Relationships Between Depression, Anxiety, and Residual Problems Following

Recovery From Guillain-Barré Syndrome: A New Zealand Survey

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Abstract

The present study retrospectively examined the relationships between mental status and residual problems following recovery from Guillain-Barré Syndrome (GBS), and investigated whether depression and anxiety were common post GBS sequelae. Participants were drawn from past and present GBS patients who read about the postal survey in the newsletter of the New Zealand GBS Support Group. Of the 49 adults who responded, 44 individuals completed and returned the questionnaires sent to them via the Support Group Co-ordinator. The set of 4 questionnaires comprised (a) a brief questionnaire about GBS, (b) the McMaster Health Index Questionnaire (MHIQ), a generic quality of life instrument that measures physical, social, and emotional functioning, (c) the Beck Depression Inventory-II (BDI-II), and (d) the 6-Item Short Form of the State Scale of the State-Trait Anxiety Inventory (STAI-6). The MHIQ was completed twice, retrospectively from the point in time when GBS was most severe, and from the present point in time. The results showed that half the sample were acutely ill over 6 years ago, yet the majority of the sample reported a number of residual problems with varying levels of severity. Time since diagnosis did not appear to moderate the number or severity of residuals. Fatigue was the most common residual (93.2%), but pain and motor-related problems were also common. The majority of participants scored within the minimal depression and anxiety ranges on the BDI-II and the STAI-6, suggesting that depression and anxiety were not common long-lasting sequelae to GBS in this sample. Future research using a prospective design could focus on the incidence of depression and anxiety during the actual recovery phase. A study that focussed on the perspectives of caregivers and families would also add important information to the small body of literature regarding the psychosocial aspects of GBS.

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Chapter 1

Introduction and Overview

Guillain-Barré Syndrome (GBS) is described by Meythaler, DeVivo, and Braswell (1997) as "an immunopathy associated with an acute, often fulminate, evolution of a demyelinating inflammatory polyradiculoneuropathy" (p.411). GBS is now widely believed to be a diverse disorder that includes both demyelinating and axonal forms (Ho & Griffin, 1999). According to Lennon, Koblar, Hughes, Goeller, and Riser (1993), its annual incidence is 1-2 per 100,000 people. In the United States, this translates to about 5,000 new cases annually (Meythaler et al., 1997), and it is thought to be the most common cause of acute neuromuscular paralysis in developed countries.

Ho and Griffin (1999) note that because GBS is a heterogenous disorder, widely different clinical manifestations are reported. In general, most people who suffer from GBS do recover fully (Lennon et al., 1993); however, a significant proportion of individuals are left with varying degrees of residual deficits. Of the percentage who experience residual effects as a result of GBS, Meythaler et al. (1997) estimate that there may be anywhere from 25,000 to 50,000 individuals in the United States who currently have some form of long term disability secondary to GBS.

In recent years, a large body of literature about GBS and related disorders has developed. The majority of the literature, however, originates from countries other than New Zealand. To date, there are no published studies regarding the incidence or the sequelae to GBS in New Zealand. A recent attempt to address this gap has been carried out by Renaud (2000). As a result of this study, a profile of people who have had GBS in New Zealand is now available. Other than this ground-breaking

study, a search of the local literature revealed only a few individual case reports regarding New Zealand patients with GBS (Heaton, 1992; Nagappan & Barker, 1998). Both of these reports focussed mainly on the treatment of GBS.

Like the New Zealand literature, much of the existing international literature about GBS focuses on the clinical aspects of the disease, such as suspected etiologies or treatments (Asbury & McKhann, 1997; McCarthy, Andersson, Jormanainen, Gustavsson, & Giesecke, 1999). Only a handful of studies have considered the recovery and rehabilitation process following GBS, and even these focus mainly on the physical side of recovery (Lennon et al., 1993; Meythaler et al., 1997). The psychological and emotional impact of GBS has not been studied in depth. Given that GBS can create permanent adverse changes in a person's life, it seems reasonable to speculate that there are likely to be some psychological and emotional effects in addition to the well documented physical ones. For example, depression or anxiety may be outcomes of having to adapt to reduced physical abilities following GBS.

The purpose of the present study was to explore whether depression or anxiety are commonly experienced following GBS in a sample of New Zealand men and women who have experienced the disease. More specifically, the present investigation aimed to find out if mental status is correlated with an individual's residual effects of GBS. Residual effects were identified by each individual, and in general were shown to be of a physical or sensory nature. Individuals subjectively rated their residual effects as mild, moderate, or severe. Further questions about the severity and the course of the illness were asked in a questionnaire specifically designed for the present study. Mental status was measured by using psychometric measures of depression, anxiety, and a generic quality of life measure.

Chapter 2 presents an overview of the history of GBS followed by a section on current knowledge about its heterogenous nature, and its specific variants. The clinical features of GBS and the suspected etiologies are discussed, and this is followed by a section on the different treatments. The prognostic factors involved in recovery are outlined next, followed by a discussion about the process of physical rehabilitation during recovery from GBS. Chapter 2 concludes with a discussion of the various residual problems experienced both during and beyond recovery from GBS.

Chapter 3 examines the recent literature regarding psychosocial factors in general illness and recovery, and this concludes with a rationale for the present study. Chapters 4 to 6 cover the method, results and discussion sections. Chapter 7 discusses the limitations of the present study, outlines the conclusions, and makes some recommendations for future study.

Chapter 2

History of Guillain-Barré Syndrome and Current Knowledge

In 1859 Octave Landry reported a condition of a patient that he called 'acute ascending paralysis'(Pascuzzi & Fleck, 1997), which due to the absence of any changes in the central nervous system he attributed to a peripheral nerve disease (Ho & Griffin, 1999). Other similar cases were reported in the late nineteenth century, but it was only in 1916 following the earlier advent of diagnostic lumbar puncture that Guillain, Barré, and Strohl were able to codify the syndrome of relatively symmetrical, rapidly evolving, flaccid paralysis, areflexia (absence of reflexes), and elevated levels of spinal fluid without cells (Asbury, 1990). Pascuzzi and Fleck (1997) note that although the general clinical observations of the disease are attributed to Guillain and Barré, their colleague, Strohl, is thought to have been responsible for the electrophysiologic aspects. The initial report by Guillain, Barré, and Strohl about the two infantrymen who were affected by the disease was soon followed by description of other similar case reports, and the syndrome came to be known by its eponym of Guillain-Barré Syndrome (GBS).

Over the next decades, a series of reports and pathological studies helped to build a clearer clinical picture of the disease (Asbury, 1990). In 1955, a condition known as experimental allergic neuritis (EAN) was described by Waksman and Adams (Asbury, 1990) as a disorder induced in animals by immunisation with whole myelin or parts of specific peripheral nervous system myelin protein. EAN appeared to share similar clinical features and inflammatory lesions to GBS (Ropper, 1992). The pathogenesis of EAN was thought to be a T cell-mediated immune attack on myelin proteins (Ho & Griffin, 1999), and because of its close resemblance to GBS, it was assumed that GBS was also T cell-mediated.

The EAN analogy was endorsed by Asbury, Arnason, and Adams (1955, cited in Ho & Griffin, 1999) in their autopsy findings of 19 patients who had died of GBS. As a result of their findings, these authors identified lymphocytic infiltration and macrophage-mediated demyelination as being two important characteristic features of the early pathology of GBS. Following this discovery, the pathologic term 'acute inflammatory demyelinating polyneuropathy' (AIDP) became synonymous with the clinical term, Guillain-Barré Syndrome.

In 1956, a further variant of the disease was described in a publication by C. Miller Fisher (Pascuzzi & Fleck, 1997). Characteristics of this variant were ophthalmoplegia (paralysis of the eye muscles), ataxia (failure of muscular co-ordination), and areflexia. This variant has since been given the eponym of Fisher's Syndrome and accounts for approximately 5% of GBS cases.

In 1978 initial diagnostic criteria for GBS were devised (Asbury & Cornblath, 1990). These authors note that the basis for diagnosis of GBS can only be made in descriptive terms, due to the present state of knowledge about the disease. Diagnosis of GBS is based on clinical, laboratory, and electrodiagnostic criteria. The key features identified by Asbury, Arnason, Karp, and McFarlin (1978, cited in Asbury & Cornblath, 1990) for a diagnosis of GBS are reproduced in Appendix 1.

Current Knowledge About Guillain-Barré Syndrome

Until recently, GBS was believed to be a single disorder in spite of the fact that some cases did not fit the profile of the so-called Acute Inflammatory Demyelinating Polyneuropathy (AIDP) type (Asbury & McKhann, 1997). Investigations into GBS over the past 10 years, however, have provided new insights that seriously challenge previous

assumptions about the resemblance of the pathogenesis of GBS to EAN (Bolton, 1995).

It now appears that the EAN analogy is not as fitting as previously believed (Asbury,

1990) and that the nature of the immune response to GBS is very complex.

Increasingly, GBS is now recognised as a heterogenous disorder that includes

both demyelinating and axonal forms. In fact, Hughes, Haddon, Gregson, and Smith

(1999) argue that GBS is best considered as a spectrum of different disorders affecting

different portions of the peripheral nervous system and having different temporal

courses. This argument is supported by the classification of different variants according

to clinical, electrophysiologic, and pathologic criteria (Lu et al., 2000). While

classification of GBS into demyelinating and axonal types is now widely accepted and

used, Lu et al. (2000) note that there is some controversy about the capability of

electrodiagnostic testing to predict and distinguish between the pathology of the two

types. In spite of this, however, it is now accepted that severe inflammation can induce a

secondary axonal degeneration in the demyelinating form of GBS.

Hahn (1998) describes four main variants of GBS. The first, AIDP, refers to the

form that involves lymphocytic infiltration of spinal roots and peripheral nerves and the

subsequent macrophage-mediated segmental stripping of myelin. This causes severe

disruption to the propagation of nerve impulses, which ultimately results in nerve

conduction block and flaccid paralysis. Hahn describes AIDP as "a reactive, self-limited,

autoimmune disease" (p.637) that in most cases results in complete recovery from the

flaccid paralysis once the process of remyelination sets in. In some patients, however,

the inflammatory demyelination can be accompanied by a loss of nerve axons. This is

thought to be a secondary 'bystander' effect that results from the severe inflammation,

oedema, and swelling of nerves. Axonal loss is a key determinant in the speed of

recovery and the residual problems during the recovery process. AIDP is most common in Western countries, accounting for 85-90% of all cases of GBS (Hahn, 1998).

Another variant of GBS in which both motor and sensory fibres are affected has been described in more recent years. This variant is referred to as Acute Motor Sensory Axonal Neuropathy (ASMAN). Hahn (1998) states that there is now evidence to support the hypothesis that this variant of GBS involves a primary immune attack on motor and sensory nerve axons themselves. In such cases, the disease has been notable for the fulminant onset of severe paralysis and sensory deficits, resulting in severe muscle atrophy, with delayed and often poor recovery (Hahn, 1998). This clinical pattern is most often seen in Northern China, perhaps suggesting a genetic predisposition to a particular form of the syndrome. Environmental factors, such as diet, could also be involved.

GBS can also be characterised by weakness without sensory deficit (Lu et al., 2000). In this particular variant of GBS, electrophysiologic findings show reduced amplitude of compound muscle action potentials without any sign of demyelination, and sensory nerve conduction appears normal. This variant is referred to as Acute Motor Axonal Neuropathy (AMAN). Hahn (1998) reports that findings from studies of patients with the AMAN variant of GBS suggest that the axonal degeneration primarily involves motor-nerve terminals. Sporadic AMAN cases have been observed worldwide, representing between 10-20% of GBS patients (Hahn, 1998). Timespan of recovery varies in patients with the AMAN variant of GBS according to the severity of the axonal destruction and the vigorousness of the immune response.

Yet another variant of GBS is that referred to as the Miller Fisher Syndrome (MFS). This is described by Ropper (1992) as the most common but most aberrant of

the many variations in clinical presentation. MFS has distinct immunological and pathological features (Hahn, 1998) which involve ophthalmoplegia, ataxia, and areflexia but with little weakness (Ropper, 1992). This variant accounts for approximately 5% of patients with GBS, and is known to be triggered by certain *campylobacter jejuni* strains (Hahn, 1998), a pathogenic type of bacterium that invades the intestine, commonly causing bacterially induced diarrhoea.

Clinical Features of Guillain-Barré Syndrome

Prior to the actual onset of symptoms of GBS, a patient will often experience an acute respiratory or gastrointestinal illness that may last for several days before resolving (Pascuzzi & Fleck, 1997). One to two weeks later, this is followed by the development of an ascending paralysis. Acute GBS usually begins with fine paraesthesiae (abnormal sensations) in the toes or fingertips (Ropper, 1992). Generally, this is followed by progressive muscle weakness (Blanco & Cuomo, 1983) over the next few days. The paraesthesiae most often occur in a distal to proximal fashion, spreading from the extremities to the more proximal regions, such as the face. Weakness often ascends from the thighs to the arms in just a few days (Ropper, 1992) but sometimes footdrop or hand weakness may occur first. Patients usually report generalised pain (Blanco & Cuomo, 1983), although localised pain is often reported, particularly in the large muscles of the upper legs, flanks, or back (Ropper, 1992).

Initial examination of patients often shows a symmetric limb weakness with bilateral weakness of facial muscles in some patients (Ropper, 1992). An absence of, or diminished tendon reflexes can also occur. As the disease progresses, bowel and bladder function can be altered (Blanco & Cuomo, 1983), and in severe cases the disease will

progress to the point where respiration, eye movements, deglutition (the act of swallowing), cranial nerve disturbance, and autonomic function are affected (de Jager & Sluiter, 1991; Ropper, 1992; Zochodne, 1994). Taste loss is a very rare complaint in GBS, but it has been reported occasionally in association with severe facial nerve involvement in advanced cases (Combarros, Pascual, de Pablos, Ortega, & Berciano, 1996).

Approximately one third to one half of all GBS patients require mechanical ventilation due to severe paralysis and respiratory insufficiency (de Jager & Sluiter, 1991; Pascuzzi & Fleck, 1997). With prolonged paralysis, tracheostomy (the operative formation of an opening into the trachea through the neck) is usually performed (Blanco & Cuomo, 1983). Length of time spent on mechanical ventilation varies according to the severity of the attack.

According to de Jager and Sluiter (1991), the course of the disease can be divided into three parts. The first of these is the progressive phase, which begins with the first symptoms and lasts until the disease stops progressing. Pascuzzi and Fleck (1997) state that approximately 50% of GBS patients reach maximal weakness within one week of the onset of the illness, and 80% will have reached maximal weakness within three weeks.

The second phase is referred to as the plateau phase, the point at which the disease has reached its nadir and is no longer progressing. Pascuzzi and Fleck (1997) report that most patients tend to plateau for two to four weeks once the progression of the disease stops.

The third phase is the recovery phase, which lasts from the end of the plateau phase and continues until recovery ends. According to Pascuzzi and Fleck (1997), about

85% of patients are ambulatory within six months of the onset of GBS. Many patients, however, will experience residual problems long beyond this point. A detailed discussion about common residual problems experienced by GBS patients will follow in a later section, but at this point it is important to gain some understanding of the causes of the various types of GBS.

Etiologies of Guillain-Barré Syndrome

Just as GBS is a heterogenous disorder, so, too, are the suspected etiologies. Research in recent years has focussed on trying to locate a specific etiology for GBS, but as yet there are no real answers. What is known, is that there are often a range of antecedent events that precede the onset of the disorder. Whether these events actually trigger the disease is not entirely clear, although several authorities suggest that GBS occurs as a consequence of an immune response to the antecedent event (e.g., Rees, Soudain, Gregson, & Hughes, 1995). In approximately two thirds of all GBS patients, symptoms will follow an infection, often a mild undiagnosed gastrointestinal or respiratory illness. The organism that has most frequently been associated with GBS is *campylobacter jejuni*, the most common cause of bacterial gastroenteritis in developed countries (Rees et al., 1995). While many published findings have reported an association between GBS and *campylobacter jejuni* infection, the magnitude of the risk of becoming ill with GBS following this infection is believed to be low (McCarthy et al., 1999). This assertion is based on a study of three populations where outbreaks of *campylobacter jejuni* had occurred, involving an estimated 8000 cases. McCarthy et al. (1999) reported a maximum likelihood estimate, with a 95% confidence interval, of not more than 3 cases of GBS following 8000 cases of *campylobacter jejuni* infection. The

study by McCarthy et al., however, was based on just three outbreaks of *campylobacter jejuni,* which may only have involved a few *campylobacter* serotypes. These authors note that GBS may vary according to serotype. According to Hughes et al. (1999), there is some support for the idea that there may be a causal relationship between the involvement of specific uncommon variants of *campylobacter jejuni* and the development of GBS. The exact nature of the particular property of the organism responsible for the induction of GBS is yet to be identified.

In the study by Rees et al. (1995), there was evidence that 26% of the cohort of GBS patients had had a prior *campylobacter jejuni* infection. These authors believe that the true incidence of antecedent *campylobacter jejuni* infection is likely to be far higher than 26%, but may have been underestimated in their study and in earlier studies due to the limitations of the type of testing used. If this is so, according to Rees et al., *campylobacter jejuni* would become the most common single identifiable pathogen in GBS.

Several studies have reported a poorer prognosis and longer recovery times for GBS patients who had a prior *campylobacter jejuni* infection (Pascuzzi & Fleck, 1997; Rees et al., 1995). In these patients, a tendency to have predominantly axonal neuropathy as opposed to demyelinating neuropathy has been reported (Pascuzzi & Fleck, 1997), although the spectrum of *campylobacter jejuni*-induced GBS can range from mild cases of demyelinating neuropathy through to rapidly progressive axonal neuropathy (Rees et al., 1995). It seems to be those patients at the severe end of the spectrum who experience the most serious residual problems and delayed recoveries.

Other antecedent events reported to have occurred prior to onset of GBS symptoms include upper respiratory tract infections or a diarrhoea illness (Pascuzzi &

Fleck, 1997). Occasionally, pneumonia may precede onset of GBS symptoms, and infection with the Epstein-Barr virus has also been implicated (Hughes et al., 1999; Ropper, 1992). In other cases, a range of miscellaneous antecedent events such as Hodgkin's disease, systemic lupus, viral hepatitis, cytomegalovirus, and surgery have also been reported (Maier, Schmidbauer, Pfausler, Schmutzhard, & Budka, 1997; Pascuzzi & Fleck, 1997; Ropper, 1992). In spite of the relatively high incidence of an antecedent event prior to onset of GBS, it is important to note that in approximately one third of all cases, no antecedent event is reported. To date, no satisfactory explanation accounts for this fact.

In recent years there has been much debate about the role of vaccines in the etiology of GBS. The link between vaccines and subsequent GBS was first made in 1976 following an excessive number of reported GBS cases among recipients of the A/New Jersey/8/76 (swine flu) vaccine (Safranek et al., 1991). This vaccine was administered to 45 million people in the USA between October 1st and December 16th 1976 (Kurland, Wiederholt, Kirkpatrick, Potter, & Armstrong, 1985). Following this, 1,100 cases of GBS were reported to the Centre for Disease Control, 532 of whom had been vaccinated. There was a marked increase in the rate of GBS for the vaccinated individuals during the first six to eight weeks following the vaccination, which peaked during the third week. The temporal association between administration of the swine flu vaccine and onset of GBS symptoms was regarded as strong evidence of a causal relationship. Kurland et al. (1985), however, were concerned that this assumption of causality was based on data from a single study that was conducted during a hectic and much publicised programme, beginning just before a moratorium on the immunisations. These authors were concerned that no standardised evaluation of the reported 1,100

cases had been undertaken by a neurologist, yet all but two had been certified by the Centre for Disease Control as GBS. Furthermore, diagnostic criteria had not been established to guide and assist health officers with correct diagnosis. Systematic follow-up of cases did not occur, so there was no means of checking whether correct diagnosis had been made. On the basis of these concerns, Kurland et al. recommended a review of the medical records of the 1,098 'certified' GBS cases by a panel of neurologists with expertise in diagnosing the disease. This review was carried out, and the results supported the association between the vaccine and GBS.

In spite of this finding, controversy about this association has persisted. To address this controversy, Safranek et al. (1991) reassessed the association between GBS and the 1976-1977 swine flu vaccine. The objective of this study was to identify all vaccinated or non-vaccinated GBS patients from Michigan and Minnesota with onset of symptoms between October 1st 1976 and January 31st 1977. These two states represented approximately 10% of the 1,098 cases in the original study. After reviewing medical records from the 98 cases in the two states, Safranek et al. found that there was a significant increase in the incidence of GBS reported in the vaccinated adult population compared to the non-vaccinated adult population. These authors argue that the non-random onset of symptoms within six weeks of vaccination strongly implicates some as yet unidentified causative role attributable to the vaccine or to the circumstances related to the immunisation programme.

In the years following the 1976 association between GBS and the swine flu vaccine, subsequent studies found low relative risks between 1978 and 1988 (Lasky et al., 1998). An increased risk was found in North America for vaccinated individuals aged between 18 and 64 years in the 1990-1991 influenza season, but not in individuals

aged over 65 years. During the 1993-1994 influenza season, an increase in the number

of GBS cases following receipt of influenza vaccine was reported to the Centre for

Disease Control. Following this reported increase, a collaborative investigation

involving four states in North America was undertaken. After controlling for age, sex,

and season, there was found to be a slightly higher risk of GBS following influenza

vaccination. Lasky et al. (1998) suggest that the increase in reports of GBS following

receipt of the 1993-1994 influenza vaccine was probably due to an increase in influenza

vaccine coverage, as well as an increase in baseline incidence of GBS, rather than due to

an increase in vaccine-specific risk. Overall, the data from the study by Lasky et al.

suggest that there may have been a small risk of GBS associated with influenza vaccines

in both 1992-1993 and 1993-1994.

The role of other vaccines in the etiology of GBS has also been the subject of

research. Over the years there have been many anecdotal case reports that have linked

GBS to a range of vaccines, usually because of a temporal association between receipt of

the vaccine and onset of GBS symptoms (Hahn, 1998). Two reports from Finland

suggested an association between GBS and oral poliovaccine (Salisbury, 1998) following

a national oral poliovaccine campaign there during 1985. The evidence suggests,

however, that the incidence of GBS cases during that time had already started to increase

prior to the oral poliovaccine campaign. It seems possible, then, that this increase could

be explained by other factors, such as an influenza epidemic which occurred during the

same time period, or the circulation of wild poliovirus.

Reports of GBS following measles vaccinations have also been investigated (da

Silveira, Salisbury, & de Quadros, 1997), but a study of GBS cases from 1990 to 1994

across four South American countries showed that there was no association between

administration of measles vaccine and GBS. This study involved data from the vaccination of more than seventy million children. Da Silveira et al. (1997) concluded that the number of GBS cases due to measles vaccination must be very small, since they failed to detect a rise in GBS above the expected number. A study by Hughes, Rees, Smeeton, and Winer (1996) looked at the possible association between measles vaccine and GBS, but this time in the United Kingdom. Hughes et al. reported that the findings from their case-control studies and the literature do not suggest that there is any increased risk of GBS after measles vaccines currently used in the United Kingdom.

Although the etiologies of GBS are diverse, the same treatments are usually provided. An historical overview of treatments for GBS is presented next, followed by a discussion about the preferred current treatments.

Treatments for Guillain-Barré Syndrome

Ropper (1992) notes that the two most important advances in the treatment of GBS were introduced during the European poliomyelitis epidemics in the 1950s. These were positive-pressure ventilation (a machine which blows air into the lungs of the patient via an intratracheal tube or tracheostomy), and the improved respiratory and medical practices in intensive care units. These two advances allowed patients who suffered complications from immobilisation and respiratory failure to survive and recover from paralysis. As a result, the mortality rate from GBS was sharply reduced.

Historically, corticosteroids were the treatment of choice in acute GBS, and in spite of a lack of evidence of any beneficial effect, they were the mainstay of treatment for 50 years or so (Ropper, 1992). Two randomised, controlled trials in 1978 and 1991 showed there to be no benefit from the use of corticosteroids in the treatment of GBS,

and it has now been widely accepted that this is not a useful treatment for GBS (Ropper, 1992).

In recent years, alternative treatments have been found to be more useful. In 1978, the first report regarding the efficacy of plasmapheresis in acute GBS was published (Pascuzzi & Fleck, 1997) and since then, several studies have corroborated its usefulness (McKhann, 1990). Plasmapheresis has the effect of removing potentially pathogenic soluble factors from the circulation (Hartung, Pollard, Harvey, & Toyka, 1995). In GBS, some of the pathogenic factors implicated are thought to be antibodies, cytokines, or other soluble mediators. The process of plasmapheresis involves removal of some of the patient's blood, separation of the liquid part, and the return of the blood cells to the body (Steinberg, 1998). The procedure involves the withdrawal of blood via an intravenous line in one arm and the return of the blood via a second intravenous line in the other arm. The process takes 2-3 hours, and the exchange rate would normally be a total of 200-250 ml per kilogram of body weight. Plasmapheresis is usually carried out over a period of seven to fourteen days (Steinberg, 1998).

Plasma exchange has been found to be most effective if treatment is begun within two weeks of onset of illness (Ropper, 1992). Although some patients may have relapses between the second and fourth weeks following treatment with plasma exchange, these relapses are reportedly responsive to further plasma exchanges (McKhann, 1990). Studies have shown that plasmapheresis shortens the length of time by half that patients require mechanical ventilation (Ropper, 1992), and that they achieve independent walking earlier (McKhann, 1990). A drawback of plasmapheresis is that special equipment is required which may only be available at large hospitals (Steinberg, 1998).

In 1988 and 1989, reports were published about the efficacy of high-dose
intravenous immune globulins (IVIG), or gamma globulin, in the treatment of patients
with severe GBS (Pascuzzi & Fleck 1997; Steinberg, 1998). The use of IVIG as a
treatment for GBS followed the observation that beneficial effects had been found using
infusions of IVIG to treat other immunologically mediated diseases, such as the chronic
inflammatory form of demyelinating polyneuropathy (McKhann, 1990; Ropper, 1992).
One study which compared the use of IVIG and plasma exchange in the treatment of
GBS found that not only was IVIG at least as effective as plasma exchange, but that
more patients who received IVIG improved at a faster rate, and were discharged from
hospital on average two weeks earlier than those who received plasma exchange (van der
Meché, Schmitz, & The Dutch Guillain-Barré Study Group, 1992). In 1994, a pilot
study by the Dutch Guillain-Barré Study Group trialed the use of IVIG combined with
methylprednisolone (MP), and the results suggested that the combined IVIG-MP
treatment was more effective than IVIG alone. A later study by Korinthenberg and
Schulte-Mönting (1996) in childhood GBS, however, did not find any indication that the
combination of MP with IVIG increased the effectiveness of the treatment.

Although the mechanisms by which immunoglobulins alter disease are not yet
entirely clear (Misbah & Chapel, 1993), the most recent research suggests that
intravenous immunoglobulins can interfere with the immune system at several levels; for
example, inhibition of complement binding and membrane attack, and that they may also
promote remyelination in demyelinating disease associated with viral infections (Hadden
& Hughes, 1999; Stangel, Toyka, & Gold, 1999). IVIG is now used as a treatment for a
range of demyelinating neuropathies, neuromuscular transmission defects, and
inflammatory myopathies. According to Dalakas (1999), for each disorder there appears

to be a predominant mechanism dictated by the underlying immunopathogenetic cause relevant to that specific disorder. In GBS, although the target antigen is as yet unknown, both humoral and cellular immune mechanisms are believed to be implicated.

The issue of the preferred treatment, that is, plasma exchange versus IVIG, has been the subject of much debate in recent years. According to Dalakas (1999), the central issue is one of convenience and practicality given their similar efficacy and cost. In general, IVIG may be preferred for patients in rural areas as plasma exchange is not likely to be available in smaller centres. IVIG is also easier to administer (Hahn, 1998; Steinberg, 1998) and does not require the specialised equipment or level of training that administration of plasma exchange requires. Hughes (1996) argues that IVIG is likely to be safer than plasmapheresis for patients with autonomic instability and nosocomial infections, both of which commonly occur in GBS. Plasmapheresis can be hazardous under these circumstances (Hartung et al., 1995), and it can not be used with patients who have suffered a recent myocardial infarction, angina, or who have active sepsis (Ropper, 1992).

Mild adverse reactions to IVIG also occur, and may include headaches, flushing, low backache, nausea, and wheezing (Misbah & Chapel, 1993). Such reactions are often associated with the rate of the infusion, and reportedly abate when the infusion rate is slowed down. Adverse skin reactions have also been reported occasionally and are thought to be an allergic reaction to the IVIG (Hamdalla, Hawkes, Spokes, Bamford, & Goulding, 1996). In rare cases, severe immunological reactions to IVIG have been reported, including aseptic meningitis, thromboembolic stroke, and renal failure (Korinthenberg & Schulte-Mönting, 1996).

Despite the risks associated with both plasma exchange and IVIG, the vast majority of GBS patients respond well to either of these treatments. If plasma exchange or IVIG is provided within the early stages of the disease, several studies have shown that recovery from GBS is hastened (e.g., van der Meché et al., 1992). The next section discusses some of the prognostic factors associated with recovery from GBS.

Recovery From Guillain-Barré Syndrome: Prognostic Factors

For many GBS patients, recovery is spontaneous and there are no, or at most few, residual problems (Zelig et al., 1988). For a significant number, however, the outcome is not so positive and patients are left with residual disabilities of varying severity. Winer, Greenwood, Hughes, Perkin, and Healy (1985) estimate that approximately 16% of GBS patients are left with residual functional deficits that may persist for some time and which frequently become permanent disabilities.

In their study of 71 patients with GBS, Winer et al. (1985) found that poor outcome was associated with three main clinical features. These included a deficit severe enough to require ventilation (80% of those patients with poor outcome), failure to start improving within one month of onset (80% of those patients with poor outcome), and an interval of more than three weeks from maximum deficit to onset of improvement (60% of those patients with poor outcome). Poor prognosis has also been linked to particularly severe motor deficit, with a greater risk of residual disability (Winer et al., 1985).

In a recent study by the Italian Guillain-Barré Study Group (1996), recovery was found to be adversely affected by increasing age, disease severity, and by the presence of electrophysiological features of axonal damage. According to Ho et al. (1997), recovery

from axonal forms of GBS will necessarily be slow and incomplete because axonal regeneration rarely exceeds 1mm/day in adults. In older adults, this rate may be even slower, due to poor axonal outgrowth and regeneration and less effective remyelination in the elderly (The Italian Guillain-Barré Study Group, 1996).

In addition to these prognostic factors, other factors are believed to influence outcome. A study by Ng et al. (1995) found that duration of disease nadir and duration of ventilation both correlated with outcome at three, six, and twelve month periods following onset of GBS. Type of antecedent illness has also been shown to be an important prognostic factor in recovery. The Italian Guillain-Barré Study Group (1996) found that recovery was slower following antecedent gastroenteritis illness such as *campylobacter jejuni*, whereas recovery was faster following antecedent influenza illnesses. This finding is consistent with those from earlier studies, where poorer prognosis and longer recovery times have been reported for GBS patients who had a prior *campylobacter jejuni* infection (Pascuzzi & Fleck, 1997; Rees et al., 1995). This is most likely to be due to the tendency for the neuropathy to be predominantly axonal rather than demyelinating.

Meythaler et al. (1997) note that, in spite of the significant numbers of GBS patients who experience residual disabilities, there is a lack of research in the area of rehabilitation outcomes. These authors argue that without proper assessment of the physical sequelae of GBS (including secondary medical complications), and without outcome studies on the psychosocial effects, the magnitude of the problem GBS presents will remain unknown. The next section will review the existing literature on the process of physical rehabilitation during recovery from GBS.

Physical Rehabilitation Following Guillain-Barré Syndrome

Ng et al. (1995) argue that early and aggressive physiotherapy intervention during the acute phase of GBS can lessen the risk of limb contractures and pressure sores due to paralysis. This involves frequent alteration of limb positioning, passive limb movements, and splinting where necessary. Once patients can achieve head control, even while mechanically ventilated, early mobilisation from bed to chair is encouraged.

Zelig et al. (1988) state that once GBS patients are weaned from the respirator, they must proceed slowly with physical rehabilitation. In general, rehabilitation will be gradual and will vary according to the severity of the disease. Rehabilitation will involve ambulation training and training in activities of daily living. Tempest-Roe (2000) emphasises that exercise during the recovery period should start slowly and gradually build up, as over-exercise will result in fatigue and setbacks.

Meythaler et al. (1997) note that rehabilitation approaches to GBS have been based on those associated with other illnesses. They point out that while comprehensive rehabilitation models providing a continuum of care have been developed for patients with spinal or traumatic brain injuries, no such model has been developed for GBS patients. This may well be due to the relatively low incidence of the disease. Whatever the case, the outcome is that rehabilitation for GBS patients is far from standardised. Lennon et al. (1993) point out that some patients receive intensive regimes of physiotherapy, hydrotherapy, and occupational therapy throughout their recovery as inpatients and outpatients while others only receive passive movements during the acute stage, or a supervised gym programme as an outpatient. There may be no attention paid to strengthening of specific muscle groups. In addition to physiotherapy during recovery

from GBS, Tempest-Roe (2000) stresses the importance of occupational therapy, and speech and language therapy for some patients.

In a personal account of her experience with GBS, Nancy Cuomo, a nurse, describes the terror she felt during the progressive phase of the disease (Blanco & Cuomo, 1983) and summarises her experience of GBS as 'devastating'. Blanco and Cuomo (1983) emphasise the need for medical staff to pay attention to the emotional needs of the patient and to ensure personal care is carried out regularly. They also highlight the important role families can play in participating in some aspects of patient care, for example, assisting with feeding, turning, and helping with physical and occupational therapy exercises.

A similar personal account of an experience with GBS is provided by a female medical practitioner who experienced what it was like to be a patient with this disease (Bowes, 1984). During the progressive phase of GBS, Bowes describes her terror as her condition deteriorated, and her anger towards nursing staff who did not always treat her with care or respect. Bowes identified encouragement from medical staff and support from family and friends as key factors during her recovery. Like Blanco and Cuomo (1983), Bowes emphasised the importance of attention to personal care by medical staff.

In a recently published personal account of his experience with GBS, Heywood (1999), a New Zealander, describes it as 'sheer hell'. A lack of information about the disease meant he and his wife had no idea about what to expect during the recovery process. Following his discharge from hospital, Heywood reported that no outpatient rehabilitation services were arranged for him, and it was only largely through his wife's efforts that outpatient physiotherapy was instigated.

Although many GBS patients make a full and spontaneous recovery, this is by no means the case for some. As many as 16% of GBS patients are left with residual disabilities ranging in degrees of severity. Some of these disabilities may persist permanently for some individuals. The next section discusses the nature of the residual problems experienced by GBS patients.

Residual Problems During Recovery From Guillain-Barré Syndrome

Even though a significant number of GBS patients experience residual disabilities, research in the area of rehabilitation outcomes for GBS patients is lacking (Lennon et al., 1993; Meythaler et al., 1997). Although a large body of literature exists regarding the clinical aspects of GBS, only a handful of studies have explored the residual problems experienced by many GBS patients during their recovery. In general, the most frequent residual effects of GBS include reduced mobility, muscle weakness, limb weakness, fatigue, pain, numbness, and tingling.

De Jager and Minderhoud (1991) argue that residual motor problems can be classified according to the difficulty for the patient, and list four such classifications as no difficulty, motor deficit but not bothersome, slight motor problems, and severe motor problems. In their study, de Jager and Minderhoud found that 65% of their sample of 57 patients with severe GBS were left with residual motor signs. According to these authors, between 15% and 30% of mild GBS cases experience residual motor problems, increasing to 70% in severe cases. Often, residual paresis can be found in all muscle groups; usually it is located distally in the lower limbs, but sometimes may involve the upper limbs (de Jager & Minderhoud, 1991).

Not uncommonly, GBS patients may experience unilateral facial palsy. Residual areflexia is also found in 10% to 45% of patients, and most often affects leg reflexes, such as ankle jerks (de Jager & Minderhoud, 1991). Residual sensory deficits are also experienced by as many as 30% of GBS patients; in the study by de Jager and Minderhoud (1991), half of the sample reported sensory deficits which were not confined to one typical nerve area.

Reasons for persistent disability were identified in a study by Lennon et al. (1993), based on their sample of 10 GBS patients. These were broadly identified as muscle weakness, sensory dysfunction, other medical conditions, contractures, fatigue, and psychological factors such as depression, anxiety, and reduced motivation. Lennon et al. (1993) argue that their study highlights the need for a higher profile to be given to the psychological aspects of recovery from GBS, as well as to community reintegration issues and vocational retraining (see also Renaud, 2000).

Fatigue has also been highlighted as a common residual complaint following GBS. Bernsen, de Jager, Schmitz, and van der Meché (1999) found in their follow up study of 122 patients three to six years after onset of GBS, that many patients reported persistent deficits in physical activity. Another recent study was conducted by Merkies, Schmitz, Samijn, van der Meché, and van Doorn (1999) to determine the severity and prevalence of ongoing fatigue following GBS. A finding from this study was that fatigue is a prominent and highly disabling sequelae to GBS. Fatigue was found to be independent of the time that had elapsed since the acute phase of the disease, and was not statistically significantly associated with variables such as the duration of the disease. On the basis of their findings, Merkies et al. argued that fatigue should be considered as a seriously disabling entity to GBS patients. Parry (personal communication, 11 April,

2000) attributes the cause of ongoing fatigue following GBS to the process of collateral sprouting of surviving axons. He argues that while this is a very effective means of restoring strength, fatigue is a result because the muscle must work harder to achieve its goals.

A second residual complaint following GBS that has received attention in the literature is pain. A study by Ropper and Shahani (1984) that analysed the clinical features of pain found that 55% of their sample of 29 GBS patients experienced pain early in the course of the disease. These authors argue that patients describe a pain that is characteristic of GBS and that this should aid in early diagnosis. In their sample, patients described discomfort in large proximal muscles in the lower back area, the buttocks, quadriceps, and hamstrings. They described the sensation of pain as similar to that which occurs the following day after vigorous exercise, and discriminated it as different to the pain that accompanies viral infections or direct muscle trauma.

In a clinical review of the literature on pain and GBS, Pentland and Donald (1994) note that the distinction between paraesthesiae (abnormal sensations such as burning or prickling) and dysaesthesiae (painful and persistent sensations induced by gentle touch) has often not been made, and until the last decade or so descriptions of paraesthesiae and pain are frequently found together. According to Pentland and Donald severe lumbar pain is a common presenting feature of GBS and often precedes weakness by days. Pain in the lumbar, thoracic, or cervical area may be transient or persistent. Neck pains associated with meningism (a condition due to pain in the meningeocortical region of the brain) have been noted in 37% of GBS cases (de Jager & Sluiter, 1991) and it is thought that the meningeal irritation occurs as a result of swelling around nerve roots. Joint pain has been reported by some GBS patients (Soryal, Sinclair, Hornby, &

Pentland, 1992, cited in Pentland & Donald, 1994), but it is unclear whether this is a primary or secondary phenomenon.

Pentland and Donald (1994) note that chest pains may occur in GBS as a result of autonomic dysfunction; blood pressure and heart rate are frequently affected by the disease. Constipation and urinary retention can also result in pain, as can abdominal pain from ulcers - a known complication in GBS. Other pain may result from pressure due to poor positioning while paralysed and painful medical procedures that may not always be carried out with sensitivity and care.

Pharmacological treatment for pain associated with GBS is varied and varying degrees of relief have been reported (Pentland & Donald, 1994). Tricyclic anti-depressants are used to treat dysaesthetic extremity pain. Moulin (1998) reports that corticosteroids such as methylprednisolone may relieve severe pain because of their anti-inflammatory effect at nerve root level. The importance of supportive measures alongside pharmacological treatments for controlling pain is highlighted by Moulin, Hagen, Feasby, Amireh, and Hahn (1997). Such measures include the use of air mattresses, padding over knees and elbows to prevent pressure palsies, and careful turning and positioning of patients.

In their prospective longitudinal survey of the character, intensity, and frequency of pain in a sample of 55 GBS patients, Moulin et al. (1997) found that 85% of the sample reported pain on admission to hospital. Of these, 47% described the pain as either distressing, horrible, or excruciating. On the basis of this study, Moulin et al. identified three discrete pain syndromes. The first involved a deep aching or throbbing pain in the lower back area that radiated into the buttocks, thighs, and calves. The second type involved dysaesthetic extremity pain, described as burning, tingling, or

shock-like. This type always included the legs and occasionally the upper extremities. The third and least frequently occurring type of pain syndrome was myalgic-rheumatic extremity pain, described as aching or cramping pain that was occasionally associated with joint stiffness. Pain in GBS is believed to be caused by the direct effects of injury to nerves, but it can also be an outcome of paralysis and subsequent immobilisation (Moulin, 1998).

Residual problems may persist for many months or even years (Tempest-Roe, 2000) following GBS, and may worsen during times of stress, illness, or tiredness. Despite these severe and disabling problems, there is surprisingly little research about the psychological and emotional impact of these during the recovery process. To counter this lack, Eisendrath, Matthay, Dunkel, Zimmerman, and Layzer (1983) conducted a prospective study of the psychosocial aspects of managing GBS during the progressive, plateau, and recovery phases of the disease. A finding from their sample of 10 patients was that six main psychosocial issues consistently arose. The first of these was the importance of being informed about the GBS process and outcome for both patients and their families. The second issue involved the importance of finding an effective means of communicating while paralysed. The third issue involved the need for a consistent standard of care by medical staff, and the need for an advocate to represent patient interests and to facilitate some control over their situation. The fourth issue involved fear and anxiety associated with ventilator failure and the tracheostomy procedure, highlighting a need for reassurance and explanations about procedures. The fifth issue was the need to effectively manage hallucinations and pain associated with GBS. All six issues were reported to be pertinent during the progressive phase of GBS, although management of hallucinations and pain were also identified as relevant to the plateau

phase. The sixth issue identified by Eisendrath et al. was that during the plateau phase patients exhibited emotional symptoms such as depression. Some patients expressed anger towards family and medical staff during this phase too. Depersonalisation was observed in some patients during the plateau phase, possibly due to a loss of social support from family and friends following the initial crisis phase.

During the recovery phase of GBS, Eisendrath et al. (1983) noted that recovery was frequently marked by reports of considerable pain, often accompanied by depression and anxiety about the future. Such findings are not surprising, as Tempest-Roe (2000) aptly points out. Prior to onset of GBS, patients are generally fit, healthy, and in control of their lives. Within days, they may be completely paralysed and unable to breathe without mechanical ventilation. At this point, the GBS patient may be facing death or permanent disability.

Some individuals will have an acute stress reaction to this situation (Tempest-Roe, 2000) which involves feeling tense, irritable, and preoccupied with worries. Such a reaction will obviously vary according to a range of factors, some of which include severity of illness, personality, information given, and emotional support from family and friends. In addition to depression during recovery from GBS, anxiety is also commonly reported (Tempest-Roe, 2000) and patients may feel apprehensive about something bad happening to them at any time. There is also likely to be a sense of grief and helplessness with the realisation that quality of life might be adversely affected, possibly permanently.

In a recent single case report of a 24-year old female, a diagnosis of Post Traumatic Stress Disorder as a sequela of GBS was made (Chemtob & Herriot, 1994). GBS had occurred four years earlier and the patient had required mechanical ventilation for 10 days. Following her physical recovery, she began to experience cycles of severe

anxiety, sleep disturbance, fatigue, tearfulness, and flashbacks of being on the respirator. Emotional numbing and diminished responsiveness to the external world were also apparent. Following treatment with focused brief psychotherapy, the symptoms diminished. Chemtob and Herriot (1994) argue that while Post Traumatic Stress Disorder might be a relatively rare occurrence following GBS, its recognition as a sequela to medical illness has important implications for clinical reasons. Not only do patients who are acutely physically ill have to contend with pain and discomfort, they must also contend with accompanying psychological and emotional effects. If these aspects are ignored and left untreated, additional suffering may unnecessarily occur.

Teitelbaum and Kettl (1988) provide an earlier example of successful brief psychotherapy treatment for a depressed 48-year old female patient with GBS. This treatment was provided alongside physical therapy during the patient's rehabilitation in hospital. After several sessions, her mood reportedly improved.

In summary, residual problems following GBS most commonly include reduced mobility, limb weakness, muscle weakness, fatigue, pain, numbness, and tingling. These can range in degrees of severity, and in some cases residual problems can persist for many years. Not surprisingly, some GBS patients are likely to have an acute stress reaction to their illness and its aftermath, and they may experience anxiety and depression about the future. Despite the likelihood of such sequelae, there is a noticeable lack of research in the area of the psychological and emotional impact of GBS. In contrast, a large body of literature has developed in the past three decades regarding the psychological factors in general illness and recovery. Much of this literature focuses on diseases such as cancer or heart disease. Some of this literature will be overviewed in the

next section, and it will be argued that the psychological sequelae to GBS are likely to be

similar to those of other serious illnesses.

Chapter 3

Psychological Factors in General Illness and Recovery

The idea that psychological factors can have an impact on physical wellbeing has long been accepted (Clarke, 1998). The once dominant biomedical model (which focuses mainly on biological factors in medicine) has steadily been replaced by models that account for other relevant dimensions to wellbeing, such as social, emotional, and psychological dimensions. Studies of hospital inpatients and outpatients have repeatedly shown concurrent psychological and psychosocial problems with physical illness (e.g., Sherbourne, Wells, Meredith, Jackson, & Camp, 1996; Williamson, & Schulz, 1992). These factors are now being considered in medicine, now that the means by which they can contribute to physical illness are being elucidated.

Clarke (1998) reviews the current evidence that psychological factors are important in physical illness and recovery, using the biopsychosocial model described by Engel (1980, cited in Clarke, 1998). He argues that the strength of this model is that it recognises the presence of each component (physical, psychological, and emotional) without making assumptions of causality. So, when depression is present with physical illness, the biopsychosocial model does not assume that the underlying cause is necessarily due to physiological or autonomic factors; it may instead be the result of a patient's reduced motivation to live or to co-operate with treatment.

Clarke (1998) argues that depression in the presence of physical illness is frequently erroneously regarded as 'understandable' and therefore not clinically important. Furthermore, Sherbourne, Wells, Hayes, et al. (1994) argue that there has been a tendency to regard depressive symptomatology in the medically ill as transient and therefore intervention has been seen as unnecessary. Yet studies have shown that

untreated psychiatric co-morbidity contributes significantly to incomplete recovery, increased mortality, and longer duration in hospital.

Lipowski (1983) defines psychosocial reactions to physical illness as "a set of cognitive, emotional, and behavioural responses induced in every sick person by ... the illness-related information they receive" (p.1069). Lipowski argues that a person's psychosocial reaction to illness influences the course and outcome of any serious illness, particularly chronic physical illness. After appraising information about their illness, patients formulate personal meaning or subjective significance about it. Four broad variants of meaning described by Lipowski include illness as a challenge or threat, illness in terms of loss, illness in terms of gain or relief, and illness in terms of punishment. The determinants of which of these variants of meaning a patient will adopt will vary according to intrapersonal, interpersonal, illness-related, and socio-cultural and economic factors (Lipowski, 1983). A patient's emotional response to illness is intertwined with the meaning attributed to the illness, and will have an important bearing on how the patient copes with the illness and the recovery process. While Lipowski highlights the need for medical staff to clinically assess a patient's emotional state, the difficulty of doing so is acknowledged, due to the similarity between symptoms of psychiatric disturbance, such as depression, and those of the illness itself. For example, symptoms such as fatigue or sleep and appetite disturbance are common in both depression and some physical illnesses.

According to Rodin and Voshart (1987), the occurrence of depression in the medically ill is likely to be a result of a complex interrelationship amongst multiple factors, including personality, coping mechanisms, presence or absence of social support, and the genetic or biologic predisposition to depression. Rodin and Voshart also

hypothesise that the meaning or symbolic significance attributed by individuals to their illness is likely to be related to the degree of psychological stress experienced, rather than the degree of disability resulting from the illness.

Rodin and Voshart (1987) highlight the importance of distinguishing between clinical and non-clinical depression in the medically ill. Whereas many medically ill patients may report mild depressive symptoms, it may be only susceptible individuals who are at risk for major depression. Sherbourne et al. (1994) point out that there is accumulating evidence that medically ill patients with subthreshold depression, that is, depressive symptoms in the absence of depressive disorder, do have substantial morbidity and dysfunction.

According to Saravay, Pollack, Steinberg, Weinschel, and Habert (1996) the majority of studies show that severity of depression and the presence of a medical illness are predictors of the chronicity of depression. Mild depression tends to be affected by the severity of the medical illness and tends to remit once improvement in the medical condition occurs. Moderate to severe depression, however, is more likely to persist chronically irregardless of improvement in the medical condition (Saravay et al., 1996). Although the reasons for this are not entirely clear, one possible explanation is that severe depression may feed on itself, so that the depressed individual becomes trapped in a pit of hopelessness and despair.

While the literature has tended to focus on depressive symptomatology in the medically ill, anxiety has been given less attention. Sherbourne et al. (1996) argue that medical illness may be worsened by anxiety, and they highlight the importance of identifying co-morbid anxiety in the medically ill. In a study by Wells, Golding, and Burnam (1988) a strong association was found between chronic medical conditions and

psychiatric disturbance, with the three most common disturbances being depression, anxiety, and substance use disorders.

As previously outlined, most of the literature regarding the psychological factors in illness and recovery has been drawn from studies of patients with relatively common illnesses such as cancer, heart disease, and diabetes. Studies about the psychological sequelae in neural disorders such as multiple sclerosis (MS) have found that depression is the most frequently occurring psychological problem, with prevalence rates varying between 27% and 54% (Vleugels et al., 1998). Similarly, mood changes are common after stroke, and as many as 40% to 50% of stroke patients may be classified as depressed at 12 months post stroke (Jones, Charlesworth, & Hendra, 2000). Whether the prevalence of depression is similar for GBS patients is unknown, as there is a lack of studies examining the incidence of depression or anxiety during and post GBS. There may be important differences in the causes of depression or anxiety in MS patients and GBS patients, so predictions about depression in GBS patients based on the prevalence of depression in MS patients could be misleading. For example, depression or anxiety in neural disorders such as MS and stroke may have a neurological basis, or they may be a psychological response to the illness (Vleugels et al., 1998). Depression or anxiety in GBS patients are less likely to have a neurological basis, because the primary site of attack in GBS is the Schwann cell surface (Sheikh et al., 1998). Schwann cells are a type of glial cell found in the peripheral nervous system, but they are not found in the central nervous system. Therefore, psychological distress in GBS patients is more likely to be a psychological response to the illness.

Rationale for the Present Study

Most studies about GBS have focused on the biological aspects of the disease and its sequelae in terms of physical outcomes. Aside from the few personal accounts written by individuals who have experienced GBS (e.g., Blanco & Cuomo, 1983; Bowes, 1984; Heywood, 1999), only a handful of studies have examined the psychosocial aspects of GBS (e.g., Bernsen, Jacobs, de Jager, & van der Meché 1997; Meythaler et al., 1997). A possible explanation for this is that GBS is a relatively rare disease with a low incidence.

The purpose of the present study is an attempt to address this gap, by exploring some of the psychological sequelae to GBS in a New Zealand sample of individuals who have experienced the disease. Specifically, the aim of the study is to examine whether depression and anxiety are correlated with the severity of residual problems as a result of GBS.

The present study aims to highlight the importance of psychological and emotional factors during and beyond recovery from GBS, and the need for attention to be paid to these dimensions alongside the more overt physical aspects of GBS. The information obtained from the participants of the present study will primarily be of use to individuals who have experienced GBS, their caregivers, their families, and to all health professionals involved in caring for GBS patients throughout the course of the illness and recovery. Increasing the awareness of GBS patients and their families about what they might expect as a result of the disease may not only prepare them for what lies ahead, but may also assist them to cope through the recovery process.

Similarly, such information might also assist health professionals to sensitively meet the specific care needs of GBS patients during the recovery phase. Given the low

incidence of GBS, information about the disease is not likely to be readily accessible to health professionals and nor is it likely to be part of their core training. In order for health professionals to adequately meet the care needs of GBS patients throughout all phases of the disease, it is important that they not only have a good understanding of the physical and medical aspects of the disease, but that they also have a good understanding of the psychological and psychosocial factors that influence recovery.

To find out if mental status was correlated with an individual's level of residual effects of GBS, participants in the present study completed a set of four questionnaires. The first questionnaire was designed specifically for this study and involved answering demographic questions and questions about the experience of having GBS and residual problems (Appendix E).

The second questionnaire was the McMaster Health Index Questionnaire (MHIQ) which participants completed twice (Appendix F). The MHIQ is a 59-item self-administered quality of life measure that assesses the physical, social, and emotional dimensions of health (Bowling, 1997). The MHIQ was completed the first time retrospectively. Participants were asked to complete the questionnaire thinking back to when their symptoms were most severe. It was completed the second time from the present point of view. The purpose of this was to compare the changes in individuals' abilities as they recovered.

The third questionnaire completed by participants was the Beck Depression Inventory-II (BDI-II) which is a 21-item self-administered instrument used to screen for severity of depression (Appendix G). The BDI-II was developed for the assessment of symptoms corresponding to criteria for diagnosing depressive disorders listed in the

Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (American

Psychiatric Association, 1994, cited in Beck, Steer, & Brown, 1996).

The fourth and final questionnaire completed by participants was the short form

of the state scale of the Spielberger State-Trait Anxiety Inventory (STAI-6) (Appendix

H). This measure is a 6-item self-administered instrument which measures state anxiety

(Marteau & Bekker, 1992). The psychometric properties of these tests will be

considered in detail in the next chapter.

Chapter 4

Method

Research setting

The present research was initially advertised in the quarterly newsletter of the

New Zealand Guillain-Barré Syndrome Support Group with a statement about the

purpose and aims of the study (Appendix B). Individuals who had experienced GBS

were invited to signal their interest in participating in the research by contacting the Co-

ordinator of the Support Group. A total of 49 individuals contacted the Co-ordinator

and indicated that they wished to participate in the research.

Ethical Issues

The present study was designed in accordance with the ethical guidelines of the

New Zealand Psychological Society and was approved by the Massey University Human

Ethics Committee.

Participants

Of the 49 sets of questionnaires sent out, 44 individuals completed and returned

them. The mean age of the participants was 62.0 years with a standard deviation (SD) of

12.4. Slightly more males (54.5%) than females (45.4%) responded to the survey, and

the majority were of New Zealand European ethnicity. It is not known whether the

participants in the present study are representative of all individuals who have

experienced GBS in New Zealand, as not all present and former GBS patients are

members of the New Zealand GBS Support Group. Participants were drawn from those

who have access to the New Zealand GBS Support Group newsletter, so only those who had access to the newsletter would have been able to participate.

The New Zealand GBS Support Group has 289 present and former adult GBS patients on the mailing list (J. Murray, personal communication, 22 January, 2001). It is not known whether the characteristics of those who chose to respond to the survey ($\underline{n}$ = 44) are any different from those who chose not to respond. Therefore, caution is required in generalising the present findings.

The Measures and Their Psychometric Properties

1. GBS Questionnaire

Due to the lack of a brief questionnaire specific to the experience of having GBS, one had to be designed for the purpose of the present study (see Appendix E). The questionnaire began with a paragraph containing information about the questionnaire with an instruction for the responses to be those of the individual with GBS rather than those of another person assisting with its completion. The first section involved circling appropriate responses to demographic questions about gender, current age, ethnicity, and spouse. The second section involved circling appropriate responses or providing brief answers to questions about the acute phase of the disease. Three questions related to current medications, two of which were about medications for depression or anxiety.

The third part of the questionnaire involved circling appropriate responses to questions about residual physical and sensory problems resulting from GBS. In the fourth part of the questionnaire participants provided written answers to questions about issues relevant during recovery, such as factors that were helpful or not helpful. Finally, the last page of the questionnaire was left for participants to make any further comments.

It was estimated that completion of this questionnaire would take approximately half an hour.

2. The McMaster Health Index Questionnaire (MHIQ)

For the purpose of the present study, a decision was made to use a health-related quality of life measure rather than an activities of daily living instrument, as the latter tend to measure physical health status only. Quality of life measurement has grown in the last 30 years from small beginnings into what is described by Gill and Feinstein (1994) as a large academic enterprise. Indeed, a search of the relevant literature soon revealed a proliferation of instruments, and a large body of literature devoted to the measurement of quality of life. As Gill and Feinstein point out though, there is little agreement about what quality of life actually means, and terms such as health status, functional status, and quality of life are often used interchangeably (Guyatt, Feeny, & Patrick, 1993). To some people, the term is synonymous with capacity to perform in social and personal roles appropriate to others of the same age, sex, intelligence, and social class. To others, the term refers to an individual's perception of wellbeing or lack of it (Sartorius, 1993). Indeed, Gill and Feinstein argue that quality of life should not just be a description of patients' functional health status, but should be a reflection of the way they perceive and react to their health status and to other non-medical aspects of their lives. According to Gill and Feinstein, quality of life is something that is a uniquely personal perception of the patient, and to measure this appropriately they argue that each patient's individual views and reactions should be incorporated. Still others understand quality of life to refer to objective indicators such as availability of food, shelter, employment, and human rights. Sartorius notes that terms such as 'positive health',

'wellbeing', 'satisfaction', and 'happiness' have also been used synonymously with 'quality of life'.

In general, two basic types of quality of life instruments exist - disease specific instruments, or generic instruments that are intended to be applicable to a range of health problems. Most such instruments reflect the multidimensionality of quality of life by scoring several scales rather than a single one (Fitzpatrick et al., 1992). A drawback of generic quality of life instruments is their insensitivity to measuring change in quality of life. Fitzpatrick et al. argue that this happens because generic instruments may include items not relevant to the particular disease, they may include items that assess static factors, or they may contain broad categories that are insensitive to subtle changes over time.

Selection of which quality of life instrument to use should be made according to the appropriateness for the particular health problem in question (Fitzpatrick et al., 1992), and how the instrument will perform in the required situation (Fletcher et al., 1992). Practical concerns are also important; for example, the instrument should be reasonably brief and simple to complete (Guyatt et al., 1993), although not at the expense of omitting or losing important information.

An advantage of generic quality of life instruments is that comparisons across illnesses can be made. Another advantage is that they can document the range of disability in a particular patient group, not just those restricted by physical limitations only (Guyatt et al., 1993). In spite of these advantages, Fletcher et al. (1992) note that the inclusion of both disease specific and generic instruments in a study is commonly recommended. These authors recommend the use of a validated generic quality of life instrument supplemented by dimensions specific to the illness and the study.

In a review of 43 indices of functional disability, Feinstein, Josephy, and Wells (1986) highlight six prominent problems that were frequently noted. The first of these is that many instruments fail to take into account the patient's collaboration or effort in performing tasks, which may mean that the ratings for the magnitude of the performed tasks are misleading. The second problem is that most instruments fail to establish which of their disabilities are priorities for therapy for each patient. This is likely to vary considerably according to a range of individual needs and lifestyles. The third problem is that some instruments are not sensitive to change in ability over time. Feinstein et al. argue that special transition indices should be developed to counter this problem. The fourth problem occurs when multiple variables are aggregated as summations. Feinstein et al. point out that hierarchical scales can avoid the loss of descriptive power. The fifth problem refers to the lack of conceptual justification for development of new instruments, and lack of documentary comparison of performance for old and new instruments. The final problem involves the appropriate use of existing instruments, based exclusively on available reliability and validity information at the expense of clinical sensibility.

Of the many health related quality of life indices and profiles, there is no agreement about a 'gold standard' (McDowell & Newell, 1996). Selection of a quality of life instrument for the present study involved consideration of practical details. First, the measure had to be one that could be self-administered because the study was carried out via a postal survey. Second, it needed to be reasonably simple and easy to complete given that many of the respondents were likely to have varying degrees of disability. Third, it needed to measure dimensions relevant to the study - such as social and emotional functioning, in addition to physical functioning. The McMaster Health Index

Questionnaire (MHIQ) (see Appendix F) was selected for the present study because it appeared to meet all of these criteria, and it also appeared to have adequate information pertaining to reliability and validity issues.

The MHIQ was initially developed in Canada in 1976 as a measure of physical, social, and emotional functioning. The rationale for the development of independent measurements of these three dimensions was the authors' recognition that any two individuals with the same level of physical disability may differ greatly in their social and emotional functioning (Bowling, 1997). The MHIQ was developed with the aim of producing a health status measure for use in general populations, and is intended for use in health services evaluation and in clinical research - principally for outpatients and people living in the community (McDowell & Newell, 1996).

The conceptual basis for the MHIQ was the World Health Organisation definition of health which defines health status as "a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity" (World Health Organisation, 1958, cited in Chambers, 1993, p.132). This definition was used to guide the content of the questionnaire. Items for the physical functioning scale were drawn from existing measures such as the KATZ Index of Activities of Daily Living (McDowell & Newell, 1996), the St Thomas Health Survey Questionnaire, the Spitzer Mental Health Status Schedule, the Cornell Medical Index, and a range of survey instruments (Bowling, 1997). The physical functioning items covers aspects of physical health such as mobility, self care, communication and global physical functioning (Chambers, 1993).

The social functioning items were guided by a review of sociological leisure studies and social participation (Bowling, 1997). These items cover general wellbeing,

role performance, family participation, relations with friends, and global social functioning (Chambers, 1993).

The emotional functioning items were drawn and adapted from the Social Readjustment Rating Scale, the FIRO-B Interpersonal Behaviour Scale, and instruments presented in Measures of Social Psychological Attitudes (Chambers, 1993). The original draft version of the MHIQ contained 172 items, but this was shortened to the current 59-item version in the early 1980s (McDowell & Newell, 1996). The final 59 items were selected on the basis of their responsiveness to change in function and their ability to predict global assessments by general practitioners of physical, social, and emotional functioning (Chambers, 1993).

The MHIQ is designed to be relevant to the point in time at which it is completed. It does not ask participants to report changes in any of the three domains of functioning (Chambers, 1993). A deliberate attempt was made to phrase the items in the performance mode rather than the capacity mode in order to avoid ambiguity about implied willingness or ability of respondents in functioning. Furthermore, it was intended to elicit information on activities observed at the time the questionnaire is completed. Questions, therefore, are framed as 'did you...' (performance mode) rather than 'can you..." (capacity mode) (Chambers, 1993).

The MHIQ has been used in a range of settings and Chambers (1993) presents evidence regarding its reliability and validity. Reliability of the MHIQ has been tested on physiotherapy patients, psychiatric patients, and patients in a rehabilitation clinic. Chambers reports that test re-test co-efficients of 0.53, 0.70 and 0.48 were found in the physical, social, and emotional domains of functioning, respectively for the physiotherapy patients. In the psychiatric patients, the test re-test co-efficients were better - 0.95, 0.77

and 0.66 for the three domains of functioning. For the rehabilitation clinic patients, the test re-test co-efficient for the physical functioning scores was reported to be a satisfactory 0.80.

Chambers (1993) outlines some of the strengths and weaknesses of the MHIQ by addressing each of the six problems discussed by Feinstein et al. (1986) outlined above. With regard to the issue of patient collaboration, Chambers acknowledges that the MHIQ does not include items regarding patient effort or support in performance. He suggests that the MHIQ could be improved by including a single question about the availability of a person who could support the patient if necessary, and by recognising non-human support such as the use of ramps for wheelchair-bound individuals.

Regarding the issue of patient preferences, Chambers (1993) acknowledges that the MHIQ items are pre-selected for the patient and therefore may not include items that are important to specific patients with specific diseases. To counter this problem, Chambers suggests supplementing items that have a specific bearing on the study questions in order to improve the validity of the results. In the present study, participants completed a separate questionnaire relevant to their experience of GBS, so it was not considered necessary to supplement items on the MHIQ.

With regard to the issue of measuring change over time, Chambers (1993) argues that the MHIQ physical function scores have been shown to reflect clinically important change. He notes, however, that the social functioning and emotional functioning scales have been found to be less sensitive to change. Chambers points out that the usefulness of the MHIQ score to detect change will depend on the applicability of the instrument to the particular study question, and analysis of individual item changes to determine which ones contributed to the changed score. Chambers suggests that the MHIQ could be

supplemented with transition items so that change might be better detected. Because of the retrospective nature of the present study, participants completed the MHIQ twice so that changes over time along the three dimensions could be detected. The MHIQ was completed from the point of view when GBS was at its most severe, and then from the present point of view. A limitation of this procedure is that responses may not be accurate because participants' recall of historical events is likely to be imperfect. This issue will be discussed in a later section under limitations of the present study.

Regarding the problem of hierarchical aggregation, Chambers (1993) points out that the MHIQ scoring is achieved by reporting disaggregated physical, social, and emotional scale scores. A single score for the MHIQ is not calculated, which means that the relative importance of each of the three components is determined by the investigator, or as Feinstein et al. (1986) suggest, relative importance could also be decided by the patient.

With regard to the problem of documentary justification, Chambers (1993) argues that the MHIQ scores on the three domains correlate with other global quality of life instrument scores. In spite of this, Chambers notes that future uses of the MHIQ will be better justified with the accumulation of further documentary evidence as to how it compares with other generic quality of life instruments.

Regarding the final problem highlighted by Feinstein et al. (1986) of suitability of established indices, Chambers (1993) argues that the MHIQ has been widely used because it is simple to use and has proven itself useful as a general measure of quality of life when supplemented with clinically relevant indicators. He points out that because it has been around for a long time now, it has been used in a range of settings, which has resulted in accumulation of evidence regarding its validity and reliability. Chambers

cautions, however, that future use of the MHIQ must be determined by its relevance and applicability in addressing the particular questions being asked in a study.

3. Beck Depression Inventory-II (BDI-II)

To screen for current depression amongst the participants in the present study, a decision was made to use the BDI-II for two main reasons. First, the BDI-II can be self-administered and it only takes 5-10 minutes to complete. Second, the BDI-II has widespread use and its psychometric properties are well-documented (Dozois, Dobson, & Ahnberg, 1998).

The BDI-II (see Appendix G) is a 21-item self-report measure that screens for severity of depression in adults and adolescents aged 13 years and older (Beck, Steer, & Brown, 1996). Suggested cut scores for detecting depression are provided by the authors. A score between 0-13 is the suggested guideline for minimal depression, a score between 14-19 for mild depression, a score between 20-28 for moderate depression, and a score between 29-63 for severe depression. Beck, Steer, and Brown (1996) note that the decision to use different cut scores for the BDI-II must be based on the characteristics of the sample and the purpose for which the test is being used. A discussion about the cut scores used in the present study will follow later in this section.

The original BDI was first developed in 1961, but this was later revised in 1979 to the BDI-IA. In 1996, the BDI-IA underwent a major revision to bring it into line with assessing the symptoms corresponding to diagnostic criteria for depressive disorders listed in the *Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM-IV)* (1994, cited in Beck, Steer, and Brown, 1996). Changes from the BDI-IA to the BDI-II included re-labelling or re-wording all but three of the items, replacing some

of the items, and clarifying others (Beck, Steer, Ball, & Ranieri, 1996). Other changes included adding a header to each item, to provide focus for the examinee on the purpose of the statement, and extending the time frame for the BDI-II ratings to 2 weeks, to increase temporal compatibility with DSM-IV criteria (Dozois et al., 1998).

The psychometric properties of the BDI-II were initially investigated by using samples drawn from four different psychiatric outpatient clinics ($\underline{n} = 500$) and one college student group ($\underline{n} = 120$) (Beck, Steer, & Brown, 1996). Reliability of the BDI-II has been evaluated via a range of methods (Farmer, 1999). Test re-test reliability was assessed over a 1-week interval and a high correlation was obtained ($r = .93$) (Beck, Steer, Ball et al., 1996). Item-option characteristic curves were generated, to show how well the 4 statements in each symptom group differentiate from one another, and how well each set of item options measures the underlying dimension of self-reported depression. All 21 items demonstrated increasing monotonic relationships with overall self-reported depression, and 17 of the 21 items reflected appropriate ordinal rankings regarding discriminating those with more depression from those with less (Beck, Steer, & Brown, 1996).

Validity of the BDI-II has since been evaluated with a range of outpatient subsamples (Farmer, 1999). When the BDI-IA and the BDI-II have been administered on the same occasion, the average correlation between the scores has been high ($r = .93$). Convergent validity has been assessed by correlating scores on the BDI-II with scores on the Beck Hopelessness Scale, and the Revised Hamilton Psychiatric Rating Scale for Depression, showing moderately high correlations between these measures ($r = .68$, $r = .71$, respectively). Correlation tests between scores on the BDI-II and the Revised Hamilton Anxiety Rating Scale have been carried out, and a moderate correlation

($r = .47$) has been cited as evidence of reasonable discriminant validity. A study by Beck, Steer, Ball, et al. (1996) found that there were comparable high levels of internal consistency between the BDI-IA and the BDI-II, and that both versions displayed similar patterns of relationships with the same psychosocial characteristics, such as sex, ethnicity, and age.

A factor analysis carried out by Dozois et al. (1998) found that two main factors best summarised the items on the BDI-II. These have been described as Cognitive-Affective, which consists of 10 items, and Somatic-Vegetative, which consists of the remaining 11 items. As a result of their study, Dozois et al. concluded that the BDI-II is a stronger instrument in terms of its factor structure than the BDI-IA.

Of the 11 items that comprise the Somatic-Vegetative factor on the BDI-II, 5 items are somatic in content. These items refer to loss of energy, changes in sleeping pattern, changes in appetite, fatigue, and loss of interest in sex. In medical populations the diagnosis of depression is not straightforward (William & Richardson, 1993), and either under-diagnosis or over-diagnosis of depression can result. Under-diagnosis may occur when patients or medical staff attribute somatic symptoms solely to the medical illness, which may result in a failure to treat depressive disorder in medically ill patients. Over-diagnosis may occur when somatic symptoms related to the medical illness are mistaken for depression, which may result in unnecessary psychiatric intervention. Pachana, Gallagher-Thompson, and Thompson (1994) note the importance of determining the contribution that illness, pain, or medication might make to depressive symptoms when completing an assessment for depression, and point out that none of the existing depression measures are specifically designed to make these distinctions.

Bearing these issues in mind with the present sample, a decision was made to extract each participant's scores from the 5-somatic items on the BDI-II from the remaining items. Separate analyses of the scores from the somatic items were then carried out.

Williams and Richardson (1993) note that somatic symptoms tend to increase in frequency and severity in the higher age groups, yet the BDI-II manual does not suggest age-related cut scores to address age differences. Indeed, Farmer (1999) suggests that the clinical sample used to generate the cut scores on the BDI-II is unrepresentative in a number of respects, although age is not mentioned. Pachana et al. (1994) note, however, that the BDI has been used effectively to screen for depression with the elderly, and states that it has adequate sensitivity and specificity for detecting the level of depression. In the present study the majority of the participants (68.1%) were aged over 60 years at the time they completed the BDI-II. So, it is possible that their responses to the somatic items of the BDI-II may have been related to their age rather than to their GBS, or their depression.

4. The 6-Item Short Form of the State Scale of the State Trait Anxiety Inventory (STAI-6)

The original STAI was developed in 1970 and it consists of two 20-item scales. The first scale measures 'state' anxiety (how a person feels currently), and the second scale measures 'trait' anxiety (how a person generally feels) (Spielberger, 1989). In 1983, the STAI was revised, and according to its author, this resulted in improved psychometric properties (Spielberger, 1989). The STAI can be self-administered and it only takes 5-10 minutes to complete, and over the past 30 years it has had widespread

use both in clinical and research settings. In terms of its psychometric properties, the STAI has shown uniformly high correlations between the state and trait scales, ranging from .96 to .98 (Spielberger, 1989).

For the purposes of the present study, it was only necessary to screen for current anxiety, that is, state anxiety. For that reason, a decision was made to use a shortened version of the STAI, that included items from the state scale only (see Appendix H). A 6-item version of this scale was developed in 1992 (STAI-6) for use in circumstances where the full 40-item version of the original STAI is not appropriate (Marteau & Bekker, 1992). Although the 6-item short form has not yet been standardised, Marteau and Bekker (1992) carried out two studies to (a) select the smallest subset of anxiety-present and anxiety-absent items from the full-form which is highly correlated ($r > .90$) with scores obtained using the full-form, and (b) determine the reliability and validity of the 4-item and 6-item versions of the 20-item state scale as a basis for choosing the optimal short form. The results from their study showed that correlations between subsets of 4 and 6 items were greater than $r = .90$. In order to determine the reliability and validity of the 4-item and 6-item versions of the state scale, internal reliability and concurrent validity were assessed. The findings from this study showed that the STAI-6 produced similar scores to those obtained using the full 20-item state scale, and reliability co-efficients for the 4-item version and the 6-item version were $\alpha = .82$ and $\alpha = .77$, respectively. To investigate concurrent validity of the 4-item and the 6-item versions, the comparability of pro-rated scores from both scales with the use of the full scale was used. No differences in mean scores between the 6-item version and the full-form were found, whereas the pro-rated means obtained from the 4-item version were all significantly higher than the means obtained from the full-form. On the basis of this,

Marteau and Bekker concluded that the 6-item version had greater validity than the 4-item version. Further testing on the 6-item form was carried out to find out if it was sensitive to detect changes in anxiety detected by the full form. Marteau and Bekker found in a further study that the mean scores obtained from the 6-item short from were similar to the mean scores obtained from the full-form. As a result of these findings, Marteau and Bekker concluded that when compared to the full-form of the STAI, the STAI-6 offers a briefer and more acceptable scale for individuals completing it.

The STAI-6 can be self-administered and takes only a minute or so to complete. Each of the 6 items is weighted from 1 to 4, and total scores on the STAI-6 are calculated by adding the scores from the three anxiety-present items, then reverse scoring and adding the totals from the three anxiety-absent items. Total scores from the 6-items range from a minimum of 6 to a maximum of 24.

Procedure

The present study was carried out by way of a postal survey that consisted of four self-administered questionnaires, one of them completed twice. To preserve the anonymity of the participants, each participant's set of questionnaires was pre-coded with a number, thus ensuring the questionnaires from each set would not be mixed up. The sets of questionnaires were sent to the participants via the GBS Support Group Co-ordinator, along with an information sheet about the study (Appendix C) and a consent form (Appendix D) to be signed and returned to the Co-ordinator. The completed questionnaires were returned to the Co-ordinator, who then sent them to the researcher for analysis.

Chapter 5

Results

The present study sought to investigate whether mental status was correlated with residual effects from GBS in a New Zealand sample. Part 1 of this chapter will examine the demographic characteristics of the participants and the biomedical features of GBS. In Part 2, the results from the MHIQ, the BDI-II, and the STAI-6 will be presented, and the relationships between mental status and the residual problems post GBS will be examined. Finally, Part 3 will provide a summary of the most difficult aspects of participants' experiences of GBS, and an overview of the factors that either helped or hindered their recovery. In addition, this section includes suggestions by participants about factors that might have helped their recovery. Part 3 is in narrative form, as participants responded to open-ended questions on the GBS questionnaire.

Part 1: Demographic Characteristics and Biomedical Features of GBS

The demographic characteristics of the participants (Table 1) include their gender, ethnicity, and age at the time the survey was conducted. There was a slightly higher ratio of males to females (24:20) who completed the survey ($\underline{N}$ = 44). The almost even gender split in the present sample reflects the tendency for GBS to affect both genders equally. The majority of the participants in the present study described their ethnicity as New Zealand European (90.9%). The remaining minority (9.1%) described themselves as European/Maori, Australian, European, and Pacific Islander. Due to the very small numbers of ethnic groups other than New Zealand European, no analyses of ethnic differences were carried out.

Table 1

Demographic Characteristics of GBS Participants

	Participants	
Characteristics	**n**	**%**
Gender		
Male	24	54.5
Female	20	45.5
Ethnicity		
New Zealand European	40	90.9
European/Maori	1	2.3
Pacific Islander	1	2.3
Australian	1	2.3
European	1	2.3
Age when survey completed		
30-39 years	3	6.8
40-49 years	5	11.4
50-59 years	6	13.6
60-69 years	16	36.4
70-79 years	12	27.3
80-89 years	2	4.5

Participants' ages at the time the survey was conducted varied considerably,

ranging between 32 and 82 years ($M = 62.0$, $SD = 12.4$). Well over half of the

participants (68.2%) were aged over 60 years when they completed the survey. This is

consistent with findings from Renaud's (2000) study of New Zealand people with GBS. Renaud found that the incidence of GBS in her sample ($\underline{N}$ = 119) was highest for the 50-59 year old age group. Renaud cites Hahn's (1998) hypothesis as a possible explanation for this; that increased susceptibility to immune disorders may be caused by a failing of immune-suppressor mechanisms in older people.

Biomedical features of GBS included participants' experiences when the GBS was most severe, as well as their experiences of residual problems during recovery. Participants were asked to report their ages at the time diagnosis was made, the severity of the diagnosis, whether or not they were admitted to hospital, and to an Intensive Care Unit (ICU), and whether they had required mechanical ventilation when the disease was at its most severe. Participants then listed the residual problems they experienced, and they subjectively rated these as mild, moderate, or severe. Residual problems will be discussed in depth in a later section.

At the time GBS was diagnosed, participants' ages ranged from 11 to 75 years ($\underline{M}$ = 54.0, $\underline{SD}$ = 14.5). Table 2 compares the participants' ages at onset of GBS with their ages at the time the survey was completed. While more than two thirds (68.1%) were aged between 40 and 79 years at the time they were diagnosed with GBS, the overwhelming majority (93.1%) were aged between 40 and 89 years at the time the survey was completed.

Table 2

Participants' Ages at Onset of GBS Compared With Ages at
Completion of Survey

	Age of onset			Age now	
Years	$\underline{n}$	%		$\underline{n}$	%
10-19	1	2.3			
20-29	3	6.8			
30-39	2	4.5		3	6.8
40-49	8	18.1		5	11.4
50-59	11	25.0		6	13.6
60-69	14	31.8		16	36.4
70-79	5	11.3		12	27.2
80-89				2	4.5

There was considerable variation within the sample regarding the length of time
since the diagnosis of GBS was made. No participants reported a diagnosis within the
past year. Length of time since diagnosis varied from 1 year ago to 26 years ago
($\underline{M} = 8.0$, $\underline{SD} = 6.2$). Table 3 shows the length of time since diagnosis of GBS as a
function of gender, according to whether the diagnosis was made within the past 6 years,
or over 6 years ago. The number of participants diagnosed with GBS over 6 years ago is
higher for males than females, but the number of participants diagnosed within the last 6
years is higher for females than males. A later section will examine whether length of
time since diagnosis has a moderating effect on severity of residual problems.

Table 3

Length of Time Since Diagnosis of GBS as a Function of Gender

No. of years ago	Male		Female	
	n	**%**	**n**	**%**
≤ 6 years	10	22.7	12	27.2
> 6 years	14	31.8	8	18.1

Although participants were not asked to specify which variant of GBS they were diagnosed with, they were asked to report the severity of the diagnosis they were given, as mild, moderate, or severe. The majority (61.4%) reported that their diagnosis was classified as severe. Of the remaining 38.6% of participants, 29.5% received a diagnosis of moderate GBS, and 9.1% received a diagnosis of mild GBS. Not surprisingly, 95.4% of participants reported that they were admitted to hospital. The 4.6% ($n = 2$) who did not require hospital admission had both received mild diagnoses of GBS.

A crosstabulation between gender and severity of diagnosis showed that the observed count was slightly higher than the expected count for females diagnosed with mild GBS, whereas when the diagnosis was severe, the observed count was a little higher than the expected count for men. Table 4 shows the crosstabulation results for the severity of diagnosis according to gender.

Table 4

Crosstabulation Between Gender and Severity of Diagnosis

Diagnosis type		Male	Female	Total
mild	Count	1.0	3.0	4.0
	Expected Count	2.2	1.8	4.0
mod.	Count	7.0	6.0	13.0
	Expected Count	7.1	5.9	13.0
severe	Count	16.0	11.0	27.0
	Expected Count	14.7	12.3	27.0
Total	Count	24.0	20.0	44.0

Length of hospital stay varied considerably amongst the participants. Of the 95.5% per cent who were admitted to hospital, the duration of time spent in hospital varied from a minimum of 5 days to a maximum of 570 days ($\underline{M} = 120.1$, $\underline{SD} = 136.3$). The large standard deviation illustrates the great variation in severity of GBS and/or in the recovery period.

Table 5 provides a breakdown of the duration of time spent in hospital for the participants. It can be seen that 40.4% of those hospitalised spent three months or longer in hospital. Severity of diagnosis was statistically significantly correlated with the total length of time spent in hospital ($r = .47$, $p < 0.01$), as would be expected. However, assuming a linear relationship between time spent in hospital and GBS severity, variance accounted for is only $r^2 = .22$. Thus, factors other than severity are involved in length of stay in hospital (e.g., age of patient).

Table 5

Duration of Total Time Spent in Hospital

No. of days	n	%
≤ 7	4	9.1
≤ 28	9	21.4
≤ 60	20	47.6
≤ 90	25	59.5
> 90	17	40.5

Note. Maximum n value = 42.

Of those who were hospitalised (n = 42), 50% were admitted to an Intensive

Care Unit (ICU). There was considerable variation in the length of time spent in ICU,

ranging from a minimum duration of 1 day to a maximum of 270 days. The mean time

spent in ICU was 18.6 days, although due to the large range, the standard deviation was

high (SD = 44.6). Severity of diagnosis was correlated with the length of time spent in

ICU (r = .27, p = .07), but, again, the small amount of variance accounted for (.07)

suggest other factors are involved.

A crosstabulation between severity of diagnosis and whether or not admission to

ICU followed showed that for those who received a diagnosis of moderate GBS, the

observed count for admission to ICU was lower than the expected count. For those

who received a diagnosis of severe GBS, however, the observed count for admissions to

ICU was well above the expected count, as Table 6 shows.

Table 6

Crosstabulation Between Admission to ICU and Diagnosis Severity

Diagnosis type		Admission to ICU Yes	No
mild	Count	1.0	1.0
	Expected Count	1.0	1.0
mod.	Count	2.0	11.0
	Expected Count	6.5	6.5
severe	Count	18.0	9.0
	Expected Count	13.5	13.5
Total	Count	21.0	21.0

Note. Maximum n value = 42.

Of the participants who were admitted to hospital ($n = 42$), 50% were subsequently admitted to ICU ($n = 21$). Length of time spent in ICU and the total length of time spent in hospital were statistically significantly correlated ($r = .68$, $p = 0.01$).

Of the participants who were admitted to ICU, 66.6% subsequently required mechanical ventilation due to their paralysis. A crosstabulation between severity of diagnosis and whether ventilation was required showed that when the diagnosis was mild or moderate, the observed count for whether ventilation was required was below the expected count. When the diagnosis was severe, however, the observed count was much higher than expected for those who required ventilation, as Table 7 shows.

Table 7

Crosstabulation Between Severity of Diagnosis and

Whether Ventilation was Required

Diagnosis Type		Ventilator Required	
		Yes	No
Mild	Count	0.0	1.0
	Expected Count	1.3	0.6
Mod.	Count	1.0	1.0
	Expected Count	4.1	2.1
Severe	Count	13.0	5.0
	Expected Count	8.6	4.3
Total	Count	14.0	7.0

Residual Problems

Although many people do make a full recovery from GBS, for some the outcome

is not so positive. Affected individuals may experience a range of residual problems

following GBS. Participants in the present study were asked to report any residual

problems, and the 7 most common ones identified in the literature were listed on the

questionnaire. These consisted of fatigue, pain, reduced mobility, muscle weakness, limb

weakness, numbness, and tingling. Participants were asked to rate them as mild,

moderate, severe, or not applicable. A space was also provided on the questionnaire so

that other residual problems could be reported. Table 8 shows the percentage of

participants who reported experiencing the seven most common residual problems

according to the rated severity of each one.

Table 8

Residual	Mild	Mod.	Severe	n	%
Fatigue	38.6	50.0	4.5	41	93.2
Pain	34.1	22.7	9.1	29	65.9
Reduced Mobility	22.7	29.5	13.6	34	77.3
Muscle Weakness	34.1	34.1	15.9	37	84.1
Limb Weakness	29.5	34.1	15.9	35	79.5
Numbness	34.1	29.5	2.3	29	65.9
Nerve Tingling	36.4	25.0	9.1	31	70.5

Note. Maximum n value = 41.

As shown in Table 8, the most commonly reported residual problem was fatigue (93.2%), with 50% of the participants rating this as moderate. The next most common residual problems were related to motor activities, and included reduced mobility (77.3), muscle weakness (84.1%), and limb weakness (79.5%). Pain was reported by two thirds of the participants (65.9%), as was nerve tingling (70.5%) and numbness (65.9%).

Of those who reported experiencing one or more of the 7 most common residual problems (n = 41), a total of 16 participants (39.0%) reported experiencing all 7 of them. Almost two thirds of these participants were male (62.5%). Just over half (56.2%) of this group of participants had been diagnosed with GBS within the past 6 years, while the remaining 43.8% had been diagnosed over 6 years ago. An analysis of the severity of the 7 most common residual problems will follow in a later section.

In addition to the 7 most commonly reported residual problems following GBS, participants reported a diverse range of other residual effects. These can be broadly grouped as motor, sensory, or cognitive deficits, damage to nerves, or general medical problems. Table 9 lists the percentage of participants who reported these residual problems according to the rated severity of each one. The large number of residual problems illustrates the wide range of GBS symptoms, a factor that probably contributes to the difficulty of diagnosis. Further analysis of the residual problems listed in Table 9 was precluded due to the low numbers of participants who reported them.

Table 9

Less Common Residual Problems Reported by Participants

Residual Problem	Severity	n	%
Body Cramps	severe	2	4.5
Reduced feeling in fingers	moderate	3	6.8
Shaking hands	moderate	2	4.5
Impaired smile	moderate	3	6.8
Sensitive eyes	moderate	2	4.5
Short term memory loss	moderate	2	4.5
Cognitive problems	moderate	1	2.3
Reduced foot/hand co-ordination	severe	2	4.5
Dropped feet	severe	1	2.3
Poor circulation in feet	moderate	1	2.3

Residual Problem	Severity	n	%
Weak left side	mild	1	2.3
Unable to rise from floor	severe	1	2.3
Burning sensations	severe	2	4.5
Skin problems	mild	1	2.3
Thyroid problems	severe	1	2.3
Speech/vocal chord problems	moderate	2	4.5

Note. Maximum n value = 3.

To investigate whether length of time since diagnosis had a moderating effect on the number and severity of residual problems reported, the sample was split in half (n = 22) and assigned to one of two groups according to whether the GBS diagnosis was made within the past 6 years (Group 1) or over 6 years ago (Group 2). This split was calculated by rank ordering the number of years since diagnosis for each participant from the shortest to the longest time, then working out the halfway point, which fell at 6 years or less. Only the 7 most commonly reported residual problems were included in the following analysis, the less common residual problems listed in Table 9 being omitted. As Table 10 shows, the percentage of participants who reported experiencing any of the 7 main residual problems was almost the same for the two groups. These data suggest that the number of residual problems does not decrease with the passage of time.

Table 10

Number of Participants Who Reported 7 Most Common Residual

Problems as a Function of Time Since Diagnosis

	Group 1 (%) (≤ 6 years)	Group 2 (%) (> 6 years)	n
Residual Problem			
Fatigue	51.2	48.8	41
Pain	51.8	48.2	29
Mobility	50.0	50.0	34
Muscle Weakness	48.6	51.4	37
Limb Weakness	48.6	51.4	35
Numbness	48.3	51.7	29
Tingling	48.4	51.6	31

Note. Maximum n value = 41.

Severity of residual problems was scored by the participants rating each residual

problem 1, 2, or 3 for mild, moderate, and severe, respectively, thus allowing a maximum

total of 21 across the 7 most common residual problems. Mean severity totals were

computed for the two groups across the 7 residual problems to investigate whether

length of time since diagnosis had a moderating effect on the severity of the residuals.

Table 11 compares the severity of the 7 most common residual problems for the two

groups.

Table 11

Severity of Diagnosis as a Function of Time Since Diagnosis

Residual	n	Group 1 % (≤ 6 years)			n	Group 2 % (> 6 years)		
		Mild	Mod.	Severe		Mild	Mod.	Severe
Fatigue	21	47.6	47.6	4.8	20	35.0	60.0	5.0
Pain	15	53.3	46.7	-	14	50.0	21.4	28.6
Reduced Mobility	17	64.7	23.5	11.8	17	23.5	53.0	23.5
Muscle Weakness	18	50.0	38.9	11.1	19	31.6	42.1	26.3
Limb Weakness	17	47.0	41.2	11.8	18	27.8	44.4	27.8
Numbness	14	50.0	50.0	-	15	53.3	40.0	6.7
Tingling	15	46.7	53.3	-	16	56.2	18.8	25.0

The mean total for mild severity was slightly higher for Group 1 (M = 8.6, SD = 1.5) than Group 2 (M = 6.6, SD = 1.7). For residuals rated as moderate severity, the mean totals were almost the same for both groups, (M = 7.1, SD = 1.8), and (M = 7.0, SD = 3.3) for Groups 1 and 2, respectively. For residuals rated as severe, the total mean was higher for Group 2 (M = 3.4, SD = 1.7) than Group 1 (M = 1.8, SD = 0.5). These means suggest that in this sample, residual problems are at least as severe, and in some cases more severe, for those who were diagnosed with GBS more than 6 years ago. This is particularly so for motor-related problems. The means also suggest that length of time since diagnosis did not have a moderating effect on the number or severity of residual problems reported. As a result, no further analyses along divisions of time since diagnosis were carried out.

Of the total number of participants who reported residual problems ($n = 41$),

severity totals ranged from a low of 2 (9.8%) to a maximum of 20 (2.4%). The mean

total across the 7 most common residual problems was 9.0 ($\underline{SD} = 4.7$). Gender did not

account for much difference; the mean total for males was 9.1 ($\underline{SD} = 5.4$) while the

mean total for females was 8.9 ($\underline{SD} = 3.9$). An independent samples t-test (2-tailed) for

equality of means showed that this difference was not statistically significant,

$t (39) = 0.09, p = .93$.

For those who were admitted to ICU ($n = 21$), the mean total for severity of

residual problems was 11.1 ($\underline{SD} = 4.6$) compared to a mean total of 6.9 ($\underline{SD} = 4.0$) for

those who were not admitted to ICU ($n = 21$). An independent samples t-test (2-tailed)

showed that the mean total of severity of residual problems was statistically significantly

related to whether participants were admitted to ICU, $t (40) = 3.20, p = .003$.

For those who required mechanical ventilation while in ICU ($n = 14$) the mean

total for severity of residual problems was 11.6 ($\underline{SD} = 5.1$), compared to a mean total

of 10.3 ($\underline{SD} = 3.8$) for those who did not require ventilation ($n = 7$). This difference was

not statistically significant, $t (19) = 0.59, p = .56$.

Part 2. Quality of Life Following GBS, and Relationships Between Depression,

Anxiety, and GBS: Results from the MHIQ, the BDI-II, and the STAI-6

1. Quality of Life - The McMaster Health Index Questionnaire (MHIQ)

Participants were asked to complete the 3 subscales of the MHIQ that measured

physical, social, and emotional functioning. To investigate whether functioning along

these three dimensions changed during and following recovery from GBS, participants

completed the MHIQ twice. The first version was from a retrospective point of view, and required participants to recall their level of functioning when GBS was at its most severe. The second time was from the present point of view (when the survey was completed). This version required participants to report their current functioning.

Table 12 compares the mean scores for the three MHIQ subscales from the two perspectives in time. Two participants completed only one version of the MHIQ; one did not complete the retrospective version of the MHIQ, and the other did not complete the present version. The data from the versions they completed could not be included in the following analysis because it involved pairing the scores from the two versions.

Possible scores on each of the MHIQ items range from a minimum of 0.0 for poor functioning to a maximum of 1.0 for good functioning. The highest possible scores on the three subscales physical scale are 19, 25, and 25 for the physical, social, and emotional scales, respectively. Scoring of the MHIQ does not involve summing the totals of the three subscales, as each of these are treated independently. As shown in Table 12, at the time the survey was completed there was improvement in all three domains of functioning from when GBS was at its most severe to the point at which the survey was completed. The greatest improvement was in physical functioning, which is not surprising given that the majority of the participants were completely paralysed when the GBS was at its most severe. The mean difference of 0.63 in physical functioning across the two points in time was statistically significant, $t(40) = 15.3, p < .001$).

Social functioning showed less improvement across the two points in time although due to the large range in scores across the sample on this subscale, the standard deviations were far higher for both points in time on the social functioning sub-scale than for either the physical or the emotional functioning subscales. The mean difference

between the scores in social functioning across the two points in time (0.19) was

significant, $t(40) = 10.7, p < 001$.

Emotional functioning also showed less improvement than physical functioning

across the two points in time. The mean difference of 0.19 was statistically significant,

$t(40) = 4.9, p < 001$.

Table 12

Comparison of Mean Scores on the 3 MHIQ Subscales Across Time

	Most Severe		**Present**			
	M	**SD**	**M**	**SD**	**M Difference**	**SD**
MHIQ Sub-scale						
Physical	.13	.14	.76	.22	.63	.26
Social	.57	.11	.76	.25	.19	.11
Emotional	.62	.22	.80	.11	.19	.24

Note. Maximum n value = 42

Individual scores on all three subscales varied across the two points in time.

When the raw scores on each of the MHIQ subscales are transformed, they range from a

minimum score of 0.00 to a maximum score of 1.00. Poor functioning is defined by a

score of 0.5 or less, and good functioning is defined by a score of greater than 0.5. Table

13 compares the changes in the levels of functioning across time on each of the three

subscales. The data from the 2 participants who completed only 1 of the 2 versions of

the MHIQ are included in the following analysis.

Table 13

Changes in Functioning Across Time on the 3 Subscales of the MHIQ

MHIQ Sub-scale	Point in Time	% Participants ≤ score of .5 Poor Function	% Participants > score of .5 Good Function
Physical Function	GBS severe	97.7	2.3
Physical Function	Now	18.6	81.4
Social Function	GBS severe	18.7	81.3
Social Function	Now	2.3	97.7
Emotional Function	GBS severe	27.9	72.1
Emotional Function	Now	0.0	100.0

Note. Maximum n value = 43

As shown in Table 13, only 2.3% of participants scored in the good functioning range on the physical function subscale when GBS was at its most severe, compared to 81.4% when the survey was completed. In spite of the diversity and severity of the residual problems reported, the majority of participants reported an overall improvement in physical functioning from when the GBS was most severe.

A total of 97.7% of participants scored in the good functioning range on the social subscale when the survey was completed, and all of the participants scored in the good functioning range on the emotional functioning subscale at that point in time. While there was less overall improvement in the scores on both subscales across the two points in time compared to the physical function subscale, this can be explained by the higher scores on the social and emotional functioning subscales when GBS was most severe.

The majority of participants reported that their social and emotional functioning was good when GBS was at its most severe, notwithstanding the devastating physical consequences. Although this result was not expected, it is consistent with Renaud's finding (2000) that perceived emotional difficulties systematically declined with age. The majority of the participants in the present study were aged over 60 years when the survey was completed. Thus, the high reported level of social and emotional functioning is consistent with Renaud's observation that older people in her study were less inclined to perceive that they had emotional problems. This issue will be examined in more depth in the discussion section.

There was a statistically significant inverse correlation between the total number of residual problems and current level of physical functioning ($r = -.68, p < .001$). That is, the lower the number of residual problems, the higher the level of physical functioning. Correlation tests were carried out on social and emotional functioning (at both points in time), and the total number of residual problems, but none of these were statistically significant.

A chi-square analysis showed that physical functioning at both points in time was related to the severity of the diagnosis: When GBS was at its most severe, $\chi^2 (2) = 7.63, p = .02$, and at the time the survey was completed, $\chi^2 (2) = 6.18, p = .05$.

To investigate whether severity of diagnosis, admission to ICU, and ventilation had any impact on present physical functioning, the mean scores on the physical subscale of the MHIQ were compared. A higher mean score on the physical sub-scale (from the present point of view) was obtained for those who received a mild GBS diagnosis ($\underline{n} = 4$; $\underline{M} = 0.90, \underline{SD} = 6.75$) than for those who received a severe GBS diagnosis ($\underline{n} = 27$; $\underline{M} = 0.69, \underline{SD} = 0.23$). The mean score for those who required ICU admission ($\underline{n} = 21$) was

lower for present physical functioning ($\underline{M}$ = 0.66, $\underline{SD}$ = 0.24) than for those who did not ($\underline{n}$ = 21; $\underline{M}$ = 0.84, $\underline{SD}$ = 0.16). There was little difference in the mean scores for those who required ventilation ($\underline{n}$ = 14), and for those who did not. For those who required ventilation the mean score was 0.62 ($\underline{SD}$ = 0.23), compared to a mean score of 0.74 ($\underline{SD}$ = 0.25) for those who did not require ventilation.

Pearson correlation tests showed that there were inverse relationships between the scores on all three subscales of the MHIQ (completed from the present point of view) and the scores on the BDI-II. For the physical subscale, the correlation was statistically significant (r = -.41, p = .007); for the social subscale, the correlation was slightly higher (r = -.53, p = .001), and for the emotional subscale the correlation was similar to that of the physical subscale (r = -.45, p = .002). These relationships suggest that the higher the level of physical, social, and emotional functioning, the lower the level of depression tends to be. The results from the BDI-II are presented in the next section.

2. Depression - The Beck Depression Inventory-II (BDI-II)

Participants were asked to complete the BDI-II to screen for current depression. For the purposes of the present study, the cut score guidelines suggested by the authors of the BDI-II for screening severity of depression were followed. For individuals scoring within a range of 0 to 13, severity of depression is rated as minimal. A rating of mild depression is given for scores ranging between 14 to 19, moderate depression for scores ranging between 20 to 28, and severe depression for scores ranging between 29 to 63 (Beck, Steer, & Brown, 1996).

Of the participants who completed the BDI-II in the present study ($\underline{n}$ = 43), the scores ranged from 0 (4.5%) to 22 (2.3%). The mean total score was 7.2 ($\underline{SD}$ = 5.0).

A total of 37 participants (86.0%) scored within the minimal depression range, 5

participants (11.7%) scored within the mild depression range and 1 participant (2.3%)

scored within the moderate depression range. No participants scored within the severe

depression range. Only 2 participants (4.5%) reported that they were prescribed anti-

depressant medication at the time the survey was completed. One of these participants

scored within the minimal range of depression, while the other scored within the mild

range.

To investigate whether there were any relationships between the scores on the BDI-

II and residual problems, the participants were divided into 2 groups, according to

whether they scored within the minimal depression range (Group 1, n = 37), or within

the mild or moderate depression range (Group 2, n = 6). Mean scores on the BDI-II for

the two groups were then compared with the mean scores for the number and severity of

the 7 most common residual problems experienced (fatigue, pain, reduced mobility,

muscle weakness, limb weakness, numbness, and tingling). Table 14 shows that there

was little difference between the groups in the mean number of the 7 main residual

problems reported.

Table 14

Comparison of BDI-II Mean Scores with Number and Severity of Residuals

	Group 1 (n = 37) (Minimal depression)		Group 2 (n = 6) (Mild or mod. depression)	
	M	**SD**	**M**	**SD**
Score on BDI-II	5.6	3.0	17.2	3.1
No. of residuals	5.4	1.8	5.8	1.0
Severity of residuals	8.9	4.6	11.0	4.6

Note: Maximum n value = 43

However, the BDI-II scores were statistically significantly related to the total number of residuals experienced ($r = .28$, $p = .06$), and the group with mild or moderate depression ($\underline{n} = 6$) did have a higher mean score of severity across the 7 main residual problems than the group with minimal depression ($\underline{n} = 37$). These results suggest that there may be a small relationship between the presence of depression and the total number of residual problems experienced.

To investigate if there were differences between the two groups in severity of the 7 main residual problems, mean scores were calculated for each residual problem. The maximum severity score possible for each residual problem was 3. Table 15 shows that there were higher means for severity of all 7 main residual problems for the group with mild or moderate depression. Fatigue showed the greatest difference in means between the two groups, but there was little difference for motor-related residuals.

Table 15

Comparison of BDI-II Mean Scores with Severity of Each Residual

	Group 1 ($\underline{n} = 37$) (Minimal depression)		Group 2 ($\underline{n} = 6$) (Mild or mod. depression)	
	M	**SD**	**M**	**SD**
Fatigue	1.4	0.7	2.2	0.4
Pain	1.1	0.9	1.2	1.2
Reduced Mobility	1.3	1.0	1.7	1.0
Muscle Weakness	1.5	0.9	1.7	1.0
Limb Weakness	1.5	1.0	1.7	1.0
Numbness	1.0	0.9	1.2	0.8
Tingling	1.08	0.9	1.5	1.0

Note: Maximum $\underline{n}$ value = 43

Mean differences between the two groups for age of onset, current age, and years since diagnosis were also examined. As shown in Table 16, there was very little difference between the means for these two groups on any of these 3 variables.

Table 16

Comparison of BDI-II Mean Scores with Age of Onset of GBS, Current Age, and Years Since Diagnosis

	Group 1 ($\underline{n}$ = 37) Minimal depression)		Group 2 ($\underline{n}$ = 6) (Mild or mod. depression	
	M	**SD**	**M**	**SD**
Age of onset	54.4	13.9	54.7	17.9
Current age	62.4	11.8	63.5	15.2
Years since diagnosis	8.0	6.4	8.8	5.9

Note: Maximum $\underline{n}$ value = 43

In line with Williams' and Richardson's (1993) suggestion for separate scoring of somatic items when assessing medical populations for depression, each participant's scores from 5 somatic items on the BDI-II were extracted and separate analyses were completed. The rationale for this was an attempt to clarify items that might be related to the disease process rather than to depression. Of the 21 BDI-II items, 5 relate to physiological functioning. The items extracted include questions about fatigue, loss of energy, loss of interest in sex, increased or decreased sleep, and increased or decreased appetite. Table 17 shows the percentage of participants who responded to the somatic items, according to whether they scored within the minimally depressed range ($\underline{n}$ = 37), or the mildly and moderately depressed range ($\underline{n}$ = 6). The following analysis should be

interpreted with caution because of the small number of participants in the mild or moderately depressed group.

Table 17

Responses to Somatic Items on BDI-II: Group 1 (Minimal Depression) Compared to Group 2 (Mild or Moderate Depression)

Item on BDI-II	Total (%) $\underline{n} = 43$	Group 1 (%) $\underline{n} = 37$	Group 2 (%) $\underline{n} = 6$
Fatigue	79.1	78.4	83.3
Loss of energy	86.0	83.8	100.0
Loss of interest in sex	53.5	45.9	100.0
Changes in sleep:			
Increased sleep	23.3	13.5	83.3
Decreased sleep	51.2	56.8	16.7
Changes in appetite:			
Increased appetite	7.0	8.1	0.0
Decreased appetite	18.6	18.9	16.7

Note: Maximum $\underline{n}$ value = 43

As shown in Table 17, loss of energy and fatigue were reported by the highest total percentage of participants. When the percentages of participants in each of the two groups were compared, a higher percentage of those in the mild and moderately depressed group ($\underline{n} = 6$) responded to 4 of the 5 somatic items. The one exception was the item involving changes in appetite.

To assess the contribution of the scores for the somatic items to the overall scores on the BDI-II, the scores for each of the 5 somatic items were extracted from each participant's overall score ($\underline{n}$ = 43). The mean score of the remaining 16 items was 3.1 ($\underline{SD}$ = 3.7). Scores on these items ranged from 0 to 15, and 95.4% of participants scored within the minimal depression range. The remaining 4.6% scored within the mild depression range, following extraction of the 5 somatic items' scores.

Table 18 compares the mean overall scores on the BDI-II for Group 2 ($\underline{n}$ =6) with their scores once the 5 somatic items had been extracted. Only 33.3% of the group still fell within the mild or moderate depression range after exclusion of the 5 somatic items, with the remaining 66.6% now falling within the minimal range of depression.

Table 18

Comparison of Mean Total Scores on BDI-II with Mean Scores Minus 5 Somatic Items for Group 2

	Overall score (All 21 items)		**Score** (Minus 5 items)	
	M	**SD**	**M**	**SD**
Group 2	17.2	3.1	10.8	3.7

Note. Maximum $\underline{n}$ value = 6

In general, the results from the BDI-II suggest that the majority of the participants were not suffering from depression when the survey was conducted. In this sample, then, it seems that depression is not a common sequela following recovery from GBS. Due to the retrospective nature of the present study, it was not possible to ascertain whether depression was experienced by any participants during the acute phase

of GBS. This issue will be explored in more detail in the discussion section. The next

section examines whether the participants were experiencing anxiety at the time the

survey was completed, and whether there were relationships between the severity of the

GBS and anxiety.

3. Anxiety - The 6-Item Short Form of the State Scale of the State Trait Anxiety Inventory (STAI-6)

Participants were asked to complete the 6-Item Short Form of the State Scale of

the State Trait Anxiety Inventory (STAI-6) to screen for current anxiety. Possible scores

on the STAI-6 range from a minimum of 6 to a maximum of 24. Of the participants who

completed the STAI-6 in the present study ($n = 43$), the scores ranged from 6 (27.9%)

to a maximum of 16 (6.9%). The mean total score was 9.7 ($\underline{SD} = 3.6$). There was very

little gender difference, although male participants scored slightly higher on the STAI-6

($\underline{M} = 10.1$, $\underline{SD} = 3.8$) than female participants ($\underline{M} = 9.2$, $\underline{SD} = 3.2$). No participants

reported that they were prescribed anti-anxiety medication at the time the survey was

completed. Nearly three quarters of the participants (72.1%) scored 12 or less on the

STAI-6, and the remaining 27.9% scored between 13 and 16.

The relationship between the scores on the STAI-6 and the number of residual

problems was not significant ($r = .15$, $p = .33$), so no further analyses along these lines

were carried out. Similarly, none of the correlations between scores on any of the MHIQ

subscales and the STAI-6 reached statistical significance.

To find out if there were differences for those whose experience of GBS were

severe, mean scores on the STAI-6 were examined according to the severity of the

diagnosis, whether admission to ICU was required, and whether mechanical ventilation

was required. As shown in Tables 19 and 20, there were very few differences in the

mean scores for any of these three variables.

Table 19

Comparison of Mean Scores on STAI-6 According to Severity of Diagnosis

Severity of Diagnosis	**M**	**SD**	**n**	**%**
Mild	9.3	2.6	4	9.1
Moderate	10.3	4.4	13	29.5
Severe	9.3	3.4	27	61.4

Note. Maximum n value = 43

Table 20

Comparison of Mean Scores on STAI-6 According to Severity of GBS

Variable	**Yes** **M**	**SD**	**n**	**%**	**No** **M**	**SD**	**n**	**%**
Admission to ICU	10.0	3.3	21	47.7	9.4	4.0	23	52.3
Ventilation required	10.0	3.4	14	31.8	9.9	3.4	30	68.2

Note. Maximum n value = 43

A chi-square analysis showed that diagnosis type did not result in a higher score

on the STAI-6 (χ^2 (2) = .26, p = .88). The results from the STAI-6 suggest that the

majority of the participants were not experiencing anxiety at the time the survey was

completed. It remains unknown whether anxiety was experienced by any participants

during the acute phase of GBS. The STAI-6 is designed to screen for current anxiety,

and participants were not asked to comment on anxiety levels during the acute stage of

their illness.   On the basis of the results from the STAI-6 and the BDI-II, it seems that

neither depression nor anxiety were common sequelae following recovery from GBS for

the majority of the participants.   Some possible explanations for this will be presented in

the discussion chapter.

Part 3. Important Factors in Recovery from GBS

As part of the GBS questionnaire, participants were asked some open-ended

questions about important factors in their recovery.   These questions specifically asked

participants to identify (a) the most difficult aspects of having GBS, (b) the factors that

assisted and hindered their recovery, (c) the factors that would have been helpful when

they were most ill and during their recovery.   Although there was great variation in the

responses to these questions (some participants chose not to respond, or to respond to

only some of the questions), several common themes emerged.   These will be presented

in narrative form, in terms of the general themes that were represented rather than as

direct quotes.

For almost all of the participants, the most difficult aspect of having GBS centred

around two main themes.   These can best be described as (a) the loss of independence

and having to learn to depend on others, and (b) the physical limitations that resulted

from GBS, including the ongoing residual problems for many.   Another commonly

expressed difficulty for many was a lack of information available to them and their

families about GBS.   Many participants simply did not know what to expect during the

course of their illness and beyond, and they did not know where to source information.

Slow diagnosis was an issue raised by several participants, who expressed frustration

because they perceived that this had resulted in treatment not being available as quickly

as it could have been. Some participants expressed the view that their recovery was hampered by the length of time it took for the GBS to be diagnosed.

With regard to the factors that were helpful to recovery, the two most commonly expressed ones were support from family and friends, and a positive mental attitude. Many participants also reported that they were determined to recover. Other commonly expressed factors that were helpful to recovery were good nursing care and regular physiotherapy throughout the recovery process. Some participants commented that an early diagnosis of GBS helped their recovery.

Participants identified several factors that hindered their recovery from GBS. The most common of these was a perceived lack of follow-up and support in terms of rehabilitation in the community. Many participants expressed frustration and disappointment about the lack of supportive services available to them following their discharge from hospital. Several participants reported that they needed home help but they were not told by anyone whether they were entitled to access this. Similarly, many reported that they were not able to access regular physiotherapy once they were discharged from hospital. Another commonly expressed factor that hindered recovery was a perceived lack of knowledge about GBS by medical staff. Several participants expressed the view that at times this led to insensitive care. Some participants reported that sometimes they felt medical staff were sceptical about how ill they really were, and they commented that they were left feeling like they were imagining their symptoms.

In terms of what might have been helpful to the participants when they were ill, many reported that more knowledge about GBS would have helped them to cope better when their illness was at its most severe and during recovery. Several participants reported that it would have been really useful to have had contact with someone who had

experienced GBS, so that they could see for themselves that they would recover. For those participants who did have contact with a former GBS patient, this was highlighted as a real boost to their recovery. Many participants expressed the view that they would have benefited from regular supportive community-based services such as physiotherapy and home help during their recovery. Some participants commented that a handbook about GBS designed for medical and nursing staff would have been useful for those who had never cared for a GBS patient.

Finally, many participants commented on the insights they had gained as a result of their experience with GBS. These included a greater understanding and empathy for people with chronic illnesses and disabilities. Several participants expressed the view that their experience with GBS has resulted in a greater appreciation for their lives, and many stressed how important the ongoing support and love from their families and friends had been to their recovery.

Summary

The majority of the participants in the present study were of New Zealand European ethnicity, and there was a slightly higher proportion of males. The mean age of onset of GBS was 53.9 years, and most participants were aged over 60 years when the survey was completed. Time since diagnosis varied, ranging from 1 year ago to 26 years ago, with a mean of 8 years since diagnosis. Almost two thirds of the participants received a diagnosis of severe GBS, and all but 2 were hospitalised. Length of hospitalisation varied considerably, from 5 days to 570 days. Almost half the participants spent over 3 months in hospital, and there was a statistically significant relationship between the severity of the diagnosis and length of time spent in hospital. Half of the

hospitalised participants were admitted to ICU, and two thirds of these required mechanical ventilation due to their paralysis.

The most common residual problem was fatigue, experienced by 93.2% of the participants. This was rated moderately severe by half of these participants. Residual motor deficits were also common, as were pain, nerve tingling, and numbness. A diverse range of other residual problems were reported, although these were experienced by a minority. Length of time since the GBS was diagnosed was not found to have a moderating effect on the number, or the severity of residual problems.

Results from the MHIQ showed that the greatest improvement across the two points of time was along the dimension of physical functioning. This improvement can be explained by the recovery in physical functioning following what many described as 'total paralysis' when the GBS was at its most severe. There was a moderate correlation between current level of physical functioning and the number of residual problems, but the correlations between current social problems, emotional problems, and the severity of residual problems did not reach statistical significance. Level of physical functioning at both points in time was found to be related to the severity of the GBS diagnosis.

The correlations between the 3 subscales of the MHIQ (from the present point of view), and the scores on the BDI-II suggest that the higher the level of physical, social, and emotional functioning, the lower the level of depression. The majority of the participants scored within the minimal range of depression on the BDI-II, and the number of residual problems was not found to be statistically significantly related to scores on the BDI-II. For the minority group who scored within the mild or moderate range of depression, mean scores for severity of residuals were slightly higher than for the majority group who scored within the minimal depression range. Of the most

common residual problems, fatigue was more severe for the mildly or moderately depressed participants. Following extraction of the scores from the somatic items from the BDI-II, only 2 participants still scored within the range of mild depression.

The majority of participants scored under half on the STAI-6, and the number of residual problems was not found to be statistically significantly related to scores on the STAI-6. There was very little difference in mean scores relating to the seriousness of the GBS and STAI-6 scores.

In general, these results suggest that in the present sample depression and anxiety were not long-lasting sequelae to GBS for the majority of the participants. This issue will be discussed in more detail in the next chapter. The final chapter will conclude with a discussion about the limitations of the present study, the conclusions, and some suggestions for further research.

Chapter 6

Discussion

The present study was conducted via a postal survey and consisted of 4 questionnaires. The purpose was to investigate whether depression and anxiety were correlated with residual effects following GBS. The few previous published studies that have examined the psychosocial sequelae to GBS (Chemtob & Herriot, 1994; Eisendrath et al., 1983; Lennon et al., 1993; Teitelbaum & Kettl, 1988) have found that depression and anxiety are common outcomes during recovery. This chapter discusses the findings from the present study, and comparisons are drawn with Renaud's (2000) findings from her recently completed study of New Zealanders with GBS.

Part 1: Demographic Characteristics and Biomedical Features of GBS

GBS can strike any person, regardless of age, gender, or ethnic origins. The incidence does tend to be slightly higher amongst older people, although it is not clear why this is so. One possible explanation is proposed by Hahn (1998), who suggests that immune-suppressor mechanisms may weaken in older people, thus increasing susceptibility to immune disorders. The majority of the participants in the present study (68.1%) were aged 50 years or over when GBS struck, and almost all (81.7%) were aged over 50 years when the survey was conducted. The mean age of onset was 54.0 years ($\underline{SD}$ =14.5). The age distribution of the present participants roughly matches that of the larger group from which the sample was drawn. In the recent study of New Zealanders with GBS by Renaud (2000), 86.2% of the sample of 119 participants were aged over 40 years when GBS struck, with a mean age of 51.3 ($\underline{SD}$ =16.8). The gender splits in both Renaud's (2000) study and the present study were almost even, which is

consistent with the tendency for the disease to strike males and females fairly evenly. However, of the 289 adult past and present GBS patients in New Zealand known to the GBS Support Group, there is a slightly higher proportion of females than males (165:124) (J. Murray, personal communication, January 22, 2001). The actual number of individuals who have had GBS in New Zealand is currently unknown, as GBS is not a notifiable disease and there is no national database of the number of past and current cases.

The length of time since diagnosis of GBS varied considerably amongst the participants in the present study. Half of the participants had been diagnosed with GBS over 6 years ago, while the remaining half were diagnosed within the past 6 years. When the survey was completed, none of the participants were still acutely ill, and the most recent diagnosis was just over 1 year ago. A later section will examine the length of time since diagnosis in relation to the occurrence of depression and anxiety, as this is likely to be confounded by the participants' varying stages of recovery.

Almost two thirds of the participants in the present study (61.4%) reported receiving a diagnosis of severe GBS, and not surprisingly, all but 2 individuals were hospitalised. Both of these participants received mild GBS diagnoses. The remaining 2 participants who received mild GBS diagnoses reported the shortest periods of hospitalisation. The debilitating impact of GBS is starkly reflected in the duration of hospitalisation experienced by most participants. The range was large, from 5 to 570 days, with a mean of 120 days ($\underline{SD}$ = 136.3) spent in hospital. In today's era of early discharges from hospital, a stay of 3 months or more is indeed significant. Just under half of the participants spent this long or longer in hospital.

Half of those hospitalised spent time in an ICU, and there was a statistically

significant correlation between the length of time spent in intensive care and total time

spent in hospital. Two thirds of those who were admitted to intensive care required

mechanical ventilation due to compromised respiratory function resulting from paralysis.

Participants were not asked to specify the length of time they required assisted

ventilation.

Residual Problems

Winer et al. (1985) estimate that approximately 16% of GBS patients are left

with residual functional deficits that may persist, and which frequently become

permanent disabilities. Assuming that the participants in the present study are roughly

representative of GBS sufferers in New Zealand, the findings are fairly consistent with

Winer et al.'s estimate that 16% of GBS sufferers experience ongoing residual deficits.

For example, the sample (n = 44) accounts for 15.2% of the known adult past and

present GBS patients in New Zealand (n = 289). Almost all of the present participants

reported residual deficits as a result of GBS, with fatigue being experienced by the

highest percentage (93.2%). This was followed by residual motor deficits, pain, and

nerve tingling. Length of time since diagnosis did not have a moderating effect on either

the number or the severity of the residuals experienced. In short, the passage of time did

not diminish the residual deficits, and if anything, severity for motor-related residuals,

pain, and nerve tingling was higher for those who had been acutely ill longer than 6 years

ago. One possible explanation for this may lie in the availability of treatments to those

who were acutely ill more than 20 years ago. Plasma exchange (PE) was first trialed in

1978, but may not have been available in New Zealand until later. The first reports about

the efficacy of intravenous immune globulins (IVIg) were published in 1988 and 1989 (Pascuzzi & Fleck, 1997), but IVIg would not have been widely available in New Zealand until some time after that. For those participants who were acutely ill over 20 years ago, treatments such as PE and IVIg would not have been available. The participants in the present study were not asked to report which treatments (if any) they had received, so it is not possible to examine whether the severity of residual problems was related to treatment received. This issue will be discussed in more depth in a later section regarding the limitations of the present study.

It is relevant to note, however, that in the first study of its kind about GBS in New Zealand, Renaud (2000) found that while half the sample (49.6%) reported receiving PE, the majority of the participants (82.4%) also reported permanent residual damage following GBS, and the relationship between residual problems and whether PE was received was not statistically significant. In short, PE did not influence the development of long-term deficits in her sample of 119 participants. A possible explanation for this is that PE and IVIg are known to be most efficacious when administered within 2 weeks of onset of GBS (Ropper, 1992), and there are optimum levels of these treatments that maximise their benefits. Renaud noted that no information about the timeliness, or the level of treatments was obtained from the participants in her study, yet these factors may well have had a bearing on the efficacy of the treatment.

In the present study, half of the sample were admitted to an ICU, and the reported severity of the residual problems was higher for this group than for those who did not require admission to an ICU. A statistically significant relationship was found between admission to an ICU and severity of residual problems. Some authorities postulate that the suspected etiologies of GBS play a role in the severity of the disease

(Pascuzzi & Fleck, 1997), and several studies have shown that a prior infection with *campylobacter jejuni* results in poorer prognosis and longer recovery times (Rees et al., 1995). Participants in the present study were not asked to comment on the suspected etiology of the GBS, so it was not possible to examine whether there were relationships between severity of the disease and the suspected etiologies, or between the severity of the residual problems and the suspected etiologies. In Renaud's (2000) study, 46.2% of the participants reported having an antecedent viral or bacterial infection prior to GBS. In that study, however, no information about the severity of the disease or the severity of the residual deficits was gathered. Renaud noted that over a quarter of her participants (27.7%) did not offer any comment about the suspected etiology, a finding that is consistent with international studies where no antecedent event is reported in one third of all GBS cases (Pascuzzi & Fleck, 1997).

Of all the reported residual problems resulting from GBS, fatigue was by far the most commonly experienced one in the present study. This finding is consistent with several other studies (Bernsen et al., 1997; Lennon et al., 1993), and Merkies et al. (1999) described fatigue as a prominent and highly disabling sequelae to GBS. The results from the present study regarding the incidence of post GBS fatigue support the findings by Merkies et al. that fatigue was independent of the time that had elapsed since the acute phase of GBS, and that it was not related to duration of the disorder. In the present study, nearly of all of the participants experienced fatigue regardless of the length of time since diagnosis.

Also consistent with other studies (de Jager & Sluiter, 1991; Ropper et al., 1984), pain was commonly experienced by the participants in the present study. Those who reported severe pain were all from the group who had been diagnosed with GBS

over 6 years ago. As with fatigue, pain did not lessen with the passage of time. The majority of studies that have examined the incidence of pain associated with GBS have focussed on pain during the acute phase of the illness (Moulin et al., 1997; Pentland & Donald, 1994; Ropper et al., 1984). Yet as Tempest-Roe (2000) points out, residual problems such as pain can persist for months or even years. Although Eisendrath et al. (1983) observed 20 years ago that recovery from GBS is frequently marked by reports of pain, a surprising lack of research on pain during recovery and post GBS has been carried out since then.

The incidence of motor-related deficits following GBS has received more attention in the literature. One explanation for this is that physical deficits are visible whereas pain or fatigue are not. De Jager and Minderhoud (1991) reported that 65% of their sample of 57 severe GBS patients were left with residual motor deficits. They estimate that between 15% and 30% of mild cases experience residual motor problems, increasing to 70% in severe cases. In the present study, 77.3% of the sample reported reduced mobility following GBS, with over half describing the severity as mild or moderate. As with other residual problems, the severity of the motor deficits did not lessen with time. Of those diagnosed more than 6 years ago, 76.5% reported the severity of their reduced mobility as moderate or severe, compared to 35.3% in the group who were diagnosed within the past six years. In the latter group, 64.7% reported the severity as mild. The reasons for this are unclear, although improved efficacy in treatment may be one possible factor.

Very little has been written about the numbness and nerve tingling that often follows GBS. Yet these two residual complaints are documented in the literature as being common sequelae to the disorder (de Jager & Minderhoud, 1991). In the present

study, length of time since diagnosis did not lessen the severity of either of these residual problems, and mild or moderate numbness and nerve tingling was experienced by half of the participants in each of the two groups, irrespective of whether their diagnosis of GBS was within the past 6 years or longer ago.

Part 2: Quality of Life Following GBS, and Relationships Between Depression, Anxiety, and GBS.

1. Quality of Life - The McMaster Health Index Questionnaire (MHIQ)

Although the MHIQ was designed to be relevant to the point of time at which it is completed, participants in the present study were asked to complete it twice. The first version was from a retrospective perspective, that is, from the point in time when GBS was most severe. The second version was completed from the current perspective, that is, at the point in time when the survey was conducted. The rationale for this was an attempt to measure change along the three domains of functioning across two points in time. Because of the retrospective nature of the study, there was no other way of doing this. The drawbacks using a measure that was not designed for this purpose, and the pitfalls of asking participants to rely on retrospective memory will be discussed in the section on limitations of the present research.

The results from the scores on the MHIQ showed that the greatest improvement across the two points in time was along the domain of physical functioning. This result was expected and can be explained by the recovery of physical function following what many participants described as 'total paralysis'. Notwithstanding the residual motor-related problems experienced by the majority of the sample, the physical functioning of

all participants improved considerably from when the GBS was at its most severe. The correlation between current physical functioning and the total number of residual problems suggested that the lower the number of residual problems, the higher the level of physical functioning. The majority of participants scored within the 'good' functioning range when the survey was conducted.

While there was less overall improvement reported in the domains of social and emotional functioning than in physical functioning, this can be explained by the overall higher reported functioning in these two domains when GBS was most severe. Given the devastating physical impact of GBS during the acute phase, it seems somewhat remarkable that the majority of participants reported their social and emotional functioning to be 'good' at this time. Just under three quarters of the sample (72.1%) fell within the good functioning range on the emotional domain of functioning when GBS was at its most severe, while over three quarters (81.3%) fell within this range on the social domain of functioning. These results must be interpreted with caution, however, as participants were required to rely on retrospective memory, and had to recall affective states and social circumstances that dated back several years in some cases. It seems reasonable to assume that the participants' memories of their physical state would have been recalled with greater degrees of accuracy, as paralysis is a life-changing event that is likely to be remembered. By the same token, the ability to recall one's emotional state and social circumstances from that time may be subject to greater interference. For example, it is not a pleasant experience to 'dredge up' past feelings of distress, and the passage of time does tend to blur memories. For those who have been acutely ill, the experience of being in intensive care, on medication, and the effects of the illness itself may combine to interfere with an individual's awareness of their affect and their social

circumstances, thus impeding their recall of these events. Ideally, an assessment of emotional and social functioning should be carried out during the acute phase of the illness. Again, this is one of the limitations of retrospective studies.

A second possible explanation for the high level of social and emotional functioning when GBS was at its most severe may be related to the age factor. Renaud (2000) found in her study that there was a relationship between age and the reported presence of distress during the acute phase of GBS. Specifically, perceived emotional difficulties systematically declined with age, with older people being less inclined to perceive that they had emotional difficulties. In the present study, the majority of the sample (68.1%) were aged over 50 years when GBS struck, and an even greater number (81.7%) were aged over 50 years when the survey was completed. Post GBS, Renaud found that fewer people reported emotional problems.

The correlations between the scores on the three subscales of the MHIQ completed from the present point of view and the BDI-II suggested that the higher the level of physical, social, and emotional functioning, the lower the level of depression. A discussion about the findings from the BDI-II follows next.

2. Depression - The Beck Depression Inventory-II (BDI-II)

According to Saravay et al. (1996), mild depression in the medically ill tends to be affected by the severity of the illness and usually remits once improvement in the medical condition occurs. This is in contrast to moderate or severe depression, which is more likely to persist chronically irregardless of any improvement in health. Due to the retrospective nature of the present study, it was not possible to ascertain whether participants were depressed during the acute phase of their illness and whether this

remitted once their health improved. The results from Renaud's (2000) study, however, suggest that this may have occurred for some of her 119 participants. Although that study was also retrospective in nature, and the participants were not formally screened for depression during the acute phase of GBS, they were asked to report on 'emotional difficulties' during that time. Of the 73.9% who reported a range of emotional difficulties, 27.1% reported being depressed when acutely ill. This figure dropped to 18.3% post GBS.

With regard to the presence of depression at the time the survey was conducted in the present study, the majority of the participants (86.0%) scored within the minimal range of depression, suggesting that in this sample, depression was not a common sequela post GBS. The number of residual problems reported did not appear to influence whether depression was present or not, although the mean severity of the residuals was slightly higher for the 6 participants who scored within the mild or moderate range of depression on the BDI-II. Severity of fatigue was higher for this group than for any other residual problem, a finding which endorses the description of fatigue by Merkies et al. (1999) as 'highly disabling'.

Factor analyses of the BDI-II (Dozois et al., 1998) indicated that a 2-factor solution optimally summarised the data for this instrument, and its predecessor, the BDI-I. The two factors are best described as a cognitive-affective dimension, and a somatic-vegetative symptom dimension. It is the items that comprise the latter factor that need careful consideration when screening for depression in medically ill populations (Williams & Richardson, 1993), as these items may be related to disease processes rather than depression. For example, fatigue, loss of energy, changes in appetite, changes in sleep, and loss of interest in sex may all be the result of a medical condition. Furthermore, it

should be acknowledged that somatic symptoms increase with age, and Pachana et al. (1994) caution that the BDI-II was not specifically designed with elderly populations in mind. These authors point out that there is really no way to ascertain whether somatic symptoms endorsed on the BDI-II are secondary to depression, or secondary to physical illness.

With these issues in mind, the scores from the somatic items from the BDI-II were extracted in the present study and separate analyses were completed. Given the older age bracket of the majority of the participants, and the fact that the sample was drawn from a medically ill population, it seemed reasonable to expect that the scores on the somatic items would be higher. The results showed that of the 6 participants who had scored within the mild or moderate range of depression when all 21 items were scored, only 2 still fell within the mild range when the scores from the somatic items were extracted. In this sample then, long-term depression was not commonly experienced post GBS.

3. Anxiety - The 6-Item Short Form of the State Scale of the State Trait Anxiety Inventory (STAI-6)

Whilst depression amongst the medically ill has been given considerable attention in the literature, less has been written about the presence of anxiety in medically ill populations. Sherbourne et al. (1996) argue that illness may be exacerbated by anxiety, and they stress the importance of identifying and addressing co-morbid anxiety in medically ill people. In Renaud's (2000) study, participants were not formally screened for the presence of anxiety, but a significant number reported anxiety during the acute phase of GBS (14.3%), and during or beyond the recovery phase of GBS (13.3%). In

that study, less participants reported anxiety than depression, although anxiety dropped post GBS at a much smaller rate (1%) than depression (8.8%). One possible explanation for this is that the nature of the anxiety may simply shift as the illness runs its course. For example, during the progressive phase of GBS (de Jager & Sluiter, 1991) acutely ill patients may be consumed with anxiety about the possibility of death. If they require ventilation and tracheostomy procedures, they may be highly anxious that these will fail them. Depending on the extent of paralysis and their subsequent level of helplessness, acutely ill GBS patients may be very anxious about their immediate needs being adequately met. In addition to all these worries, they are likely to be very anxious and fearful about 'the unknown'. Most individuals are not likely to have heard of GBS prior to being struck down with it, and would not know what to expect in terms of its impact and recovery from it. Indeed, many participants in the present study expressed frustration about their lack of knowledge of GBS, and this will be discussed in a later section.

Once the disease reaches the plateau phase, a different set of anxieties may emerge. For example, acutely ill patients may now know that they will recover from GBS, but the extent of the recovery is still likely to be uncertain at this point, as is the length of time this will take. GBS patients may be highly anxious about being left with residual deficits and permanent disabilities.

During the recovery phase of GBS, many individuals face the prospect of an uncertain future. The issue of whether functioning will be restored to pre-morbid levels must be addressed. Indeed, Lennon et al. (1993) identified three main sources of anxiety during recovery from GBS. These involved the fear of recurrence, the level of disability

resulting from GBS, and financial worries resulting from loss of employment and the impact of that on the family.

In the present study, it was not possible to screen for anxiety during the three stages of GBS identified by de Jager and Sluiter (1991). Participants were screened for the presence of anxiety at the point of time when the survey was conducted, that is, post GBS. Almost three quarters of the sample scored under half on the STAI-6, suggesting that for the majority of participants, long-term anxiety was not commonly experienced post GBS. The presence of anxiety was not found to be correlated with the number of residual problems experienced, and a chi-square analysis showed that severity of diagnosis did not result in higher scores on the STAI-6. As with any self-report measure, there are limitations to the data gathered. This issue along with other limitations of the present study will be examined in a later section, but the next section discusses some of the important factors in recovery from GBS identified by the participants.

Part 3. Important Factors in Recovery from GBS

For the participants in the present study, the two most difficult aspects of having GBS involved the loss of independence they experienced, and the physical limitations resulting from their residual effects. These issues were also identified in Renaud's (2000) study, and she pointed out the important fact that GBS patients do not lose their awareness during the acute phase of the illness despite their physical dependence on others. Renaud argues that because GBS patients remain fully aware, medical staff may find GBS a very difficult disorder to manage, from a perspective of shared locus of control. It is dangerously easy to assume that patients lack awareness because they are immobile and unable to express themselves, and once this assumption is made, it could

be very easy to impose procedures on people with a lack of sensitivity and a lack of communication or consultation. In general, the participants in the present study did not comment on this aspect of their loss of independence, but there are several reports in the literature regarding insensitive care by medical staff when GBS patients have been paralysed and unable to communicate (Blanco & Cuomo, 1983; Bowes, 1984). In the present study, the most commonly expressed frustration regarding loss of independence related to feeling powerless and having no control over physical functioning.

With regard to the difficulties caused by residual problems identified in the present study, Renaud (2000) also found that a high percentage of her participants (82.4%) reported long-term residual deficits. This compares with 93.1% in the present study. Participants in both studies expressed similar concerns about the limitations these residual problems placed on their day to day lives. Many were left with permanent disabilities and must contend with ongoing pain or fatigue.

In addition to these difficulties, lack of available information about GBS for patients and families was another source of frustration identified in the present study. This is contrast to Renaud's (2000) finding that 70.6% of her sample were satisfied with the information they received about GBS. Sample size may be one factor in the difference here; the sample from the present study was just over a third of the size of Renaud's. Much of the anxiety expressed by participants in the present study related to a fear of the unknown, and 'not knowing what to expect throughout the phases of the illness' was a commonly expressed theme. Kenny et al. (1998, cited in Renaud, 2000) argue that knowledge strengthens an individual's coping ability by dissipating the fear of the unknown.

The other major difficulty identified by several participants in the present study involved what was perceived to be a slow diagnosis of GBS. Some expressed a belief that their recovery had been hampered as a result, and there were concerns that treatment may not have been available to them within the optimum timeframe. Diagnosis of GBS may be slow for a number of reasons. First, as a relatively rare disorder its presence might not be suspected as quickly as more common disorders. Second, before a diagnosis of GBS can be confirmed, a number of clinical, laboratory and electrodiagnostic procedures must be carried out (Asbury & Cornblath, 1990). The diagnostic criteria for GBS are set out in Appendix 1, and some of the procedures involved in diagnosing the variants of GBS may take time. For example, serial lumbar punctures are required to establish whether cerebrospinal fluid (CSF) is elevated. A timely diagnosis is of great importance, however, because treatments such as PE have been found to most effective if they are begun within two weeks of onset of GBS (Ropper, 1992). Third, the range of symptoms is very wide and a GBS patient may only experience a small subset of these.

Two main themes emerged in relation to the factors that were identified as helpful to recovery in the present study. These included the support of family and friends, and a positive mental attitude by GBS patients themselves. The majority of participants expressed their appreciation at the love, support, and care shown to them by their friends and family. In Renaud's (2000) study, the findings regarding support from family were mixed. While 36.1% described supportive relationships with their partners, 41.7% expressed the view that GBS had had an adverse effect on their relationship with partners. Poor communication, sexual dysfunction, and increased responsibilities were cited as recurring themes amongst this group. Interestingly, the majority of older

participants in Renaud's study reported more supportive relationships with partners as a result of GBS, or no change to the relationship. Renaud proposes a number of possible explanations for this finding. These include the view that older people may be more moderate when attributing negative affect, and the possibility that older people may strive for more intimate relationships than younger people. Another possible explanation is that older people may expect to encounter illness as part of the aging process, and may therefore be better equipped to cope when illness does strike. The high level of support described by participants in the present study may be one factor in the low level of current depression reported. It seems reasonable to postulate that support from family and friends could have a moderating effect on the level of distress experienced by GBS patients.

The second major theme that was identified as helpful to recovery in the present study was a positive mental attitude by the participants themselves. One individual described a 'sheer determination to recover'. This is consistent with Lipowski's (1983) assertion that a patient's emotional response to an illness has an important bearing on how the patient copes with the illness and recovery. For those who expressed determination to recover from GBS, the meaning attributed to the illness was clearly interpreted as a challenge (Lipowski, 1983), as opposed to being interpreted as a punishment, or in terms of the losses and gains it presented. It is also possible that disease type may have a bearing on determination to recover. For example, GBS and cancer are both serious illnesses, but the prognosis may be better for GBS than for certain cancer types. If patients are informed that the prognosis for recovery is good, they may be more determined and motivated to recover.

Factors such as coping mechanisms, personality, and the presence or absence of support all interact in complex ways to determine an individual's response to illness (Rodin & Voshart, 1987). The comments made by the participants in the present study bear witness to the interwoven nature of these factors, and their importance when confronted with a life-threatening, serious illness like GBS.

Factors that were commonly perceived to hinder recovery mostly involved a perceived lack of follow-up of rehabilitative and supportive services once discharge from hospital had occurred. During the recovery phase of GBS, many participants expressed the view that they were 'left alone' to cope, and that ongoing physiotherapy and hydrotherapy had not been arranged for them. Furthermore, many participants experienced ongoing difficulties with daily living tasks due to their residual problems, and they expressed frustration that they had not been offered home help. In Renaud's (2000) study, only 7 participants reported accessing home help, a very low figure given the reported frequency of residual problems experienced by participants in that study. Whether all patients' needs are routinely assessed prior to discharge from hospital is not clear, and practice may differ across the country. Given the mean duration of time spent in hospital by the present participants, however, it seems reasonable to assume that a thorough needs assessment would be of benefit prior to discharge.

A second factor perceived to hinder recovery by the present participants was what some described as a lack of knowledge by medical staff about GBS. Such comments were made in general terms, however, and they did not identify who was being referred to, for example, doctors, nurses, or other medical practitioners. Although this issue was not specifically addressed in Renaud's (2000) study, her participants were asked to report their satisfaction with medical help, and 86.8% of those who had been

treated by a specialist reported some degree of satisfaction with the medical assistance they received. Renaud cautions, however, that the term 'medical help' is ambiguous and may refer to treatment regimes or patient care. In order to accurately measure patient satisfaction, terms such as 'medical help' must be clearly operationally defined.

A desire for knowledge about GBS was a commonly expressed theme by the present participants. Many commented that more knowledge about the disease would have helped them to cope better. As outlined previously, a lack of available information about GBS for patients and families was a source of frustration for many participants, and several individuals expressed the view that 'not knowing what to expect throughout the phases of the illness' was the worst aspect of GBS. For those who were visited while ill by former GBS patients, this was highlighted as a great boost to their recovery. Many participants who did not have any contact with former GBS patients commented that this would have been welcomed. Several participants suggested that a handbook for medical staff would be useful, with information about GBS itself, and information about the specific needs of GBS patients. The next chapter will examine the limitations of the present study, before outlining the conclusions and the recommendations for further research.

Chapter 7

Limitations, Conclusions, and Recommendations for Future Research

Although the present findings contribute to the small body of knowledge about

some of the psychological sequelae to GBS, there are several limitations to the study that

must be acknowledged. These are discussed below under general headings about

sampling issues, the postal survey method used, the retrospective nature of the study, the

reliance on self-reported data, missing information about some important clinical aspects

of GBS, and areas where the findings may have been confounded. Following this

discussion, conclusions from the study will be presented along with some suggestions for

future research.

Limitations of the Present Study

1. Composition of the Sample

Ensuring that a sample is representative of the population poses many challenges

for researchers. In the present study, participants were drawn from those past and

present GBS patients who receive the quarterly newsletter of the New Zealand GBS

Support Group. The study was advertised in the newsletter (see Appendix 2) and

participation was invited from interested persons. Of the total 289 known past and

present GBS patients in New Zealand, approximately 160 have expressed interest in

carrying on as members of the Support Group and continue to receive the quarterly

newsletters (J. Murray, personal communication, January 22, 2001). It is from this pool

of people that the present sample was drawn. Of the initial 49 individuals who expressed

interest in participating, a total of 44 people completed and returned the questionnaires,

thus forming the sample size. This amounts to a 27.5% response rate from the total pool

of 160 past and present GBS patients who currently receive the NZ GBS Support Group

newsletter. The actual number of past and present GBS patients in New Zealand is not

currently known, so it is not possible to know for sure whether those who subscribe to

the NZ GBS Support Group are representative of all GBS patients in New Zealand.

The size of the sample in the present study was small, so complex analyses of the

data were precluded. A larger sample would have increased the power of the statistical

analyses carried out. The low numbers of participants who reported depression ($\underline{n} = 6$)

in the present study meant that no statistical analyses regarding depression were able to

be completed, as it probably would not have been possible to achieve results that reached

statistical significance, possibly because of type 2 statistical errors.

The vast majority of the participants in the present study described their ethnicity

as New Zealand European. Only one participant identified as European/Maori, and one

other identified as Pacific Islander. The present study relied on written questionnaires.

For cultures that value an oral tradition, this form of research may be in conflict with

cultural values, which may influence an individual's decision to participate. GBS is

known to strike indiscriminately in terms of culture, so the low numbers of Maori and

Pacific Island participants in the present study probably does not reflect the percentage of

the population of Maori and Pacific Islanders in New Zealand. Rather, it may reflect the

fact that minority ethnic groups are unlikely to join support groups.

In summary, there are several possible sampling effects from the present study.

First, it is unknown whether the participants are representative of the wider population of

New Zealand adults who have experienced GBS, which means that the results should not

be generalised. Self-selected samples, such as the present one, are likely to differ from

randomly chosen samples. Second, the largely mono-cultural, small sample in the

present study also raises questions about the representativeness of the sample. Third, the present sample comprised mostly older individuals who had been acutely ill with GBS several years ago. Quite different results would probably be obtained from a sample comprising mainly younger individuals who were acutely ill more recently.

2. Postal Survey Method

Multiple factors influence an individual's decision to participate in a study or not, but the survey nature of the present study is likely to have had some bearing on this. While some individuals prefer the anonymity of a postal survey, others prefer the personal contact an interview offers. Filling out questionnaires can be laborious, particularly for those with disabilities. In the present study, several participants required assistance with this from family members, which raises the possibility of responses being different because of the presence of another person, such as a spouse or family member. The GBS questionnaire contained a cautionary note (see Appendix 5) to counter this risk.

Postal surveys have several advantages. For example, they ensure anonymity and they are a relatively inexpensive way of gathering data across a large geographical area (Vaux, 1996). There are disadvantages, however. Some individuals may be 'put off' by filling out questionnaires, and individuals with low literacy skills may be excluded. Some people may prefer to talk to an interviewer, and in such a setting they have they opportunity to clarify issues and ask questions. This is not possible in a postal survey. Notwithstanding these limitations, exploratory surveys such as the present study are still considered useful (Leavitt, 1991) because they provide important information about a topic or a particular group of people.

3. Retrospective Nature of the Research

The present study was retrospective in nature, and participants were required to recall events from the past. There was considerable variation in the length of time since diagnosis of GBS, ranging from a minimum of 1 year ago to a maximum of 26 years ago. Half of the participants were recalling events that occurred over 6 years ago. Obviously, this raises important issues about the reliability of information based on retrospective memory. Smith, Leffingwell, and Ptacek (1999, cited in Renaud, 2000) argue that people tend to consistently overestimate their daily coping ability when they are required to retrospectively recall events. In the present study, the majority of participants tended to report their social and emotional functioning as 'good' when acutely ill with GBS, despite many being totally paralysed. This may be an example of overestimating functioning when retrospectively recalling events. The participants may have recalled their physical functioning at that time with a degree of accuracy because of the unforgettable nature of being paralysed. Memories of surprising and emotionally arousing events are referred to as 'flashbulb memories (Matlin, 1994), which are vivid memories of events that are likely to be recalled with elaborate detail. Recall of affect and social circumstances from that time may not be as accurate as the recall of the actual event, such as the paralysis and hospitalisation. For these reasons, the results from the retrospective data in the present study may be unreliable and should be interpreted with caution. Ideally, measurement of affect should occur at the time of the event. A prospective study would enable this to happen.

4. Self-Report Measures

Self-report measures provide a useful means of measuring behaviours or domains of functioning, and they can offer some assurance of reliability and validity to the data. They do have their drawbacks, however. Some of these relate to validity issues, as self-report data is subjective and validity may be compromised. For example, individuals may not perceive that they have emotional problems and therefore may not report them, but others may perceive that they do. Ideally, data should be obtained from a range of sources, including participants, significant others, and medical records.

Self-report data are also subject to a range of biases. For example, some research participants may not wish to reveal aspects about themselves that they are uncomfortable about. In the present study, depression was reported as low. Whether this is because it actually was low, or whether participants felt uncomfortable, embarrassed, or ashamed to admit to feelings of depression is not known. In Western societies, there is still a pervasive stigma associated with mental health problems. If people believe that it is not socially desirable to acknowledge such problems, they may frame their responses to questions accordingly. This is referred to as social desirability bias (Franzoi, 1996). There is also the possibility that the social stigma associated with depression and anxiety may have prevented some potential participants from becoming involved in the present research, even though the study was conducted by way of an anonymous postal survey.

In the present study, a decision was made to ask participants to complete the MHIQ twice, in an attempt to measure change in functioning across time. The author of the MHIQ clearly states that the instrument is designed to be relevant to the point of time at which it is completed (Chambers, 1993), so the validity of the data from the retrospective version in the present study is questionable. Despite this concern, the

retrospective perspective does provide useful provide a useful benchmark in terms of measuring general changes in the three domains of functioning over time. Ideally, to reliably measure changes over time, a measure would be completed at two different points in time, but due to the retrospective nature of the present study this was not possible.

Although the present study has several limitations, these do not overshadow the important information obtained about the impact of GBS in this particular sample. Whilst a prospective study would provide more reliable data, exploratory studies such as the present one are necessary when previous studies on the topic are lacking.

5. Suspected Etiologies, Variants of GBS, and Treatment Issues

Participants in the present study were not asked to report the suspected etiologies of the GBS, which variant of GBS they had been diagnosed with, or whether they had received treatment or not. Information about these three clinical issues would have been useful for several reasons. First, it is now known that GBS is in fact a heterogenous disorder (Ho & Griffin, 1999), and second, prognosis is believed to be related to the suspected etiology of GBS (Pascuzzi & Fleck, 1997) and the particular variant (Lu et al., 2000). For example, a prior *campylobacter-jejuni* infection tends to result in predominantly axonal neuropathy such as ASMAN and AMAN, and patients with these variants typically experience the most serious residual problems and delayed recoveries (Hahn, 1998; Pascuzzi & Fleck, 1997). Because the participants in the present study were not asked to provide information about these aspects of their experience with GBS, it was not possible to explore whether the suspected etiologies, the variants, and the treatment provided had any impact on the severity of the residual problems. Renaud

(2000) found, however, that there was no relationship between receipt of plasmapheresis (PE) and severity of residual problems amongst her participants, but she noted that they were not asked to report whether they had received other treatments such as IVIg. Other pertinent information about the treatment regime was not obtained either, such as how quickly it was commenced.

6. Confounds

The presence of anxiety or depression in the present study may have been confounded by the varying length of times since the diagnosis of GBS. Although there are several reports in the literature about depression and anxiety being common sequelae to GBS, these refer to the recovery period. One explanation for the low levels of depression and anxiety in the present study could be that many participants were in fact post GBS, that is, post recovery from GBS. Recovery times vary according to a number of factors, but the process can take up to 2 years. In the present sample, the mean number of years since diagnosis was 7.97 years ($\underline{SD}$ = 6.43). The small sample size precluded any analysis of depression amongst the few participants who had been diagnosed with GBS within the past 2 years.

Despite the limitations of the present study, the findings regarding the relationships between mental status and residual problems add important information to the small body of knowledge about some of the psychological sequelae to GBS. In particular, they build on the recent work begun by Renaud (2000) who has provided a first New Zealand profile of the biopsychosocial impact of GBS. The results from the present study support Renaud's argument that much work remains to be done in relation to examining the psychosocial dimension of GBS.

Conclusions

GBS is a serious illness with long-lasting consequences for many who experience it. It strikes suddenly and indiscriminately, causing previously fit and healthy individuals to be incapacitated for lengthy periods. Recovery is gradual, taking up to two years in many cases. Whilst the majority of GBS patients do make good recoveries, many individuals are left with debilitating residual problems. Almost all of the participants in the present study were still suffering the adverse effects of the residual problems resulting from GBS, and the severity of these had clearly not lessened with time. Fatigue was by far the most common residual problem, and the debilitating impact of this has drawn recent attention in the literature (Merkies et al., 1999).

The aim of the present study was to examine the relationships between mental status and the presence of residual problems during and beyond recovery from GBS. Although the results suggested that long-standing depression and anxiety were not commonly experienced by the participants, it is important to note that the majority of the sample had been acutely ill with GBS several years ago. The findings from Renaud's (2000) study seem to suggest that psychological distress may be experienced earlier in the recovery process. To reliably investigate whether this is indeed the case, a prospective research design would be necessary. The relatively low incidence rate of GBS in New Zealand and the scattered population base may preclude a large scale prospective study from being carried out, however.

Suggestions for Future Research

Due to the low incidence of GBS, it is unlikely that there would be enough individuals at the same stage of the illness at the same time in New Zealand to warrant a

prospective study being carried out. As an alternative, a series of case studies that involved tracking individuals through the stages of GBS would be one way of providing useful information. A series of case studies would also provide an effective way of reliably measuring change over time. Although case studies do not establish causal relationships and nor can the findings be generalised, they do provide important clues and information about the individuals being studied (Leavitt, 1991).

An important area that has been completely overlooked in the GBS literature is the impact on caregivers and families of GBS patients. Many of the participants in the present study commented positively about the support and care they received from their loved ones, but in Renaud's (2000) study 41.7% of her sample reported that GBS impacted adversely on the relationships with partners. In several cases, marriages ended due to the strain placed on them by the consequences of the illness. A study that examined the experiences of caregivers and families of GBS patients would provide another perspective about the psychosocial aspects of GBS.

Although depression and anxiety were not found to be commonly experienced post GBS in the present study, 73.9% of Renaud's (2000) sample reported a range of emotional difficulties during and post GBS. Of these, 27.1% reported depression and 14.3% reported anxiety during the acute phase of the illness. Post GBS, these rates dropped to 18.3% for depression, and 13.3% for anxiety. Renaud argues that there is a need for GBS patients to receive intervention from psychologists throughout the course of their illness, and she suggests that such intervention is likely to lessen the adverse emotional difficulties experienced by many. Renaud points out that whilst GBS patients and families might have access to medical social workers, this service may not necessarily be consistent. For example, medical social workers are available to some wards, but

patients transfer to other wards and there may not be follow-up by social work staff. Furthermore, medical social workers are not necessarily trained or experienced in dealing with mental health issues. Future research of GBS patients could compare the outcomes of those who received intervention from mental health workers, such as psychologists, with those who had no such support.

Several participants in the present study and in Renaud's (2000) study suggested that an information booklet about GBS and patient care needs would be a useful tool for medical staff. Future research could address this gap by eliciting information from former GBS patients about what was helpful during the different stages of the disease in terms of provision of information, treatment, medical assistance, and nursing care. A booklet could then be compiled and made available to all those medical staff involved in the treatment and care of GBS patients.

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Appendix A   **Diagnostic Criteria For Guillain-Barré Syndrome**

<u>Note.</u> From "Assessment of Current Diagnostic Criteria for Guillain-Barré Syndrome,"

by A. K. Asbury and D. R. Cornblath, 1990, *Annals of Neurology, 27*(Suppl.), 21-22.

1. Features Required for Diagnosis

A.   Progressive motor weakness of more than one limb. The degree ranges from

minimal weakness of the legs, with or without mild ataxia, to total paralysis of

the muscles of all four extremities and the trunk, bulbar and facial paralysis, and

external ophthalmoplegia.

B.   Areflexia (loss of tendon jerks). Universal areflexia is the rule, though distal

areflexia with definite hyporeflexia of the biceps and knee jerks will suffice if

other features are consistent.

II.   Features Strongly Supportive of the Diagnosis

A.   Clinical features (ranked in order of importance)

1. Progression. Symptoms and signs of motor weakness develop rapidly but cease

to progress by four weeks into the illness. Approximately 50% will reach the

nadir by two weeks, 80% by three weeks, and more than 90% by four weeks.

2. Relative symmetry. Symmetry is seldom absolute, but usually, if one limb is

affected, the opposite is as well.

3. Mild sensory symptoms or signs.

4. Cranial nerve involvement. Facial weakness occurs in approximately 50% and is

frequently bi-lateral. Other cranial nerves may be involved, particularly those

innervating the tongue and muscles of deglutition, and sometimes the

extraocular motor nerves. On occasion (less than 5%), the neuropathy may begin in the nerves to the extraocular muscles or other cranial nerves.

5. Recovery. It usually begins two to four weeks after progression stops. Recovery may be delayed for months. Most patients recover functionally.

6. Autonomic dysfunction. Tachycardia and other arrhythmias, postural hypotension, hypertension, and vasomotor symptoms, when present, support the diagnosis. These findings may fluctuate. Care must be exercised to exclude other bases for these symptoms, such as pulmonary embolism.

7. Absence of fever at the onset of neuritic symptoms.

Variants (not ranked)

1. Fever at onset of neuritic symptoms.

2. Severe sensory loss with pain.

3. Progression beyond four weeks. Occasionally, a patient's disease will continue to progress for many weeks longer than four or the patient will have a minor relapse.

4. Cessation of progression without recovery or with major permanent residual deficit remaining.

5. Sphincter function. Usually the sphincters are not affected, but transient bladder paralysis may occur during the evolution of symptoms.

6. Central nervous system involvement. Ordinarily, Guillain-Barré Syndrome is thought of as a disease of the peripheral nervous system. Evidence of central nervous system involvement is controversial. In occasional patients, such findings as severe ataxia interpretable as cerebellar in origin, dysarthria, extensor

plantar responses, and ill-defined sensory levels are demonstrable, and these need not exclude the diagnosis if other features are typical.

B. Cerebrospinal fluid features strongly supportive of the diagnosis.

1. CSF protein. After the first week of symptoms, CSF protein is elevated or has been shown to rise on serial lumbar punctures.

2. CSF cells. Counts of 10 or fewer mononuclear leukocytes/mm3 in CSF.

Variants

1. No CSF protein rise in the period of one to ten weeks after the onset of symptoms (rare).

2. Counts of 11 to 50 mononuclear leukocytes/mm3 in CSF.

C. Electrodiagnostic features strongly supportive of the diagnosis.

Approximately 80% will have evidence of nerve conduction slowing or block at some point during the illness. Conduction velocity is usually less than 60% of normal, but the process is patchy and not all nerves are affected. Distal latencies may be increased to as much as three times normal. Use of F-wave responses often gives good indication of slowing over proximal portions of nerve trunks and roots. Up to 20% of patients will have normal conduction studies. Conduction studies may not become abnormal until several weeks into the illness.

III. Features Casting Doubt on the Diagnosis

1. Marked, persistent asymmetry of weakness.

2. Persistent bladder or bowel dysfunction.

3. Bladder or bowel dysfunction at onset.

4. More than 50 mononuclear leukocytes/mm3 in CSF.

5. Presence of polymorphonuclear leukocytes in CSF.

6. Sharp sensory level.

IV. Features That Rule Out the Diagnosis

1. A current history of hexacarbon abuse (volatile solvents; *n*-hexane and methyl *n*-butyl ketone). This includes huffing of paint lacquer vapors of addictive glue sniffing.

2. Abnormal porphyrin metabolism indicating a diagnosis of acute intermittent porphyria. This would manifest as increased excretion of porphobilinogen and δ-aminolevulinic acid in the urine.

3. A history or finding of recent diphtheritic infection, either faucial or wound, with or without myocarditis.

4. Features clinically consistent with lead neuropathy (upper limb weakness with prominent wrist drop; may be asymmetrical) and evidence of lead intoxication.

5. The occurrence of a purely sensory syndrome.

6. A definite diagnosis of a condition such as poliomyelitis, botulism, hysterical paralysis, or toxic neuropathy (e.g., from nitrofurantoin, dapsone, or organophosphorus compounds), which occasionally may be confused with Guillain-Barré Syndrome.

Appendix B

Statement Published in NZ GBS Support Group Newsletter Advertising Study and Inviting Participation

Hi, my name is Cecilia Bourke and I am trying to locate willing participants for my Master of Arts research project titled "Recovery from Guillain-Barré Syndrome: Residual problems and their impact on daily functioning and psychological wellbeing in a New Zealand sample".

I am a distance student based in Timaru, and I am currently working on my thesis via Massey University, Palmerston North. My two supervisors are Dr John Podd and Dr Robert Gregory (School of Psychology, Massey University, Palmerston North).

Although there is a lot of international research and literature about Guillain-Barré Syndrome, most of it focuses on the medical aspects during the acute phase of the disease and the different treatments available. There has been very little research about the recovery process for sufferers and the impact of the disease on people's day to day lives and their emotional wellbeing. This gap in the research is surprising given the impact of Guillain-Barré Syndrome - including permanent disabilities for some sufferers. With other chronic and disabling illnesses, there is a large body of literature about the so-called 'psychosocial aspects of recovery'. This literature stresses the importance of being informed about what to expect as a result of the illness, and recognises that depression and anxiety are very common outcomes for people who are struck down suddenly by illness, particularly chronic illnesses.

The purpose of the proposed study is to explore some of the issues involved in the recovery process from Guillain-Barré Syndrome. I would like to hear from people who have either recovered from Guillain-Barré Syndrome or who are still recovering.

It is hoped that the information obtained from the participants will be of great use to other sufferers, their families, caregivers, and health professionals who are involved in their care. If people are informed about what sorts of experiences to expect during recovery from Guillain-Barré Syndrome (including depression, anxiety, fatigue, pain, and other problems), appropriate assistance can be put in place to help relieve them. Even having appropriate information may sometimes help a person to adjust to the limitations caused by their illness.

I am hoping that people who have been through the recovery process from Guillain-Barré Syndrome, or those who are currently going through it will have some ideas about what sorts of things were helpful to them. It would also be useful to hear about the things that would have been helpful. In this way, others might be helped.

Participation in this study will be completely voluntary. Nobody will have to reveal their identity because the research will be done by way of a postal survey. Participating in the study will involve completing four questionnaires (a mixture of circling boxes, and answering written questions) and will take under two hours in total. The questionnaires do not all have to be done at once and for those that need assistance, it is fine to ask someone to help with reading the questions and filling in the answers. All questionnaires will be sent out to participants through the NZ GBS Support Group, so I will not need to know anyone's name or location. The completed questionnaires can be posted (in an enclosed stamped addressed envelope) to Massey University, and they will be forwarded to me so that I can analyse the results.

Following this, I will write up my thesis, and a summary of the research results, which will be available to all participants who would like a copy. The study will be completed by November this year.

I hope to get as much information about people in New Zealand who have experienced Guillain-Barré Syndrome. Although studies in other countries have been done, this has not been the case in New Zealand. As stated, it is hoped that the information obtained through the questionnaires will be of benefit to all persons affected by Guillain-Barré Syndrome, particularly sufferers themselves and their families. I hope as many people will feel able to participate as possible.

For those who have read this and would like to participate in the study, please contact Jenny via the Support Group. She will then send you more detailed information about what exactly is involved. Thank you for taking the time to read this.

Appendix C

Participant Information Sheet

Guillain-Barre Syndrome: A Study About the Relationships Between the Severity

of GBS and Mental Health Status During Recovery

What is this study about?

The aim of this study is to explore the emotional and psychological aspects of

recovery for individuals affected by GBS. Although there is a lot of literature about the

medical aspects of GBS, there has been very little research done on the psychosocial

aspects during the recovery process. What little research has been done, suggests that

depression and anxiety are common outcomes during recovery from GBS. The present

study seeks to explore whether this is the case for GBS sufferers in New Zealand.

The study is being conducted by Cecilia Bourke, a Master of Arts (psychology)

student at Massey University, and will be jointly supervised by Dr John Podd (Senior

Lecturer) and Dr Robert Gregory (Senior Lecturer), both at Massey University in

Palmerston North.

What am I required to do?

If you agree to take part, you will need to fill out four questionnaires. The first

questionnaire is called a "GBS Questionnaire", and this focuses on your experience of

having GBS. It involves circling the most appropriate response to questions, as well as

answering six questions that require written responses. You are not obliged to answer

any questions you do not wish to answer. It is estimated that it may take about 30

minutes to answer all the questions. This questionnaire can be filled out in stages if

necessary.

The second questionnaire is the McMaster Health Index Questionnaire. This questionnaire measures a person's wellbeing and asks questions about physical, social and emotional functioning. For this study, you will need to complete this questionnaire twice, once from the point of view when your GBS was at its most severe, and the second time from the present point of view. By doing this it will be possible to compare improvements and changes in ability during your recovery. This questionnaire takes between 20-30 minutes to complete.

The third questionnaire is the Beck Depression Inventory-II, which screens for depression. This is a short questionnaire with 21 items. You circle the response that best describes how you have been feeling during the past week. This questionnaire takes about 5 minutes to complete.

The fourth and last questionnaire is the State-Trait Anxiety Inventory which screens for raised levels of anxiety. This is a very short questionnaire with only 6 items and takes less than 5 minutes to complete.

You can complete these questionnaires at your own pace and in your own time. It is suggested that you begin with the GBS questionnaire as a starting point. Completion of the McMaster Health Index Questionnaire should follow this (twice - once for when GBS was at its most severe and once for the present). Finally, the two questionnaires about depression and anxiety should be completed. You might like to complete this process over several days. It is important that you do so at your own pace. If you have special needs regarding filling out the questionnaires, and would like to participate in the study, please contact the researcher so that arrangements can be made to assist you. Should you choose to have someone to assist you with filling out the

questionnaires, it is important that the answers to the questions are yours, and not those of the person assisting.

All completed questionnaires need to returned to Massey University in the stamped addressed envelope provided. They need to be returned by **August 31st 2000.**

What can I expect from the researchers?

If you agree to take part in the study, you have the following rights:

- to an explanation of the nature of the study being undertaken, prior to your inclusion.

- to ask any questions about the study.

- to refuse to answer any particular question or to withdraw from the study at any time.

- to provide information on the understanding that that it will remain confidential to the researchers. Participants do not give their names, and all information will be identified by coded numbers rather than names. The information will be seen only by the researchers, and will be stored in a locked cabinet. It will not be possible to identify any individual in any reports that result from the study.

- to be provided with a summary of the findings from the completed study upon request.

Should you wish to clarify any of the above information or other issues relating to the study, please contact Dr Robert Gregory 06 3504158 or Dr John Podd 06 3505799 at Massey University.

Appendix D

Participant Consent Form

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to the researcher on the understanding that my name will not be used without my permission.

(The information will be used only for this research and publications arising from this research project.)

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed:

Date:

Appendix E

GBS Questionnaire

The following questionnaire relates to specific questions about your experience of GBS. First are some basic questions about personal details. Please circle the correct response. To family members or friends who assist with filling out the questionnaire, your assistance is appreciated. Please note, however, that the answers to the questions <u>must</u> be those of the person with GBS. Thank you.

Gender:	Male	Female	

Current age:	under 20 yrs	20-30 yrs	30-40 yrs	40-50 yrs
	50-60 yrs	60-70 yrs	70-80 yrs	80-90 yrs

Ethnicity:	NZ European	Maori	Other (specify)

Spouse:	Yes	No

Next are some questions about the GBS itself. Please circle the most appropriate response.

Year of GBS diagnosis: _____

Age at onset of GBS: _____

Hospitalised:	Yes	No	
Intensive Care Unit admission (ICU):	Yes	No	Not applicable
Artificial respiration needed:	Yes	No	Not applicable

Length of time in ICU: ___days ___weeks
___months not applicable

If yes, number of days/weeks/months: ___days ___weeks
___months not applicable

Total length of time in hospital: ___days   ___weeks

___months   not applicable

Severity of diagnosis given: mild   moderate   severe

List any current medications: _____

_____

Are you currently prescribed medication for depression: yes   no

Are you currently prescribed medication for anxiety: yes   no

Next, some brief questions about any residual physical problems resulting from GBS. Some examples have been listed, and space has been provided for other problems not listed. Please circle as many of the listed problems that apply to you according to severity (mild, moderate or severe). Circle mild if there is no interference with your functioning; moderate if there is some interference with your functioning, and severe if there is serious interference with your functioning. Circle not applicable if none of the residual problems apply to you. For other residual problems not listed, the same instructions apply.

Fatigue:	Not applicable	Mild	Moderate	Severe
Pain:	Not applicable	Mild	Moderate	Severe
Mobility problems:	Not applicable	Mild	Moderate	Severe
Muscle weakness:	Not applicable	Mild	Moderate	Severe
Limb weakness:	Not applicable	Mild	Moderate	Severe
Numbness:	Not applicable	Mild	Moderate	Severe
Tingling:	Not applicable	Mild	Moderate	Severe

Other (describe below):

_____	Not applicable	Mild	Moderate	Severe
_____	Not applicable	Mild	Moderate	Severe
_____	Not applicable	Mild	Moderate	Severe
_____	Not applicable	Mild	Moderate	Severe

Finally, in your own words, please comment on the following questions about your experience of having GBS. (Use the next page if more space is required).

What has been the most difficult aspect of having GBS?

_____

_____

_____

_____

What factors have assisted your recovery the most?

_____

_____

_____

_____

What factors have hindered your recovery the most?

_____

_____

_____

_____

Looking back, what would have been helpful to you when you were most ill?

_____

_____

_____

_____

Looking back, what would have been helpful to you when you were recovering?

_____

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Any other comments you wish to make?

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Thank you for participating in this study and for completing this questionnaire.

Appendix F <u>METHOD OF SCORING THE MCMASTER HEALTH INDEX QUESTIONNAIRE</u>
<u>PHYSICAL FUNCTION INDEX</u>

<u>PHYSICAL FUNCTION ITEMS</u>	<u>ITEM SCORING</u>	
	"GOOD" Function Response Weight of "1"	**"POOR" Function Response Weight of "0"**
Today, are you physically able to run a short distance, say 300 feet, if you are in a hurry? (This is about the length of a football field or soccer pitch.)	YES	NO, NO ANSWER
Today, are you physically able to take part in any sports (hockey, swimming, bowling, golf, and so forth) or exercise regularly?	YES	NO, NO ANSWER
At present, are you physically able to walk out-of-doors <u>by yourself</u> when the weather is good?	YES	NO, NO ANSWER
What is the farthest you can walk?	ONE MILE	LESS THAN 1 MILE OR MORE, BUT MORE THAN 30 FEET, LESS THAN 30 FEET, BETWEEN ROOMS, WITHIN ROOMS, CAN'T WALK AT ALL
Today, do you (or would you) have any physical difficulty at all with walking as far as a mile?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with climbing up 2 flights of stairs?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with standing up from, and/or sitting down in a chair?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with dusting and/or light housework?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with cleaning floors?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with travelling by bus whenever necessary?	NO	YES, NO ANSWER
Today, do you have any physical difficulty at all with travelling by car whenever necessary?	NO	YES, NO ANSWER
Today, do you have any physical difficulty driving a car?	NO or DO NOT HAVE LICENCE	YES, NO ANSWER

PHYSICAL FUNCTION ITEMS	ITEM SCORING	
	"GOOD" Function Response Weight of "1"	"POOR" Function Response Weight of "0"
Today, do you (or would you) have any physical difficulty at all feeding yourself?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with undressing?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with washing (face and hands), shaving (men) and/or combing hair?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with shopping?	NO	YES, NO ANSWER
Today, do you (or would you) have any physical difficulty at all with cooking?	NO	YES, NO ANSWER
Do you wear glasses?	YES or NO and	YES SOMETIMES, YES ALWAYS,
Do you have any trouble reading ordinary newsprint?	NO, NEVER and	NO ANSWER
Do you have a headache after watching television or reading?	NO, NEVER	
Do you wear a hearing aid?	YES and NO and	YES SOMETIMES, YES ALWAYS,
Do you have trouble hearing in a normal conversation with several other persons?	NO, NEVER and	NO ANSWER
Do you have trouble hearing the radio or television?	NO, NEVER	
How would you say your physical function is today? (By this we mean the ability to move around, see, hear and so forth.)	YES	NO, NO ANSWER

SUM OF ITEMS ASSIGNED "1"

PHYSICAL FUNCTION INDEX =   19

METHOD OF SCORING THE MCMASTER HEALTH INDEX QUESTIONNAIRE
SOCIAL FUNCTION INDEX

SOCIAL FUNCTION ITEMS	ITEM SCORING	
	"GOOD" Function Response Weight of "1"	"POOR" Function Response Weight of "0"
How would you say your health is today?	VERY GOOD, PRETTY GOOD	NOT TOO GOOD, NO ANSWER
Taking all things together, how would you say things are today?	VERY HAPPY, PRETTY HAPPY	NOT TOO HAPPY, NO ANSWER
In general, how satisfying do you find the way you're spending your life today?	VERY SATISFYING, PRETTY SATISFYING	NOT TOO SATISFYING NO ANSWER
What is your occupational status?	WORK FULL-TIME, WORK PART-TIME, ON VACATION, A STUDENT, A HOUSEWIFE	RETIRED, ON SICK LEAVE, NO ANSWER
How long has it been since you last had a holiday?	LESS THAN OR EQUAL TO 12 MONTHS	GREATER THAN 12 MONTHS
During the last year, have you gone on welfare (or received monies from unemployment insurance, workmen's compensation or mother's allowance)?	NO	YES, NO ANSWER
During the last year, have you retired from work?	NO	YES, NO ANSWER
Which of the following describe your usual social and recreational activities? going to a relative's home?	YES	NO, NO ANSWER
Has a relative visited you in the last week?	YES	NO, NO ANSWER
During the last year, have you separated from your spouse?	NO	YES, NO ANSWER
During the last year, have you divorced?	NO	YES, NO ANSWER
During the last year, have you had trouble getting along with friends/relatives?	NO	YES, NO ANSWER
During the last year, have you had some other problem or change in your life?	NO	YES, NO ANSWER
How much time in a one week period do you usually spend watching television?	NONE, LESS THAN 3 HOURS A WEEK, LESS THAN 1 HOUR A DAY BUT MORE THAN 3 HOURS A WEEK	2 HOURS OR MORE PER DAY, LESS THAN 2 HOURS PER DAY BUT MORE THAN 1 HOUR A DAY

SOCIAL FUNCTION ITEMS	ITEM SCORING	
	"GOOD" Function Response Weight of "1"	"POOR" Function Response Weight of "0"
Which of the following describe your usual social and recreational activities? going to church?	YES	NO, NO ANSWER
Which of the following describe your usual social and recreational activities? any other activities? (please specify)	YES, SOME ACTIVITIES	NO, NO ANSWER
Has a friend visited you in the last week?	YES	NO, NO ANSWER
Has a religious group visited you in the last week?	YES	NO, NO ANSWER
Has a social agency representative visited you in the last week? (For example, welfare, mother's allowance, workmen's compensation board, Victorian Order of Nurses.)	NO	YES, NO ANSWER
Have you used your telephone in the last week to call a friend?	YES	NO, NO ANSWER
Have you used your telephone in the last week to call a social agency representative (For example, welfare, mother's allowance workmen's compensation board, Victorian Order of Nurses.)	NO	YES, NO ANSWER
Have you been called in the last week by a social agency representative?	NO	YES, NO ANSWER
Do you have a telephone?		
How would you say your social functioning is today? (By this we mean working with others, getting along with friends or family.)	GOOD, GOOD TO FAIR	FAIR, FAIR TO POOR, NO ANSWER

SUM OF ITEMS ASSIGNED "1"

SOCIAL FUNCTION INDEX =   25

METHOD OF SCORING THE MCMASTER HEALTH INDEX QUESTIONNAIRE
EMOTIONAL FUNCTION INDEX

EMOTIONAL FUNCTION ITEMS	ITEM SCORING	
	"GOOD" Function Response Weight of "1"	"POOR" Function Response Weight of "0"
I sometimes feel that my life is not very useful	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE AGREE, NEUTRAL, NO ANSWER
I am a useful person to have around.	STRONGLY AGREE AGREE	STRONGLY DISAGREE, DISAGREE, NEUTRAL, NO ANSWER
I am inclined to feel I am a failure.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE AGREE, NEUTRAL, NO ANSWER
Many people are unhappy because they do not know what they want out of life.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE AGREE, NEUTRAL, NO ANSWER
I am a quick thinker.	STRONGLY AGREE, AGREE	STRONGLY DISAGREE, DISAGREE, NEUTRAL, NO ANSWER
Some people feel that they run their lives pretty much the way they want to and that is the case with me.	STRONGLY AGREE, AGREE	STRONGLY DISAGREE, DISAGREE, NEUTRAL, NO ANSWER
I am usually alert.	STRONGLY AGREE, AGREE	STRONGLY DISAGREE, DISAGREE, NEUTRAL, NO ANSWER
Everyone should have someone in his/her life whose happiness means as much to him/her as his/her own.	STRONGLY AGREE, AGREE	STRONGLY DISAGREE DISAGREE, NEUTRAL NO ANSWER
In a society where almost everyone is out for himself/herself, people soon come to distrust each other.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE AGREE, NEUTRAL NO ANSWER
Their are many people who don't know what to do with their lives.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE AGREE, NEUTRAL NO ANSWER
Most people don't realise how much their lives are controlled by plots hatched in secret by others.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE AGREE, NEUTRAL NO ANSWER
People feel affectionate towards me.	STRONGLY AGREE, AGREE	STRONGLY DISAGREE DISAGREE, NEUTRAL NO ANSWER
I think most married people lead trapped (frustrated or miserable) lives.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE AGREE, NEUTRAL NO ANSWER

EMOTIONAL FUNCTION ITEMS	ITEM SCORING	
	"GOOD" Function Response Weight of "1"	"POOR" Function Response Weight of "0"
Some people feel as if other people push them around a good bit and I feel this way too.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE AGREE, NEUTRAL NO ANSWER
I would say I nearly always finish things once I start them.	STRONGLY AGREE, AGREE	STRONGLY DISAGREE DISAGREE, NEUTRAL NO ANSWER
When I make plans ahead, I usually get to carry things out the way I expected.	STRONGLY AGREE, AGREE	STRONGLY DISAGREE DISAGREE, NEUTRAL NO ANSWER
It's hardly fair to bring children into the world the way things look for the future.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE AGREE, NEUTRAL NO ANSWER
Nowadays a person has to live pretty much for today and let tomorrow take care of itself.	STRONGLY DISAGREE, DISAGREE	STRONGLY AGREE AGREE, NEUTRAL NO ANSWER
During the last year, have you separated from your spouse?	NO	YES, NO ANSWER
During the last year, have you divorced?	NO	YES, NO ANSWER
During the last year, have you gone on welfare (or received monies from unemployment insurance, workmen's compensation or mother's allowance)?	NO	YES, NO ANSWER
During the last year, have you had trouble getting along with friends/relatives?	NO	YES, NO ANSWER
During the last year, have you retired from work?	NO	YES, NO ANSWER
During the last year, have you had some other problem or change in your life?	NO	YES, NO ANSWER
How would you say your emotional functioning is today? (By this we mean your ability to remain in good spirits most of the time, and to be usually happy and satisfied with your life.)	GOOD, GOOD TO FAIR	FAIR, FAIR TO POOR, NO ANSWER

SUM OF ITEMS ASSIGNED "1"

EMOTIONAL FUNCTION INDEX =   25

Appendix G

Beck Depression Inventory-II (BDI-II)

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past 2 weeks, including today**. Circle the number beside the statement you have picked. If several statement in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) of Item 18 (Changes in Appetite).

1. Sadness

0   I do not feel sad.
1   I feel sad much of the time.
2   I am sad all the time.
3   I am so sad or unhappy that I can't stand it.

2. Pessimism

0   I am not discouraged about my future.
1   I feel more discouraged about my future than I used to be.
2   I do not expect things to work out for me.
3   I feel my future is hopeless and will only get worse.

3. Past Failure
usual.

0   I do not feel like a failure.
1   I have failed more than I should have.
2   As I look back, I see a lot of failures.
3   I feel I am a total failure as a person.

4. Loss of Pleasure

0   I get as much pleasure as I ever did from the things I enjoy.
1   I don't enjoy things as much as I used to.
2   I get very little pleasure from the things I used to enjoy.
3   I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings

0   I don't feel particularly guilty
1   I feel guilty over many things I have done or should have done.
2   I feel quite guilty most of the time.
3   I feel guilty all of the time.

6. Punishment Feelings

0   I don't feel I am being punished.
1   I feel I may be punished.
2   I expect to be punished.
3   I feel I am being punished.

7. Self-Dislike

0   I feel the same about myself as ever
1   I have lost confidence in myself
2   I am disappointed in myself.
3   I dislike myself.

8. Self-Criticalness

0   I don't criticize or blame myself more than

1   I am more critical of myself than I used to be.
2   I criticize myself for all of my faults
3   I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes

0   I don't have any thoughts of killing myself.
1   I have thoughts of killing myself, but I would not carry them out.
2   I would like to kill myself.
3   I would kill myself if I had the chance.

10. Crying

0   I don't cry any more than I used to.
1   I cry more than I used to.
2   I cry over every little thing.
3   I feel like crying, but I can't.

_____ Subtotal Page 1   **Continued on Back**

11. Agitation

0   I am no more restless or wound up than usual.
1   I feel more restless or wound up than usual.
2   I am so restless or agitated that it's hard to stay still.
3   I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

0   I have not lost interest in other people or activities.
1   I am less interested in other people or things than before.
2   I have lost most of my interest in other people or things.
3   It's hard to get interested in anything.

13. Indecisiveness

0   I make decisions about as well as ever.
1   I find it more difficult to make decisions than usual.
2   I have much greater difficulty in making decisions than I used to.
3   I have trouble making any decisions.

14. Worthlessness

0   I do not feel I am worthless.
1   I don't consider myself as worthwhile and useful as I used to.
2   I feel more worthless as compared to other people.
3   I feel utterly worthless.

15. Loss of Energy

0   I have as much energy as ever.
1   I have less energy than I used to have.
2   I don't have enough energy to do very much.
3   I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

0   I have not experienced any change in my sleeping pattern   .
1a I sleep somewhat more than usual.
1b I sleep somewhat less than usual   .
2a I sleep a lot more than usual.
2b I sleep a lot less than usual   .
3a I sleep most of the day.
3b I wake up 1-2 hours early and can't get back to sleep.

17. Irritability

0   I am no more irritable than usual.
1   I am more irritable than usual.
2   I am much more irritable than usual.
3   I am irritable all the time.

18. Changes in Appetite

0   I have not experienced any change in my appetite
1a My appetite is somewhat less than usual.
1b My appetite is somewhat greater than usual.
2a My appetite is much less than before.
2b My appetite is much greater than before.
3a I have no appetite at all.
3b I crave food all the time.

19. Concentration Difficulty

0   I can concentrate as well as ever.
1   I can't concentrate as well as usual.
2   It's hard to keep my mind on anything for very long.
3   I find I can't concentrate on anything.

20. Tiredness or Fatigue

0   I am no more tired or fatigued than usual.
1   I get more tired or fatigued more easily than usual.
2   I am too tired or fatigued to do a lot of the things I used to do.
3   I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

0   I have not noticed any recent change in my interest in sex.
1   I am less interested in sex than I used to be.
2   I am much less interested in sex now.
3   I have lost interest in sex completely.

_____Subtotal Page 2
_____Subtotal Page 1
_____Total Score

Appendix H

6-Item Short Form of the State Scale of the State-Trait Anxiety Inventory (STAI-6)

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the most appropriate number to the right of the statement to indicate how you feel **right now, at this moment.** *There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.*

	Not at all	Somewhat	Moderately	Very much
1. I feel calm	1	2	3	4
2. I am tense	1	2	3	4
3. I feel upset	1	2	3	4
4. I am relaxed	1	2	3	4
5. I feel content	1	2	3	4
6. I am worried	1	2	3	4

Please make sure that you have answered *all* the questions.