

**A mixed method investigation into the psychological well-being of individuals who have
suffered from Guillain-Barré Syndrome**

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Thesis Abstract

The needs of patients who are nursed on the ICU are becoming more widely recognised and services are beginning to reflect this. However there is little research into how patients who have suffered from a severe and progressive muscular paralysis called Guillain-Barré Syndrome (GBS) experience the disease and subsequent hospitalisation. The purpose of this study was to explore how these patients experience the different aspects of the illness, including an extended period of paralysis and treatment on an ICU. This is intended to expand upon the limited research in this area and identify how the findings can inform clinical practice and future studies.

Method: A systematic literature search identified research in relation to the experiences of individuals who had GBS which was utilised to form the basis of the understanding for this study. Very little systematic research has looked at individuals' experiences of Guillain-Barré Syndrome whilst ill and their subsequent recovery. A mixed methods study was carried out with the aim of adding to this research. Interpretative Phenomenological Analysis was selected as the method of analysis for Study 1, which involved interviews with seven participants who had experienced GBS severe enough to need treatment on an ICU. This then enabled quantitative questionnaires to be disseminated which asked about individuals' levels of anxiety, depression and Post Traumatic Stress symptomatology both retrospectively and following recovery in Study 2.

Results: Study 1 found that participants experienced GBS as either a slow and frustrating, or as a rapid and scary onset. The main themes that were developed included: the paralysis being viewed as multiple losses, frustration, difficulties associated with communication loss, vulnerability and frightening hallucinations. Study 2 utilised non-parametric analyses of the data and found that participants experienced high levels of anxiety and depression at the onset of GBS and that some continued to experience anxiety, depression and post traumatic symptoms after recovery from GBS. Generally the profile suggests predominantly anxiety problems during the acute onset phase and then predominantly depression at the time of follow-up. Aspects of post traumatic stress were positively correlated with duration of mechanical ventilation which in turn was related to duration of paralysis. This challenged the hypothesis that GBS patients habituate to the experience of paralysis.

Conclusion: For some individuals, GBS was experienced as a frightening event, but one that they could draw positive things from. However, for others, GBS was experienced as a traumatic event and some of these people continued to exhibit signs of psychological distress even after recovery. It remains important for staff to feel able to speak about distressing situations with their patients and to signpost them to other psychological services if appropriate.

Key words: Guillain-Barré Syndrome; Psychological implications, PTSD, Intensive Care Unit.

Target Journal: British Journal of Health Psychology.

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Literature review	7,811	8,667
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PART ONE: LITERATURE REVIEW.

The psychological impact of suffering from Guillain-Barré Syndrome: A review of the literature

Word count: 7,811

Literature Review Abstract

Purpose: To provide an overview of the research findings in relation to experiencing Guillain-Barré Syndrome (GBS), paralysis and hospitalisation on an ICU ward. The review also incorporates appraisal of different research designs. The practical implications of different designs are considered and optimal designs for future research in this area are identified.

Method: A systematic search of electronic databases was undertaken for a select number of relevant articles. Literature focusing upon the experiences of paralysis, GBS and ICU were prioritised. This study focused on collecting qualitative literature in relation to individuals' experiences of GBS as well as quantitative information looking at prevalence rates for depression, anxiety and PTSD symptoms as a result of having GBS and experiencing paralysis/treatment on an ICU.

Results: There have been a small number of case studies carried out which have looked at individuals' experiences of having GBS. Qualitative methods have allowed for more exploration of participants' own experiences. Findings from qualitative research have identified themes around the different phases of the illness progression such as communication loss as difficult and prompting feelings of frustration. However, quantitative research has been carried out most frequently in this area, and has focused mainly on the functional status of patients after their recovery and rehabilitation. Many of these studies have identified that GBS patients continue to experience residual difficulties sometimes up to 6 years after the onset of GBS and that these functional difficulties are likely to impact on health related quality of life and psycho-social functioning.

Conclusions: Further quantitative and qualitative research methods are both required in order to effectively understand how individuals with GBS manage the onset of this illness, the prolonged period of paralysis, their treatment on an ICU as well as their recovery and coping strategies.

Key words: Guillain-Barré Syndrome, paralysis, PTSD, psychological impact, pain, ICU, communication, mechanical ventilation.

Target Journal: British Journal of Health Psychology.

1. Introduction

Three French physicians, Georges Guillain, Jean Alexandre Barré and André Strohl, are credited with describing the medical condition now called Guillain-Barré syndrome (GBS), even though it was first described in medical writings circa 1859 under the term “Landry’s ascending paralysis”. In 1916, they identified the clinical syndrome of muscle paralysis and areflexia. They added to the description the characteristic anomaly of elevated proteins in the spinal fluid, which aids in differentiating the syndrome from other neurological disorders, such as Multiple Sclerosis.

The cause of GBS is not clear, although it appears to involve an autoimmune attack on the myelin of the peripheral nerves. It appears to affect approximately 1 person in every 100,000 and onset commonly occurs within four weeks of a viral respiratory tract infection or gastroenteritis. As a result of the autoimmune attack, the myelin sheath and even the axon of the neuron can be damaged, causing nerve signals to be delayed or otherwise altered in transmission. The affected individual experiences abnormal sensations including fatigue, dizziness, muscle pain in the back and neck, and pins and needles. Near complete paralysis occurs for many people, along with breathing difficulties and numerous internal problems. Pain is a characteristic for most individuals as well, with extreme pain usually affecting the lower limbs. Abnormal sensations can also occur; often they are described as ants crawling under the skin, or feelings of tingling or numbness. Frequently individuals report a loss of ability to sense heat, textures, sensations or even locate their extremities (Steinberg, 2000).

Treatment for GBS has focused on plasmapheresis and intravenous immunoglobulin therapy, which have been found to be effective in many cases (Van der Meche & Schmitz, 1992). However, effective medical treatment does not appear to have prevented the onset of

psychological difficulties during and following recovery (Bernsen, de Jager, Schmitz, & van der Meche, 2002).

The onset of GBS is usually such that sufferers are affected very quickly. Within 48 hours the individual may have gone from carrying out their usual daily routine to being unable to move and needing treatment on a high dependency hospital ward. Severe cases of GBS warrant treatment procedures such as mechanical ventilation (MV) and intubation, which also require the patient to be medically sedated. Patients are often totally paralysed, sometimes with the ability to move their eyes but not always. Communication in these patients is extremely limited due to both the intubation tubes as well as their underlying paralysis. Impairment in communication has been described as a terrifying experience for critically ill patients and is a significant factor in the assessment of pain and other symptoms and in the patients' participation in decision making about treatment in the ICU (Ashworth, 1980).

Approximately one third of GBS patients are admitted to an intensive care unit and of that third, many require mechanical ventilation, often for prolonged periods (Sharshar, Chevret, Bourdain & Raphael, 2003). By definition, critical illness requiring intensive care treatment is a significant stressful event in itself. The life-threatening illness, the acute stress reaction, the therapeutic procedures and the ICU environment are likely to cause discomfort, and the presence of an endotracheal tube (ETT), pain, thirst, fear, anxiety, sleep disturbances, nightmares and hallucinations have been reported as common stressful experiences in ICU patients (Granja, Lopes, Moreira, Diaz, Costa-Pereira, & Carneiro, 2005). Due to the sudden onset of GBS, and that it usually attacks people who are in relatively good health, the emotional impact is often profound. Furthermore, the disease is sufficiently rare so that those affected may have little or no

knowledge of the disease and the majority of physicians; nurses and health care workers have never seen a case.

1.1 Experiencing Paralysis.

The experiences and recollections of patients undergoing therapeutic paralysis in the ICU may be similar to the reports of some patients who have experienced anaesthesia awareness (AA) (Ballard, Robley, Barrett, Fraser, & Mendoza, 2006). Wagner, Zavotsky, Sweeney, Palmeri and Hammond (1998) indicate that some patients have awareness and recall of events and experience discomfort despite being given sedatives or analgesics. Sedatives and analgesics are necessary to reduce awareness, relieve fear, increase comfort, induce unconsciousness, decrease anxiety and minimise possible complications such as Post Traumatic Stress symptoms.

As ICU's have become more sophisticated and successful in caring for and treating critically ill patients, neuromuscular blocking agents (NMBA) have been used with increased frequency necessitating mechanical ventilation (Roizen, & Freeley, 1978). Whilst the use of NMBA's is unlikely to occur frequently amongst GBS patients, as they are already experiencing paralysis, it is expected that this literature offers insight into these experiences for both GBS and non-GBS patients.

Wagner, Zavotsky, Sweeney, Palmeri and Hammond (1998) suggest that a misconception exists among nursing staff that neuromuscular blocking agents (NMBA) provide sedation and analgesia. Arbour (2004) suggests that although the patient may appear calm and relaxed, they may actually be consciously aware and be experiencing pain or anxiety. This may be similar in cases of GBS, whereby the patient appears calm and sedated but is actually experiencing, pain, discomfort or frightening sensations that cannot be easily communicated to the nursing staff.

Watling, Dasta, and Seidl, (1997) carried out a study looking at the use of sedatives, analgesics and paralytic agents on the ICU and found that patients who were paralysed, occasionally received no sedative or analgesic at all and findings from Arbour, (2004) support this by concluding that it is difficult for practitioners to determine the individual patient need for analgesia and sedation and the degree of effectiveness of the medications utilised.

Sandin, Enlund, Samuelson and Lennmarken (2000) described their prospective case study and reported that eleven paralysed patients and four non-paralysed patients had significant memory of intraoperative events. However, of the four non-paralysed patients with awareness, none of them had found the intraoperative experience traumatic or distressing, nor did they have any delayed PTSD reactions. In contrast, eleven of the fourteen paralysed patients reported intraoperative trauma and anxiety, but only six of the eleven reported intraoperative pain. Persistent postoperative psychological symptoms were associated with patients who, during the operation, did not understand why they were wakeful and why they were paralysed.

Wagner, Zavotsky, Sweeney, Palmeri and Hammond (1998) studied the experiences of 11 patients who had undergone therapeutic paralysis. Of these, 4 patients could recall a negative experience. One patient could remember being unable to move and experiencing discomfort. Another felt shaky and unable to take full breaths. The third patient experienced pain and felt uncomfortable during tracheal suctioning and reported that a nurse had been rough with him. All of the patients who had a recollection of the episode experienced fear anxiety and sleeplessness, and it could be argued, were at a greater risk of developing PTSD symptoms in the future. There is, therefore, reason to expect there may be psychological difficulties following an episode of severe GBS with full paralysis, although not necessarily due to experiencing pain.

1.2 Pain and Discomfort.

Moulin, Hagan, Feasby, Amireh, *et al.*, (1997) reported pain as very commonly occurring in GBS patients and that it poses a very significant challenge in recognition and subsequent management. GBS patients who experience total paralysis often report a high level of pain sensation as well as a lack of communication skills, although many have a full understanding of their condition and the reasons for their paralysis. Whilst there is limited literature on the psychological aspects of GBS, it was thought that the literature pertaining to anaesthesia awareness may provide some insight into the experiences that individuals suffering from GBS are likely to have. It appears that experiencing pain whilst wakeful under anaesthetic is not predictive of developing PTSD symptomatology (Wang, 2001), although experiencing paralysis is, and may therefore be comparable to GBS patients.

1.3 Post Traumatic Stress Syndrome.

Patients recovering from critical illness frequently have little or no recollection of their period in ICU, or remember nightmares, hallucinations or paranoid delusions (Jones, Griffiths, Humphris, & Skirrow, 2001). Evidence suggests episodes involving hallucinations and delusions during ICU stay are the main cause of PTSD (Griffith & Jones, 2007). Hallucinations, paranoid delusions and confusion while patients are in intensive care have been widely reported (Bardellini, Servadio, Chiarello & Chiarello, 1992) and a link has been postulated between the ICU environment and psychiatric disturbance (Dorr-Zegers, 1988). The abnormal environment of the ICU, with the lack of a clear day and night, as well as continuous noise from machines and alarms has been causally implicated with psychological disturbance (Dorr-Zegers, 1988). Dorr-Zegers (1988) also hypothesized that stress, in the form of broken sleep and excessive noise, can lead to so called 'ICU psychosis' resulting in hallucinations and psychotic behavior.

There is a lot of variance in the reported prevalence rates of PTSD in the ICU population, with a range of 14-59% being reported (Schelling, Stoll, Meier, Haller *et al.*, 1998; Stoll, Kapfhammer, Rothenhausler, Haller *et al.*, 1999; Schelling, Stoll, Kapfhammer, Rothenhausler, *et al.* 1999; Stoll & Schelling, 1998). All of these studies used the PTSS-10 (based on the DSM-III criteria) as a measure of PTSD, and in one study (Stoll *et al.*, 1999) the prevalence rate was 4% higher using the SCID (21% and 25% respectively). The lowest prevalence rate was reported by Stoll and Schelling (1998), who measured PTSD at 17 weeks post-discharge in a sample of mainly male patients (81%) who were in ICU recovering from cardiac surgery. The highest prevalence rate was found by Schelling *et al.*, (1999), who used a sample consisting of 66% women who had septic shock. This study was a retrospective, postal study with a fairly small sample size. Given that Schelling *et al.*, (1998) used a similar design in a previous study and reported a much lower rate of 27.5% in a sample of patients with Acute Respiratory Distress, it is possible that the larger proportion of women, or the fact that they had septic shock, had in some way inflated the results.

A UK study has shown an incidence of PTSD in ICU patients of 15% (Koshy, Wilkinson, Harmsworth, & Waldmann, 1997). Schelling *et al.*, (1998) considered that episodes of respiratory distress, anxiety, pain, or nightmares while in ICU could be enough to cause PTSD. These experiences were reported by 78.7% of their ICU patients and were unrelated to disease severity. Nightmares were the most commonly reported symptom in this study (63.8%). They suggest that frightening traumatic memories of ICU such as hallucinations, paranoid delusions or feelings of extreme anxiety were associated with the later development of PTSD. However, this study should be treated with caution as patients were asked about their memories any time from 6 months to 10 years post ICU discharge.

Roberts, Rickard, Rajbhandari and Reynolds (2007) found that most patients have factual memories of their ICU stay. However, delirious patients were found to have significantly less factual recall than non-delirious patients. They also discovered that adverse psychological sequelae expressed as PTSD were uncommon. They state that over one-third of patients have some degree of factual memory regarding their admission to ICU and that these memories are particularly related to artificial ventilation, suctioning and removal of the endotracheal tube (ETT).

Schelling *et al.*, (1998, 1999) and Stoll *et al.*, (1999) reported that patients who remembered multiple traumatic episodes during their stay in ICU were more likely to develop PTSD. In addition, having delusional memories without recall of factual events 2 weeks post-discharge was predictive of high scores on the Impact of Events Scale at eight weeks post-discharge (Jones, Griffiths, Humphris, & Skirrow, 2001). Interestingly, this study found that memories for factual events decreased over time, but patients who had delusional memories remembered the same number of memories at 8 weeks. The authors suggest that memory of factual events, even unpleasant ones, serve to protect from the development of PTSD, as patients can reality test their delusional memories, with factual memories (e.g., comparing a delusional memory that a nurse was trying to kill you, and a factual memory of a nurse being caring). They point out that delusional (nonfactual) memories are considered to be normal in this population, and could be drug induced, due to illness or sleep disturbance. They propose that memory for external events is reduced and memory for internal events is increased due to the nature of the ICU environment, and that challenging of paranoid delusions and beliefs should begin early in recovery in addition to exposure therapy, normalization, and education.

Nelson, Weinert, Bury, Marinelli, *et al.*, (2000) reported that PTSD symptoms were associated with a higher number of days of sedation and neuromuscular blockade, but not with the severity of the illness. However, they concede that it is possible that patients with more neuromuscular blockade had more complicated ICU stays, which could give rise to more exposure to distressing symptoms, and they also suggest that patients who are generally more anxious may well be given more sedation and may be more at risk of developing PTSD anyway. Other reported risk factors include trait anxiety (Jones, Griffith, Humphris, & Skirrow, 2001) and younger age (Scragg, Jones, & Fauvel, 2001).

In summary, the prevalence of PTSD in this population is fairly high compared to other medical groups and the literature suggests that this could be due to the recall of traumatic experiences, especially those that are delusional in nature. Illness, medication, and environmental factors may be influential, and further research is required to test out possible intervention strategies.

It is worth noting that studies which have been reported here have differed in the extent to which they have distinguished diagnostically between PTSD, its symptoms, post traumatic stress and adjustment disorder. Tedstone and Tarrier (2003) state that the symptoms of PTS are considered to be a normal reaction to a traumatic situation, and spontaneously resolve within a month. They suggest that many patients will suffer some symptoms but few develop full PTSD.

1.4 Communication Loss

It is well recognised that patients in ICU have difficulty with communication when unable to speak, for example, as a result of ventilation (Menzel, 1998). This may result in feelings of anger and low mood, which can lead to withdrawal from interaction with family and carers (Magnus & Turkington, 2006). It has been suggested that a good communication climate

between staff and patients can stimulate therapeutic recovery and positive outcomes for patients (Cassie, 1975). Although nurses are trained in being aware of the need for good communication with their patients, there is evidence to suggest that this sometimes fails to occur. Baker and Melby (1996), for example found that nurses spent on average only 5% of their time engaged in verbal communication with unconscious patients.

Communication is an important way for patients to have their needs met and it seems understandable that the less a patient can communicate, the fewer of their needs would be met. Indeed, the literature is full of patients' assertions that their needs were not met (Johnson and Sexton, 1990). Powerlessness has been shown in literature as characterising the non-vocal communication experience of patients (Schumann, 1999) and the connection between physical restriction and communication has previously been found in the work of Rime, Schiaratura, Hupet and Ghyssele (1984). They showed that the physical immobility of healthy psychology students led to reduced speaking times. Carroll (2007) carried out open-ended interviews with patients who were ventilated and non-vocal at the time. Participants described their non-vocal experience to her as *"Being trapped in a silent world makes me feel frustrated and incomplete," "Days pass in slow motion while the rest of the world speeds by," "Making and preserving connections is of paramount importance,"* and *"The powerlessness of being non-vocal was ameliorated by developing coping strategies and by consistent and reliable nursing care"* (p. 1168). Participants missed not having their voices, but also their sense of themselves as a person.

To attempt to explain the communication difficulties in the ICU, Turncock (1991, p.165) argued that it was difficult for nurses to hold 'lengthy conversations with unresponsive patients', while Leathart (1994, p. 103) stated that nurse learnt that 'by minimising interaction with

patients they can minimise their own anxiety'. Barker and Melby (1996) also argue that the small percentage of time that nurses communicated with patients was not the only problem. They found that most communication with patients was directed towards informing them of procedural matters rather than providing them with explanations about their condition and progress. Hall (1996) found that nurses were more likely to have positive interactions with ventilated patients when they perceived the patients as more responsive. Carroll (2007) also found that when nurses were more responsive to the patients in her study, this decreased the feelings of powerlessness and restriction that patients had.

Clearly effective communication would benefit patient assessments, allowing for needs to be met and facilitate improved coping strategies.

In summary, experiencing GBS might be expected to be a distressing time for individuals. There are differing challenges presented at different phases of the illness, including the diagnosis, the plateau phase, as well as difficulties faced during recovery. Experiencing paralysis and the accompanying stressors, such as pain, communication loss and frightening hallucinations, mean that this group of people experience many trying events, which in culmination may lead to the development of feelings of anger, frustration, anxiety, despondency or dissociation. The following literature review aims to explore these experiences of GBS patients in more detail so as to inform the current study and future work.

2. Aims of the Literature Review

This review aims to:

- Provide an overview of the findings from research in this area in relation to patient experiences of GBS
- Gain a clearer understanding of the psychological issues that may be pertinent to individuals who have experienced GBS
- Appraise different research designs
- Consider the implications of different research designs in practice
- Identify optimal designs for future research in this area

3. Methodology

3.1 Search Strategy and Search Terms

References were obtained by an electronic systematic literature search in the first instance and data were extracted from these using evaluation tools for quantitative, qualitative and mixed methodology forms respectively (see Appendix A for examples of the data extraction forms used). The search terms and databases used are highlighted in Table 1. In addition, key papers were reviewed for references.

3.2 Inclusion Criteria and Search Results

Studies specifically exploring individuals' experiences of GBS were prioritised as relevant to the current study. These were largely qualitative in nature and consisted mainly of single case designs. For this reason a number of quantitative papers were also included on the basis that they added to the knowledge base surrounding GBS. The search identified 20 appropriate published articles for review. Of these 20; 12 were quantitative in nature; 2 were qualitative, 2 utilised mixed methods and 4 were single case studies (See Appendix B for a

summary table of the studies included). Whilst it is appreciated that the fusing of methodological approaches when reviewing literature is undesirable, it seemed appropriate for the current research as the limited quantity and quality of literature demanded that all available literature be utilised. Also, as the current study was interested in exploring the area using both quantitative and qualitative methodologies, it seemed important to gain literature using both approaches. Several research studies are referred to within the review but were not reviewed in detail. Research papers were excluded if they were not written in English. Due to the dearth of literature in this area and although the data extraction forms highlighted methodological weaknesses in some of the included studies, it was thought appropriate to source these papers so as to aid in furthering the information gathering process and as a guide for further research to be aimed at, rather than reviewing a few methodologically rigorous studies and limiting the amount of information gained.

Table 1. Search terms and databases used in the systematic literature search

SEARCH TERMS	DATABASES	YEARS
Psychological AND Therapeutic paralysis	EBSCO: PsyArticles PsychInfo SCOPUS	1987-2010 1967-2010 2006-2010
Psychological AND Guillain-Barré Syndrome	EBSCO: PsyArticles PsychInfo SCOPUS	1987-2010 1967-2010 2006-2010

Alternative search terms and databases were searched although yielded no relevant findings. All the described literature was generated from the above databases and by following-up references. The dates described above relate to the years that the database holds electronic copies of articles and therefore the dates searched by the respective database.

4. Findings

4.1 Overview of Findings

Guillain-Barré syndrome is an acute autoimmune disease which results in rapidly deteriorating muscle strength, ultimately causing paralysis. After muscle weakness has progressed to such a degree as warranting nursing intervention on an ICU and sometimes mechanical ventilation, patients typically experience a levelling off of symptoms (the plateau phase), followed by spontaneous recovery. Several case studies have described the experiences for people during the onset of GBS, although few longitudinal and prospective studies have been carried out. Several studies have described the recovery phase of the illness, with some concentrating primarily on medical outcomes, such as walking ability and others on more psychosocial outcomes such as quality of life and participation in activities of daily living.

4.2 Experiences of having GBS.

There have been a small number of case reports (e.g. Morgan, 1991) and autobiographies (e.g. Rice, 1977) reporting personal experiences of GBS and being nursed on an ICU. However, one study which addressed this area with a larger sample size of 35, looked qualitatively at falling ill with GBS, the onset period of the disease, the diagnosis and the illness progression during individuals' hospitalisation period. This was carried out by Forsberg, Ahlstrom and Holmqvist (2008) in Sweden, and has made attempts to explore the experiences of individuals with GBS from the onset of symptoms through to the recovery and rehabilitation phase. They selected their participants from a previous study and so, whilst they collected functional information from the onset of GBS, they were interviewing participants retrospectively, at two years post onset of GBS.

They found that the onset of GBS was described as either an incomprehensible, prolonged, increasing deterioration with puzzling sensations or as a frightening, rapid onset with a sudden loss of body control. The majority of people in their study described relying heavily upon the reassurance of a positive prognosis and expressed immense confidence in being able to recover. They also reported feelings of fear and insecurity when losing body functions, thus causing feelings of helplessness. Sensations of pain, numbness and lost body image increased their feelings of vulnerability. In their study, they found that half of the ventilator-treated patients expressed vivid memories of scary hallucinations.

Such mental state abnormalities as these were first noted in the very early clinical studies of the disease (Guillain, 1953) and were described with various labels such as hallucinatory experiences, personality changes, mental disturbances and psychotic experiences (Weiss, 1991; Weiss, Rastan, Mullges, Wagner & Toyka, 2002).

4.3 Mental disturbances

In their prospective study, utilising semi-structured interviews, Weiss, Rastan, Mullges, Wagner and Toyka (2002) explored patients' experiences of emotional distress and psychotic symptoms using prospective semi-structured interviews. They interviewed 49 patients with severe GBS whilst they were being nursed on an ICU using communication aids such as alphabet boards and lip reading. They also gained additional information from carers and relatives who were also interviewed and who completed questionnaires regarding the patients' emotional state and the quality of their communication. This raises ethical issues regarding how informed consent was assessed and whether it was sensitive to patients' condition to be interviewed whilst they were paralysed and/or sedated that the authors make no reference to.

Their interviews with patients focused upon psychological symptoms such as hallucinations, delusions, the emotional state of the patients (e.g. anxiety or depression), dreams, coping ability, emotional support and overall experience in the ICU. The authors differentiated between hallucinations and delirious states as they assessed patients as being conscious and not disorientated by other cognitive deficits and utilized the DSM-IV (298.8) and ICD-10 (F23) diagnostic criteria of brief reactive psychosis in order to assess these symptoms. They reported anxiety in 82% of their patients, corresponding to the DSM-IV and ICD-10 criteria of panic disorder and acute stress disorder. Anxiety was described as being most prevalent in the initial stages of the disease and during the stage when symptom development was increasing. Sixty-seven percent of their patients presented with moderate to severe depressive episodes. A state of hopelessness was described by patients (20%) when they required artificial ventilation and feelings of depression were most commonly reported during maximum disability and after reaching remission. The authors report that ratings for depression and anxiety did not differ significantly between treating physicians, nurses and relatives during the acute stage of the disease, although they do not describe the process they employed for checking inter-rater reliability. Brief reactive psychosis was described in 25% of their sample and included optical and auditory hallucinations, delusions and oneiroid states. Four additional patients reported derealisation states and/ or illusions. Fifty-eight percent of their sample reported experiencing more frequent and intense dreaming than usual. They found that the psychotic episodes were strongly associated ($p < 0.001$) with severe muscular weakness, artificial ventilation and multiple cranial nerve dysfunction. Fifty-five percent of patients felt reassured by the ICU environment and 90% described contact with relatives to be the most helpful. Patients reported that they found the experienced loss of communication to be the most difficult aspect to cope with. The authors

conclude that motor deprivation and loss of communication were most closely connected with the occurrence of psychotic symptoms. They do not attempt to explain these symptoms in terms of the possible correlations with medications that patients may have been prescribed, despite reporting that 57% of their sample received benzodiazepines, 35% received antidepressants and 76% received neuroleptics. They suggest instead that the psychotic symptoms that their patients were experiencing were due to a severe deprivation of movement and communication abilities. They suggest that the process for developing psychotic symptoms in their patients may involve a gradual move from a stage of intense dreaming, where reality testing breaks down, to an attempt to prevent the personality from deteriorating any further by creating an imaginary world where the patient can withdraw to safely.

Cochen, Arnulf, Demeret, Neulat, Gourlet *et al*; (2005) conducted a prospective study investigating the clinical and biological correlates for mental status abnormalities in GBS and non-GBS controls. They included 139 patients with GBS and 55 without who were all placed on the ICU. Bolgert (1991) and Wegener, Tassan, Josse and Bolgert, (1995) described psychotic symptoms and a patient having awareness of vivid dreams and hallucinations respectively, although these described only single cases. Cochen *et al*; (2005) examined these symptoms in a relatively large sample size and also included associations with REM sleep patterns in 13 of their GBS patients due to previous research regarding hallucinations and dreams suggesting this link. They collected their data between 1990 and 2004, during which time they report that 170 patients were admitted to the Neurology Department in a hospital in France with suspected GBS. The study only included patients with a very definite diagnosis of GBS and excluded other strains of GBS such as Miller-Fisher syndrome. The study describes in detail the process with which the data regarding mental abnormalities was collected. They stated that from initial observations in

1990, the medical team were encouraged to collect information on the mental status changes in their patients with GBS. Patients were interviewed daily using the most appropriate method depending on their communication ability i.e. lip reading, video, writing.

Biological measures were taken three times a day for all patients, which took into account the use of psychoactive drugs. Eight (19%) of their patients with mental status abnormalities were treated with psychotropic drugs (zolpidem, lorazepam, clonazepam, midazolam, fentanyl, amitriptyline). Although the authors interestingly found that there was no difference in psychoactive treatments between patients with and without mental status abnormalities.

From the 139 GBS patients studied, 43 (31%) experienced mental status abnormalities versus the 16% of ICU controls who did ($P < 0.05$). They found no difference in sex, percentages of intubation, age, disease severity, impaired cranial nerves, infection, pain or use of psychoactive drugs between patients with short-onset of mental status abnormalities (<9 days) and those with late-onset (>9days).

The sleep studies that the authors carried out were between 2002 and 2004 and sampled 13 GBS patients and 6 tetraplegic patients without GBS in the ICU. The authors report that eight (19%) of those with mental status abnormalities reported recurrent, unusual, vivid dreams that they experienced intensely and remembered accurately. The patients reported that the dreams could occur several times a day, as soon as they closed their eyes. These dreams were described as full of colour, strange and highly emotional and some patients had the experience of leaving their body entirely. Contrary to these types of enjoyable dreams, patients also reported having nightmares about death or dying which left them feeling very scared. When questioned about these dreams, GBS patients could accurately recall these. Six of the 9 ICU control group had much less vivid dreams, including nightmares and pleasant dreams.

Thirteen (30%) GBS patients reported visual, tactile or auditory illusions. Some patients described a feeling that their bodies were tilting or that the room had shifted and that nursing staff were walking on the walls. Hallucinations were experienced by 26 (60%) GBS patients, who saw colourful, moving figures or animals. Several patients reported that they were scared to close their eyes due to the feelings of panic that was brought on by these images. Clearly, this prospective study gains valuable information about the mental status of patients whilst they were on an ICU, although the study does not indicate how ethical considerations were taken into consideration. The authors conducted interviews almost daily and observations hourly with patients who were severely ill with GBS and had limited communication abilities in many cases, therefore it would have been important to have gained ethical approval and to have considered patients abilities to give informed consent for the study and the risk posed by asking patients about their mental state whilst still on the ICU. These considerations are also pertinent for other studies which have accessed patients during vulnerable states: including the studies reported here, none of which have given details of these ethical considerations and how they were overcome.

Rosenlicht & Lee, (2000) describe a single case study in which a patient with GBS experiences hallucinations. They suggest that these types of perceptions are similar to those seen in normal dreaming and hypnagogic hallucinations. They state that dreamlike and other hallucinatory experiences may occur when there is a disruption to the corollary discharge system that allows individuals to discriminate between internally and externally generated stimuli. Sleep, particularly REM sleep, is a state of greatly reduced responsiveness to external stimuli and partial flaccid paralysis in normal sleep and is caused by the postsynaptic inhibition of motor neurons. They suggest that the sensory and motor de-myelination that occurs in GBS may allow

for the confusion between internally and externally generated sensations and thought that occur in sleep, resulting in thought having a dream-like quality. Interestingly, Cochen *et al*; (2005) have been able to explore these phenomena in far greater detail and have found evidence to support this hypothesis. They conclude that hallucinations in GBS are manifestations of a sleep and dream-related disorder and that their findings should reassure those suffering from GBS, and their carers, as to the underlying causation of these distressing experiences.

Importantly, Cochen *et al*; (2005) note that the ICU nursing staff in their study quickly became able to recognise when their patients were experiencing delusions as their faces changed and took on a scared or astonished look, or they followed imaginary objects with their eyes. It is suggested that 30 (70%) GBS patients presented transient abnormal behaviours that arose from being in a dream-like state and that most of these delusions were paranoid in nature. The authors also report that no experiences of delusions were reported in the control group, who were also being nursed on the ICU.

In summary, Cochen *et al*; (2005) found mental status abnormalities in slightly over one third of their large sample of GBS patients. These mental status abnormalities included hallucinations, paranoid delusions, vivid dreams and illusions and that these symptoms were more common in more severe cases of GBS.

The authors make reference to the fact that the ICU to which patients were admitted was an open unit with day light visible through large windows. This is contrary to many of the reports of the experiences of being nursed on an ICU in Britain, with the lack of clear night and day thought to have a causal effect on psychological symptoms (Dorr-Zegers, 1988). Whilst the scale and methodology employed in this study ensure that these findings are more easily

generaliseable to the UK, it may be suggested that incidence rates in the UK of, for example, PTS, would be slightly higher due to the differences in the ICU environment.

The prospective nature of this study and its sample size make it more reliable in its findings than other single case studies that have been carried out. The researchers were able to speak to patients at the time, or very soon after, they experienced mental status changes which meant that patient recall of these events may have been clearer than in some retrospective studies.

4.4 Psychosocial issues related to GBS

Eisendrath, Matthay, Dunkel, Zimmerman & Layzer (1983) carried out a prospective study with an emphasis on the psychosocial aspects of GBS. Whilst this study was reported in the 1980's it is one of very few which has looked prospectively at this group of people and their experiences from a more holistic viewpoint. Their sample consisted of eight (five male and three female) patients with GBS and ensuing respiratory failure. They collected data from the patient as well as their physicians, nurses and social workers so as to better understand the psychological issues that were important to this group. The average length of stay in the ICU for their patients was 65 days and the average length of time for mechanical ventilation was 55 days. They reported that several patients had visual hallucinations or illusions, and that seven individuals were noted to be depressed, although they do not state how these phenomena were assessed or whether these were the same patients in both accounts.

Eisendrath *et al*; (1983) suggest that there were six psychosocial issues that arose repeatedly in their GBS patients. They describe these as: understanding of GBS by the patient and family; communication effectiveness; patient/staff interaction and control; patient state of mind; staff interventions; management of pain and hallucinations.

Their sample consisted mainly of people who had never been hospitalised prior to having GBS and had very little knowledge of GBS prior to its onset. Resulting from individuals being given information about the prognosis of GBS during their ICU stay, seven of the eight patients stated that they clearly understood the disease process and that they could expect a favourable recovery. All eight patients reported that it was important for them to receive this information and that it was more useful to them earlier on in the course of their illness. Six patients commented that it had been useful for them to receive information about the intubation procedure and reasons for this prior to the procedure. However, this information cannot always be given to patients, particularly if the onset is very sudden or there is a rapid deterioration in their condition. Indeed, two patients from the reported sample had been intubated prior to their admission to the ICU and had not received any information regarding the procedure or about GBS more generally.

Eisendrath *et al*; (1983) managed to communicate with their patients to obtain their data using various creative means, such as communication boards, lip reading, and eye blink codes, however, out of their sample of eight patients, 50% of them reported difficulties in communicating with their care staff and that staff did not take the time to understand their needs.

The authors found that their entire sample reported moderate to severe anxiety and fear intermittently during their time on the ICU. It is unclear how these emotional states were assessed but patient concerns often centred on the potential for malfunction with the ventilator, the changing of staff and the busyness of the ICU. A quote taken from this study highlights this fear:

By far the most frightening aspect of the illness was the fear of being unable to obtain another breath if the ventilator tubing were to come off, p. 467.

In their eight patients, all of them expressed this fear, particularly in relation to not being able to signal for help should something go wrong. Patients did recognise that their anxiety levels decreased when they were given support, explanations and reassurance from family members or staff.

Seventy-five percent of their patients remembered having hallucinations and one reported visual distortions. They usually described these as distressing and that although they were frightened; this was not recognised by the staff. The study recognises the different psychological impact of the various stages of the illness, the progressive; plateau and recovery phase and makes suggestions for practical solutions to aiding patients who are suffering from GBS. However, the study failed to utilise any standardised measures for the capturing of data which suggests that the data may be fairly subjective and this makes generalising these findings more difficult. Studies that have taken place since this one have however supported these findings.

4.5 Recovering from GBS

Outcome and effectiveness of treatment in GBS is usually evaluated using muscle performance, and on this measurement, approximately 80% of GBS patients receive an evaluation of a good recovery after treatment (Hughes & Cornblath, 2005). However, quality of life and well-being may be impaired in different areas several years after disease onset, indicating incomplete long-term recovery (Rudolph, Larsen, & Farbu, 2008). Whereas most GBS patients are capable of manual work between two and seven years after the acute attack, between 25% and 85% still have residual neuropathy signs, indicating impaired physical functioning (Chio, Cocito, & Leone, 2003).

Beside a worse physical status, mental functioning may be impaired as well. Fatigue and lack of energy has been reported in 80% of patients after five years of follow-up, independent of

disability and physical functioning (Merkies, Schmitz, Samijn, van der Meche, & van Doorn, 1999). Furthermore, it appears that emotional well-being may still be altered seven years after onset, whereas social functioning seems to be more affected in earlier years after the acute attack (Merkies, Schmitz, van der Meche, Samijn, & van Doorn, 2002).

In a small interview study, including five persons focused on the rehabilitation phase, it was found that the course of GBS understandably required an adjustment to physical changes and having to cope with emotional instability (Cooke & Orb, 2003).

Dhar, Stitt and Hahn (2008) carried out a large 20 year retrospective review of all adult GBS patient medical records who had been admitted to the ICU ward at London Health Sciences Centre between 1983 and 2003. Their study looked at the morbidity and medical outcome of these patients and found that, in their sample of GBS patients requiring ICU admission, there was a high rate of major complications and that the greater proportion of their patients required mechanical ventilation (MV). They also found MV to be the factor most strongly associated with ICU morbidity. They found that 75% of their patients (including 71% of those requiring MV) had a good outcome one year after having GBS, with good outcome defined as the ability to walk independently. These findings are comparable to the Mayo Clinic study (Fletcher, Lawn, Wolter, & Wijdicks, 2000) despite some previous studies suggesting that long duration of mechanical ventilation was associated with poor medical outcome (Fletcher et al. 2000). However, despite reporting the above findings it is important to remember that this study was conducted retrospectively, up to twenty years after diagnosis in some cases, and therefore the analysis of patient outcome and functioning may be flawed. The data was gained from searching through follow-up records, which suggests that the authors could have gained important additional information if they had spoken to participants directly. The study focussed on medical

outcomes for patients, such as their ability to walk and took no account of more psych-social rehabilitation issues.

Contrary to the Dhar, Stitt and Hahn (2008) study, Forsberg, Press, Einarsson, de Pedro-Cuesta *et al.*, (2004) described significant residual impairment at two years post GBS and reported that motor and sensory impairment were still detectable in more than 50% of their 42 GBS patients. Their study provided longitudinal and prospective information on individual's quality of life and health and utilised patient's homes as the site for these evaluations, rather than in hospital or from medical records. They describe a decrease in the frequency of participant engagement in social and lifestyle activities two years after onset in 24% of their sample and suggest that their findings show evidence for the existence of considerable long-term limitations, attributable to GBS in activities and participation in everyday situations.

With regard to work capacity and employment, the Bernsen, Jager, Schmitz and van der Meche (2002) study reported that 38% of patients with severe GBS were unable to work or had been forced to change jobs 3-6 years after onset. They followed up 122 patients from between 3 to 6 years following the onset of GBS. They found that almost half of their sample reported negative comments on their present psychosocial situation, despite evidence to suggest that no further recovery can be expected 2-3 years after GBS. (Asbury, Arnason, Karp, & McFarlin, 1978) Bernsen *et al.*, (2002) found that 21% of their sample still noticed improvement after 2.5-6.5 years after GBS. Of their sample, nineteen patients complained of emotional instability and five of impaired concentration or memory disturbances. Nine patients reported that they still thought very often about the period when they were sick, twelve continued to have fearful dreams and two had other sleeping problems. Twelve patients mentioned limitations on dependence in general. However, some positive comments were also given. Six patients

mentioned that they had learned to judge the relative importance of things better and eight had learned to appreciate life more. They also reported that almost a quarter of the patients who stated that they felt completely cured still showed changes in psychosocial condition. All but one attributed these to mental changes or lack of condition. This appears to emphasise the fact that despite a patient reporting that they are completely well and having normal muscle power, there may still be the possibility of a decline in psychosocial condition that should be assessed.

Rudolph, Larsen, and Farbu (2008) analysed the long-term impact of GBS on quality of life and the relationship between clinical variables at disease onset and symptoms at follow-up to general health status. They examined forty-two patients at a median of six years post disease onset and compared them to fifty healthy controls. They found a negative long-term impact of GBS on patients' physical and functional health profile, independent from variables at the onset of the disease. Pain intensity and functional impairment were significantly higher compared with healthy controls and were related to poorer outcome. Additionally, they found persistent impairment on quality of life for the GBS patients they assessed.

4.6 Appraisal of Quantitative Research Designs

There has been a limited amount of quantitative work carried out in this area which is probably due to the rarity of the condition and subsequent difficulties in being able to access a large sample over a period of time. The more robust of the documented studies have been carried out utilising a prospective methodology, and have therefore been able to capture data close in time to the onset of the disease, rather than relying upon memories for events in retrospective studies. However, there are ethical considerations when approaching severely ill patients whilst they are heavily sedated and paralysed, and none of the reported studies make explicit reference to these issues. It remains unclear as to whom ethical approval was sought and how informed

consent was gained from patients. The studies all fail to acknowledge that patients are placed in an exceedingly vulnerable state and may therefore acquiesce to taking part in research due to fears about their future medical care.

Not all studies described how GBS was diagnosed and those that did, used varying diagnostic criteria e.g. the Asbury and Cornblath criteria, CSF examination or by electrophysiological testing. This made comparison of the different studies difficult and the inclusion of differing diagnoses was not made clear in all studies i.e. Miller-Fisher syndrome, CIDP etc.

The majority of quantitative studies focused primarily on functional status of GBS patients, including measures of walking or muscle weakness and failed to acknowledge the psycho-social aspects of the rehabilitation and adjustment phases of the illness.

Gaining accurate findings may be difficult due to the condition itself. Patients are usually unable to communicate effectively and researchers carrying out prospective work would need to be creative in their use of communication aids. This could potentially increase the bias in what researchers are documenting, based on difficulties lip reading or interpreting patients.

There may be a number of people excluded from this type of research due to previous mental health conditions, co-morbid physical health difficulties or complications arising from the GBS and the majority of studies failed to document what inclusion/exclusion criteria they used.

Quantitative research has provided some valuable findings about some aspects of suffering and recovering from GBS that suggest that patients experience different difficulties at the various stages of the illness but there is a limit to how much depth and detail can be elicited from this type of approach. One of the benefits of quantitative research is that results may be generalisable to beyond the immediate setting. However due to different treatment settings in

the different countries where research was carried out, small sample sizes and incompatible methodological approaches across the studies, generaliseability is somewhat limited within this area of research and further studies are needed.

4.7 Appraisal of Qualitative Research Designs

The qualitative literature in this area is scarce and of limited quality. Much of the qualitative literature surrounding GBS has been carried out in the form of single case studies and autobiographies. These form a basis for understanding the experiences of those who have had GBS and inform larger scale quantitative research. One large scale qualitative study has added greatly to the understanding of peoples' experiences of falling ill with GBS as well as recovering from it initially and several years after. However, the study failed to contain any significant description of how quality was maintained in the data collection and analysis. For example, there was very little mention of the use of triangulation methods and no mention of how the authors gained respondent validation. Neither were there any statements about the researchers' epistemological position or the impact of the researcher on the data. In summary, whilst single case studies, autobiographies and qualitative research has added to the understanding of individuals' experiences of GBS, the quality of this research is relatively poor and additional qualitative studies are needed to further explore some of the initial themes and findings.

5. Conclusions

In summary, literature in the area of experiencing GBS highlights the importance of acknowledging the severity of the illness for patients. The different phases of the illness present differing challenges in the management of patients by healthcare staff and in the patients' coping strategies. Staff and patients appear to find the loss of communication difficult and frustrating, although little work has been carried out on what some of the psychological barriers to staff

interaction with patients may be. Hallucinations are experienced by a significant proportion of patients whilst in the ICU being treated for GBS, which may cause significant distress, although these experiences may not be recognised at the time by healthcare staff.

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PART TWO: RESEARCH REPORT.

A mixed-Method Investigation into the Experiences of Individuals' who have suffered from
Guillain Barré Syndrome.

Word count: 11,707

Research Report Abstract

Purpose: To explore the experiences, illness perceptions and mental states of individuals who have suffered from GBS.

Method: (Study 1) Interviews were undertaken with seven individuals who had experience of GBS. The interview transcripts were analysed using Interpretative Phenomenological Analysis. The preliminary themes generated from these interviews formed the basis for questionnaire batteries which were disseminated so as to gain quantitative data on the rates of anxiety, depression and post traumatic symptomatology both retrospectively and prospectively in a sample of 136 GBS sufferers (Study 2). The questionnaire battery consisted of: The Hospital Anxiety and Depression Scale, The Revised Illness Perceptions Questionnaire, The Impact of Events Scale, The Dissociative Experiences Scale and a demographic questionnaire.

Results Study 1: Participants described having a range of experiences from having had GBS, both positive and negative. Themes identified through the process of analysis were: frustration; lack of communication; pain; vulnerability and loss of self.

Results Study 2: The study identified that 61.7% and 63.2% of the sample experienced clinical levels of anxiety and depression, respectively, during the onset of GBS and that 19.1% of participants continued to experience depressive symptoms and 25.7% continued to report a clinical level of anxiety after their recovery from GBS.

Conclusions: The current findings would suggest that individuals who have experienced severe GBS may develop some signs of psychological distress, such as anxiety, depression or PTS during and following their recovery.

Key words: Guillain-Barré syndrome, paralysis, mechanical ventilation, experiences, IPA

Target Journal: Journal of Health Psychology

STUDY ONE: A QUALITATIVE EXPLORATION OF THE EXPERIENCE OF GUILLAIN BARRE SYNDROME

1. Introduction

Merleau-Ponty (1962) described the embodied nature of our relationship to the world and how this leads to the primacy of our own individual perspective on the world. He described our embodied nature of communicating with the world as ‘the body no longer conceived as an object in the world, but as our means of communication with it’ (1962: 106). The researcher was interested in gaining a fuller understanding of what happens to individuals when they are no longer ‘embodied’ in a world, i.e. paralysed and unable to communicate.

Given the lack of research in the area of the experience of GBS and the subsequent development of psychological difficulties, it was considered useful to carry out an initial exploratory study. The aims of Study 1 were to identify salient aspects of individuals’ experiences, which could form the basis for a larger, quantitative study (Study 2). Ideally these data could then be used to help to improve and develop current and future healthcare, and wider application beyond GBS patients including anaesthesia awareness, therapeutic paralysis, Multiple Sclerosis and Myasthenia Gravis patients.

The research questions for Study 1 were:

- What are individuals’ experiences of falling ill with GBS?
- What meaning did individuals attribute to the paralysis?
- What are some of the psychological implications of falling ill with GBS?

2. Method

This section describes the study design and the rationale for selecting Interpretative Phenomenological Analysis (IPA) as the method of analysis. The current study then describes the participants who took part in the study, the development of the interview schedule, the process of transcribing and analysing the interview data.

2.1 Overall Design of the Study

It was considered appropriate to use a qualitative approach for this particular study as the researcher was interested in gaining further information on individuals' own lived experiences of having GBS. Qualitative research can be described as an 'interpretative', 'contextual' and 'naturalistic' mode of enquiry (Henwood & Pidgeon, 1996). It is an 'exploratory' method, used to explore a topic when the variables and theory base are unknown (Cresswell, 1994). As stated by Ashworth (2004) qualitative research, regardless of which specific approach, focuses on experience. The current study aimed to capture the quality of the experiences of the participants. A semi-structured interview was selected to allow for flexibility to follow up relevant areas of interest that emerged during the interview (Smith, 1995). The IPA process and the themes generated were validated by the researcher in a number of ways. These included; attending an IPA group where the generated themes were discussed and reviewed; the presentation of themes at a National GBS conference and the informal feedback given from GBS patients as well as from medical staff who are experts in the field of GBS.

2.2 Epistemology and Choice of Method

See Appendix D for a statement relating to the researchers' epistemological position.

2.3 Rationale for selecting IPA methodology for the study.

The researcher initially considered that Grounded Theory (GT) might have been the most appropriate approach for the study. However upon more detailed exploration of both GT and IPA approaches it was considered that IPA would be a more appropriate method. The researcher considered that whilst both approaches offered flexibility and opportunity for interpretation, the specific premises of IPA, which lent themselves to this particular study were (i) the underlying assumption within IPA that the sample is homogenous (in this case all participants had suffered from GBS and had been nursed on an ICU), (ii) whilst being grounded in the text, IPA seems to allow particular scope for moving beyond the text to a more interpretative and psychological level, (iii) a strong focus upon subjective experience, (iv) the absence of a pre-determined hypothesis and (v) a concern with complexity, process or novelty (Smith & Osborn, 2003). Due to the lack of research in this area, it was considered beneficial to use a method which was concerned with novelty, complexity and process. In addition the researcher did not aim to build inductive theory from the research data as would be the case with GT (Charmaz, 2006).

3. Participants

3.1 Ethical Approval

Ethical approval was sought using the Integrated Research Application System and the current study was given a favourable ethical opinion by the Nottingham 2 research committee on the 26th January 2009 (see Appendix A).

3.2 Recruitment of participants

Links were made with the GBS support group who agreed to publicise the current research study on their website (see Appendix B for the advertisement flyer). Participants could download information from the website or they could telephone/write/email and request to take part in the

research. The researcher also attended the GBS annual conference and gave out information, requesting participants who had received a diagnosis of GBS rather than any other variant of the disease. Participants were initially sought who had experienced mechanical ventilation, although this inclusion criterion altered slightly to include participants who had been on an ICU but not necessarily needed mechanical ventilation. This was due to information from the initial interviews describing that the severity of the illness was not necessarily linked to the need for mechanical ventilation and the need to develop themes that were pertinent to the majority of GBS sufferers.

3.3 The sample

Seven participants were recruited from responding to advertisements on the GBS support group website, word of mouth and flyers which were posted. All participants had had GBS with varying degrees of recovery and time since illness. All participants had been nursed on an ICU, although not all had needed mechanical ventilation. All participants were sent consent forms (see Appendix C) which they completed and returned prior to being interviewed. Participants were asked for basic demographic information, shown in Table 2. The demographic information has been presented in this format rather than individually to protect the participants' anonymity.

Table 2. Participant Characteristics

Gender		Ethnicity	
Female	6	Black African	0
Male	1	White British	6
Age		White Other	1
26-30	0	Indian	0
31-40	1		
41-50	2		
51-60	4		

3.4 Development of the Interview Schedule

The development of the interview schedule was a significant part of the study. As stated by Burman (1994) work done prior to conducting interviews is “...usually amply repaid in terms of its success and ease of analysis”. The interview schedule was written in draft and then comments were sought from the GBS support group ethics board (see Appendix D for an example).

Holloway and Jefferson (2000) stated that there are unconscious dynamics that occur in the research interview, for example defences against anxiety on either the part of the researcher, participant or both. Participants may be invested in particular positions in discourses to protect vulnerable aspects of self or be motivated (maybe unconsciously) to disguise the meaning of some of their feelings and actions. Participants may also be defending against thinking or speaking about issues that were distressing to them. In order to address this, the researcher utilised four principles adapted by Holloway and Jefferson (2000) as far as possible in the interview schedule. This entailed (i) using open ended questions; (ii) eliciting stories which anchored peoples’ accounts to actual events; for example asking “can you tell me about a time when X happened?”; (iii) avoiding ‘why’ questions, and (iv) following up participants’ themes in narrated order and using their own words and phrases.

3.5 The interview process.

Data were collected via qualitative interviews which took place in the participants’ homes or over the telephone. The researcher conducted all of the interviews using the developed interview schedule and open-ended questioning. Each interview was digitally recorded for transcription after basic demographic information had been collected; key information from the participant information sheet briefly discussed and the consent form signed (see Appendix C). The interviews lasted between 30 and 120 minutes. The interviews were conducted as

conversations with the following thematic areas in mind: the experience of the onset of GBS; the meaning the paralysis held; experiences during ICU stay, all the time holding in mind what the psychological implications of those experiences might have been. Following each interview, the participant was asked how they found the interview in order to ascertain whether the participant was distressed and required any support. They were also asked if they would like to receive feedback after completion of the research and were reminded of how to contact the researcher should they wish to discuss anything. The researcher recorded her reflections of the interview process in a log immediately after each interview.

3.6 Transcription and analysis of interview data.

The interviews were taped and transcribed verbatim, with the inclusion of pauses and emotional expressions. All of the transcribed interviews were read and listened to in their entirety to obtain an overall picture. The interview texts were read with the three themes in mind, based on the interview schedule i.e. the experience of the onset of GBS; the meaning the paralysis held; experiences during ICU stay. The interview texts were then divided into words and sentences that were related to the same central meaning.

The analysis began following the first set of interviews. The researcher approached the analysis of the interview data as suggested by Smith and Osborn (2003), with the aim of understanding the content and complexity of the psychological world of each participant rather than measuring the frequency of a particular element of their story. This process began with the analysis of what the researcher considered to be the richest of the first six interviews. All interviews were analysed by recording significant information in the left hand margin to begin with. This involved the researcher attending to participants' use of language, making connections between different parts of the transcript, observing contradictory comments, or associations

within their account. The overall aim was for the researcher to capture the essence of what was coming across from the participant, whilst asking questions about what might be absent from the account. Following this process, the researcher documented emergent themes in the right hand margin. This involved transforming the initial notes into phrases, which captured the quality of what was found in the text, whilst moving the response to a higher level of abstraction. The researcher attempted to find ways of describing the themes in a way which incorporated psychological and theoretical ideas, whilst being grounded in what the participant said. These themes were then clustered into super-ordinate themes by considering which themes seemed to be related to each other in some way. Further analysis continued during the writing up stage and the themes continued to evolve as the researcher developed her thinking about the material.

4. Results and Analysis

This section contains the results from the first level of analysis, specifically the themes that emerged from analysis of the interview transcripts. A table of these themes is shown in Figure 1. This section includes key quotes to illustrate the categories. These quotes are referenced in the text in brackets, in the form of participant number, followed by the page number (e.g. 1, 34)

4.1 Overview of themes

Figure 1: The final representation of clustered themes

1. Onset of Illness Rapid, scary onset Prolonged deterioration Body as strange Fear of getting worse Not being believed/ not receiving diagnosis/ not knowing Hope in doctors' prognosis Importance of diagnosis and information
2. Meaning of the paralysis Loss of self Frustration Inability to communicate Vulnerability Dependence/ Reliance on others
3. Experiences on ICU Humiliated/ashamed Hallucinations Pain Feeling too ill to care/wanting to die/ despondent Staff attitudes Moving wards experienced as both positive and negative events Recovery Others' attitudes to illness/disability

4.2 Experiencing the Onset of the illness.

Two themes were described, with varying subthemes, whereby falling ill with GBS was described as either a slow and prolonged, incomprehensible time or as a very rapid and scary onset. The scary, rapid onset was described as a sudden awareness that something was wrong:

Well, I was quite frightened...and these pins and needles and tingling quite came and the first thing I knew there was something terribly wrong was that I'd had pain in my lower back which was like nothing I'd, pain I'd never experienced...and it got worse and worse.

(6, 1, 5-11)

The majority of the people who experienced a rapid onset of GBS had limited memory of that time as their health deteriorated so quickly that they lost consciousness or were sedated immediately:

It all happened so quickly that you know it was frightening on the morning on which I discovered that it was there and advancing very, very quickly but I guess by 11 o'clock you know half past eight I first discovered it and by 11 o'clock I was effectively paralysed. I lost consciousness as I was going into the hospital. I don't think anyone had enough information to give me it was so very quick (3, 4, 8-12).

The accounts from these people also illustrated how they weren't able to gain information about GBS due to the rapid decline in their health, however, they also recognised that information on their condition at that stage would not have been useful to them.

The persons experiencing a slow and progressive illness described this as being difficult due to different factors from the ones described above. Individuals talked about making repeated visits to their GP's, having telephone consultations and visiting their local A&E departments seeking a diagnosis or explanation for their symptoms. They report that they knew that something wasn't quite right with their health but that their symptoms were strange and unexplainable:

It was quite a few weeks before full diagnosis was given so for quite a while I didn't know what was wrong with me. The first symptoms I had were due to loss of mobility, just gradual, pins and needles in legs and realising something peculiar was happening and that got worse over several days....so to start with it was painful so and there was not knowing what was wrong, but wanting to know what was wrong so they could fix me. (1, 1, 5-16)

Interviewees spoke about the uncertainty associated with not knowing what was wrong with them and that receiving a diagnosis and therefore a prognosis may have helped to alleviate some of the anxiety they were feeling. These anxieties may have been about being paralysed permanently or even dying, although the majority of people stated that they did not imagine that there was something drastically wrong with them, although friends and family were worried about serious ill health:

Now I think Warren (husband) was worried that it was cancer. I knew there was something wrong with me but once the blood tests came back clear I thought well that would have shown up, anything major would have shown up in the blood but I just couldn't understand what it was...so I knew there was something but I didn't have a clue about what it was and then you start to think am I imagining this? (7, 4, 9-14)

Participants were asked about their fears around GBS and about what was going through their minds when they were becoming ill. The majority of people interviewed stated that they never allowed themselves to think the worst. The people who experienced a rapid onset of GBS found that they didn't really have the time to think the worst as they often had no memory for the initial onset of their illness:

To be honest I don't think I ever really thought about it. I don't remember having such thoughts as I think back later and think "Oh my God, am I going to be paralysed forever?" I don't think I ever thought it, I don't really think I thought anything at all. (2, 6, 16-19)

People spoke often, although not always explicitly, about the trust that they had for doctors and medical procedures. This sometimes caused difficulties for people who had not been given a firm diagnosis and often felt that they were given a message of not being believed:

So they gave me some aspirin for the pain in my legs but couldn't find anything wrong with them at all...a locum came down and said there was absolutely nothing he could do, there was nothing wrong with my limbs you know, get over it basically. (2, 1, 12-18)

All of the individuals who had experienced a prolonged onset of GBS made reference to not being believed and this causing them greater distress and uncertainty about their condition:

And the doctor took one look at me and said "Oh well, I think you're depressed" and we got back in the car (7, 3, 12-13).

All the participants described sensations which were unusual to them and suggested that they experienced their bodies as strange also:

Then I started with pins and needles in my legs but it was a painful pins and needles, it actually burned when I touched my legs, it burnt when I touched my legs on the covers and there seemed to be a weakness in them, they seemed to be grumbling a bit (2, 1, 6-9).

And I did have a very weird sensation, my toes were always cold. But it wasn't the toe that they'd wrapped up at the bottom of my leg, it was the one over there that I couldn't move back...and it was really cold and it was hurting me and nobody could help because it wasn't, it was like a limb being amputated the message obviously wasn't getting through and my toes were cold (2, 19, 8-17).

Another participant spoke about feeling as though her legs were tucked up under her, even though her husband showed her that her legs were flat out on the bed. These sensations bore a resemblance to that of phantom limb pain and became the cause of distress for some people as they were unable to communicate their needs to the care staff.

4.3 The Meaning of Paralysis for Individuals

Participants spoke about feelings of loss during the paralysis:

I think it was the inability to let anyone see that inside the lump of dough on the bed was somebody with a sense of humour and a reasonably active mind and I wasn't that person anymore, I think it robbed me of me...For all the time I was in hospital I ceased to be me and I resented it (2, 14, 5-10)

The sense of loss seemed to take many forms, with some people speaking about the loss of bodily functions and abilities, whilst others spoke about the loss of a sense of self and that whilst they were paralysed they felt unable to communicate important aspects of their personality to others. Feelings of frustration were common across all participants' accounts of being paralysed:

Lots of feelings of frustration, confusion, other people coming in and going home and I wasn't (1, 3, 11-13).

Being unable to communicate appeared to be the source of a lot of frustration for patients and induced feelings of vulnerability and isolation:

I mean the worst thing was when I had to go into that room by myself for the night. That was frightening...and they just left me in that room...and I couldn't get enough noise out of my voice to call anyone and I was quite frightened then (4, 5, 5-13).

The majority of people interviewed stated that the paralysis had understandably left them feeling vulnerable and trapped. Being dependent upon others was an unusual and difficult way of relating to others:

The nurses were chatting and they were talking about their lottery tickets and if they won the lottery and yeah this used to be my dream, I could go along with that and suddenly I couldn't and I thought it would not make one iota of difference if I was a

multimillionaire, I would still be totally and utterly imprisoned in this body, perhaps not in this room, I might have pleasanter surroundings, but I would still be totally imprisoned and having to face up to this...and you're totally reliant on other people for totally everything, yes it is frightening, it is very, very worrying (2, 10, 1-7)

4.4 Experiences whilst being nursed on an ICU

Interviewees spoke about their feelings of humiliation and feeling ashamed that they needed to be cared for by others after their own body had let them down:

Everything else just seemed like the final degradation and the final humiliation, I mean to need to have someone to wash you and wipe you...I know you can keep an open mind and females wash fellas but I still don't like having my bits wiped by a man, it just wasn't nice and erm it altogether it wasn't a very pleasant experience. (2, 7, 3-8)

The majority of participants spoke about unusual experiences such as strange nightmares and frightening hallucinations. One interviewee appeared to interpret her feelings of pain and constipation as something more sinister:

I had surgeons wielding knives and taking my bowels out (2, 18, 21-22)

Whilst another patient thought that their tracheotomy site was much larger than it really was and that nurses were trying to kill her:

In my mind the hole in my neck (tracheotomy site) was about this big (signals about 6 inches in diameter)... and I had this idea that they were throwing the empty (saline) bottles down into my lungs and I really believed it and I was terrified that I would just die and nobody would know why (1, 12, 3-7).

One man described his memories of his hallucinations:

There was a long period of being half awake and half asleep but I don't know quite how to describe it but it was if I were in perpetual darkness. I knew what was going on around me but that merged into the hallucinations that I was having so the reality became part of the hallucinations. It became hard to tell what was real from what wasn't although I wasn't trying to tell what was real and what wasn't at that stage because it all seemed real to me (3, 2, 16-21).

Interviewees remembered the feelings of pain that they experienced, during the onset of GBS and throughout their recovery. One man spoke about being moved in a sling from his bed to a chair and his belief that the nursing staff did not realise how much pain he was in:

I don't think that the staff appreciated how painful it was. The first time it was attempted was in the first hospital...but I did pass out with the pain in the sling and the people doing it, I don't think they had any appreciation of how much it could be hurting me because I was a fit individual with nothing wrong with my bones or my joints. It may be that they thought because I was paralysed I couldn't feel anything (3, 7, 18-23).

Some participants spoke about their feelings of despondency, although, for most, these were quite fleeting:

I just felt so poorly and if I'd been able to die then and there, if I'd been given a choice, I would have said let me go, I don't want anymore of this, I was in so much pain all the time. (2, 6, 18-21)

Another female participant remembered feeling very low during her stay on ICU:

There was one night where I just lay there and thought, I've had enough, I don't want to do this anymore (1, 14, 5-6).

However, most of the participants could remember both positive and negative aspects of their care:

Some would take patience and time, come close and try to see what I was saying, others wouldn't and you knew which ones they were cos you could see the fear on their faces, was fear on the part of the nursing staff that they wouldn't be able to understand that made them not understand (2, 4, 1-5)

Moving wards was also experienced as both a positive and a negative event:

I do remember other moves and they've played a really important part (laughs) in my life that er I was moved from the hospital to rehab unit it was the first time that I'd been out in the open air even just you know those few yards from the doors to the ambulance and it was raining and I just thought it was wonderful to feel the rain on my cheeks (1, 9, 8-12).

Similarly to the start of the illness, participants viewed their recovery as either slow and arduous or rapid, which helped them to feel optimistic about their progress:

The recovery once my lungs were better seemed to go at a frantic pace, it was really very, very good. You know I went down to physiotherapy in a chair and came back on a zimmerframe on one of the days which was absolutely, tremendously exciting and one day when they gave me two walking sticks when they said you can go to the toilet on your own was absolute bliss you know it was really magical (2, 5, 17-22).

For some participants there seemed to be a parallel between feeling invisible or having very little physical impact on the ward and experiencing the same feelings during recovery:

Cos when I was on the crutches and also on the sticks I'd, when I was shopping people were so inconsiderate and in the wheelchair, I couldn't believe how people, they just,

you're not there, they'd cut you up, they'll walk into you, they'll knock you over, you just might as well be invisible (4, 13, 1-3).

Whilst some interviewees stated that they did not think about GBS coming back and that they didn't worry about it:

I don't know how I would cope if it came back again but like I don't worry about Polio, I don't worry about any other disease you know, there's no point in worrying about it. If it's going to happen, it's going to happen (3, 9, 13-15).

Some people were very fearful of a re-occurrence:

I would not go through that again. I absolutely could not. I think it was just the nightmare, the situation of being so trapped and so vulnerable I really could not and would not (2, 21, 11-14).

5. Discussion

The aim of the current research study was to explore the experiences of individuals who had suffered from severe GBS and been nursed on an ICU. The results suggested that the majority of the current sample were able to cope psychologically with the different stressors that GBS generated at the different stages of the illness, although for some people the loss of their sense of identity and their heightened feelings of vulnerability were difficult to manage. The themes which emerged from the research are discussed in relation to previous research and relevant theory and ideas for future research. This is followed by a consideration of the clinical implications and conclusions from the research.

5.1 Interpretation of Results

The current qualitative study describes the personal experiences of having GBS. Whilst individuals had all suffered from a severe form of GBS there were many different themes that were generated from the seven interviews and not all are discussed in detail.

Interviewees spoke about either a rapid, incomprehensible onset or a slow and scary progression of their condition. Individuals' memories for the subsequent events varied considerably, possibly depending on the medications they were given and the speed of the onset. Those who experienced a slower progression of GBS had more time to think about what might be happening to them, although they reported that they rarely thought about serious medical conditions or that they might die. All participants spoke about being given reassurance by healthcare professionals and that this reassurance enabled them to feel hope for their recovery.

Participants reported that their bodies became scary and unreal to them, with some experiencing dissociative type symptoms or 'phantom limb' sensations. Pain was also highlighted as an issue for most participants and that it was difficult to let staff know about their needs with regards pain management. Again, it was important for individuals to gain reassurance from staff or loved ones. This is made particularly difficult in GBS due to the communication difficulties associated and individuals reported that the lack of communication abilities was the most frustrating part of the illness. Lack of communication abilities also left people feeling that they were not whole and that they had lost a part of their self which could not be communicated to staff.

The experience of paralysis was spoken of as a general sense of frustration and loss. People experienced the loss of their bodies as a significant one, which was generally felt more keenly when they had been used to being particularly active prior to having GBS i.e.

sportsman/woman. The reliance on others and the vulnerability that this created was difficult for most to cope with and hallucinations that were described often contained issues around these feelings.

Once individuals were able to measure their recovery, most of them reported that this seemed to occur very rapidly for them, although some felt that their progress was painstakingly slow. Throughout all of the interviews analysed, participants spoke about the impact that their family and staff had had upon their recovery. Many were able to think about both positive and negative aspects of their care and highlighted that more needs to be done to educate staff to the unique needs of GBS patients.

5.2 Methodological Issues

It is important to remember that GBS is a syndrome and therefore most people have differing experiences. Whilst seven interviews were carried out with people who had had GBS, the use of IPA necessitated a degree of homogeneity in the data. It was therefore decided to focus only on the people who had experienced severe GBS. It is possible that even though seven interviews were carried out, that for some, the experiences that they recognise will be different or not represented here despite efforts to express a wide range of experiences. However, some of the themes generated during the current study bear a resemblance to themes developed by Forsberg, Ahlstrom and Holmqvist in their 2008 study. This would suggest that participant's views were represented by the themes developed and the current study supports the findings from the earlier study.

Ethical issues were considered whilst carrying out the current project, in particular, that participants were being asked to speak about an event that they may have found traumatic or upsetting. Participants were asked about how they were feeling at the start and end of interviews

and how speaking about GBS had affected them. All of the participants stated that speaking about their experiences had been helpful, even those whom had spoken about upsetting aspects of having GBS. Therefore it may have been that participants edited what they chose to speak about, however, the process of keeping a research diary and reflecting on the interview process and transference issues soon after the interview had taken place may have helped to eliminate some of this bias.

6.3 Clinical Implications

The function of the qualitative element of the current study was to inform the quantitative section, which is detailed in Study 2 and aimed to follow-up on some of the clinical implications linked with the findings of Study 1. Participants who experienced a slow onset of GBS spoke about their frustration at not being believed by their primary health care professional and that this led to them doubting their own symptoms. Knowledge about the symptoms and treatment of GBS does appear to be improving, although for these patients, who may or may not have presented atypically, a firm, swift diagnosis may have prevented further deterioration in their condition and their mental state. Similarly, continued support and education for staff working with GBS patients would be welcomed as all of the people interviewed stated that they didn't feel that staff appreciated some of their difficulties. Some psychological difficulties during and following GBS may also be alleviated if staff felt more able to communicate with patients and help to normalise some of their experiences.

STUDY TWO: A RETROSPECTIVE INVESTIGATION OF THE MENTAL STATE AND ILLNESS PERCEPTIONS OF GUILLAIN BARRE PATIENTS

1. Introduction

Despite the limited literature in the area of the psychological implications of experiencing GBS, there has been some support for the hypothesis that experiencing GBS could be experienced as a traumatic and significant life event which has been found in the ICU and therapeutic paralysis literature.

1.1 Anxiety and depression

Advances in supportive therapy now mean that many patients survive acute, severe illnesses, such as GBS, which in the past may have resulted in death. However, the combined after-effects of illness and the intensive care experience, together with often unrealistic expectations of what is an uncertain recovery period have been linked to both short and long-term psychological consequences (Scragg, Jones & Fauvel, 2001). Recently there have been several studies conducted looking at the emotional outcome of being nursed on an ICU, with anxiety being reported by between 11.9% and 43% of patients, and depression by between 9.8% and 30% (Rattray, Johnston & Wildsmith, 2005). Post-traumatic stress responses have also been recognised as occurring in response to critical illness (Mayou & Smith, 1997).

Studies have also suggested that patients who have experienced severe GBS demonstrate high levels of anxiety during the initial stages of the disease and when symptom development was increasing and that depressive symptoms were more commonly reported during maximum disability and after reaching remission (Weiss, Rastan, Mullges, Wagner & Toyka, 2002).

According to the behavioural model of Lewinsohn and colleagues, disease leads to depression only if it interferes with the persons' normal level of functioning (Zeiss, Lewinsohn, Rohde & Seeley, 1996). Because GBS is a disease that can affect multiple domains of

functioning, it is possible that Lewinsohn's model might go some way to explaining the development of depression amongst this patient group.

Lewinsohn's model suggests that disease will lead to depressive affect only if it disrupts physical or psychosocial functioning (Lewinsohn, 1974). For example, physical dysfunction caused by a disease might interfere with a person's ability to compete in sports, perform at work or socialise with friends. If a person's ability to obtain positive reinforcement is disrupted then it is proposed that dysphoric mood will result (Lewinsohn, Hoberman, Teri & Hautzinger, 1985).

Consistent with Lewinsohn's model, health related quality of life was found to be negatively affected in GBS and related to physical functioning (Demir & Koseoglu, 2008) and physical disability was found to be associated with psychosocial problems in GBS (Bernsen, de Jager, Kuijer, van der Meche *et al.*, 2010).

1.2 Psychological concepts of potential relevance to the experience of GBS

Psychodynamic principles.

Key indicators of psychic trauma were delineated by Freud in the 1920's and were subsequently added to by Ferenczi (1933) when he added 'betrayal of trust' as an important factor. It has also been hypothesised that experiencing traumatic events can lead to an arousal of annihilation anxieties. In annihilation anxieties, the basic danger involves a threat to psychic survival, experienced as a present menace or as an anticipation of an imminent catastrophe. The experience entails fantasies and/or feelings of helplessness in the face of inner and/or outer dangers against which the person feels he can take no protective or constructive action.

The construct derives from Freud's view of a traumatic situation where the person is faced with a quantity of stimulation that he/she cannot discharge or master, a failure of self-regulation. Derivatives of underlying annihilation anxieties are fears of being overwhelmed,

destroyed, abandoned, mortified, mutilated, suffocated or drowned, of intolerable feeling states, losing mental, physical or bodily control, of going insane, dissolving, being absorbed, invaded, or shattered, of exploding, melting, leaking out, evaporating or fading away (Freud, 1922).

Annihilation experiences and anxieties are universal in early childhood, where psychic dangers are regularly experienced as traumatic. It was considered that these psychodynamic principles may go some way to understanding the anxieties that patients display whilst paralysed with severe GBS as case studies suggest that feelings of vulnerability and fear of being killed are common themes in hallucinations of people with GBS (*e.g.* Cochen, Arnulf, Demeret, Neulat, *et al.*, 2005).

Behavioural principles.

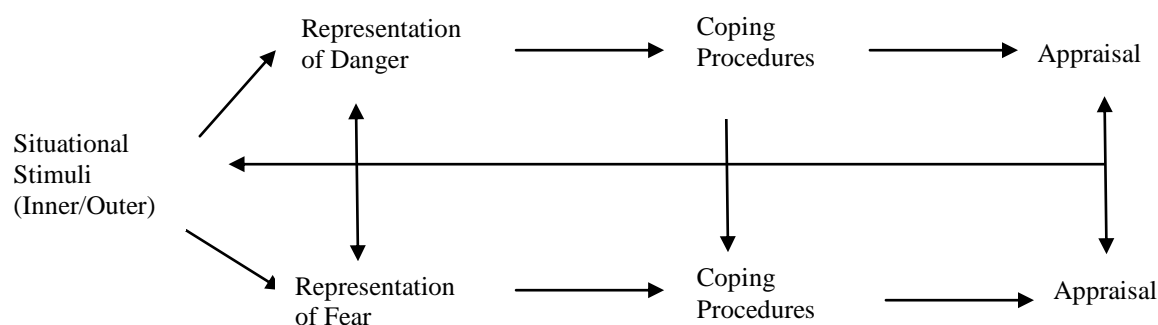
Habituation is an example of non-associative learning in which there is a progressive diminution of behavioural response probability with repetition of a stimulus. Habituation need not be conscious, for example, a short time after a human dresses in clothing, the stimulus that wearing clothes creates disappears from our nervous systems and we become unaware of it. In this way, habituation is used to ignore any continual stimulus, presumably because changes in stimulus level are normally far more important than absolute levels of stimulation. This sort of habituation can occur through neural adaptation in sensory nerves themselves and through negative feedback from the brain to peripheral sensory organs. The current study was interested in the behavioural principle of habituation and in exploring whether patients who are paralysed for any length of time actually become habituated to the experience of paralysis or whether they remain anxious and in shock or whether this anxiety actually increases the longer the paralysis persisted.

Cognitive Principles.

Illness perceptions are the organised cognitive representations or beliefs that individuals have about their illness. These perceptions have been found to be important determinants of behaviour and have been linked to a number of outcomes such as functional recovery and treatment adherence (Weinman, Petrie, Sharpe & Walker, 2000). Recent studies in primary care have highlighted the importance of patients' beliefs and emotional responses to their illness as being important in influencing their satisfaction with healthcare consultation, reassurance following negative medical testing and future healthcare use (Petrie, Jago & Devich, 2007). Research has also found that illness perceptions have a correlation with a number of behaviours in chronic illness, including self management behaviours and quality of life, but there has been very little research undertaken looking at acute illnesses, such as GBS, which are not as clearly linked to personal factors such as diet, exercise and smoking habits as some other chronic conditions.

Important in this area of research is Leventhal's (1970) seminal theoretical work examining how patients evaluate health threats by constructing their own representations or perceptions which influence their patterns of coping. The parallel processing of health threats model which he developed has two major features which are: 1) the parallel or relatively independent processing of the cognitive representation of the danger and of the processing of fear and 2) the separation of the representation of the disease threat from the plan and/or procedure for performing the protective response. This early work raised the possibility that there was parallel processing of health information, since it indicated that the cognitive representation of the threat and the emotional representation could be processed independently.

Figure 2. A Descriptive Model for Classifying and Identifying Variables. The parallel response model (Leventhal, 1970).



These cognitive, emotional and behavioural responses are self regulatory in that they both impinge upon and are influenced by the individuals' self concept. Thus health threats can have major effects on self-perception but appraisals of health threat can be moderated by such factors as personality and age (Skelton and Croyle, 1991).

Jopson and Moss-Morris (2003) used hierarchical multiple regression analysis to demonstrate that illness severity accounted for the majority of the variance in physical and role dysfunction, while patients' illness representations were the most significant predictors of levels of social dysfunction, fatigue, anxiety, depression and self-esteem. In this way, it was considered that the current study could take into account participants' illness perceptions and identify if there was any relationship with anxiety, depression and post traumatic stress symptomatology.

1.3 Conclusion

In summary, these findings would suggest that GBS patients experience a high level of anxiety during the initial stages of GBS and that this decreases over time but that depressive symptoms may increase during later stages of the illness due to the development of subsequent functional difficulties. Illness perceptions that individuals hold may also play an important role in the development of psychological difficulties following an illness.

Three types of psychological model have been briefly reviewed as possible frameworks for the exploration of the traumatic experience of GBS onset. The second study is now presented which is a quantitative study of mental state and illness perceptions in GBS.

1.4 The Current Research Study

Utilising previous literature in the areas of patients' experiences of being nursed on an ICU, illness perception, paralysis and GBS, as well as the interview data generated in Study 1, the research questions that were developed are highlighted below:

- What is the extent of the psychological morbidity for patients at the time of having GBS?
- Do a proportion of people who have had GBS continue to experience anxiety or depression or develop Post Traumatic Stress symptomatology after they have recovered?
- Does the length of time under sedation or on mechanical ventilation correlate with the severity of anxiety, depression or PTS symptoms described?
- Does the length of time since illness impact on levels of anxiety, depression and/or PTS symptoms?
- Do participant's illness perceptions correlate with their experiences of depression, anxiety or PTS symptoms?
- Is there a correlation between people's illness perceptions and their scores on measures of depression or anxiety?

2. Method

2.1. Overall Design of the Study

Links were made with the GBS support group who agreed to publicise the current research study on their website (see Appendix B for the advertising flyer). Participants were asked to complete two questionnaires twice (the HADS and the IPQ-R), once in relation to their present mental state and once in relation to their first memories of the acute GBS episode. Questionnaires contained these instructions and there was also an information sheet detailing these procedures sent out with the questionnaires. Quantitative methodology was utilised to examine the data obtained from questionnaire batteries that were sent out to participants. Received questionnaires were scored and data inputted using SPSS (version 16.0).

2.2 Participants

Individuals who were members of the GBS Support Group provided a potential pool of participants. Participants could download information and questionnaire packs from the website or they could telephone/write/email and request questionnaire packs to be sent to them. The researcher also attended the GBS annual conference and gave out questionnaire packs, which were returned at the end of the day. A correlational analysis and multiple regression were planned for the analysis of the data and therefore the smallest number of participants to allow Study 2 to be viable was 110. $N=110$ was based upon carrying out a multiple regression (with eight predictor variables) with a medium effect size of 0.13 (power = 0.80) (Clark-Carter, 1997). The total number of participants included in the current study was 136. The researcher was unable to obtain information on the response rate due to questionnaires only being sent out to individuals who had already expressed an interest in the study rather than wasting resources and sending packs out to all previous GBS patients who were members of the GBS support group.

Participants were sought on the basis of their diagnosis, which had to have been GBS and not any other strain of the disease. Participants of any age, who had experienced differing levels of severity of GBS, differing recovery status and time since illness were included in the study. Participants were excluded if they described a history of drug or alcohol misuse or if they had had contact with mental health services prior to having GBS. The current study was not able to identify whether patients potentially had any neurological or cognitive deficits.

2.3 Questionnaires utilised

- The Hospital Anxiety and Depression Scale (HADS) (Snaith & Zigmond, 1994)

See Appendix J

- The Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002).

See Appendix K

- The Impact of Events Scale (IES) (Horowitz, Wilner, & Alvarez, 1979).

See Appendix L

- The Dissociative Experiences Scale II (DES II) (Carlson & Putnam, 1993).

See Appendix M

2.4 Procedure

Participants identified themselves to the researcher via email, letter or telephone contact. They were then sent a questionnaire pack which consisted of:

- A demographic questionnaire which asked about age, gender, severity of the illness on a categorical scale, length of time since acute episode to present, length of time on a ventilator, aspects of life that had been impacted on due to GBS as well as other areas the researcher thought important to gain information on (see Appendix F).

- An information sheet detailing which questionnaires were included, how many times to complete them, general completion instructions and contact details of the researcher (see Appendix E).
- Two copies of the Hospital Anxiety and Depression Scale (HADS), one to be completed thinking back to how one felt when they first had GBS and one to be completed thinking about how they felt currently. The instructions that participants received were: ‘Please complete this questionnaire thinking back to the first memories you had around the time of the onset of GBS’ and ‘Please complete this questionnaire thinking about how you feel currently about having had GBS’ (see Appendix G).
- Two copies of the Revised Illness Perceptions Questionnaire (IPQ-R), to be completed twice, once thinking back to how they felt when they first had GBS and one to be completed thinking about how they felt currently. The instructions that participants received were: ‘Please complete this questionnaire thinking back to the first memories you had of the onset of GBS’ and ‘Please complete this questionnaire thinking about how you feel currently about having had GBS’ (see Appendix H).
- The Impact of Events Scale (IES) was included and completed once, participants were asked to think about how having had GBS had impacted upon them in the last seven days (see Appendix I).
- The Dissociative Experiences Scale (DES). Participants were asked to complete this once, thinking about the last seven days and whether they could relate to any of the experiences (see Appendix J).
- A stamped addressed envelope to post the completed questionnaires back to the researcher.

The researcher sent out all the questionnaire packs to participants who expressed an interest. The questionnaires were then scored and the data inputted using the statistical software, SPSS (version 16.0).

3. Results and Analysis

3.1 Data Analysis Strategy

Prior to analysis all data were examined to see whether they met the criteria for parametric statistics. Field (2005) suggests that three criteria are prerequisites for stringent use of parametric tests: homogeneity of variance, normal distribution, and scores measured on an interval scale. The data were checked for homogeneity of variance using Levene's Test, and normal distribution was checked using the Kolmogorov-Smirnov and Shapiro-Wilk tests. Field (2005) advocates that for most statistical tests it is sufficient that the data are *approximately* normally distributed. Although plotting a histogram is a means of visually assessing for normal distribution, it does not provide a robust statistical analysis. For this reason Q-Q normal probability plots were used to back up the histogram results. In this type of plot the data points cluster around a straight line if the sample is normally distributed and represents matching between 'observed' values and 'expected' values. Although calculations and plots were undertaken for all scores, it was not deemed appropriate to present all the raw data in the Appendices. Where the data violated the assumptions for parametric testing, non-parametric tests were carried out. Whilst it is appreciated that these tests are not as powerful as their parametric counterparts, it was not deemed appropriate to use parametric tests.

3.2 Participant demographics

Table 3 shows the breakdown of the sample by gender

Gender	N	%
<i>Male</i>	72	52.9
<i>Female</i>	63	46.3

As can be seen from Table 3 there was an equal split between males and females who took part in the current study.

Table 4 Age and time spent ventilated and/or sedated

Descriptor	N	Minimum	Maximum	Mean	Std. Dev.
Age (years)	127	15	88	63.5	13.93
Time ventilated (months)	67	0.3	10	1.58	1.59
Time sedated (days)	41	1	112	24.94	25.06

Table 4 also highlights that there was a large proportion of respondents who failed to include the information for the time ventilated and time sedated categories which impacted upon further analysis.

Figure 3: Showing the numbers of participants in each group according to the time since the acute onset of their GBS.

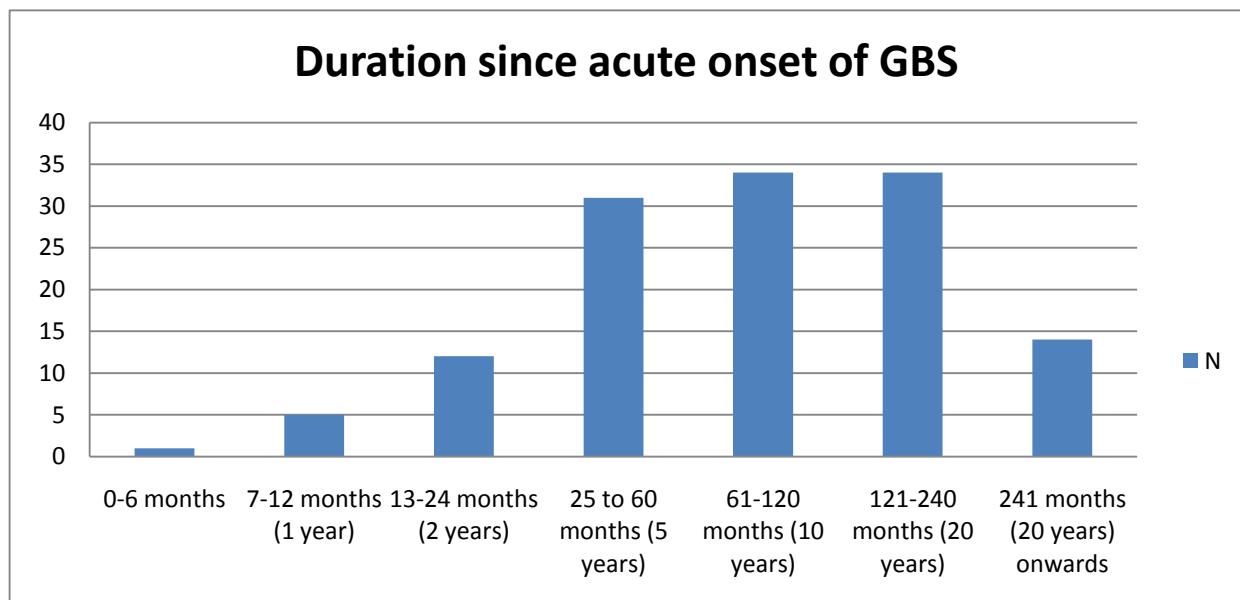


Figure 3 shows the numbers of participants in each group according to how long it has been since their acute onset of GBS. As can be seen, the majority of participants had GBS over 5 years ago, with Table 5 demonstrating that the mean time since illness for this group was 111.51 months (9.25 years).

Table 5: Showing the mean duration since illness onset

N	Min.	Max.	Mean	Std. dev.
132	6	512	111.51	99.673

3.3 Anxiety and Depression at the onset of GBS.

The first research question related to whether a proportion of individuals who suffered from GBS developed anxiety and or depression at the time of their illness. This research question utilised the findings from the HADS anxiety and depression subscales which participants were instructed to complete whilst thinking back to how they were feeling at the onset of the GBS. The HADS also provides an indication of the prevalence of ‘normal’, ‘mild’, ‘moderate’ or ‘severe’ cases of anxiety and depression in this group.

Descriptive statistics were used to identify the numbers of participants whose scores on the anxiety subscale fell within the cut-off ranges as described by the HADS i.e. 0-7 Normal; 8-10 Mild; 11-14 Moderate and 15-21 Severe. During the initial stages of their GBS, n=39 (28.7%) fell within the ‘normal’ range; n=21 (15.4%) scored between 8 and 10, which places them within the ‘mild’ category; n=32 (23.5%) fell within the ‘moderate range’ and n=31 (22.8%) described symptoms consistent with severe anxiety (as described by the HADS).

Figure 4: Showing the scores within cut-off ranges as described by the HADS (anxiety subscale)

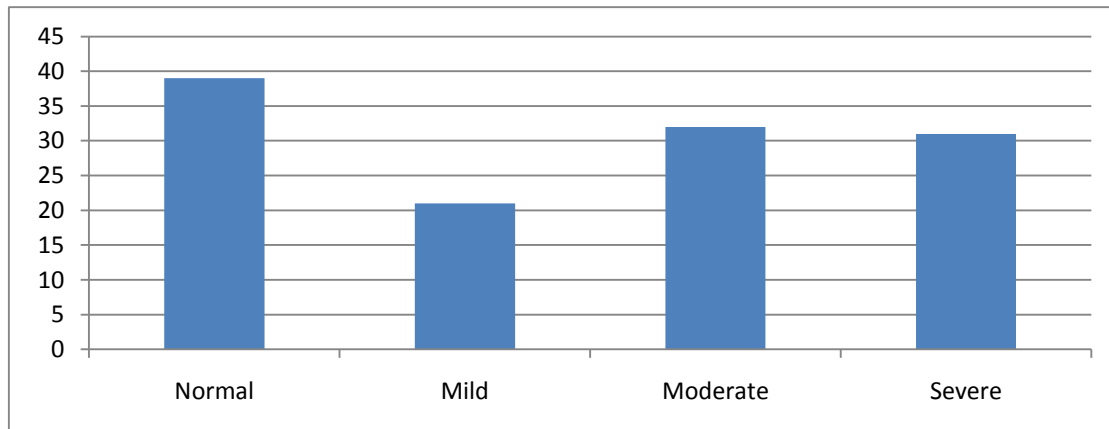


Figure 4 shows the number of participants whose anxiety scores fell within the four cut-off ranges on the HADS during the initial phase of their GBS. As can be seen, just over 60% of the samples' scores were described as mild/moderate or severe and therefore could be described as warranting further clinical input. Thinking back to the onset of GBS, almost a third of participants would not have rated themselves as anxious. There was no significant difference between males and females scores on the HADS subscales either pre or post GBS.

The same procedure was utilised to establish the numbers of individuals who fell into the different cut-off ranges on the HADS depression subscale. Descriptive statistics showed that at the onset of GBS, n=37 (27.2%) participants fell within the 'normal' range; n=15 (11%) fell within the 'mild' range; n=25 (18.4%) fell within the 'moderate' range and n=46 (33.8%) fell within the 'severe' range. Figure 5 shows this breakdown of scores in visual terms.

Figure 5: Showing the scores within cut-off ranges as described by the HADS (depression subscale)

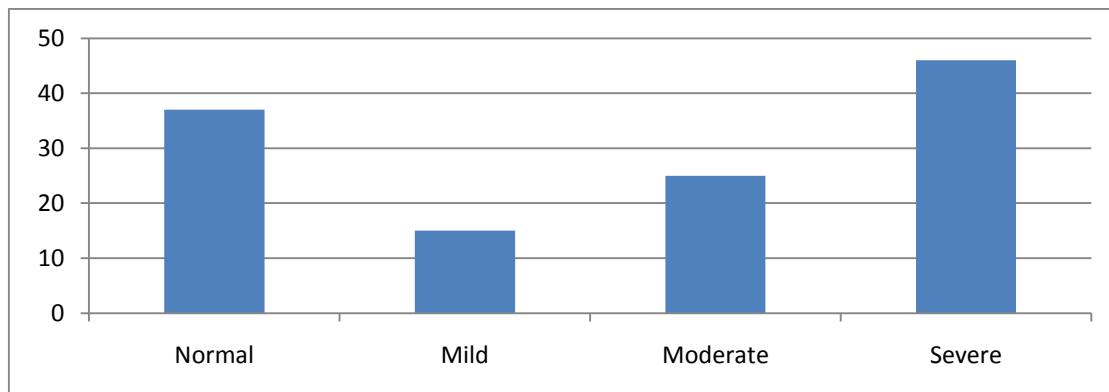


Figure 5 shows the number of participants whose depression scores fell within the four cut-off ranges on the HADS during the initial phase of their GBS. Of note is that almost one third of the sample (63.2%) described between a 'mild' to 'severe' level of depression during the initial stages of having GBS.

Normative data for the HADS were obtained to perform a comparison (Crawford, Henry, Crombie & Taylor, 2001). These norms were collected from 1792 members of the general adult population. When comparing the data from the current study and the normative data using a t-test it was found that the mean score for the anxiety subscale of the HADS at the onset of GBS was significantly different to the normative mean ($t= 12.02$, $df= 1913$, $p<0.0001$). Robust and detailed normative data relating to an ICU, rather than a general population, was recognized to have been a more reliable comparison although could not be sourced from available literature.

The same procedure was used to assess whether the depression scores for the onset of GBS were significantly different from the norms and it was found that they were ($t=25.56$, $df=1913$, $p<0.001$).

3.4 Anxiety, depression and Post Traumatic Stress after recovery from GBS.

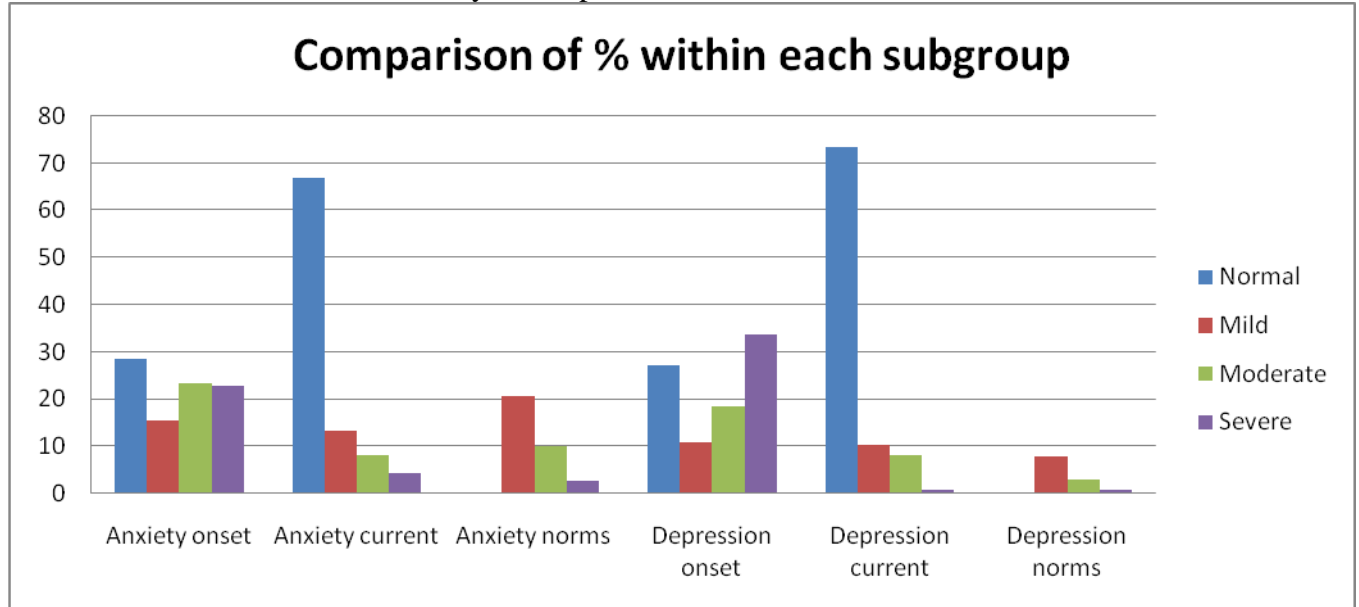
At the onset of GBS, 39 (28.7%) participants' scores on the anxiety scale of the HADS placed them within the normal range (as measured by the HADS) as compared to 91 participants (66.9%) after GBS recovery. On the depression scale, the number of participants who scored within the normal range increased from 37 (27.2%) at the time of onset of GBS to 100 (73.5%) after recovery from GBS. Duration since the onset of GBS did not correlate with any of the HADS scores.

Table 6: Shows the scores pre and post GBS on the HADS subscales (anxiety and depression)

Descriptor	N	Min	Max	Mean	Std. Dev
HADS Anxiety score (at onset)	123	0	21	10.54	5.86
HADS Depression score (at onset)	123	0	21	11.70	6.28
HADS Anxiety score (current)	126	0	18	5.81	4.16
HADS Depression score (current)	126	0	20	4.60	3.66

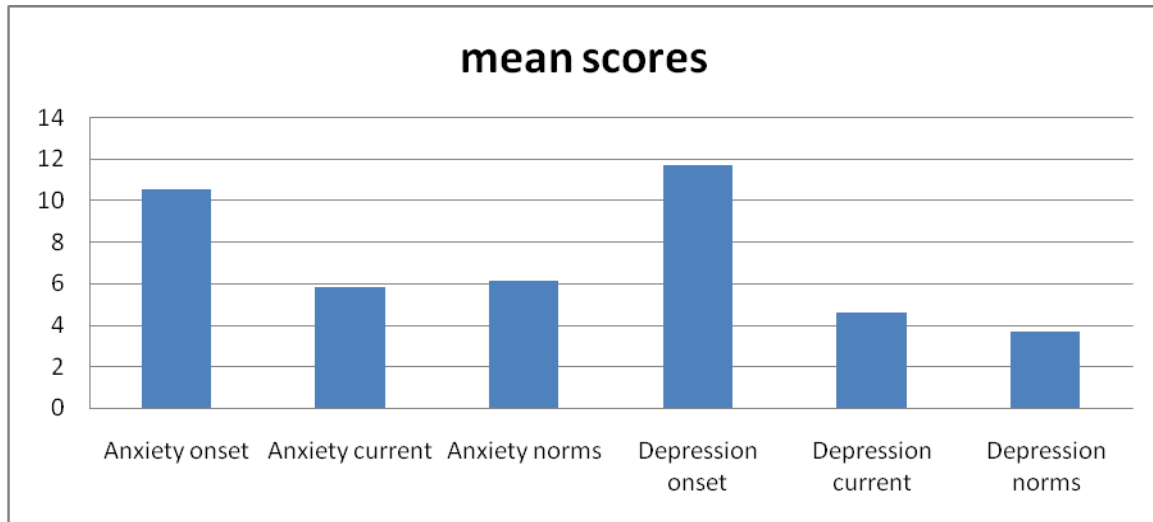
The above table shows the means on both subscales (anxiety and depression). A Wilcoxon Signed Ranks test was carried out as the non-parametric equivalent of a dependent t-test to examine whether there was a significant difference between the at onset and post scores on the anxiety and depression scales of the HADS (anxiety: $z=7.451$, $df=118$, $p<.000$) (depression: $z=8.327$, $df=118$, $p<.000$). The means for both the anxiety and depression subscales were significantly lower when measured after GBS as compared to during the early onset of GBS.

Figure 6: showing a comparison between the percentages obtained from the current study and normative data for the HADS anxiety and depression subscales



Normative data for the HADS were obtained to perform a comparison (Crawford, Henry, Crombie & Taylor, 2001). These norms were collected from 1792 members of the general adult population. On the Anxiety scale the percentages of the total sample classified as mild, moderate or severe using Snaith and Zigmond's (1994) criteria were 20.6, 10.0 and 2.6%, respectively. For the Depression scale, the corresponding percentages were 7.8, 2.9 and 0.7%.

Figure 7 shows the means obtained from the current sample and a comparison with the normative data from Crawford, Henry, Crombie and Taylor (2001).



A t-test was carried out to assess whether the means obtained from the current study were significantly different to the means from the normative sample (Crawford, Henry, Crombie & Taylor, 2001). It was found that the post GBS anxiety scores were not significantly different from the normative data ($t=0.946$, $df=1916$, $p<0.345$) whereas the depression scores were ($t=3.21$, $df=1916$, $p<0.0014$).

Post Traumatic symptomatology was assessed using the IES and the DES both at single time points, asking participants to rate their experiences during the past week.

Table 7: shows the descriptive statistics for the DES scores

N	Min	Max	Mean	SD
126	0	70	6.68	8.32

The DES was utilised to assess for dissociative experiences which can be a symptom of Post Traumatic Stress, it was found that $n=3$ (2.2%) scored as having dissociative experiences warranting further clinical exploration (i.e. scores >30). Another $n=3$ (2.2%) scored between 20 and 29. Therefore 4.4% of people after GBS reported that they were experiencing some degree of dissociative experience (as measured by the DES).

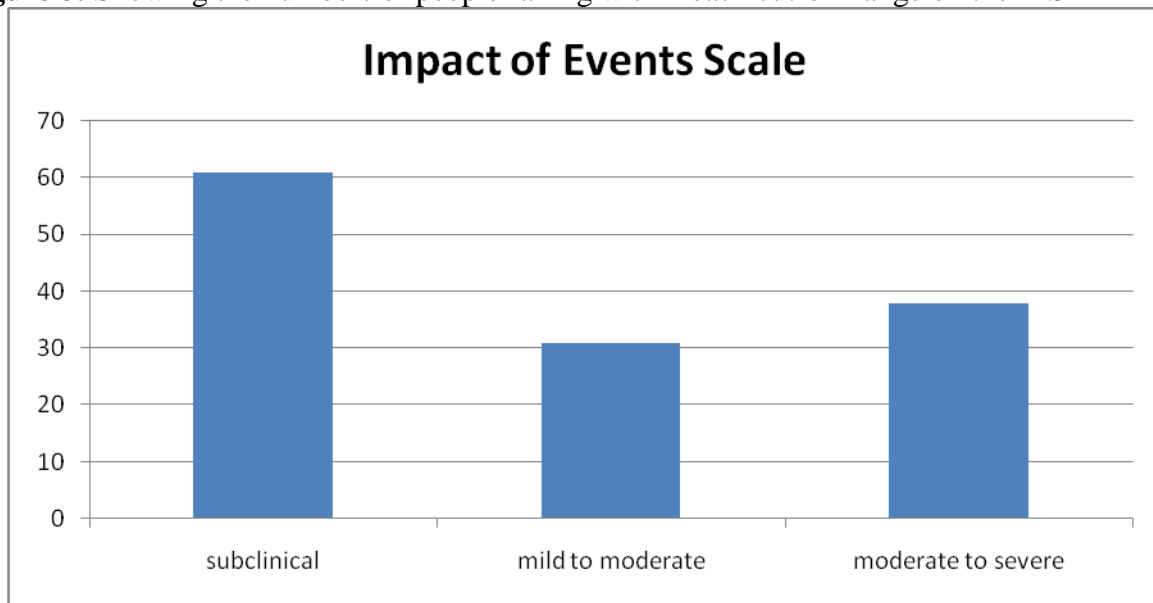
Table 8: showing the means of different diagnostic groups scored on the DES (Ijzendoorn & Schuengel, 1996)

Diagnostic Group	N	M
Anxiety Disorder	468	10.16
Eating Disorder	345	14.51
Personality Disorder	462	16.80
Schizophrenia	63	19.10
Affective Disorder	81	19.43
PTSD	259	32.58
Normal	1578	11.05
Student/Adolescent	5676	14.40
Seizure Disorder	130	8.12
Psychiatric Patient	1302	16.39
War Veteran	62	20.58
Abused	238	27.06
GBS current study	126	6.68

However, when compared to the normative data gained by Ijzendoorn and Schuengel's (1996) meta-analysis of the DES within different clinical settings, it can be seen that the current study produced the lowest mean scores for the DES when compared to the other diagnostic groups, including non-clinical samples. A t-test was carried out using the normative data for the 'normal population' as shown in Table 9 which showed that the mean obtained from the current study was significantly different ($t=5.02$, $df=1582$, $p<0.001$).

On the IES, $n=31$ (22.8%) of the sample fell within the 'mild to moderate' cut-off range which is scores between 9 and 25. The 'moderate to severe' is a range of 26 and above and $n=38$ (27.9 %) of people fell into this category. Therefore 50.7% of the sample continued to experience intrusive thoughts or avoided certain situations related to having had GBS.

Figure 8: Showing the numbers of people falling within each cut-off range on the IES



Sundin and Horowitz (2003) evaluated the IES and included comparison data which the researcher has added the current study data alongside so as to gain a contextual understanding of which clinical population the findings from the current study are most comparable to.

Table 9: Summary of IES normative data (Sundin & Horowitz, 2003)

Type of event	Time Since event	N	Intrusion, m (SD)	Avoidance, m (SD)	Time since event	N	Intrusion, m (SD)	Avoidance, m (SD)
Comparison Groups	17wk	446	2.1 (2.5)	2.5 (4.7)	8 mo	123	1.4 (3.1)	1.7 (3.6)
Illness and Injury	1 wk	48	14.9 (7.7)	9.6 (6.7)	6 wk	44	10.3 (8.6)	8.1 (8.5)
Natural Disaster	16 wk	36	9.2 (8.3)	10.5 (9.2)	16 mo	35	6.4 (7)	6.8 (8.9)
Bereavement	<1 wk	33	17.6 (9.1)	16.7 (9.0)	1 wk	55	15.3 (9)	14.6 (9.7)
Violence and Assault	17 wk	51	17.3 (10.1)	14.3 (9.1)	58 wk	53	9.6 (8.4)	10.4 (9.1)
GBS					111 mo	124	8.8 (8.5)	7.4 (8.6)

Note that although in the current study the IES was carried out on average nine and a quarter years after the onset of GBS, the mean scores for intrusion and avoidance are comparable to the

scores obtained for individuals who had recent experiences of violence and natural disaster suggesting that the experience of GBS continues to be traumatic for some people.

A t-test was carried out to assess whether the findings from the current study were comparable to the normative data shown above. The t-test utilised the normative data from the post event, comparison groups data and found that the means obtained from the current study, for both the intrusion and avoidance scales were significantly different (intrusion: $t=8.96$, $df=245$, $p<0.001$; avoidance: $t=7.32$, $df=245$, $p<0.001$).

3.5 Sedation and mechanical ventilation

Associations between variables pertaining to the length of sedation, length of mechanical ventilation and severity of the illness and measures of anxiety, depression, dissociative experiences and intrusion/avoidance were analysed using a non-parametric correlation test (Spearman Rank Correlation Coefficient). This measure was selected on the basis that some of the measures did not meet the parametric criteria. The main findings as shown in Appendix M were as follows:

- 1) No correlation was found between the severity of the illness and levels of depression/anxiety/dissociation and intrusion/avoidance.
- 2) Length of time ventilated correlated with scores on the DES (.259, $p<0.05$) and IES (.285, $p<0.05$) indicating that the more time patients spent being ventilated, the higher their scores on the DES and IES. Length of sedation did not correlate with any other variables.

Several stepwise multiple regressions (backwards method) were also carried out. This method was used due to the limited literature base on which to base a hypothesis for testing, for which the use of a stepwise multiple regression has been advocated (Menard, 1995). Due to suppressor

effects which are more likely to occur when carrying out a forward multiple regression, it was deemed appropriate to use the backward method to avoid Type II errors. However, the findings from the analyses did not suggest that any of the variables contributed significantly to the model (see Appendix O for outputs).

3.6 Illness perceptions

A Wilcoxon Signed Ranks test was used to assess whether there were significant differences between participants' illness perceptions at the time of onset and post GBS.

Table 10: Showing the Wilcoxon Signed Ranks output for the IPQ subscales

	Identity	Timeline	Consequence	Control	Treatment	Coherence	Cyclical	Emotional
Z	-6.390	-9.051	-5.692	-4.916	-2.146	-5.094	-2.336	-5.374
Sig. (2-tailed)	.000	.000	.000	.000	.032	.000	.020	.000

As can be seen from Table 10, the means of the IPQ pre and post scores are significantly different on all subgroups of the IPQ.

Associations between variables pertaining to participants' illness representations at the time of onset of GBS and measures of anxiety, depression, dissociative experiences and intrusion/avoidance were analysed using a non-parametric correlation test (Spearman Rank Correlation Coefficient). The main findings are shown in Appendix M. Associations between variables pertaining to participants' current illness representations of GBS and measures of anxiety, depression, dissociative experiences and intrusion/avoidance were analysed using a non-parametric correlation test (Spearman Rank Correlation Coefficient). The main findings are also shown in Appendix P.

4. Discussion

The current systematic literature review highlighted the limited research looking at the psychological implication of experiencing GBS on patients. However, from available, relevant literature and the findings from Study 1 it was found that the illness progression itself as well as experiencing mechanical ventilation, hallucinations and being cared for on an ICU were all described as distressing events for patients. Due to the rarity of the condition, patients and staff alike were likely to have had a limited understanding or knowledge around GBS and this also added to feelings of frustration and fear on the part of the patients. The culmination of these experiences was found to lead patients to feel anxious (particularly during onset), depressed (particularly during the recovery phase) and develop symptoms of PTSD (i.e. hypervigilant to symptoms returning/ nightmares or flashbacks of their time in ICU etc.).

It was also found that two separate types of illness onset were evident despite only the rapid onset of GBS being discussed in the medical literature. Both onset types (fast and slow) was found to have caused GBS patients distress, although for differing reasons and highlights an important distinction for healthcare staff to be aware of due to the differing psychological reactions patients may have.

Eisendrath, Mathay, Dunkel, Zimmerman and Layzer (1983) described six psychosocial issues which they found arose repeatedly in their GBS patients. They describe these as: understanding of GBS by the patient and family; communication effectiveness; patient/staff interaction and control; patient state of mind; staff interventions and management of pain and hallucinations. The current Study 1. supports these themes as being important to GBS patients.

Research has suggested that the hallucinations and psychotic experiences that patients are faced with when being nursed on an ICU may be due to a severe deprivation of movement and communication which leads to the blurring of their own internal and externally generated

sensations. Both Weiss, Rastan, Mullges, Wagner, *et al.*, (2002) and Cochen, Arnulf, Demeret, Neulat, *et al.*, (2005) support these observations. These findings have real-life implications for patients who become distressed about having hallucinations and psychotic experiences and these can be normalized for the patient.

4.1 Findings in relation to anxiety and depression

The current study using the HADS at the onset of GBS would suggest that 61.7% and 63.2% of the sample experienced some level of anxiety and depression respectively. Whilst the current analyses do not show whether the same people who experienced higher levels of anxiety/depression continued to suffer from these, there was a significant lowering of the scores on the HADS when people were asked to think about how they felt currently as compared to during the onset of GBS. However, it is important to recognise that a significant percentage of people (25.7% and 19.1%) continued to report that they were experiencing mild to severe levels of anxiety or depression after their recovery from GBS. The means for the HADS anxiety subscale that were obtained, when compared to normative data from Crawford, Henry, Crombie and Taylor (2001) were not significantly different from scores that would be expected from the general adult population, suggesting that the anxiety levels for the majority of participants had fallen to within normal ranges. However, participants' depression scores appeared to remain high, and even after an average of nine and a half years after the onset of GBS, participants' scores remained significantly higher than those obtained from comparison group data (Crawford, Henry, Crombie & Taylor, 2001). These findings would support Lewinsohn's model of depression, and are similar to those obtained by previous studies, which have suggested that depression is commonly reported in GBS patients during the recovery phase of their illness and when physical functioning is impacted upon (Weiss, Rastan, Mullges, Wagner, *et al.*, 2002).

These findings would also suggest that a quarter of the sample continue to experience anxiety which would warrant clinical intervention. Further research is needed to examine this finding in greater detail. These findings are important for healthcare providers as there appears to be a group of people for whom the experience of GBS has left with feelings of anxiety or depression which would warrant further intervention and support. However, it is also important to note that the current study cannot actually conclude that these findings are solely due to experiencing GBS. There may be other factors impacting on these findings, for example, the average age of the sample was 63.5 and the ageing process and life transitions may be important to consider.

Similar to other research, for example, Rattray, Johnston and Wildsmith's (2005) study, the current study did not find that the severity of GBS correlated with any other ratings of anxiety, depression or PTS. Rattray *et al.*, (2005) suggest that emotional outcome after being treated in intensive care is associated with both objective and subjective indicators of the intensive care experience, but not to illness severity.

4.2 Findings in relation to Post Traumatic symptoms

Post Traumatic Stress symptoms were assessed using the IES and the DES. Findings from the current study would suggest that having had GBS has greatly affected individuals, with approximately half of the sample (50.7%) reporting that they continue to be affected by intrusive thoughts about the GBS or that they avoided certain situations that reminded them of the GBS. When comparing the current study with data obtained by Sundin and Horowitz (2003) it appears that the means obtained were comparable to data obtained from individuals who had experienced a natural disaster approximately 16 months previously or violence and assault 58 weeks previously, and were significantly higher than data obtained from comparison groups (Sundin & Horowitz, 2003). These findings would suggest that the current sample reported a significant

degree of traumatisation, in the form of intrusive thoughts or avoidant behaviours. The current study is unable to conclude that these findings are directly linked to GBS and not other life events that participants have experienced and further research is needed to clarify this issue. The current sample were asked for information about previous mental health consultations and no-one reported that they had any previous contact with mental health services. However, it is not known if participants suffered any previous forms of trauma or whether there were co-morbid issues, such as current health problems or subsequent difficulties following the GBS that they were referring to when completing the IES or the DES. Nevertheless, participants were instructed to focus on intrusions and avoidance that related specifically to the onset of the GBS when completing these questionnaires.

In terms of experiencing dissociative symptoms approximately 4.4% of the current sample reported that they had some level of dissociative experiences, which, as measured by the DES, may warrant further intervention. However, these findings were not above the normative data for other traumatized groups, or even for 'normal' or 'student' samples obtained by Ijendoorn and Schuengel (1996). Therefore it may be that a significant minority experience these symptoms even though the group as a whole did not score highly on the DES.

The length of time that participants were ventilated showed a significant relationship with both the DES and the IES and would suggest that patients who were ventilated for a longer period of time developed more difficulties associated with Post Traumatic Stress than other GBS patients. Whilst these findings would suggest that undergoing mechanical ventilation was traumatic for some people and that the longer they were ventilated, the more difficulties they may have, it must be highlighted that not all participants gave this information. This may have been due to a lack of memory for the events or a lack of willingness to think about it. The

duration of ventilation may not be the problem itself, but more an indicator of the duration of paralysis. Rattray, Johnston and Wildsmith (2005) suggest that emotional outcome after being in ICU can be attributed to personal characteristics and length of stay in ICU. This suggests the behavioural habituation hypothesis does not apply since it would predict the opposite relationship.

4.3 Findings in relation to illness perceptions

High scores on the identity, timeline, consequences and cyclical dimensions represent strongly held beliefs about the number of symptoms attributed to the illness, the chronic nature of the condition, the negative consequences of the illness and the cyclical nature of the condition. High scores on the personal control, treatment control and coherence dimensions, represent positive beliefs about the controllability of the illness and a personal understanding of the condition.

Identity.

The current study shows that participants with high scores on the identity subscale, rated at the time of having GBS, also had high scores on ratings of their anxiety and depression levels at the time of having GBS. How they viewed the illness also appeared to correlate with their current anxiety levels. This may be due to limited knowledge regarding GBS at the time of admission and an attitude that the symptoms and the illness itself were very serious. The attributions that participants placed on the symptoms of their GBS when rating it in the present showed that these beliefs maintained a level of anxiety and depression for people, and significantly correlated with their scores on the IES and the DES. This may be due to participants gaining knowledge about what symptoms are attributable to GBS and that they have recovered or are still recovering from a very serious illness.

Timeline (acute/chronic).

At the time of their illness, or just falling ill with GBS, participants who scored higher on this subscale also scored highly on all measures, except the current depression score. This would suggest that participants who viewed their illness as more chronic in nature experienced higher levels of anxiety, depression and PTS at the time of their illness and after their recovery. When rated currently and presumably once patients had been informed about their illness and the nature of the recovery process, the timeline subscale only correlated with their current levels of anxiety and depression scores. This may suggest that the serious nature of the illness caused some participants to feel anxious and depressed even after recovery. It may also have been that participants were unaware at the time of having GBS how long the recovery process would take, and that for some, this was longer than they had anticipated.

Consequences.

High scores on the consequences subscale represents beliefs about the negative consequences attributed to having GBS. In the current study it was found that high scores on this subscale both at the time of having GBS and currently had strong correlations with almost all the psychological measures (excluding the HADS depression score at the onset of GBS). As would be expected, this would suggest that participants who attributed a greater number of negative personal consequences to their illness also rated higher levels of anxiety, depression and PTS.

Personal Control.

The personal control subscale measures positive beliefs about the controllability of GBS. The current research study did not find any significant correlations between this subscale of the IPQ and any other psychological measurement that was used. This may be because participants did not feel they had any great level of personal control or agency in their illness or recovery.

However, it is important to note that whilst participants may not have felt they had control over their illness, this did not appear to contribute to the development of anxiety, depression or PTS.

Treatment Control.

This subscale measures patients' beliefs about the impact that treatment has upon their illness. Many GBS sufferers are not aware of the treatment that they are given due to being sedated or unconscious, and some have reported that they feel too ill to really be interested in their treatment options. The findings from the current study would suggest that participants did not report high levels of treatment control and that this did not impact majorly on their ratings of anxiety, depression or PTS. The current levels of anxiety and depression as well as dissociative symptoms that were rated did correlate with the treatment control subscale and may suggest that participants did not feel that their treatment helped to control their illness or symptoms effectively.

Illness Coherence.

This subscale relates to how much patients understand or comprehend their illness. The current study found that illness coherence did not correlate with any psychological measures, (with the exception of the HADS anxiety score rated currently) and would suggest that making sense of their knowledge about the illness did not impact significantly upon the development of any psychological difficulties either at the time of having GBS or after recovery.

Timeline Cyclical.

The timeline cyclical subscale on the IPQ measures beliefs about whether or not patients view their illness as cyclical in nature. As GBS is not a cyclical condition it was not expected that participants would rate it as such, however the current study showed correlations between

the timeline scale (measured at onset and currently) and some of the psychological measures at different time points.

Emotional Representations.

This subscale on the IPQ measures how having the illness makes people feel emotionally, and it was thought to be one of the more important subscales in terms of its possible impact on the development of psychological difficulties. The current study shows that the emotional representations of the illness were significantly correlated with all of the measures of psychological functioning (with the exception of the HADS depression at onset score).

Previous studies have not utilised the IPQ-R for assessing illness perceptions in acute conditions such as GBS and therefore comparisons are difficult and further research is needed to put these findings into context.

4.4 Methodological Issues

Issues relating to the completion of questionnaires

Participants were asked to complete the HADS and the IPQ-R twice, once thinking back to how they had felt when they first had GBS and one, thinking about how they felt about their GBS now. It was important for the researcher to try to gain some information on the changes in participant's mental states that may have occurred since the onset of GBS. It was not possible to carry out the study prospectively and gain such a large sample, therefore it was decided to ask people to think back to how they were feeling at the onset of GBS. Obviously this design is flawed and methodological issues are discussed further in the discussion and critical appraisal.

There were also difficulties with the wording of these instructions due to the variance in the experience of the onset of GBS for people. Some individuals were able to remember the very first symptoms and have very detailed memory for this time, whereas others became ill very

quickly and may have required sedation, limiting their memory. The GBS support group suggested the wording of the instructions so as to gain information from as many people as possible, although it is not clear as to the period that participants are referring to in their responses. The current study is unable to substantiate whether or not participants fully understood the instructions given that related to the completion of the questionnaires. Every effort was made to make the instructions given clear and understandable. Each questionnaire pack contained a set of instructions and the questionnaires themselves had completion instructions. Indeed, very few participants contacted the researcher to seek clarification on the completion of these questionnaires so it is hoped that individuals found the instructions easy to follow.

It is also not known how easily participants found thinking back to the onset of their GBS, and how valid this was. The average time since illness was just over nine years and so it may have been difficult for participants to remember their feelings around the onset of their illness. It may also be that their current feeling about GBS could have altered their perception of how they felt at that time. Some patients will have been given sedatives at the time of onset and particularly if they required ICU admission and mechanical ventilation, and this will have impaired recall of this period.

Another difficulty was that the HADS and the IPQ-R were not standardised to be used retrospectively and therefore the psychometric assumptions of these tools have been contravened. It is also likely that participants completed the two sets of questionnaires very closely in time, increasing the likelihood of contamination of current mental state with retrospective recall.

Population sampling biases

Whilst obtaining participants from the GBS support group gave access to a large sample size, the underlying difficulty with accessing potential participants in this way is that this sample may be unrepresentative of the GBS population. It is not known whether individuals who felt particularly traumatised by GBS are more likely to be members of the group or are less likely to join due to avoidance of difficult issues.

Obviously a prospective research project would be time-consuming and costly and would require medical access to patients as they were admitted and was not feasible for this project, although this would be a suggestion for further research.

It remains unclear as to whether the more severely traumatized individuals were missed from this study or whether GBS sufferers felt able to disclose their traumatic experiences. The current study aimed to explore these issues and further research could be carried out in order to clarify these. It would be helpful if future research were conducted prospectively and asked about levels of psychological distress throughout the differing phases of the illness rather than at two snap shot points in the illness trajectory which is reliant upon the participant's memory for events and may be biased.

However a significant strength of the study was the use of mixed methods which allowed the quantitative data collection to provide a large amount of useful information highlighted as important during the interviews. Ideally, future research could concentrate on the psychological implication of having GBS and use a prospective research methodology so as to decrease some of these highlighted methodological weaknesses.

4.5 Clinical Implications

There are a number of clinical implications linked with the findings of the current research. References were made by some participants to feelings of frustration at the lack of ability to communicate their needs and that staff could do much to help facilitate their communication. It may be helpful for future work to explore the barriers to effective staff/patient communication and find ways of supporting staff to communicate openly and honestly with their patients.

It is also important to note that a large proportion of the current sample suffered from some degree of anxiety, depression and/or PTS and that these feelings may well have decreased if they had felt able to explore these with staff familiar with GBS or contact was encouraged between former GBS patients and current GBS sufferers. A small yet significant proportion of the current sample continued to experience anxiety, depression and/or PTS and it would appear that they have not received any support regarding these feelings. It remains important for staff to assess the level of distress in their patients and feel confident in speaking to patients openly about this.

4.6 Future research

The current study was exploratory in nature and aimed to gain some information about what having GBS was like for patients and how to improve their experiences on the ICU. Future research could address the methodological issues that have been highlighted as well as add to the knowledge base in this area. One of the difficulties with future research which would need to be overcome is that in order to carry out any prospective work, then the involvement of multiple sites throughout the world would be needed. Future research could address some of the following areas:

- Look in more detail at the occurrence of two separate subgroups in GBS, the rapid onset and the slow onset, and assess the different psychological profiles and outcomes
- Using more diagnostic tools, identify the rates of PTSD among the GBS population
- The influence of medication on hallucinations and other mental state abnormalities
- Coping strategies employed by paralysed patients at different stages of GBS
- The frequency of phantom limb type experiences for patients
- The impact of delivering different types of information at different stages of GBS
- The barriers to effective staff/patient communication in the ICU
- Psychodynamic aspects of hallucinations whilst on an ICU

4.7 Conclusions from both studies

Study 1

Interviews with participants would suggest that people experienced GBS as a rapid and scary illness or as a slow, frustrating progressive illness. The majority of individuals found the experience of being nursed on the ICU a distressing one and that hallucinations and nightmares played a role in this. Participants attributed feelings of loss to their experience of paralysis and expressed that this was a frustrating and difficult time for them and their loved ones. Many people however, felt that they could find something positive to have come from having GBS such as changing their pace of living or commencing voluntary work to help others. Some people however, did find GBS to be a significantly traumatising experience, reporting that not only the GBS itself but also the care that they received left them very fearful that GBS may return.

Study 2

The questionnaire study examined individuals' illness perceptions and mental health after having had GBS. The questionnaire study found that a small proportion of GBS sufferers

continue to experience clinical levels of anxiety, depression and PTS symptoms, even years after their initial diagnosis of GBS, although it would appear that anxiety is more commonly reported during the initial stages of GBS and depression more so during the recovery phase. High levels of intrusive thoughts and avoidant behaviours were also reported which suggests that it remains important for staff to be aware of the levels of distress in their patients and for support to continue to be offered to GBS sufferers.

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Part Three: Critical Appraisal

1. Choice of Research Project

The original idea for the research emerged after I attended a lecture on anaesthesia awareness and became interested in the role that habituation may play for traumatised patients. My research supervisor has previous experience in this area and had carried out research and written articles regarding anaesthesia awareness. He had recently supervised a project looking at memory in anaesthesia awareness (AA) and so had made contacts within the ICU and medical professional arena. However, I was aware that carrying out research in this group would be difficult given the small number of cases in the UK throughout the year. It was during my research into AA that I became aware of Guillain-Barré syndrome and that I was interested in the experiences of having GBS. Again, I was aware that GBS was a very rare condition and was concerned with gaining a large enough sample to be able to generalise my findings.

I had previously gained a MSc in Rehabilitation Psychology, during which time I worked closely with patients who were suffering from different neurological conditions. My final dissertation explored the role of coping strategies on quality of life, pain and disability in Multiple Sclerosis patients. I felt that I would be able to maintain a high level of enthusiasm for the current research project, given that I had enjoyed carrying out similar work previously and because I felt a great deal of empathy for the individuals who suffer with such illnesses.

I did not have personal experience of GBS prior to conducting the study, although have lived with a sibling with severe epilepsy and have always been sensitive to the difficulties associated with living with a debilitating condition. As I had not previously carried out qualitative research, this seemed an ideal opportunity for me to further explore my own beliefs about illness and recovery as well as add to the limited literature on the psychological

implications of being paralysed by GBS. I therefore felt that this would be a worthwhile and satisfying piece of work to undertake.

2. Developments in Methodology and Design

After initially becoming interested in GBS and having briefly looked through literature pertaining to GBS, I became aware that very little literature explored the psychological aspects of having GBS. I therefore decided to attend the GBS annual conference to gain further information and create contacts in the field. It was through obtaining contact with the GBS support group that enabled me to consider carrying out a larger scale piece of research utilising a mixed methodology. I felt that an initial exploratory piece of work would need to be carried out to inform further research. My choice of methodology was therefore one which involved a great deal of thought and deliberation and I eventually chose to use Interpretive Phenomenological Analysis (IPA) over Grounded Theory (GT) or Thematic Analysis (TA) for the initial, exploratory study. On balance IPA seemed more appropriate for the study. The main reasons for this were that IPA seeks to describe rather than explain (Jeffcote, 2005) and this seemed appropriate given there was not a specific research hypothesis that I was exploring. I was aware that grounded theory might have allowed for more scope in terms of considering group psychological processes or development of a group or organisational model. This could have been an interesting idea to consider but it may be that this is more realistic as a next step. There are clear links between TA and GT with the creation and application of codes to the data, however, GT differs from other analytic methods which seek patterns in the data but are theoretically bound. IPA is attached to a phenomenological epistemology (Smith & Osborn, 2003) which gives experience primacy. In contrast to IPA or GT, TA is not wedded to any pre-existing theoretical framework (Braun & Clarke, 2006). Whilst advocates of GT would view the

flexibility involved in TA methods to allow for a wide range of analytical options, I felt that with limited time and constraints on my word count, the potential range of things that could have been said about the data were too broad for this study. However, it may be worthwhile to utilise this method in further qualitative explorations of this area. TA is widely used despite there being no clear agreement about what TA is and how you go about doing it (Attride-Stirling, 2001). I felt, as a novice qualitative researcher, that this would increase the difficulty for me to understand and carry out TA appropriately, whereas much has been written about IPA and clear guidelines exist on how to complete qualitative research in this way. Given that this study was intended as very open and exploratory in nature, I still consider IPA to be the right choice of methodology overall.

Utilising a mixed methodology was something that I was anxious about. I struggled with understanding the different epistemological stances and read many papers which discussed the inappropriateness of conducting mixed methods research. However, I came to the understanding that whilst I was using two different approaches to my research, they were grounded on similar perspectives with respect to ontological and epistemological questions about reality and the construction of knowledge (Lund, 2005) and that the goal of using a mixed methods design was to draw on the strengths of both and minimise the weaknesses of either of these approaches (Johnson & Onwuegbuzie, 2004).

3. Conducting the Research

I had previous experience of applying for ethical approval for research and so was aware of the delays that can occur and the difficulties that this would cause given that I had a limited amount of time in which to complete the current study. I therefore attempted to make my application as transparent as possible, with detail about all aspects of the study. The ethical approval process that I went through was probably made easier because I did not ask to access

NHS patients per se and did not request to interview patients whilst they were still in hospital. For these reasons I did not need to apply for R&D approval either, which also made the process easier and quicker. The GBS support group were invaluable in their help and support throughout this project and they allowed my study to be publicised on their website and passed on contact information to me when appropriate.

4. The Interview Process

I found the research interview difficult to adapt to, and at times I was aware of preventing myself from treating it as a clinical interview. I felt that my limited previous experience of qualitative research may have had an impact upon my confidence in this area. Initially I found myself wanting to explore some themes in more detail and explore the meaning behind statements, as I would normally do during a therapy session. The degree to which I felt this occur appeared to be due to how much I empathised with the research participants and whether I felt that I wanted to help them, in a clinical sense rather than in the capacity of a researcher. After every interview that I conducted I wrote in a reflective journal and I found that this helped me to think about these feelings of transference and to improve my interview technique.

I noticed that the interview process seemed different with some participants and upon reflection, the interviews that I conducted face-to-face with participants felt more comfortable and I seemed to gain more useful information from them. It was difficult to gain a sense of how the participants were feeling when I could not gauge their reactions so easily over the telephone. In hindsight I now believe that it would have been advisable to conduct all the interviews face-to-face to gain a depth of information that I believe may have been missed by carrying out telephone interviews. Upon reflection of the interviews I also became aware of my own feelings towards participants and that this was in part due to picking up on agendas that the participants may have

had that were not necessarily appropriate for the study to mention. For example, one participant had beliefs that her illness was caused by traumatic events which had occurred in her childhood. This interview left me with a feeling that I wanted to help this person and that they needed protecting. I very much felt that some participants felt comfortable taking on the sick role and that GBS was very much a part of their identity. I also felt that some participants enjoyed being interviewed and felt that by telling their story they would be helping others with the condition. I was very aware of this dynamic during interviews and it made me feel a sense of responsibility in making sure I did a good job in representing their views. These issues made me become very aware of the importance of power dynamics within the research interview.

Throughout the research I kept in mind that my own previous experiences might have been impacting upon how I was interpreting the interview material. In order to address this I was careful to ensure that my analysis and interpretations were grounded in what participants said (Smith & Osborn, 2003). It is not really possible to know how it would have been different or similar if I had experienced GBS myself, although I believe that being empathic and curious about participants' stories was very useful within the IPA framework.

5. Engaging with the Research

5.1 Engagement during the analysis

I believe that due to my experiences whilst interviewing participants, I felt very aware of doing a good piece of work and hearing all the views put forward. I believe it was this that enabled me to feel engaged with transcribing the interviews as I felt very much immersed in the stories being told. I enjoyed listening to the interviews, although did find the process of transcribing quite a laborious one, and I gained much from being able to listen to the accounts numerous times.

5.2 Supervision and Reflection

At times I found myself struggling with my own feelings of wanting to help the people I was representing and to produce an informative and useful piece of work for GBS sufferers. I reached a point of accepting that this may have been a parallel process and that I was maybe experiencing something of what it is like to experience GBS and to feel helpless and in need of information. The process of reflection was very helpful in terms of exploring different explanations for what I was experiencing and making some sense of my reactions to the analysis. In addition, keeping notes at each stage of the research process was helpful as a way of reflecting and keeping in mind some of what I was experiencing at the time. Being part of a qualitative group also helped in terms of sharing experiences with others and gaining different perspectives on these experiences.

5.3 Impact of External Events and Personal Experiences on Engagement

Throughout the research I was aware that there were a number of reasons why I might have been struggling to engage with the research more generally. I found that my motivation in general fluctuated in response to current external and internal experiences. During the course of the research I found that my enthusiasm for the topic did alter but that I generally felt engaged and excited by the research throughout. I don't consider that there were any major internal or external events which impacted on my research and I believe that this enabled me to concentrate on transference issues from the interviews in a focused manner.

6. Writing Up

The writing up of the study was a process I found uncomfortable at times. I was very aware that I was writing about real people, and that as such I had a responsibility to do this in a conscientious way. I found it difficult to make bold statements, and at time felt as though I veered towards being over cautious. This was particularly evident in my development of the themes and not feeling comfortable in making too many psychological interpretations.

Another example of my caution was an initial tendency to include a large number of quotes for each theme, as if to confirm that my interpretations were backed up by examples. However this made the results section too lengthy and difficult to read. I then became more selective about my examples, in the hope that it would make it less arduous for the reader. I wondered if this tendency towards caution was an aspect of qualitative research in general or whether it was something specific about my particular study or me as a researcher. I concluded that it was probably a combination of these three factors.

7. Conclusions and Learning points

The experience of carrying out the research has been extremely valuable as a learning opportunity. I feel I have learnt a great deal about myself as a researcher and about the process of carrying out research in general.

7.1 Research Skills

Using a mixed methods design has renewed my enthusiasm for research in general and by completing this piece of research within the context of a doctorate training programme I consider my research skills and knowledge to have developed significantly. As a result I am certain I would not shy away from research opportunities in future and am actively seeking to further my research experience by gaining a job as a newly qualified Clinical Psychologist in an area where

there is scope to carry out research. I would like to further develop the skills I have acquired and consider the contribution to research to be an important role for clinical psychologists. I consider what I have learnt in terms of planning research to be invaluable and I have a much greater awareness of how important it is to plan research thoroughly and consider all aspects of the research in advance.

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