myth*. New York: Doubleday.
- Carr, D. (1986). *Time, narrative and history*. Bloomington: Indiana University Press.
- Chamberlain, K., Stephens, C., & Lyons, A. (1997). Encompassing experience: Meanings and methods in health psychology. *Psychology and Health*, 12, 691-709.
- Cornblath, D. R., Mellits, E. D., Griffin, J. W., McKhann, G. M., Albers, J. W., Miller, R. G., Feasby, T. E., Quaskey, S. A., & The Guillain-Barré Syndrome Study Group (1998). Motor conduction studies in Guillain-Barré Syndrome: Description and prognostic value. *Annals of Neurology*, 23, 354-359.
- Crossley, M. L. (1999). Stories of illness and trauma survival: Liberation or repression? *Social Science & Medicine*, 48, 1685-1695.
- Crossley, M. L. (2000). *Introducing narrative psychology: Self, trauma and the construction of meaning*. Buckingham: Open University Press.
- Driver goes back for a look. (2000, January 7). *The Nelson Mail*, p.4.
- Del Vecchio-Good, M., Munakata, T., Kobayashi, Y., Mattingly, C., & Good, B. (1994). Oncology and narrative time. *Social Science and Medicine*, 38, 855-862.
- Denzin, N. K. (1994). The art and politics of interpretation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp.500-515). Thousand Oaks, CA: Sage.
- Emmons, R. A., Colby, P. M., & Kaiser, H. A. (1998). When losses lead to gains: Personal goals and the recovery of meaning. In P. T. Wong & P. S. Fry (Eds.), *The human quest for meaning: A handbook of psychological research and clinical application* (pp. 163-178). New Jersey:

Lawrence Erlbaum Associates.

Feasby, T. E., Gilbert, J. J., Brown, W. F., et al (1986). An acute axonal form of Guillain-Barré polyneuropathy. *Brain*, *109*, 1115-1126.

Feasby, T. E., Hahn, A. F., Brown, W. F., Bolton, C. F., Gilbert, J. J., & Koopman, W. J. (1993). Severe axonal degeneration in acute degeneration in acute Guillain-Barré syndrome: Evidence of two different mechanisms? *Journal of Neurological Science*, *116*, 185-192.

Fife, B. L. (1994). The conceptualization of meaning in illness. *Social Science & Medicine*, *38*, 309-316.

Frank, A. W. (1991). *At the will of the body: Reflections on illness*. Boston, MA: Houghton Mifflin.

Frank, A. W. (1993). The rhetoric of self-change: Illness experience as narrative. *The Sociological Quarterly*, *34*, 39-52.

Frank, A. W. (1997). *The wounded storyteller: Body, illness, and ethics*. Chicago: The University of Chicago Press.

Frank, A. W. (2000). The standpoint of the storyteller. *Qualitative Health Research*, *10*, 354-365.

Frankl, V. E. (1984). *Man's search for meaning: An introduction to Logotherapy* (3rd ed.). New York: Touchstone.

Gallagher, P., Allen, D., & MacLachlan (2001). Phantom limb pain and residual pain following lower limb pain following lower limb amputation: A descriptive analysis. *Disability & Rehabilitation: An International Multidisciplinary Journal*, *23*, 522-530.

Garro, L. (1994). Narrative representations of chronic illness experience: Cultural models of illness, mind and body in stories concerning Temporomandibular Joint (TMJ). *Social Science and Medicine*, *38*, 775-788.

Gergen, K. J., & Gergen, M. M. (1986). Narrative form and the construction of psychological science. In T. R. Sarbin (Ed.), *Narrative psychology* (pp. 22-44). New York: Praeger.

Good, B., & del Veccio-Good, M. (1994). In the subjunctive mode: Epilepsy narratives in

Turkey. *Social Science and Medicine*, 38, 835-842.

Greenburg, M. A. (1995). Origins of ruminative thought: Trauma, incompleteness, nondisclosure, and suppression. *Journal of Applied Psychology*, 24, 1262-1296.

Gregory, R. J. (1999). Cosmological rehabilitation: A call to action. *Journal of Religion, Disability & Health*, 3, 73-78.

Gregory, R. J. (2002). *The dart man: Neurological impairment and social reactions*. Manuscript submitted for publication.

Griffin, J. W., & Ho, T. W. (1993). The Guillain-Barré syndrome at 75: The Campylobacter connection. *Annals of Neurology*, 34, 125-127.

Guillain-Barré Syndrome Foundation International (n. d.). *What is Guillain-Barré Syndrome (GBS)?* Retrieved December 28, 2000, from <http://www.guillain-barre.com>.

Guillain-Barré Syndrome Support Group of New Zealand (n. d.). *Guillain-Barré Syndrome: A short guide for patient, relatives and friends*. [Brochure]. New Plymouth: Guillain-Barré Syndrome Support Group, New Zealand.

Guillain-Barré Syndrome Support Group of the United Kingdom (page updated January 2000a). *CIDP (Chronic inflammatory demyelinating polyradiculoneuropathy)*. Retrieved August 7, 2001, from <http://www.gbs.org.uk/cidp.html>.

Guillain-Barré Syndrome Support Group of the United Kingdom (page updated July 2000b). *The Guillain-Barré Syndrome patient in intensive care*. Retrieved December 28, 2000, from <http://www.gbs.org.uk/red.html>.

Guillain-Barré Syndrome Support Group of the United Kingdom (page updated July 2000c). *Information pages: Guillain-Barré Syndrome*. Retrieved from <http://www.gbs.org.uk/blue.html>.

Guillain-Barré Syndrome Support Group of the United Kingdom (page updated January 2001). *Other variants and related conditions*. Retrieved August 7, 2001, from <http://www.gbs.org.uk/variants.html>.

Hadden, R. (2000). Investigating the immune system and antibodies in trying to understand how GBS damages nerves. Retrieved December 28, 2000, from <http://www.gbs.org.uk/rep2000.html>.

- Hahn, A. F. (1997). Guillain-Barré syndrome: an evolving concept. *Current Opinion in Neurology*, 10, 363-365.
- Hahn, A. F. (1998). Guillain-Barré syndrome. *The Lancet*, 352, 635-641.
- Heller, J., & Vogel, S. (1986). *No laughing matter*. New York: G. P. Putman.
- Herzlich, C., & Pierrot, J. (1985). The social construction of the patient: Patients and illnesses in other ages. *Social Science and Medicine*, 20, 145-151.
- Ho, T. W. (1998, Winter). Treatment for GBS [Special issue]. *The Communicator*. 2.
- Ho, T. W., Li, C. Y., Cornblath, D. R., Gao, C. Y., Asbury, A. K., Griffin, J. W., & McKhann, G. M. (1997). Patterns of recovery in the Guillain-Barré Syndrome. *Neurology*, 48, 695-701.
- Hollway, W., & Jefferson, T. (2000). *Doing qualitative research differently: Free association, narrative and the interview method*. London: Sage.
- Hughes, R. A. C. (2000). *Treatment Review of GBS and CIDP*. Retrieved December 28, 2000, from <http://www.gbs.org.uk/rep2000.html>.
- Hughes, R. A. C., & Hadden, R. (1999, Spring). Different types of Guillain-Barré Syndrome [Special issue]. *The Communicator*. 2.
- Hydén, L.C. (1997). Illness and narrative. *Sociology of Health & Illness*, 19, 4869.
- Jacobs, B. C., Rothbarth, P. H., van der Meché, F. G. A., Herbrink, P., Schmitz, P. I. M., de Klerk, M. A., & van Doorn, P. A. (1998). The spectrum of antecedent infections in Guillain-Barré syndrome. *Neurology*, 51, 1110-1115.
- Kleopa, K. A., & Brown, M. J. (2000, Spring). Disability after “recovery” from GBS. *The Communicator*. Retrieved December 28, 2000 from <http://www.webmast.guillain-barre.com/news>.
- Korotkov, D. (1998). The sense of coherence: Making sense out of chaos. In P. T. Wong, & P. S. Fry (Eds.), *The human quest for meaning: A handbook of psychological research and clinical application* (pp. 51-70). New Jersey: Lawrence Erlbaum Associates.
- Koski, C. L., & Laskey, T. (1998, Winter). Influenza vaccination and Guillain-Barré Syndrome. *The Communicator*. 3.

- Lennon, S. M., Koblar, S., Hughes, R. A. C., Goeller, J., & Riser, A. C. (1993). Reasons for persistent disability in Guillain-Barré syndrome. *Clinical Rehabilitation*, 7, 1-8.
- Lieblich, A., Tuval-Mashiach, R., & Zilber, T. (1998). *Narrative research: Reading, analysis, and interpretation*. Thousand Oaks, CA: Sage.
- MacLachlan, M. (2001, August). *Phantom embodiments: From neural anomaly to body plasticity*. Paper presented at the Second International Conference on reconstructing Health Psychology: Critical and Qualitative Approaches. Birmingham, UK.
- Mathieson, C. M., & Barrie, C. M. (1998). Probing the prime narrative: Illness, interviewing and identity. *Qualitative Health Research*, 8, 581-601.
- Mathieson, C., & Stam, H. (1995). Renegotiating identity: Cancer narratives. *Sociology of Health and Illness*, 17, 283-306.
- McBroom, A (1979). The Rose [Recorded by B. Midler]. On *The Rose* [album]. USA: Fox Fanfare Music Inc.
- McLeod, J. G. (1995). *GBS: A GP's guide to diagnosis & management*. Retrieved December 28, 2000, from <http://www.ozemail.com.au/~guillain/gp.html>.
- Meythaler, J. (2000). *GBS Review Course*. Paper presented at a meeting of GPs in the USA. [Obtained from J. Murray, Secretary, GBS Support Group of New Zealand].
- Meythaler, J., De Vivo, M. J., & Braswell, W. C. (1997). Rehabilitation outcomes of patients who have developed Guillain-Barré syndrome. *American Journal of Physical & Rehabilitation*, 76, 411- 419.
- Minichiello, V., Aroni, R., Timewell, E., & Alexander, L. (1990). *In-depth interviewing: Researching people*. Sydney: Longman Chesire.
- Murphy, R. F. (1987). *The body silent*. New York: Henry Holt.
- Murray, K. D. (1995). Narratology. In J. A. Smith, R. Harré & L. Van Langenhove (Eds.), *Rethinking psychology* (pp. 179-195). London: Sage.
- Murray, M. (1997). A narrative approach to health psychology: Background and potential. *Journal of Health Psychology*, 2, 9-20.

Murray, M. (1999). The storied nature of health and illness. In M. Murray, & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp. 83-97). London: Sage.

Murray, M. (2000). Levels of narrative: Analysis in health psychology. *Journal of Health Psychology, 5*, 337-347.

Ng, K. K. P., Howard, R. S., Fish, D. R., Hirsch, N. P., Wiles, C. M., Murray, N. M. F., & Millar, D. H. (1995). Management and outcome of severe Guillain-Barré syndrome. *Quarterly Journal of Medicine, 88*, 243-250.

Nurmikko, T. (2000). *Mechanisms and treatment of pain in GBS & CIDP*. Retrieved December 28, 2000, from <http://www.gbs.org.uk/rep2000.html>.

O'Conner, K., & Chamberlain, K. (2000). Dimensions and discourses of meaning in life: Approaching meaning from qualitative perspectives. In K. Chamberlain & G. T. Reker (Eds.), *Exploring existential: Optimizing human development across the life span* (pp.75-91). Thousand Oaks, CA: Sage.

O'Leary, A. (1990). Stress, emotion, and the human immune function. *Psychological Bulletin, 108*, 363-382.

Parry, G. J. (1993). *Guillain-Barré Syndrome*. New York: Thieme Medical Publishers.

Parry, G. J. (1999, Spring). Guillain-Barré Syndrome and the autonomic nervous system [Special issue]. *The Communicator, 4-5*.

Parry, G. J. (2000, Spring). Residual effects following Guillain-Barré. *The Communicator*. Retrieved December 28, 2000, from <http://www.webmast.guillain-barre.com/news>.

Pleasure, D. (1999). Immunological and infectious disease of the peripheral nerves [Review of the book *Immunological and infectious disease of the peripheral nerves*]. *The New England Journal of Medicine, 340*, 325.

Polkinghorne, D. (1988). *Narrative knowing and the human sciences*. Albany, New York: State University of New York Press.

Polkinghorne, D. F. (1995). Narrative configuration in qualitative analysis. *Qualitative Studies in Education, 8*, 5-23.

- Powell, J. (2000). *Emotional aspects of GBS*. Retrieved December 28, 2000, from <http://www.gbs.org.uk/aftergbs.html>.
- Prince, G. (1982). *Narratology: the form and functioning of narrative*. Berlin: Walter de Gruyter & Co.
- Reissman, C. K. (1993). *Narrative analysis*. Newbury Park, CA: Sage.
- Reker, G. T. (2000). Theoretical perspective, dimensions and measurement of existential meaning. In K. Chamberlain & G. T. Reker (Eds.), *Exploring existential: Optimizing human development across the life span* (pp.39-55). Thousand Oaks, CA: Sage.
- Renaud, A. (2000). People with Guillain-Barré Syndrome: Biopsychosocial impact (A first New Zealand survey). Unpublished master's thesis, Massey University, Palmerston North, New Zealand.
- Robinson, I. (1990). Personal narratives, social careers and medical courses: Analyzing life trajectories in autobiographies of people with Multiple Sclerosis. *Social Science and Medicine*, 30, 1173-1186.
- Ropper, A. H. (1992). The Guillain-Barré Syndrome. *The New England Journal of Medicine*, 326, 1130-1136.
- Ropper, A. H. (1998, Winter). Pain in Guillain-Barré Syndrome [Special issue]. *The Communicator*. 2-3.
- Ryff, C. D., & Singer, B. (1998). The role of purpose in life and personal growth in positive human health. In P. T. Wong & P. S. Fry (Eds.), *The human quest for meaning: A handbook of psychological research and clinical application* (pp. 213-235). New Jersey: Lawrence Erlbaum Associates.
- Sacks, O. (1985). *The man who mistook his wife for a hat*. London: Picador.
- Sacks, O. (1989). *Seeing voices*. London: Picador.
- Sacks, O. (1991). *Awakenings*. London: Picador.
- Sacks, O. (1995). *An anthropologist from mars*. London: Picador.
- Sacks, O. (1996). *The island of the colour blind*. London: Picador.

Sarbin, T. S. (1986). The narrative as a root metaphor for psychology. In T. R. Sarbin (Ed.), *Narrative psychology: The storied nature of human conduct* (pp. 3-21). Westport, CT: Praeger.

Sheets-Johnstone, M. (2000). The psychology of what is and what should be. [Review of the book *Maps of meaning: The architecture of belief*]. *Psychology*, *11*, 124.

Smith, M. M., Collins, A. F., Morris, P. E., & Levy, P. (1995). *Cognition in action* (2nd ed.). Hove: Lawrence Erlbaum Associates.

Sommer K. L., & Baumeister, R. F. (1998). The construction of meaning from life events: Empirical studies of personal narratives. In P. T. Wong & P. S. Fry (Eds.), *The human quest for meaning: A handbook of psychological research and clinical application* (pp. 143-161). New Jersey: Lawrence Erlbaum Associates.

Spink, M-J. P. (1999). Making sense of illness experience: Integrating the cultural-historical and local-situated levels for understanding meaning. In M. Murray, & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp. 83-97). London: Sage.

Steinberg, J. (1997, Fall). The Guillain-Barré Syndrome: A family of disorders. *The Communicator*. 6.

Steinberg, J. (1998). Guillain-Barré Syndrome: Acute Idiopathic Polyneuritis and chronic inflammatory polyneuropathy (8th ed.). Wynnewood, PA: Guillain-Barré Syndrome Foundation International.

Steinberg, J. (2001, Spring). Can Guillain-Barré Syndrome recur? *The Communicator*. 4.

Taylor, S. E. (1990). Health psychology: The science and the field. *American Psychologist*, *45*, 40-50.

The Italian Guillain-Barré Study Group. (1996). The prognosis and main prognostic indicators of Guillain-Barré syndrome: A multicentre prospective study of 297 patients. *Brain*, *119*, 2053-2061.

Weiten, W. (1995). *Psychology: Themes and variations* (3rd ed.). Pacific Grove, CA: Brooks/Cole.

Wherry, J. N., McMillan, S. L., & Hutchison, H. T. (1991). Differential diagnosis and

treatment of conversion disorder and Guillain-Barré Syndrome. *Clinical Pediatrics*, 30, 578-585.

Winer, J. (2000). *CIDP aftercare*. Retrieved December 28, 2000, from <http://www.gbs.org.uk/rep2000.html>.

Wright, P., & Treacher, A. (1982). Introduction. In P. Wright & A. Treacher (Eds.), *The problem of medical knowledge* (pp. 1-22). Edinburgh: Edinburgh University Press.

Zeldow, P. B., & Pavlou, M. (1984). Physical disability, life stress and psychosocial adjustment in multiple sclerosis. *Journal of Nervous and mental Disease*, 172, 80-84.

Zika, S. C. (1996). *Psychosocial correlates of the short term of multiple sclerosis*. Unpublished doctoral dissertation, Massey University. Palmerston North.