The lived experience of adults with myasthenia gravis: A phenomenological study

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i. Abstract

Myasthenia gravis (MG) is a disorder of the neuromuscular junction (NMJ) that causes fatigue and fluctuating muscle weakness. The physiology of this disease is well understood and there are numerous medically focused articles that outline historical data, randomized controlled trials of treatment options and unusual case studies. There is limited nursing literature about MG; most nurse-led research focuses on fatigue. No published research examines the life experiences of people with MG.

The aim of this study was to examine and understand the lived experiences of adults with MG. An interpretive phenomenological approach has been used that applies the research methodology of van Manen (1990). Seven people living with MG were interviewed and their experiences of the disease recorded. Questions were broadly worded about various topics related to MG, that included diagnosis, symptoms, treatments and coping strategies, and were guided by individual experiences. Thematic analysis revealed that MG affects every aspect of a person’s ‘lifeworld’: their sense of time, body, space and their relationships with others.

The findings of this study highlight three main themes embedded in the data that a person with MG experiences: living with uncertainty, living with weakness and living with change. These experiences have been interpreted and discussed to gain a deep understanding of the meaning of the disease. This study raises awareness of MG for nurses and other health professionals. It provides a unique view of the disease and explores the meaning of MG, from a perspective where a paucity of such literature exists.
I firstly need to acknowledge my wonderful husband Hamish, without whose support and encouragement I could not have undertaken this research project. You have selflessly provided me with the time needed to complete this thesis, I am thankful and eternally grateful to you for this. To our lovely daughters Gretchen, Emily and Johanna: thank you for your understanding and being quiet when I had to study. To my extended family and dear friends: thank you for all of your support. For a working mother this research project was a huge commitment and your acceptance and understanding of this was important to me.

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Finally, I must thank the people who were interviewed for this study. Without these seven people this piece of work would not exist. Each person was welcoming and supportive of me as a researcher, generous with their time and open about their experiences with MG. Their enthusiasm to share so we can learn was a humbling experience.
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Figure 1. The interrelated experiences in adults with myasthenia gravis
v. List of abbreviations

ACh  acetylcholine  
AChRs  acetylcholine receptors  
ALS  amyotrophic lateral sclerosis  
BMI  body mass index  
CHDB  Canterbury District Health Board  
CP  cerebral palsy  
FVC  forced vital capacity  
GBS  Guillain-Barré syndrome  
GP  general practitioner  
IVIG  intravenous immunoglobulin  
MDA  Muscular Dystrophy Association of New Zealand Inc  
MD  muscular dystrophy  
MG  myasthenia gravis  
MND  motor neuron disease  
MS  multiple sclerosis  
NERF  Nursing Education and Research foundation  
NGT  nasogastric tube  
NMJ  neuromuscular junction  
NZ  New Zealand  
SMA  spinal muscular atrophy  
UK  United Kingdom
1. Introduction

This study examines the lived experiences of adults living with myasthenia gravis (MG). The interest in this topic arose when the researcher was working as a registered nurse caring for people with the disease in an acute hospital setting. The researcher had an understanding of the physical science of the disease, but little awareness and insight into the human aspects as experienced by patients themselves. Hence an interpretive phenomenological approach was chosen, with the aim of examining and understanding the lived experiences of people with MG.

Interpretive skills are at the heart of nursing practice (Benner & Wrubel, 1989) and nurses care for people during health and illness, growth and loss as it is experienced or lived. Benner and Wrubel (1989) believe it is important for nurses to see the patient in their context, know what the illness has interrupted and how the patient understands their symptoms. Human experiences are a valuable source of knowledge for nurses (Mackey, 2005). Gaining knowledge of another person’s particular experience through empathic acquaintance is a key component to Carper’s (1978) aesthetic pattern of knowing. The aim of nursing research is to develop knowledge that has depth and diversity (Mackey, 2005) and many nurse theorists and researchers have used a phenomenological approach to their work (Benner, 1984; Benner & Wrubel, 1989; Spichiger, Wallhagen, & Benner, 2005). Nursing involves people and their life experiences therefore phenomenology is a valuable method to address research questions that relate to nursing and nursing practice (Earle, 2010; Speziale & Carpenter, 2007).

The symptoms of generalised MG were first documented in 1672 by Thomas Willis (Hughes, 2009), who described people with excessive muscle weakness that became worse during the day. Hughes (2009) provides evidence that Willis was not only able to recognise MG but also had theories of its causation; remarkably similar to the current physiological understanding of MG. MG was initially called Erb-Goldflam disease and subsequent accounts have been described in medical literature by many 19th Century authors (Hughes, 2009). The term ‘myasthenia gravis’ was first used in 1895 (Ceremuga, Yao, & McCabe, 2002; Conti-Fine, Milani, & Kaminski, 2006; Ropper & Samuels, 2009). ‘Myasthenia’ is derived from the Greek words for muscle and weakness, while ‘gravis’ is the Latin word that means severe (Conti-Fine, et al., 2006).
MG, as a chronic health condition, is a severe and debilitating disease. The disruptions it causes to the physicality of one’s body, to lifestyle, and to one’s self-image make it imperative that gaining understanding and insight into patient experiences is essential. This thesis, although drawing on a small group from a defined geographical area, sets out to address the gap in qualitative representations of the disease. The structure of the thesis is set out below.

The literature review, chapter two, examines a broad range of research and well-established information available about MG, including pathophysiology, diagnostic procedures, treatment options and nursing considerations. There are no published studies that examine the lived experiences of people with MG; therefore the literature detailing neurological conditions with similar features to this disease have been included. The gaps identified in the literature review support the need for this qualitative inquiry into the lived experiences of people with MG.

The methodology, chapter three, builds on the identified phenomenological literature, as it relates to nursing and the lived experience. The philosophical underpinnings and research methods of van Manen (1990) are utilised. The ethical considerations of this study are also outlined in this chapter. To gather personal experiences for this study, seven adults with MG were interviewed on a broad range of topics. The transcribed interviews were sent to the participants to review the content before they were returned to the researcher for data analysis.

Chapter four details the findings and analysis of the personal experiences of MG based on the seven transcripts. The findings have been grouped into four ‘existentials’ developed by van Manen (1990) that represent the ‘lifeworld’ of a phenomenon: ‘lived time’ (temporality), ‘lived body’ (corporeality), ‘lived space’ (spatiality) and ‘lived other’ (relationality). Although each ‘existential’ is presented separately, it is essential that they are considered, as a whole to truly reflect the lived experience of MG. The findings have been illustrated in diagram form, and it is important to note that these findings are the researcher’s interpretation of the experience of MG from the data obtained.

The discussion, chapter five, illuminates the human experience of MG and discusses the three main themes identified from the data: living with uncertainty, living with weakness and living with change. Each of these themes are in turn discussed using
van Manen's four ‘existentials’ to ensure all dimensions of the experience are addressed. The implications for nursing and nursing practice are discussed, and recommendations from this study are outlined. This study started as a blank canvas: each step of the research process has resulted in more shapes and potential configurations as the meaning of the disease took place. Interpretation of the data has resulted in colour flooding onto the canvas. The final result is a metaphysical landscape which has graphically captured meaning and the lived experience of MG.
2. Literature Review

This chapter examines the already established knowledge surrounding MG, in particular patient experiences and associated nursing implications. Most nursing articles outline the pathophysiology of MG and list treatment options (Armstrong & Schumann, 2003; Augustus, 2000; Cunning, 2000; Fischer, 2004; Yee, 2002). There was limited nurse-led inquiry, with the only two research articles located involving fatigue (Grohar-Murray, Becker, Reilly, & Ricci, 1998; Kittiwatanapaisan, Gauthier, Williams, & Oh, 2003) and Yee (2002) briefly discussed MG from a patient’s perspective. As no research articles were found that addressed the lived experiences of people with MG, the lived experiences of people with other types of neurological disease have been included, as symptoms of these conditions are similar to those of MG. This review identifies gaps and several areas for further development and research by nurses in New Zealand (NZ) and supports the research question for this study. There are several sections to this literature review which highlight the complex and intricate nature of this disease. Each section includes information surrounding physical symptoms, diagnostic procedures, treatment options and nursing considerations that set the foundations required to examine the lived experience of MG from a patients perspective. Establishing a pre-understanding of the available literature will enhance the phenomenological meaning of this disease as it is experienced.

2.1 Search strategy

Several health-related databases were searched for this review. There were difficulties sourcing current nursing research, hence medical and allied health studies have been included to further understand MG and how it is experienced. MG has been widely investigated by medical researchers using case studies and historical data. Some case studies were excluded because they focused on unusual presentations and cannot be generalised to every person with MG. Much of the historical data obtained is interesting, but has little value for this current study.

The keywords ‘myasthenia gravis’ and ‘lived experience’ were used when searching electronic databases through the University of Otago library. It was important that 'myasthenia gravis' was in the title, because there is a vast amount of available
literature involving MG and it is sometimes grouped in with other neurological conditions. ‘Myasthenia gravis’ and ‘lived experience’ were searched separately because no articles or research about the lived experiences of people with MG were located: this was also a significant finding of LaDonna (2011). Therefore, phenomenological studies addressing the concept of lived experience were widely searched. Most of these studies focus on nurses’ or caregiver’s experiences, while other patient-focused studies were generally in the areas of oncology, cardiology and mental health. Very few articles examine the lived experiences of illness using van Manen’s (1990) philosophical framework.

Core databases searched included Cumulative Index to Nursing and Allied Health (CINAHL), Ovid full nursing texts, PsychINFO, Medline, PubMed, EMBASE, AMED, Index NZ, Web of Science, TRiP, Medsafe and the Cochrane database. Key articles were frequently obtained in each database. Locating research on the lived experiences involved searching through numerous titles and abstracts to identify if they focused on a phenomenon similar to MG. All articles reviewed were written in English and in full text format. The dates for this literature review were limited from 2000 to 2012, unless they had particular relevance to this study.

To gain an understanding of the pathophysiology, the disease and its implications, four text books were reviewed: Hickey (2009) and Barker (2008) are leading neuroscience nursing authors. Previous editions of Hickey’s (2009) textbook have been cited in much of the nursing literature reviewed. A recent neurology textbook by Ropper and Samuels (2009) was examined, as was Kaminski (2009) who is a neurologist and widely published author in the field of MG. Some autobiographies written by people with MG were also sourced and examined for this literature review. From the individual’s perspective, these books are interesting, but mostly focus on negative health experiences.

After selected abstracts were screened, the full research articles were reviewed to gain an understanding of how the results were obtained and judge overall relevance and robustness. Every article with important concepts relating to patient experiences and nursing was noted. Articles of interest were either printed or photocopied and kept in a reference folder. PDF files were saved and an Endnote library was created to organise references.
Internet searches, using the key words ‘myasthenia gravis’ located informative websites and support groups. There are two main NZ websites: the Neurological Foundation of NZ and the Muscular Dystrophy Association of NZ Inc (MDA). These sites are interesting, but most of the information is based on data retrieved from overseas websites. Although these websites are not considered scholarly work, they do provide background information, resources and support for patients with MG and their families: they also offered links to books written by people with MG, some of which were obtained for this study. With advancing technology, social networking sites are becoming increasingly popular as people with MG share their experiences online. These avenues have not been explored in this study.

Despite a lack of primary nurse-led research about the lived experiences of people with MG, the search strategy was effective because it yielded a vast amount of information that addresses all aspects of MG and has provided a sound literary background for this study.

2.2 Definition

MG is a rare, chronic disease of neuromuscular transmission characterised by fatigue and fluctuating muscle weakness (Hickey, 2009; Lindsay, Bone, & Fuller, 2010). An autoimmune process destroys acetylcholine receptors (AChRs) at the postsynaptic muscle membrane, which results in muscle weakness distal to that synapse (Cavel-Greant, 2008; Hickey, 2009). The main muscles affected are skeletal (Alshekhlee, Miles, Katirji, Preston, & Kaminski, 2009), in particular the voluntary muscles innervated by motor nuclei of the brainstem (Ropper & Samuels, 2009).

2.3 Pathophysiology

Muscle weakness and fatigue are caused by the failure of effective neuromuscular transmission at the postsynaptic membrane (Ceremuga, et al., 2002; Ropper & Samuels, 2009). Ineffective neuromuscular transmission occurs because of the destruction of nicotinic post synaptic AChRs by acetylcholine receptor antibodies (Abbott, 2010; Lindsay, et al., 2010). This results in the decreased strength of muscle contractions and, with repetition, there is less acetylcholine (ACh) available which causes the muscle to
become fatigued (Abbott, 2010; Hickey, 2009). Acetylcholine receptor antibodies are found in up to 90% of people with MG (Cavel-Greant, 2008; Lindsay, et al., 2010) and cause problems in different ways. They can bind to AChRs, blocking access of ACh but not damaging the receptor, or, they can bind to AChRs damaging the receptor which results in it being broken down and absorbed into muscle. Because B-cell auto-antibodies attack the alpha sub unit of the AChR, MG is sometimes referred to as a B-cell mediated disease (Cavel-Greant, 2008).

2.4 Classification

MG can be classified by the above antibody type, gene mutation or change of function (Cavel-Greant, 2008): ocular myasthenia is characterised by ptosis and diplopia, (Kaminski, 2009) bulbar myasthenia is when the disease progresses to cranial nerves causing facial and oropharyngeal muscle weakness, and generalised myasthenia is where the muscles of the limbs, neck, shoulders, hands, diaphragm and abdomen are affected (Fischer, 2004). Lindsay, Bone and Fuller (2010) suggested up to 40% of people with ocular myasthenia will develop generalised myasthenia.

2.5 Presenting symptoms

Signs and symptoms of MG are a result of fluctuating strength in voluntary muscles (Kaminski, 2009). Weakness can be pronounced or subtle and disease severity is based on which muscles are affected (Armstrong & Schumann, 2003). Cavel-Greant (2008) stated that affected muscle groups vary in each person and symptoms can change daily. The symptoms of MG can be grouped into those that affect the cranial nerves (ocular and bulbar) and those that affect the limb and trunk (including respiratory) which is similar to how the disease is classified. Ptosis can be unilateral or bilateral (Barker, 2008) and occurs because the extra ocular muscles are weak (Cavel-Greant, 2008; Cunning, 2000; Hickey, 2009; Ropper & Samuels, 2009). Ptosis can consequentially cause blurred or double vision (Barker, 2008) and these ocular symptoms can occur in up to 90% of people with MG (Costello, 2006; Ropper & Samuels, 2009).

Bulbar weakness can result in facial weakness, dysarthria, dysphonic speech, dysphagia and nasal regurgitation of fluids (Kaminski, 2009; Lindsay, et al., 2010).
Facial weakness can cause difficulty chewing, a reduced gag reflex and sometimes choking on fluids, including saliva (Cavel-Greant, 2008). Weakness of the jaw can cause the mouth to hang open; while weak muscles in the neck can allow a person’s head to droop forwards (Lindsay, et al., 2010). Facial weakness can also produce an expressionless mask-like appearance that makes it difficult for a person to smile, causing a characteristic ‘myasthenic snarl’ (Cavel-Greant, 2008; Lindsay, et al., 2010). Voice may sound nasal and different because of flattening of the nasoloabial fold (Hickey, 2009; Palmieri, 2005). Ropper and Samuels (2009) suggested that the muscles involved with facial expression, mastication, swallowing and speech are affected in up to 80% of patients with the disease. Dysphagia associated with MG can account for weight loss of 5-10kg for a person in the months prior to diagnosis (Kaminski, 2009).

Progression to generalised weakness involves the diaphragm, intercostal and neck muscles which can result in breathlessness and dyspnoea (Cavel-Greant, 2008; Hickey, 2009; Palmieri, 2005). Limb weakness is usually bilateral in the muscles closer to the torso, especially the hips, shoulders, upper arms and legs (Cavel-Greant, 2008). In addition to limb weakness, fatigue is also a symptom of MG (Barker, 2008; Hickey, 2009) which may increase during the day and improve with rest (Armstrong & Schumann, 2003; Cavel-Greant, 2008).

### 2.6 Prevalence

There is great variance in relation to the prevalence rates of MG in the literature. Kaminski (2009) states the range is 0.5-20.4 people per 100 000, which is consistent with other literature reviewed for this study (Armstrong & Schumann, 2003; Cavel-Greant, 2008; Costello, 2006; Cunning, 2000; Hickey, 2009; Lindsay, et al., 2010; Yee, 2002). Barker (2008) and Palmieri (2005) suggested that around 20 per 100 000 people are affected in the United States and similar prevalence rates have been found in Japan, Norway, Sweden and the United Kingdom (UK) (Matsui, et al., 2009). There are no areas of high or low prevalence or areas of disease clusters (Kaminski, 2009). It is unclear from the literature why prevalence rates are so varied. Barker (2008) suggested prevalence rates have increased over recent decades due to better recognition of MG, resulting in earlier diagnosis and treatment of the disease. There is currently no national database of people with MG in NZ. The Ministry of Health in NZ collects diagnosis and ethnicity...
statistics in relation to discharges from public hospitals, however it is unclear if these are individual discharges or patients with multiple admissions, and subsequent discharges from hospital. The neurology department at Christchurch hospital has a database of patients diagnosed with MG.

2.7 Mortality

Historically, there has been a higher incidence of respiratory tract disease as the underlying or contributing cause of death in people with MG (Owe, Daltveit, & Gilhus, 2006; Ropper & Samuels, 2009) and, in recent years mortality rates in people with the disease has reduced from 75% to less than 5%. The introduction of immunosuppressants and improved intensive care has been significant and may be responsible for reduced mortality in this population (Hill & Ben-Shlomo, 2008).

2.8 Gender differences

The literature in this area is conflicting, but there does appear to be differences in the incidence of MG between males and females. Hickey (2009) and Lindsay et al. (2010) suggested MG is more common in women than men, with the peak age of diagnosis for women being between 20 and 30 years and men between 50 and 60 years. Alshekhlee, Miles, Katirji, Preston and Kaminski (2009) reported a higher prevalence of females in hospital admissions and suggest MG is more common in younger females and older men. However, Barker (2008) stated males are now more affected than females, suggesting average age of onset for men is in the seventh and eighth decades. Ropper and Samuels (2009) believed females under the age of 40 years are affected more than males, but in later life, men are affected more than females. Kaminski (2009) maintained MG has a bimodal age distribution in both women and men, but peaks earlier in women. Thymomas¹ are more common in men between the ages of 50 and 60 years (Ropper & Samuels, 2009) and ocular MG occurs more frequently in males (Costello, 2006).

¹ A thymoma is a rare tumour of the thymus gland caused by epithelial neoplasms (Kaminski, 2009).
2.9 Ethnic differences

There is little data on ethnicity in the literature. Augustus (2000) and Barker (2008) noted MG occurs in all ethnic groups. Matsui et al. (2009) found that MG is unrelated to ethnicity, however Kaminski (2009) suggested there is a higher incidence of the disease among African-Americans. In NZ, MG with thymoma occurs more frequently among Māori or Pacific Island people and presents at a younger age in these populations (Fink, Wallis, & Haydock, 2001). In relation to MG, there is no recent ethnicity data available from the NZ Ministry of Health.

2.10 Thymus involvement

The association between MG and thymus abnormalities (thymoma and hyperplasia\(^2\)) is well established in the literature. It is thought that these thymic abnormalities may be responsible for causing the immune attack on the AChRs (Barker, 2008). The thymus is an important gland in the development of the immune system (Ropper & Samuels, 2009; Yee, 2002) and its main function is to produce T-cell lymphocytes (Lindsay, et al., 2010). Cavel-Greant (2008) explains that T-cells stimulate AChR-reactive B-cells, transforming them into plasma cells, which produce AChR antibodies. A thymoma is a rare thymic tumour that can occur in 10-15% of patients with MG (Aarli, Gilhus, Romi, & Skeie, 2009; Armstrong & Schumann, 2003; Barker, 2008; Chaudhuri & Behan, 2009; Costello, 2006; Leddy & Chutkow, 2000; Ropper & Samuels, 2009; Tsinzerging, Lefvert, Matell, & Pirskanen-Matell, 2007; Yee, 2002). Thymomas are derived from epithelial cells of the thymus and are the most common form of anterior mediastinum neoplasm in adults (Clayton, Kathiravel, & Singh, 2007). The presence of a thymoma is an indication for thymectomy (Armstrong & Schumann, 2003). Hyperplasia of the thymus gland can occur in up to 65% of patients with MG (Chaudhuri & Behan, 2009; Costello, 2006; Ropper & Samuels, 2009; Tsinzerging, et al., 2007).

\(^2\)Hyperplasia means the tissue of the thymus has enlarged because extended perivascular spaces have filled with lymphoid tissue (Kaminski, 2009).
2.11 Related disorders

Lambert-Eaton myasthenic syndrome is a disorder related to MG where patients have proximal weakness, especially in the lower limbs, and frequent associated carcinomas (Barker, 2008). Congenital myasthenia gravis syndromes are rare and inherited and involve genetic defects in neuromuscular transmission (Abbott, 2010; Chaudhuri & Behan, 2009). It is important to distinguish these variants from ocular, bulbar and generalised MG because they are often referred to in the literature.

2.12 Older adult considerations

Older adults with neurological disease can have unique needs due to the normal pathophysiology of aging. These can include physical and cognitive limitations, visual and hearing deficits, fatigability, decreased muscle mass and general frailty (Barker, 2008). It has been reported that there is a higher incidence of MG in adults over 65 years of age (Casetta, et al., 2010; Matsui, et al., 2009; Vincent, Clover, Buckley, Evans, & Rothwell, 2003) and may be under-diagnosed in this population. Vincent et al. (2003) believed this may be due to co-existing morbidities older people have that may mask the symptoms of MG, while Matsui et al. (2009) suggested increasing incidence could be the result of the ageing population in general, improvements in diagnostic tests or an increased awareness of MG. Previous under-diagnosis may explain a reported increase of MG in individuals over 50 years of age (Aarli, et al., 2009; Tsinzerling, et al., 2007). Thymoma is more common with late onset patients, as is an increase incidence of bulbar symptoms and progression to more severe disease (Kaminski, 2009).

2.13 Pregnancy considerations

Literature on pregnancy and MG is sparse, but it is generally agreed that pregnancy can unpredictably alter the course of MG (Barker, 2008; Gurjar & Jagia, 2005; Kaminski, 2009). Complete remission, clinical improvement, acute exacerbation and change in symptoms of MG have been documented with pregnancy (Gurjar & Jagia, 2005). Pregnancy does not worsen the long term effects of MG, but it can manifest during pregnancy and post-partum periods (Hoff, Daltveit, & Gilhus, 2007). It is unclear from the literature if MG is hereditary, but Kaminski (2009) suggested that up to a third
of infants can develop neonatal MG\(^3\). Hoff, et al. (2007) found thymectomy may have a protective effect against neonatal MG. While most women can have a successful pregnancy and delivery (Cavel-Greant, 2008), it is important to note that the treatments for maternal MG can affect the foetus (Kaminski, 2009).

2.14 Myasthenic crisis

A myasthenic crisis is a dangerous and potentially fatal complication of MG. This type of crisis involves a sudden onset of severe muscle weakness that can cause respiratory failure leading to the patient requiring intubation and ventilation (Agarwal, Reddy, & Gupta, 2006; Alshekhlee, et al., 2009; Hickey, 2009; Jacob, Viegas, & Hilton-Jones, 2007). Muscle weakness is caused by decreased neuromuscular transmission at the synapse (Vaidya, 2006) and can be caused by a lack of anticholinesterase medication or precipitating factors such as infection, surgery or stress (Augustus, 2000; Barker, 2008; Cavel-Greant, 2008; Hickey, 2009). In addition to these factors, Jacob, Viegas and Hilton-Jones (2007) suggested pregnancy, some medications, electrolyte imbalance and anaemia can cause a crisis. Exacerbation of MG causing respiratory failure can occur in up to 20% of patients (Agarwal, et al., 2006; Jacob, et al., 2007) and is more likely to occur within the first two years after diagnosis (Kaminski, 2009). Myasthenic crisis should be diagnosed and treated promptly and it is important that nurses are able to identify this medical emergency (Chaudhuri & Behan, 2009; Jacob, et al., 2007; Kutzin, 2011). Jacob et al. (2007) recommended nursing care during this time should be confident and reassuring because emotional stress caused by the crisis can worsen the symptoms.

2.15 Cholinergic crisis

A cholinergic crisis can occur because of the toxic effects, or overmedication, of anticholinesterase drugs (Hickey, 2009; Ropper & Samuels, 2009; Yee, 2002). Similar to myasthenic crisis, the symptoms of a cholinergic crisis include worsening muscle weakness, increased sweating, saliva and bronchial secretions, small pupils and respiratory failure (Lindsay, et al., 2010). This type of crisis is rare (Kaminski, 2009;)

\(^3\)Neonatal MG is a temporary variant of MG where antibodies are transferred from a mother to her newborn at birth (Abbott, 2010).
Ropper & Samuels, 2009) and management involves withdrawing cholinesterase inhibitors, supportive care and close monitoring of respiratory function (Jacob, et al., 2007).

2.16 Diagnosis

Diagnosis of MG involves a detailed history and physical examination (Barker, 2008) and the clinical presentation will determine what diagnostic tests are performed (Meriggioli & Sanders, 2005). However, the variable symptoms of MG can pose challenges in the diagnosis (Abbott, 2010). It is important to consider these diagnostic procedures, as they may be significant for a person with MG.

The Tensilon\(^4\) test involves administering edrophonium, a short-acting anticholinesterase drug (Armstrong & Schumann, 2003). Edrophonium works by inhibiting enzyme action, which prevents the breakdown of ACh molecules and therefore improves muscle weakness (Cavel-Greant, 2008; Meriggioli & Sanders, 2005). Edrophonium has a rapid 30 second onset of action and a short five minute duration of action (Hickey, 2009; Vaidya, 2006). The diagnosis is considered positive if there is an improvement in muscle strength in a previously weak muscle (Meriggioli & Sanders, 2005).

Nerve conduction studies involve repetitive nerve stimulation as well as single fibre electromyography. The first involves stimulating a motor nerve repetitively while recording the compound muscle action potential (Meriggioli & Sanders, 2005). An abnormal result is likely to be observed in weak muscles (Armstrong & Schumann, 2003). Single fibre electromyography is a selective recording technique where a needle electrode is used to identify and record action potentials from individual muscle fibres to detect delay or failure of neuromuscular transmission (Barker, 2008; Hickey, 2009).

Immunological tests can also provide specific diagnostic confirmation of MG (Heldal, Owe, Gilhus, & Romi, 2009; Meriggioli & Sanders, 2005). The level of AChR antibodies, for example, is elevated in 80-90% of patients with generalised MG (Cavel-Greant, 2008; Costello, 2006; Hickey, 2009; Ropper & Samuels, 2009; Tsinzerling, et al.,

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\(^4\) Emergency equipment, including atropine, should be available throughout the administration of edrophonium (Woodward & Waterhouse, 2009).
A CT scan of the mediastinum may be ordered to detect the presence of a thymoma (Barker, 2008).

2.17 Treatment options

Because there is no cure, treatment options are aimed at managing the symptoms of MG and can include medication, plasmapheresis\(^5\), intravenous immunoglobulin (IVIG) and thymectomy. Drug management is aimed at minimising the autoimmune response and maximising the amount of ACh available (Davidson, Hale, & Mulligan, 2005). It is important to understand the variety of treatment options and why they are used because they can be significant experiences of MG.

2.17.1 Anticholinesterase drugs

Anticholinesterase drugs are the first line approach for managing the symptoms of MG (Barker, 2008; Hickey, 2009) and are the longest established treatment option (Lindsay, et al., 2010). Anticholinesterase drugs work by inhibiting cholinesterase, the enzyme that breaks down ACh (Lindsay, et al., 2010). Anticholinesterase drugs allow larger amounts of ACh in the synapse for a longer time resulting in more effective nerve transmission (Hickey, 2009; Woodward & Waterhouse, 2009). Pyridostigmine bromide (Mestinon) is the most common anticholinesterase drug used to treat the symptoms of MG (Barker, 2008; Kumar & Kaminski, 2011). Doses are individualised and improvement in muscle weakness can occur within 15-30 minutes after oral administration with the effects lasting up to four hours (Hickey, 2009). The nursing literature recommends administering pyridostigmine before meals to optimise muscle function for chewing and swallowing (Hickey, 2009; Palmieri, 2005; Woodward & Waterhouse, 2009).

2.17.2 Immunosuppressant drugs

Anticholinesterase drugs can improve symptoms in most patients, but some people may require additional immunosuppressive drugs (Conti-Fine, et al., 2006). These are

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\(^5\) Plasmapheresis involves the removal of auto-antibodies from the blood and is sometimes referred to as plasma exchange (Kaminski, 2009).
generally used when patients have inadequate control with pyridostigmine (Armstrong & Schumann, 2003; Hickey, 2009). Prednisone, a corticosteroid, is most commonly used and can provide significant improvement in these patients (Barker, 2008; Kumar & Kaminski, 2011). Although corticosteroids have the desired effect of inhibiting antibody production, they do have a myriad of unwanted effects (Kumar & Kaminski, 2011; Yee, 2002). Barker (2008) suggested that the adverse effects of steroids are often related to the dose and length of time they are used. For example, cyclosporine is an alternative immunosuppressant that inhibits T-helper cells and enhances T-suppressor cells (Armstrong & Schumann, 2003). Barker (2008) stated this drug is often used to help patients reduce prednisone doses but does need careful monitoring to prevent renal toxicity. Azathioprine (Imuran) is another alternative if patients are unable to tolerate prednisone, or if prednisone is contraindicated (Hickey, 2009; Ropper & Samuels, 2009), however it can take several months to work (Barker, 2008). Mycophenolate mofetil can be used in patients who do not respond well to steroids or in those who require extremely high maintenance doses of steroids (Lindsay, et al., 2010). Other immunosuppressant drugs that can be used in the treatment of MG symptoms include Tacrolimus, Cyclophosphamide, Methotrexate and Rituximab (Kumar & Kaminski, 2011).

2.17.3 Plasmapheresis and IVIG

Plasmapheresis is used as an option for patients in myasthenic crisis and prior to thymectomy (Armstrong & Schumann, 2003; Cavel-Greant, 2008; Kaminski, 2009; Lindsay, et al., 2010). The benefits of plasmapheresis can last up to six weeks (Barker, 2008; Cavel-Greant, 2008), but there can be complications and side effects (Jacob, et al., 2007; Kumar & Kaminski, 2011). IVIG is a purified immunoglobulin fraction derived from pools of plasma donors (Cavel-Greant, 2008; Koski & Patterson, 2006) and can also be used as a short-term treatment for worsening symptoms (Augustus, 2000; Barker, 2008; Hickey, 2009; Ropper & Samuels, 2009). There is limited evidence of its effectiveness (Kaminski, 2009), but it is thought IVIG has a suppressive effect on the patient's immune system (Ceremuga, et al., 2002).
2.17.4 Thymectomy

Thymectomy can result in an improvement in patients with generalised MG and may induce remission (Cavel-Greant, 2008; Costello, 2006). It can also reduce the need for immunosuppressant drugs for some people (Leddy & Chutkow, 2000). Thymectomy is performed electively and not during acute exacerbation of symptoms, as the procedure is stressful and can further worsen muscle weakness (Ropper & Samuels, 2009). As previously mentioned, the indication for thymectomy is when thymoma is present or if the benefits of surgery are expected to outweigh the risks in patients with generalised MG (Lindsay, et al., 2010).

2.18 Nursing Considerations

2.18.1 Respiratory

Assessment and management of muscle weakness, respiratory pattern and airway protection are major nursing considerations in a patient with MG (Hickey, 2009). Up to 40% of patients with MG can experience respiratory problems that relate to muscle weakness (Owe, et al., 2006). Rapid, shallow breathing can indicate muscle fatigue (Kaminski, 2009), and weaker respiratory muscles can cause a decrease in lung expansion and affect the ability to cough and clear the airway. Respiratory failure can occur within minutes once breathing muscles are affected during an exacerbation (Cunning, 2000). Prudlo, Koenig, Ermert and Juhász (2007) suggest up to 20% of patients may require mechanical ventilation during the course of the disease. It is important to monitor a patient’s respiratory function, including assessing respiratory rate, oxygen saturation and arterial blood gases, the use of accessory muscles, forced vital capacity (FVC) as well as monitor for signs of aspiration (Woodward & Waterhouse, 2009). FVC rates are important in MG than peak flow, because peak flow is a measurement of airway resistance and people with MG, in respiratory difficulty, do not have narrowed airways (Woodward & Waterhouse, 2009).

Unpredictable deterioration of respiration, including sleep related problems, can occur in patients with MG (Prudlo, Koenig, Ermert, & Juhász, 2007). Patients with disorders of the neuromuscular junction (NMJ) can have respiratory insufficiency which

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6 FVC measures the volume of air that can be exhaled from the lungs after taking a deep inspiratory breath (Woodward & Waterhouse, 2009).
may occur during sleep despite normal daytime pulmonary function (Cavel-Greant, 2008; Happe, 2003). Happe (2003) suggested sleep apnoea can occur in 60-75% of patients and, despite being correlated with body mass index (BMI), believes nocturnal respiratory problems are under-diagnosed in patients with MG. In a large Canadian study, patients with MG that were most at risk of obstructive sleep apnoea were likely to be older males taking corticosteroids and had an increased BMI (Nicolle, et al., 2006).

2.18.2 Cardiac considerations

Owe, Daltveit and Gilhus (2006) stated that unspecific electrocardiogram changes, myocarditis, disorders of rhythm and impaired diastolic filling can be linked to thymoma. Although cardiac involvement in MG is not a significant risk, thymomas can produce a neoplastic invasion and infiltration of the heart and surrounding structures and cause disorders of rhythm (Owe, et al., 2006). Cardiac monitoring is essential during myasthenic crisis (Agarwal, et al., 2006) and certain drugs, for example beta-blockers and anti-convulsants, should be avoided or used with caution in patients with MG (Ceremuga, et al., 2002).

2.18.3 Dysphagia and nutritional considerations

Dysphagia is a presenting symptom in up to 24% of patients with MG (Colton-Hudson, et al., 2002). In a study of 20 MG patients, Colton-Hudson et al. (2002) assessed the accuracy of a bedside assessment in predicting aspiration and the frequency of silent aspiration. Despite a small sample size, seven of these 20 participants aspirated, with four doing so silently (Colton-Hudson, et al., 2002). Although this study found it difficult to draw conclusions about patterns of dysphagia in MG, it does highlight the risks of dysphagia, including aspiration that can lead to pneumonia. Kaminski (2009) recommended the assessment of oropharyngeal muscles for any difficulty in swallowing, choking while eating, wet sounding voice or stridor. Patients with MG may need different forms of nutrition during the course of their illness (Cereda, Beltramolli, Pedrolli, & Costa, 2009) and nutritional supplements should be considered if there is nutrition-related risk.
2.18.4 Fatigue

People living with chronic illness can experience fatigue that is persistent and debilitating (Wilson, Whitehead, & Burrell, 2011). Grohar-Murray, Becker, Reilly and Ricci (1998) suggested fatigue is personal with perceptions based on cultural interpretations that are multidimensional and multi-causal. Fatigue is a symptom often associated with neurological illness and has been reported in people with multiple sclerosis (MS) (Barker-Collo, Cartwright, & Read, 2006; Miller & Jezewski, 2006), motor neuron disease (MND) (McCabe, Roberts, & Firth, 2008), muscular dystrophy (MD) (Boström & Ahlström, 2004; LaDonna, 2011) and cerebral palsy (CP) (Sandström, 2007). As previously mentioned, fatigue is frequently reported in people with MG (Grohar-Murray, et al., 1998), can include mental and physical fatigue (Kaminski, 2009) and have the potential to challenge a person’s psychological well-being.

In a large, nurse-led study Grohar-Murray et al. (1998) surveyed patients with MG and found changing lifestyle, recognising limits and avoiding stress were key cognitive interventions to help combat fatigue, while energy conservation was the main physical intervention to reduce fatigue. Significant differences in the fatigue scores between women and men were consistent with other studies, although the reason for this was unclear (Grohar-Murray, et al., 1998). In a study that supports these findings, Kittiwatanapaisan, Gauthier, Williams and Oh (2003) used questionnaires to survey 67 people with MG and also found the best predictor of fatigue severity was activity restriction. BMI did not correlate to fatigue score, but did correlate with activity restriction (Kittiwatanapaisan, et al., 2003), however 70% of participants were overweight and had additional health problems in this study. Symonette, Watson, Koopman, Nicolle and Doherty (2010) reported patients with MG experienced higher levels of fatigue and muscle strength than the controls, but no difference in muscle fatigue. Again, in this study, all of the patients in the MG group had increased BMI (Symonette, Watson, Koopman, Nicolle, & Doherty, 2010).

2.18.5 Exercise and activity

Emerging literature is now focussing on the benefits and importance of exercise and activity in combating fatigue rather than focussing on the importance of energy conservation and rest (Davidson, et al., 2005). Davidson, Hale and Mulligan (2005) highlight an individual with MG who, after following a prescribed exercise programme,
reported decreased levels of fatigue. Grohar-Murray et al. (1998) found 20% of their participants used low impact aerobic exercise to reduce fatigue. There is very little literature about the effects of MG on occupation, leisure and domestic activities. Grohar-Murray et al. (1998) suggested up to 90% of people with MG change their lifestyle due to their fatigue from MG. Leddy and Chutkow (2000) highlighted the lack of research regarding people with MG and sport, suggested people are restricted by the disease itself, the complications of MG and treatment for the disease. The MG literature suggests a balance between exercise and rest to manage fatigue, with rest to be had predominantly during acute phases.

2.18.6 Pain

Pain is not usually an associated experience of MG (Kaminski, 2009; Ropper & Samuels, 2009), however, due to weakened muscles of the neck and back, some people can experience vague aches and pains caused by supporting the head (Armstrong & Schumann, 2003; Cavel-Greant, 2008; Kaminski, 2009; Ropper & Samuels, 2009).

2.18.7 Psychological Considerations

In general, patients with chronic medical conditions are more likely to be at an increased risk of depression and anxiety (Greenberg, 2007). Most of the literature that focuses on understanding the pathophysiology and treatment options of MG shows there is limited information relating to the psychological aspects of this disease. MG can have a significant impact on quality of life, and Kaminski (2009) believed that mental health can be affected, even in patients with mild forms of the disease. Barker (2008) suggested a patient may look depressed if facial muscles are weak and may appear anxious or confused if there is respiratory insufficiency. Kittiwatanapaisan et al. (2003) found fatigue and depression were correlated, and recommends assessing patients for depression. Chaudhuri and Behan (2009) maintained that psychological support is important for patients with MG, particularly when recovering from a crisis. Writing from personal experience, Yee (2002) suggested nurses should provide a calm environment and positive reinforcement: she believed that supportive family and friends helped her get through difficult times with the disease. There is little other information available about how people cope with their symptoms of MG.
2.18.8 Patient education

Kaminski (2009) believed education is the most important factor in helping people with MG to achieve optimal health and recommended various internet sites where people can obtain resources and join support groups. All the nursing literature reviewed stressed the importance of providing education to patients with MG (Armstrong & Schumann, 2003; Augustus, 2000; Cunning, 2000; Hickey, 2009; Kittiwatanapaisan, et al., 2003; Yee, 2002). Education about the drugs used to treat the symptoms of MG and drugs to avoid was emphasised in most of the nursing literature reviewed, in addition to the signs, symptoms and differences between cholinergic and myasthenic crises.

2.19 Lived experience research

There is limited literature on the lived experiences of people with neurological conditions, especially neuromuscular disorders (LaDonna, 2011). As previously mentioned, there is no published research about the lived experiences of people with MG. For this study, the experiences of people with other neurological conditions with similar symptoms to MG have been explored and include: Guillain-Barré Syndrome (GBS), stroke, MS, motor neuron diseases, MD and CP.

GBS is an acute inflammatory polyneuropathy characterised by motor weakness, flaccid paralysis and areflexia (Hickey, 2009). Like MG, GBS affects people differently with symptoms ranging from mild to severe (Forsberg, Åhlström, & Holmqvist, 2008). Forsberg, Alström and Holmqvist (2008) examined the experiences of people during the onset of illness, diagnosis and subsequent hospital care, identifying a number of themes relating to the initial phase of GBS. Stroke can be either ischemic or haemorrhagic in origin (Hickey, 2009) and, depending on the location within the brain, can produce similar symptoms to MG, including body weakness, visual disturbances and dysphagia (Burton, 2000). Burton (2000) interviewed people living with stroke and identified issues with physical, emotional and social recovery.

Three articles addressed the experiences of people with MS (Barker-Collo, et al., 2006; Courts, Buchanan, & Werstlein, 2004; Miller & Jezewski, 2006). MS is a degenerative, inflammatory neurological disease characterised by demyelination of axons in the brain (Courts, et al., 2004). Visual disturbances, fatigue, sensory and motor symptoms vary in MS and the disease is classified depending on its clinical course.
(Hickey, 2009). Barker-Collo, Cartwright and Read (2006) examined the early experiences of people living with MS: although this research was focussed on psychology perspectives, it was conducted in NZ and used van Manen’s (1990) thematic analysis to identify themes surrounding pre-diagnostic stage, diagnostic experience, reaction to diagnosis and living with MS. Courts, Buchanan and Werstlein (2004) used focus groups to identify four themes related to the lived experiences of people with MS that include the feeling that nobody would listen, symptom devastation, issues around regaining control and being an advocate of lifestyle changes (Courts, et al., 2004). Miller and Jezewski (2006) used a pharmacological viewpoint from which to interview people with relapsing MS and identified themes in relation to choosing treatment, self-management and side effects.

Motor neuron diseases are a group of progressive muscle disorders that destroy motor neurons (Barker, 2008). These diseases include amyotrophic lateral sclerosis (ALS) and spinal muscular atrophy (SMA) and have symptoms that include fatigue and weakness of voluntary muscles, similar to that of MG. Several articles were located that examined the experiences of people living with MND, specifically ALS (Brown & Addington-Hall, 2008; Foley, O’Mahony, & Hardiman, 2007; Hughes, Sinha, Higginson, Down, & Leigh, 2005; King, Duke, & O’Connor, 2009; O’Brien, 2004; Young & McNicoll, 1998) and SMA (Lamb & Peden, 2008). In a UK based study, Brown and Addington-Hall (2007) analysed the narratives of 19 people with various types of MND to identify themes of how people lived and coped with their disease. King, Duke and O’Connor (2009) used a grounded theory approach to explore the experiences of people with ALS/MND and identified a process of dealing with change in this population. Using an occupational therapy perspective, Foley, O’Mahony and Hardiman (2007) examined quality of life issues in people with ALS which produced similar findings to previous studies. O’Brien (2004) investigated the views of people with MND and identified their desire for information. Young and McNicoll (1998) obtained demographic data and interviewed 16 Canadians with advanced ALS and despite a social work focus, found that humour, faith and relationships were significant. Hughes, Sinha, Higginson, Down and Leigh (2005) interviewed 19 people with MND in a UK based qualitative study about living with the disease and their experiences with service providers. This exploratory study found themes leading to adjustment on numerous levels in people with MND and supports existing literature surrounding the psychological effects of chronic disease in
general. Lamb and Peden (2008) found that living with SMA is challenging, constantly changing and identified significant positive themes that included strong relationships, symptom management and an optimistic life view (Lamb & Peden, 2008).

Muscular dystrophy (MD) is the term given to a group of hereditary progressive conditions in which variants affect different muscle groups (Nätterlund, Sjöden, & Ahlström, 2001). MD produces symptoms that include muscle weakness and fatigue (Boström & Ahlström, 2004). Nätterlund et al. (2001) interviewed people with several variants of MD in relation to their illness experience highlighted problems with daily life and identified coping strategies. Boström and Ahlström (2004) interviewed people with MD over a ten year period and found body functioning, mental functioning, activity limitation and restricted participation were the key themes. Cerebral palsy (CP) is a non-progressive disorder resulting from injury when the brain is developing (Sandström, 2007) and people with this condition can experience musculoskeletal problems and fatigue. Although this study had a physiotherapy focus, Sandström (2007) identified themes around perceptions and strategies in relation to living with a disabled body.

As mentioned, allied health disciplines have researched and written about patients experiences: occupational therapy (Foley, et al., 2007), social work (Young & McNicoll, 1998) physiotherapy (Forsberg, et al., 2008; Sandström, 2007) and psychology (Barker-Collo, et al., 2006). It is acknowledged and agreed that there is a lack of literature in relation to some neurological diseases (King, et al., 2009; LaDonna, 2011; Lamb & Peden, 2008; Sandström, 2007). This highlights the importance the contributions of other health disciplines, in addition to nursing, in bringing about an understanding of patient experiences.

Hollyhead (1990) shared some of her thoughts about being an inpatient with the aim of helping her recovery from an exacerbation of MG. She recalled feeling frightened and upset when her condition deteriorated (Hollyhead, 1990). Hollyhead (1990) described herself as ‘depressed’, after having a respiratory arrest, found plasmapheresis ‘traumatic’ and frequently felt ‘shattered’ after treatments. This highlights some of the emotions experienced by a person with MG. Cavel-Greant (2008) included a small section containing comments from people that have MG on a variety of topics including early symptoms, doctors and the diagnostic process, living with MG, hospital care and family.
Some people have published books about their individual experiences with MG (Atkins, 2010; Byars, 2007; Gray, 2011; Gress, 2005; Hill-Putnam, 2010; Smart, 2006). The focus of these publications are stories, journeys and reflections on life events, and they all include specific examples of how they have experienced MG. Although interesting and informative, some detail the battle to get a diagnosis or focus on negative health care experiences. What stands out in this autobiographical literature is that every person experienced an array of emotions because of their MG and developed innovative ways to adapt to their symptoms. Supportive family and friends were important and some reflected on the joy of having children after being unwell (Byars, 2007; Gray, 2011; Gress, 2005; Hill-Putnam, 2010; Smart, 2006). The importance of faith was significant to some who included poetry, inspirational comments and passages from the Bible in their books (Byars, 2007; Gray, 2011; Hill-Putnam, 2010).

2.20 Gaps in the literature

The pathophysiology of MG is well established in the literature and the results of this literature review provide a broad understanding of the aspects of this disease. MG has been widely researched by the medical profession, often with a focus on randomised controlled trials of treatment options, unusual case studies or analysing historical data and trends. There is very little nursing literature available on MG, most articles are not research, but rather, dated summaries from textbooks or medical journals (Armstrong & Schumann, 2003; Augustus, 2000; Cumming, 2000; Fischer, 2004). These articles were interesting, but disappointing from a nursing research perspective, as most merely outlined information that could be accessed from textbooks and websites. Most of these articles describe the disease and outline nursing care of a patient with MG, but lacked academic structure and had few references. Only two nurse-led studies that explored fatigue and MG were located (Grohar-Murray, et al., 1998; Kittiwatanapaisan, et al., 2003). The nursing literature is disappointing and highlights the need for quality nursing research within this specialist area.

In recent years, nurses have embraced research that examines and explores the patient’s experience of illness and disease. However, there is a lack of research about people’s experiences with neurological disease and notably even less about the experiences of MG. A gap in the neuromuscular literature, specifically MG, in relation to
qualitative research has already been established (LaDonna, 2011) and is the reason why research on the lived experiences in other neurological disorders has been included in this review. Yee (2002) provided a short patient perspective on MG that was enlightening, and outlined good information on the medication to avoid, but provided few references. Although dated, Hollyhead (1990) shared an insightful description of her experiences. Little information on coping with MG was located therefore the impact the disease has on everyday life, employment and hobbies is largely unexplored. The literature does not explore cultural and ethnic aspects of MG or alternative medicine and complementary therapies used by patients. Some phenomenological nursing research claimed to have used van Manen’s (1990) methodology, but on closer examination, it was only used for the analysis of data and not related to the four ‘existentials’ he developed.

Finally, there is a lack of NZ research in relation to people living with MG with very little published in recent years. The Ministry of Health in NZ only records patient discharges from publicly funded hospitals, there is no national data base like other countries, for example Norway (Heldal, et al., 2009). The contradictory gender differences highlights the need for consistent data collection not only in NZ, but internationally.

2.21 Summary

Significant issues associated with MG were identified in this review. Presenting symptoms of muscle weakness can be subtle or severe and some patients may have additional difficulties with their thymus gland. There are several tests used to diagnose the disease that usually involve the administration of edrophonium, nerve conduction studies and blood tests. Treatment options usually include taking regular prescribed medication and sometimes medically invasive procedures. Despite an abundance of literature available about MG, several gaps have been identified that support the need for this study. This literature review highlights the lack of information on the lived experiences of people with MG, a lack of nursing research and a lack of NZ research. These voids support the need for nurse-led research that explores the experience of people with MG within the NZ context, which this study addresses.
3. Methodology

This chapter outlines the research aim and design, explores the background of phenomenology and the branches into which it has evolved. It is important to distinguish the difference between phenomenology as a philosophy and phenomenology as a research method. The phenomenological philosophy and research methodology of van Manen (1990) has been examined because it has been used in this study. Phenomenology as it relates to nursing has been discussed and the rationale for using this interpretive approach has been outlined.

3.1 Research Aim

The purpose of this qualitative study was to develop rich, detailed and insightful perspectives from adults living with MG. The patient’s own experiences may help nurses and other health professionals develop a deeper understanding of the human experience of MG. By understanding peoples’ experiences of MG, this study will raise awareness and help nurses and other health professionals plan and provide appropriate care for this unique group of patients. The research question for this study was: What are the lived experiences of people with myasthenia gravis?

3.2 Research Design

An interpretive phenomenological approach developed by van Manen (1990) has been used for this study. Van Manen (1990) stated that any human experience can become the topic of phenomenological inquiry and he developed a modern extension of that espoused by traditional European philosophers which he described as a ‘human science’ approach to researching the lived experience. By using this philosophical research design the aim was to not merely generate a description of MG, but to understand thorough interpretation and identify common themes of the lived experience.
3.3 Rationale for methodology

There is strong evidence that an interpretive phenomenological approach is an appropriate method for investigating a particular unique phenomenon (Holloway & Wheeler, 2010; Lopez & Willis, 2004; Moule & Goodman, 2009; Polit & Beck, 2008; Speziale & Carpenter, 2007; van Manen, 1990). This interpretive phenomenological approach fits well with the discipline of nursing, where understanding unique individuals and their meanings and interactions is crucial to nursing practice (Lopez & Willis, 2004).

The literature review in this study highlighted the vast amount of information that explains the physical science of MG, but it also identified the lack of information about people’s experiences coping with the disease. Polit and Beck (2008) suggested an interpretive approach is especially useful when a phenomenon has been poorly defined or conceptualised. This method is especially useful in understanding the phenomena of health and illness because it seeks to study the person in the situation rather than isolating situation variables (Benner, 1985). This is supported by LaDonna (2011) who maintained a qualitative research approach is a beneficial method to explore the individual experiences of living with a chronic neuromuscular disease.

By using an interpretive phenomenological approach the aim of this study was not just to generate a description of MG but, through data extraction and interpretation to understand and gain insight as to the lived experience in people with MG. For nurses, and other health professionals, it is essential to understand not only the underlying pathophysiology when caring for people with MG, but it is just as important to understand how the disease is experienced. Van Manen (1990) maintained a deeper understanding of meaning is gained from insightful descriptions using this method.

3.4 Phenomenology

Phenomenology is derived from the Greek word ‘phainomenon’ which means appearance (Holloway & Wheeler, 2010). The origins of phenomenology date back to the work of philosopher Immanuel Kant in the 18<sup>th</sup> century (Holloway & Wheeler, 2010; Moule & Goodman, 2009; Speziale & Carpenter, 2007): a phenomenological approach involves exploring and understanding the everyday life experiences of people (Polit & Beck, 2008), within a cultural context (Crotty, 1998) and with the aim of revealing potential meaning and describing the lived experience (Speziale & Carpenter, 2007). As
a philosophy, phenomenology has three main streams: descriptive, interpretive or hermeneutic and existentialist. Some philosophers have developed methods to guide research within these streams.

3.4 Descriptive Phenomenology

Descriptive phenomenology identifies ‘essences’ that best describe the lived experience of a phenomenon (Moule & Goodman, 2009). Edmund Husserl (1859-1938) is considered central to the development of descriptive phenomenology (Holloway & Wheeler, 2010). Husserl maintained that human experiences have value and should be investigated using a scientific approach (Lopez & Willis, 2004). Husserl developed the idea that the researcher should shed all personal knowledge when investigating the essential lived experience of a phenomenon. This is known as phenomenological reduction or bracketing (Holloway & Wheeler, 2010). Husserl’s major concepts of ‘intersubjectivity’ and ‘lifeworld’ (Lebenswelt) have been modified and developed by other philosophers including Giorgi, Colaizzi and Spiegelberg (Speziale & Carpenter, 2007).

3.4.2 Interpretive (Hermeneutic) Phenomenology

Martin Heidegger (1889-1976) was a student and colleague of Husserl. Heidegger was interested in ontological ideas and developed the notion of ‘Dasein’, an explanation of the nature of ‘being’ and ‘existence’ (Holloway & Wheeler, 2010). Heidegger believed the interpretation of experiences helped with understanding (Holloway & Wheeler, 2010) and developed the concept of “phenomenological seeing” (Crotty, 1998, p.96). The term ‘hermeneutics’ is derived from the word Hermes, the name of a Greek god, who is thought to have interpreted messages in ancient times (Lopez & Willis, 2004) and explain the decisions of the gods to humans (Crotty, 1998). Heidegger felt it was important to interpret and understand human experiences rather than to just describe core concepts and essences (Lopez & Willis, 2004; Moule & Goodman, 2009; Polit & Beck, 2008). Heidegger developed interpretation as both a concept and as a methodology, with the aim to seek an understanding of the meaning of ‘Being’ (Mackey, 2005). Interpretivism is an attempt to understand human and social reality by uncovering meaning hidden in the text that is embedded in history and culture.
Other philosophers who have used or modified this approach include Ricoeur and Gadamer (Speziale & Carpenter, 2007).

### 3.4.3 Existentialist Phenomenology

The philosophical concepts of ‘embodiment’ and ‘being-in-the-world’ have been further developed by some philosophers (Speziale & Carpenter, 2007). Jean-Paul Sartre (1905-1980) believed a person’s conscious and behaviour (existence) came before character (essence) (Holloway & Wheeler, 2010). Merleau-Ponty’s (1908-1961) interest was in the creation of a science of human beings (Holloway & Wheeler, 2010) and he developed concepts involving interior and exterior perception (Speziale & Carpenter, 2007).

### 3.5 Van Manen’s philosophy and research methodology

Van Manen (1990) built on the work of Heidegger and Merleau-Ponty, by developing a modern extension of these traditional European methods. Van Manen (1990) advocated a ‘human science’ approach to researching the lived experience and used this term interchangeably with the terms ‘phenomenology’ and ‘hermeneutics’. Van Manen (1990) believed phenomenology is the study of essences and descriptions of meanings as they are lived; lived experience is the explication of phenomena as they present themselves to consciousness. Van Manen (1990) stated the aim of phenomenology is to develop a deeper understanding of the nature or meaning of our everyday experiences and gain insightful descriptions of how the world is experienced. It is important for health professionals to understand how a person’s body is experienced in wellness and illness (van Manen, 1998).

Van Manen (1990) believed phenomenological research was the human scientific study of phenomena, and, in the search for what it means to be human, has developed a research approach for analysing data based on his interpretations. Six methodological themes can be used as an guide when undertaking phenomenological ‘human science’ research (van Manen, 1990). These themes are not necessarily procedural steps, but are aimed at highlighting inventiveness and stimulating insight into a phenomenon. Firstly, it is important to turn to the phenomenon of interest that “commits us to the world” (van
Manen, 1990, p.30). Earle (2010) suggested this is where researchers’ have a responsibility to demonstrate their precise knowledge about a phenomenon. Secondly, it is important to investigate an experience as it is lived rather than conceptualising it (van Manen, 1990). This is where the researcher should become immersed in the phenomenon in order to develop an in-depth understanding of the lived experience (Earle, 2010). The third methodological theme is where van Manen (1990) stressed the importance of reflecting on essential themes which characterise the phenomenon. Earle (2010) suggested this is the primary means that can reveal the essence of an experience and is a thoughtful way to extract essential themes. Next, van Manen (1990) suggested that themes can then be described through the art of writing and rewriting. This is how structure and meaning of an experience can be revealed (Earle, 2010). The fifth methodological step involves the importance of maintaining a strong and orientated approach in relation to the phenomenon (van Manen, 1990). Earle (2010) suggested this is when the researcher should aim for the best possible interpretation of the phenomenon and should ‘externalise’ the experience by crafting a text that is full of meaning. The final methodological theme is balancing the research by using parts and whole, because van Manen (1990) believed research and writing are closely related.

Despite having an education background and focus, the methodological themes of van Manen (1990) can be used within other disciplines, including nursing. This is highlighted in his later work where the ‘human science’ approach is used in a variety of fields including psychology, arts and design, communication technology, religion and health science (van Manen, 2005). As hermeneutic phenomenology is a ‘human science’ that studies people, van Manen (1990) suggests instead of using terminology such as ‘subjects’ or ‘individuals’, the term ‘person’ should be used as it refers to the uniqueness of each human being. Care has been taken to ensure participants are referred to as ‘people’ or ‘person’ in this study.  

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7 Van Manen (1997) has published a second edition of his original book which is identical to the first edition except for an updated preface, so the original text has been referred to in this study.
3.6 Nursing and phenomenology

Benner (1984) has also described nursing as a ‘human science’ with care as its central role. Describing, explaining and predicting phenomena is of special concern to the discipline of nursing (Carper, 1978). Carper (1978) felt understanding health and illness was important to the art of nursing and highlighted the significance of identifying this from patients. This remains relevant today especially due to advances in science, technology and the complexity of the patients nurses care for. Benner (1985) suggested that having understanding of human practices, skills and relationships can promote healing. Interpretive phenomenology has been influential in nursing (Holloway & Wheeler, 2010) and can help to interpret culturally sensitive health knowledge for practice, education, research and policy (Lopez & Willis, 2004).

3.7 Ethical considerations

The selection of a significant topic that has the potential to improve patient care is the first step in creating ethical research (Polit & Beck, 2008). Study supervisors and Canterbury District Health Board (CDHB) neurologists were consulted to ensure all ethical issues were addressed in an appropriate manner. Due to the on-going effects of a natural disaster in the Canterbury region, care and sensitivity was demonstrated when recruiting people for this study. In consultation with the study supervisors, a decision was made not to recruit any more people for this study after February 2011, as it was deemed unethical and inappropriate to continue recruitment at that time.

3.7.1 Informed Consent

The ethical principle of respect for human dignity involves the right to self-determination and the right to full disclosure (Polit & Beck, 2008). These two elements are the basis for informed consent. Each person in this study had a reasonable period of time and the right to decide voluntarily to participate. Each person was aware they could refuse to give information and withdraw from the study at any time. To ensure each person was able to make an informed decision, the primary researcher was responsible for explaining the study over the phone when she was contacted by people interested in participating in this study. The researcher’s responsibilities were outlined, and the risks and potential benefits of the study were stated at this time when verbal
consent was also obtained. Each person agreed to be interviewed in their own home. When meeting face to face the researcher was able to further explain the study and answer questions. Informed consent was voluntary, free from coercion and documented by the researcher and each person on a signed consent form (Appendix G).

The researcher works as a clinical nurse specialist on a neuroscience unit that admits patients with MG. Due to the rare nature of MG and the geographical area, the researcher was involved in the care of two people interviewed and may be involved in future care of the people interviewed. The researcher’s role was clearly explained to each person in the study and they were under no obligation to participate if they felt uncomfortable being interviewed by someone who had nursed them in the past and was connected to a health service they may enter in the future.

3.7.2 Minimisation of Harm

The ethical principle of beneficence involves the right to freedom from harm and the right of protection from exploitation (Polit & Beck, 2008). The people in this study were not subjected to unnecessary risks, harm or discomfort, including physical, emotional, social or financial harm. The need for sensitivity was important because this study involved in-depth exploration into highly personal experiences. Fatigue and length of interview time was potentially a concern which was discussed with each person before the interview commenced. Three people chose to have a support person present during the interview. At the conclusion of the interview each person was thanked and asked if they could provide a pseudonym for their transcript to maintain anonymity. The pseudonyms appearing in this thesis were selected by each person to denote themselves.

3.7.3 Privacy and Confidentiality

The research principle of justice involves research participants having the right to privacy and confidentiality (Polit & Beck, 2008). This principle governs the way personal information is stored and is designed to protect personal information against loss, access, use, modification, or misuse. All attempts to maintain privacy and confidentiality were made during this study. Potential adult participants with a diagnosis of generalised MG, were identified by a neurologist at Christchurch Hospital.
The neurologist was able to inform the researcher if the people were in reasonable health and well enough to be interviewed. Speziale and Carpenter (2007) suggest this purposive method of sampling is effective in selecting people based on their particular knowledge of a phenomenon. Once people with MG were identified, an information pack was sent to them using the last mailing address their neurology clinic letter was sent to.

To ensure privacy and confidentiality, all written material relating to the people interviewed was kept at the researcher’s place of study and electronic data stored on the researcher’s personal computer. The primary researcher and study supervisors were the only people who had access to the raw data for this study. Each person interviewed was sent two copies of their transcript; one to keep for their own reference and the other to check it was a correct account of what they had wanted to share. This was a way of further establishing trustworthiness (Speziale & Carpenter, 2007). Each person had the opportunity to ensure they approved of the data obtained by the researcher. At the completion of this study, all electronic data and written material will be stored in accordance with the University of Otago’s data storage policy. Data will be kept for ten years and the University of Otago will be responsible for its safe keeping.

### 3.7.4 Study approval

Locality approval was obtained by the CDHB in February 2010 (Appendix B) and ethical approval for this study was granted by the Upper South B Regional Ethics Committee in April 2010 (Appendix C). The Ethics committee was sent progress reports in May 2011 and April 2012.

### 3.7.5 Funding

A grant was awarded by the Nursing Education and Research Foundation (NERF) to the researcher in March 2012 (Appendix J).
3.8 Cultural considerations

Cultural consultation and approval with the Research Manager of Māori Health occurred in February 2010 (Appendix A). Māori are a growing population (Robson & Harris, 2007) and it is important to plan effective and appropriate health care now and for the future as the Māori population is on average younger than other New Zealanders. As all research conducted in NZ is relevant to Māori, as Tangata whenua or indigenous people, this research will contribute to efforts to improve health outcomes and reduce inequalities by providing knowledge to Māori and health professionals caring for Māori. The consent form included options for an interpreter in eight languages as per the University of Otago policy (Appendix G). Everyone interviewed understood and spoke English so no interpreters were required for this study. Ethnicity data was collected using the 2006 Census question as per the University of Otago requirements (Appendix H).

3.9 Recruitment

The information pack sent to potential participants included a letter explaining the study (Appendix D), an information sheet (Appendix E), an expression of interest form (Appendix F) and a return stamped self-addressed envelope. Recruitment occurred over a three month period (December 2010 – February 2011). Initially, six information packs were sent, with five people expressing interest in the study. Four of these people were interviewed. A further four information packs were sent, with three people expressing interest and subsequently interviewed. There was potential difficulty in recruiting enough people for this study due to the small number of people with MG on the CDHB Neurology department database. However, people responded very quickly to the information pack that was sent to them and seemed enthusiastic to share their experiences with the researcher. People who volunteer for hermeneutic interviews have “more than a passing interest in the research project” (van Manen, 1990, p.98) and he suggested this is because they care about the topic and research question. Four women and three men were interviewed. The age range was 31-86 years. Five people identified as NZ European, one as Samoan and one as other (English). All had a diagnosis of generalised MG and reported being well enough to participate.
3.10 Interviews

A Sony voice recorder (ICD-UX200F) was used to record each interview. Before commencing the interview, a short recording of the person and researcher talking was used to assess sound clarity. This also gave the person being interviewed a chance to see and hear the voice recorder operate and alleviate any apprehensions they may have had. The researcher conducted a semi-structured in-depth interview guided by what experiences each person chose to share. The Questions for Interview Schedule (Appendix I) was used as a guide and covered a range of topics related to MG that were identified from the literature review. These questions were broadly worded to cover areas including diagnosis, symptoms, treatment and coping strategies. Each person was interviewed once. Interview times ranged from 48 minutes – 1 hour and 47 minutes in duration. People were very open about their experiences with MG. Most people spoke at length about the time before they were diagnosed and were reflective when they spoke, particularly if it had been a number of years since they had first experienced their symptoms.

3.11 Transcripts

After each interview the voice recording was saved, with password protection, on the researcher’s personal computer. All of the interviews were transcribed by the researcher. Six interviews were listened to three times for transcribing and one interview was listened to four times. Transcribing times ranges from 9 hours to 23 hours for each interview. An electronic copy of the transcript was sent to the researcher’s supervisors to check. As previously mentioned, each person was sent two printed copies of their transcript: one to keep and the other to read and check if it was an accurate account of what they wanted to share. Some people chose to omit, alter words or sentences and some added further comments or information to the transcript to clarify what they had said. Four transcripts were returned to the researcher using a stamped self-addressed envelope and one person provided feedback to the researcher by email.
**3.12 Data Analysis**

### 3.12.1 ‘Existentials’

Van Manen (1990) described four ‘existential’ themes that are present in the ‘lifeworlds’ of all human beings and can help guide in the reflection process. These ‘existentials’ have been used as major headings for the findings of this study. ‘Lived time’ (temporality) is subjective time and involves the “temporal way of being in the world” (van Manen, 1990, p.104). ‘Lived body’ (corporeality) refers to the way “we are always bodily in the world” (van Manen, 1990, p.103) and means our physical or bodily presence reveals something about us. ‘Lived space’ (spatiality) is ‘felt’ space and “refers us to the world or landscape in which human beings move and find themselves at home” (van Manen, 1990, p.102). The concept of ‘lived other’ (relationality) involves the lived relations maintained with others in shared interpersonal space (van Manen, 1990). These four ‘existentials’, on a phenomenological level, are considered to be fundamental components to the structure of a person’s ‘lifeworld’. Van Manen (1990) believes while they can be differentiated, they cannot be separated because together they form the detailed unity of the ‘lifeworld’. The ‘existentials’ can provide guidance with phenomenological writing because it enables the researcher to examine the experience of the phenomenon as a whole (Dowling, 2007).

### 3.12.2 Themes

A theme has been defined as “an element which occurs frequently in the text” (van Manen, 1990, p.78). However, it is important to consider how a theme relates to the phenomenon being studied. Van Manen (1990) believed that themes emerge because there is a desire to make sense of something, they can give shape to a concept and can describe the context of a notion. Van Manen (1990) also suggested that themes enable control and allow structure to the process of research and writing.

### 3.12.3 Thematic Analysis

After the transcripts were returned to the researcher formal data analysis commenced. A large amount of data was obtained as the information and stories shared by people were detailed and could have been interpreted in a variety of ways. Thematic
analysis is a systematic approach to interpreting text and is the actual process of recovering themes. Van Manen (1990) suggested that isolating thematic statements can be achieved in three ways: the ‘holistic’ or ‘sententious’ approach, the ‘selective’ or ‘highlighting’ approach and the ‘detailed’ or ‘line-by-line’ approach. In this study, the ‘selective’ or ‘highlighted’ approach was used because the researcher felt this was the best method to seek meaning from the data obtained that would reflect the experiences of people with MG. Using the ‘selective’ or ‘highlighting’ approach involves listening to the interview, while transcribing, and reading the text several times and identifying what statements and phrases that seem essential or revealing about an experience (van Manen, 1990). Each transcript was read through with words and sentences crossed out in pen if they were not useful, irrelevant or contained too much identifying material. Relevant text was analysed, with descriptions identified, highlighted and clustered into categories, which included words, sentences and passages. Benner (1985) suggests interview excerpts, or ‘exemplars’, can be used to present evidence of a theme to the reader. ‘Exemplars’ are salient excerpts characterising common themes or meanings across informants (Crist & Tanner, 2003).

Data analysis was a lengthy process, and care was taken to read and re-read the transcripts, highlighting excerpts and identifying their relevance to and congruency with each of the ‘existentials’. Van Manen (1990) believed ‘human science’ research strives for precision and exactness with data, and stresses the aim of interpretive descriptions is exact fullness and completeness of detail. This relates to van Manen’s (1990) notion that researchers should craft or weave the text, because intricate care must be taken with data.

3.12.4 Seeking Meaning

Van Manen (1990) believed meaning is multi-dimensional and multi-layered, so it can never be defined in a single definition. Meaning involves trying to unearth something ‘telling’, something ‘meaningful’ and something ‘thematic’ in transcripts (van Manen, 1990). Van Manen (2007) further developed Heidegger’s concept of ‘in-being’ and suggests the ‘reward’ of phenomenology are moments of ‘seeing meaning’ or ‘in-seeing’. The main purpose of phenomenological reflection is to grasp the essential meaning of a phenomenon and van Manen (1990) outlined a number of steps to achieve this. These steps have been used in the analysis of data. Lopez and Willis (2004)
suggested that meaning is not always apparent to participants, but that it can be gleaned from the narratives produced by them.

3.12.5 Reflexive writing

Holloway and Wheeler (2010) stated important elements of phenomenological research are reflexive writing and aesthetic presentation. Van Manen (1990) argued that ‘human science’ research is rigorous when it is ‘strong’ and ‘hard’ in a moral, spirited sense and explains that phenomenology is simply the application of ‘logos’ which means language and thoughtfulness to a ‘phenomenon’ which is an aspect of the lived experience. Reflective and thoughtful writing is central to van Manen’s (1990) philosophy and an important part of relaying the lived experience, so the utmost care has been taken to consider this with the written aspects of this study.

3.13 Summary

Interpretive phenomenology has been developed from 20\textsuperscript{th} century European philosophy, in particular the work of Martin Heidegger. The philosophical underpinnings are multifaceted and the methodological applications continue to evolve. Interpretive phenomenology is a systematic study of human experience (van Manen, 1990) that can illuminate unique phenomenon and is particularly useful within the discipline of nursing. The design of this unique study has used the philosophical research methods of van Manen (1990) as a guide. Themes were identified using the ‘selective’ or ‘highlighting’ approach and the findings have been clustered into the four ‘existentials’ that represent the ‘lifeworld’ which are presented in the next chapter.
4. Findings and Analysis

Van Manen (1998) believed that serious illness can impact on a person’s sense of time and priorities, their experience of space, their relations with others and their sense of self and body. This chapter closely examines the findings of this study under four ‘existentials’. Whilst the people in this study all had differing experiences of MG, strong themes emerged that contained embedded meaning and illuminated the lived experience in adults with MG. It became evident during interviewing, transcribing and data analysis, that the emotional aspects of this disease are an integral part of living with MG: these have not been separated and instead are included within each ‘existential’. Throughout this chapter participant experiences have been presented with verbatim excerpts from their transcripts used to emphasise each ‘existential’: namely ‘lived time’, ‘lived body’, ‘lived space’ and ‘lived other’.

‘Lived time’ involved people’s experiences in relation to the concept of ‘time’ and included the sub-categories of ‘past time’, ‘present time’, and ‘future time’. ‘Lived body’ highlighted physical symptoms and their effect a person’s body. This theme involved sub-themes where people talked about experiences with difficulty breathing, swallowing, communicating, visual disturbances, facial and limb weakness, fatigue and the associated psychological effects. ‘Lived space’ explored the space people entered when living with MG and included the sub-categories of ‘restricted space’, ‘improved space’ and ‘home space’. ‘Lived other’ examined the relationships people had with others. This theme involved sub-themes which included family relationships, friendships, interactions with health professionals and spiritual relationships.

Finally, it is significant to note that ‘lived time’, ‘lived body’, ‘lived space’ and ‘lived other’ all interrelate with each other to illuminate the lived experience of MG. As previously mentioned, van Manen (1990) believed these themes can be differentiated but not separated because together they form a detailed unity of the ‘lifeworld’. Three main experiences of MG emerged and were consistent among all of the people interviewed and has been presented in diagram form.
4.1 People interviewed

The seven people interviewed for this study are now introduced. The pseudonyms used were chosen by each person themselves.

John was an 80 year old retired man who lived with his supportive wife. John had several other health concerns and relied heavily on his wife during the interview. He was diagnosed while in hospital for an unrelated surgical procedure. Although sometimes vague, he was able to give insightful, amusing examples to illustrate his experiences of MG, although he did think his symptoms were due to old age.

Beth was an 85 year old retired woman who, despite frequently talked about other topics, provided astute descriptions of her experiences with MG. Beth was in remission from MG after a brief hospital admission, but had on-going problems with fatigue and also thought her symptoms were age-related.

Fred was a 70 year old retired man who lived with his wife and was diagnosed as an outpatient. He had difficulty articulating words during the interview, which he was very conscious of. Fred was sometimes vague about his symptoms and was apologetic during the interview, blaming age for his forgetfulness. He used humour when sharing his experiences of MG.

Sharon was an active 30 year old woman. She had been in remission for a few years following two hospitalisations. Sharon was assertive, well informed and gave comprehensive descriptions of her experiences with MG. She was extremely positive, used humour to illustrate the impact of the disease on her life and finally felt like she had control of her symptoms.

Margaret was a 65 year old married semi-retired woman with adult children. She had been in remission for several years after being admitted to hospital for her MG and had a positive view on life. Margaret had a good understanding of how MG affected her and developed numerous coping strategies to manage her symptoms.

George was a 65 year old man that lived with a supportive wife and teenage children. He had a recent hospital admission for MG and still had on-going difficulty with fatigue and muscle weakness. MG had a profound effect on George’s life, and his mood was also affected. Despite this, he used a lot of hilarity and wit when sharing his unique experiences of MG.
Bunty was an 80 year old widow that lived independently in a rest home. She was an outgoing, positive woman with a strong family support network. She had recently been in hospital because of her MG and continued to experience mild symptoms. Bunty had a good understanding of how MG affects her, but also felt her symptoms were age-related.

The people interviewed for this study were all enthusiastic in sharing their experiences with MG for a variety of reasons. Sharon was so grateful to be diagnosed by a medical student and was willing to ‘help’ making several references to this when being interviewed. Sharon hoped by sharing her experiences she will help people learn. Bunty was eager to be interviewed because she had had such a positive experience while in hospital and wanted to ‘give something back’. George felt talking about his experiences was a chance to ‘unload’ what he felt was the burden of this chronic disease. He sensed it was not fair on his family and friends because MG constantly dominated his conversations with them.

4.2 ‘Lived time’ (temporality)

‘Lived time’, also called ‘temporality’, is subjective time that includes dimensions of past, present and future that shape a person’s ‘landscape’ (van Manen, 1990). ‘Lived time’ has been interpreted as a person with MG reflected on past experiences, current experiences and their thoughts about the future. ‘Past time’ involved the period before diagnosis, where people experienced concern about their symptoms, frustration when misdiagnosed and reassurance when they were diagnosed. ‘Present time’ highlighted the experience of taking regular medication for the treatment of symptoms and the experience of fatigue. ‘Future time’ illustrated the planning involved with MG and the genuine fear of relapses people had. Being in hospital was a significant experience of MG and has been included in ‘lived space’.
4.2.1 Past time

Initial symptoms: “What is happening to me?”

John knew something was not right when he started to lose his voice and had difficulty swallowing when he was in hospital recovering after an operation for an unrelated condition.

“I couldn't swallow. My whole throat system was closing up”.

Bunty reported she lost interest in life prior to her diagnosis, became tearful and isolated herself. She had difficulty eating food and started to lose weight. When her head started to drop she felt frustrated and embarrassed.

“I could not eat anything. I was having difficulty swallowing. At night here by myself I would choke every night”.

She remembered feeling frightened when she had these choking episodes and her solution was to eat more slowly, often taking up to an hour to eat a meal. Bunty also had difficulty with double vision, facial weakness and noticed slight changes in her voice. She likened it to everything in her face collapsing.

“I found that one eye was closing and I could hardly see. I did notice that instead of smiling I grimaced. I couldn't smile, my mouth wouldn't work properly. I did not know what was wrong with me”.

Fred was at a family function and had trouble talking, difficulty chewing and was concerned that people might think he was intoxicated.

“I thought that’s funny, I couldn’t chew properly. I didn’t know what to do”.

Sharon initially experienced body weakness which she ignored, until it became much worse. She remembered her smile was affected at her brother’s birthday party, and her friends and family made comments about her facial weakness. Sharon initially played down her symptoms and blamed tiredness because she was working long hours.

“It started kind of with my smile. I couldn't smile at all and my eyes wouldn't really open fully. It was really, really slow. I'm talking maybe a month and slowly progressed. I left it and then my speech started going as well. I had absolutely no smile, and I couldn't talk properly”.

Beth had mainly ocular symptoms prior to her diagnosis but felt her speech and swallow were “not quite right”. At the time, she was not feeling well and felt “lifeless”.
She could not specifically define what was wrong with her eyes, but noticed her symptoms worsened when she was driving.

“It must have been getting worse, but you are not sort of aware of it. It’s like the left eye feels as though it is dashing over to your right eye. I actually was driving the car holding an eye open and I thought I’ve got to park this car and get a taxi”.

Margaret felt her signs of MG were present for some years, prior to her rapid onset of symptoms. She often played down her symptoms and described herself as “tired”, “lazy”, “overweight” or “unfit”.

“Complete weakness. And my legs were so tired and so heavy. I would go to turn and then I would fall down and then of course I could not get up again. Just to hold things was hard. And then it just very quickly went downhill”.

Benner and Wrubel (1989) suggested that concept of ‘time’ creates a story. This was evident in this study because every person spoke about their past experiences with MG. Each person started talking about their journey with MG from the beginning, which involved them sharing when they first experienced symptoms. They recalled where they were in relation to ‘time’ when they experienced these unusual symptoms that caused worry and concern for them.

Misdiagnosis: “This can’t be a stroke, it must be something else”

Three of the people interviewed had the experience of misdiagnosis. During this time they became frustrated and worried, but also scared because they knew something was not right. Sharon was originally diagnosed with Bell’s palsy, was told to wait and her symptoms would resolve.

“So, I left it for a week and it got substantially worse. I could not put on socks and I couldn't dress myself”.

When Sharon’s symptoms did not get better she went to see another doctor, who told her she had Bell’s palsy on both sides of her face. To Sharon’s relief, the doctor sent her to the hospital where she was eventually diagnosed. Fred had on-going visual problems and facial weakness that became worse during the day. When he saw his doctor he was diagnosed as having had a stroke. When his symptoms became worse, he returned to his doctor who told him that he’d had another stroke. However, Fred could not understand why he would wake up in the morning symptom free, and by lunch time
had developed weakness and double vision. Fred arranged to see a specialist who diagnosed him with MG.

“I didn’t want to let it go any further”.

Bunty’s family thought she was depressed. Her doctor arranged for her to attend outpatient treatment sessions for a few months to see if she would feel better. Bunty felt this was actually a positive experience because the strategies she learned there, in particular relaxation and breathing exercises, helped her when she was subsequently diagnosed with MG. Misdiagnosis can occur in patients with MG (Kaminski, 2009). Sharon, Fred and Bunty all experienced an extended period of uncertainty and worry prior to being accurately diagnosed.

**Diagnosis: “It was he who picked it, he put all those symptoms together”**

Beth, Margaret, George, and eventually Fred, were promptly diagnosed with MG. Margaret was diagnosed soon after a rapid onset of symptoms.

“So I went to the doctor and fortunately he had seen it a couple of times before, so within half an hour I was in hospital”.

She felt reassured being in hospital and relieved when nerve conduction studies explained her symptoms.

“Interesting, because I could see it. Well there’s your answer. That’s why I am doing it. It didn’t give me what it was but you could see why. Because some parts were completely blank”.

Fred described feeling very reassured when the specialist diagnosed him immediately after having the Tensilon test (see 2.16). He was given a prescription for Mestinon (see 2.17.1) and felt his symptoms improved within a week. Beth also recalled having the Tensilon test prior to being diagnosed.

“And then it went in and I could count to ten properly. And that was the test. It was like a miracle. It really was. When you couldn’t speak properly and then you could”.

Diagnosis can profoundly change a person’s life and van Manen (2005) likened the experience of diagnosis to a puzzle being solved because it provided a sense of certainty. In this study, diagnosis was seen as a positive experience that explained symptoms and alleviated fear. After diagnosis people felt reassured because they had a
genuine answer for what they were experiencing, but also relieved they did not have other neurological diseases, specifically MS or MND.

4.2.2 Present time

Medication: “I counted twenty pills a day!”

Sharon reported she took a long time to get used to all her medication because there were not only steroids, but a lot of “others”. John, Beth and Fred talked about their increased need for medication and were overwhelmed by the amount and frequency of tablets they had to take. All related their set ‘medication time’ to when they ate a meal. Bunty reflected positively on her ability to adjust her dose of Mestinon.

“Mestinon is good, I think. It is a good one. I don't mind. I take that four times a day and I can take up to six if I am feeling a little bit in my eyes or I am over tired. I keep a chart and I tick it off every time I take it. And now I get them in a bubble, delivered weekly and I have to take those regularly”.

Margaret took Mestinon half an hour before getting out of bed each morning. George spoke about having control of his medication for a disease he has little control over.

“I am very concerned about my dosages. I look after my own drugs so that I know what's going on”.

Taking medication was a part of the lived experience of MG. Interestingly, most people had a structured daily pattern for taking their medication. The need for regular medication was ritualistic and built into everyday routines: ‘time’ was set aside for taking medication. For some of the people interviewed, there was often little choice in taking regular daily medication, meaning limited control. However, some people were given the option by their physician to take an extra dose of Mestinon if they feel their symptoms became worse on any particular day. Bunty embraced this as it gave her some control over how she managed her disease. Fred, on the other hand, was determined not to take any extra medication because he viewed this as “defeat”. George went to great lengths to document everything in relation to his MG when he was discharged from hospital, which supported Benner and Wrubel’s (1989) finding that self-monitoring and medications are part of the everyday life experience with chronic illness.
Fatigue: “I have to have my sleep in the afternoon”

John described extreme tiredness, even stating his “eyes get tired”. He generally slept more, needed an afternoon sleep and sometimes fell asleep before he was supposed to go to bed in the evenings. He regularly needed to rest during the day.

“It comes right after a while. Half an hour or something like that”.

Bunty was also troubled by fatigue. She made herself rest every afternoon and always went to bed early. Beth was affected by tiredness and regularly fell asleep in her armchair during the day.

“I do drop off to sleep quite often and it takes me ages to wake up. (Laughs). The doctor said the falling asleep and that was your age. Granted, but to me, it’s not naturally me. It’s not in my makeup”.

George continued to battle fatigue.

“I mean I collapse and I am useless. The things I do, I try to do the laundry and I try to empty the dishwasher and sometimes clean up the stove. And that’s about it. And I can watch one programme and I can do two or three emails and that's it. I’m stuffed for another hour. I have to lie down. I don’t know what to do. I lie there. I mean, the best thing I can do is lie there. Lie on my back with my eyes closed wearing pair of sunglasses during the day. That way I am resting the eyes to the maximum.”

Sharon occasionally had what she described were “down days”. She did not sleep during the day, but said she would lie down and watch television. Margaret was unsure about her fatigue, but was aware that repetitive work made her feel tired quickly.

“I tend to have times during the day that I will sit down for five minutes before I start that, but I don’t know if that is just the symptoms or whether that’s just me. I do a couple of hours gardening and I come in and will sit down for five”.

Varying degrees of fluctuating fatigue was experienced by all of the people interviewed in this study. Fatigue was debilitating and invaded a person’s sense of ‘time’. Most people had a good understanding of their fatigue and talked about how it affected them on a daily basis. All identified that they knew when they needed to rest and built in allocated ‘rest time’ into their everyday routines. John and George were visibly fatigued during their interviews, but insisted that they continue as they both felt it was important for their stories to be recorded. Every person talked about daily strategies to manage fatigue. Although this is a coping strategy and more situated in ‘lived space’,
it was clear that the severity of fatigue was particular to each individual, was experienced daily and effected people in different ways.

4.2.3 Future time

Unknown: “I just don’t want to go backwards”

The people interviewed spoke largely about their past and present experiences of MG and did not discuss the future in depth. In this study ‘future time’ involved people planning for the future and talking about their fear of relapse or their condition worsening. Bunty shared how she was going to plan her weekend.

“Well I am tired now, today, because I have had two late nights. But I am resting up all weekend. I've got nothing on tomorrow apart from exercises and I've got all weekend to do nothing and I will probably have a lot of rests”.

Sharon would at some stage like to start a family.

“And the only time I think that we will go back and really spend time with (neurologist) is when I get pregnant.”

George was scared that his disease will worsen.

“With myasthenia gravis you don’t know what could happen, what the hell is around the corner”.

Bunty occasionally developed neck weakness and tired eyes. She knew she needed to be careful not to get over tired when this occurred and had concerns about becoming unwell again.

“They're the two things that worry me a bit”.

Margaret said she often found it frustrating when she had “no strength”. She admitted she was often over-cautious and tried not to “over-do” things because she did not want her symptoms to get worse.

“It worries me that relapse. I don’t know how common it is. I don’t like the thought of going backwards. But I am aware that it is every possibility. Because you live with this fear. Lapses”.

It is understandable to note that for some people who had experienced severe muscle weakness and breathing difficulties, the thought of having a relapse in the future
was frightening for them: this was an element of the unknown and uncertainty associated with ‘future time’.

The word ‘time’ can be interpreted in many ways and is used in a variety of contexts within the English language: it can be associated with a particular event in a person’s life. All the people interviewed vividly recalled the ‘time’ they first started experiencing unusual symptoms, and their eventual diagnosis was in ‘the past’. Structured ‘time’ was built into daily life to ensure time for medication and rest periods. ‘Future time’ was experienced as detailed planning for some, but also an element of uncertainty or unknown in relation to the fear of disease progression.

The concept of ‘time’ can be used in relation to a clock or watch, where a person can pinpoint time measured in seconds, minutes or hours. When referring to the onset of symptoms, the people in this study used descriptions of ‘time’, either hours, days, weeks or months, when sharing an experience. People also used verbs that described ‘time’ during their interviews, in particular the length of ‘time’ taken to do an activity. Sharon, George and Bunty all talked about how long it took to eat a meal. Sharon and Margaret recalled symptoms developing slowly, while George remembered how quickly his breathing deteriorated and Beth was astounded at how rapid the Tensilon test was.

People’s perception of ‘time’ was individual. Sharon and Bunty kept a record of events during their hospital experiences in a diary. Benner and Wrubel (1989) stated symptoms like weakness and fatigue can shape a person’s sense of ‘time’, meaning people can become more aware of their symptoms and spend a lot of time thinking about them. Each interview was itself just a snapshot of ‘time’ and reflected where each person was in their own ‘time’ on the day they were interviewed. The temporal dimensions of ‘lived time’ are one aspect of MG and it is important to consider the other ‘existentials’ developed by van Manen (1990) to understand the meaning of the lived experience of MG.

4.3 ‘Lived body’ (corporeality)

Van Manen (1990) also referred to ‘lived body’ as ‘corporeality’. Every person has a physical or bodily presence that enables them to see, hear, feel and sense things in their own world (van Manen, 1998). The symptoms of MG are essentially physical, and
as noted above, can have a dramatic effect on a person’s body, which was highlighted in this excerpt from George:

“For you are a different person now than you will ever be again. You’ve changed. Because a whole new thing has opened up inside you, a whole new awareness. And you feel it physically in your body, you can actually feel it”.

The people interviewed all recalled times when their bodies did not work properly. They all expressed concern, worry and, at times, were scared when their body was failing them. Often other people noticed or commented on their altered physical appearance. Some of the people interviewed used humour when they described symptoms, even when recalling episodes of severe muscle weakness or visual problems. ‘Lived body’ has been interpreted as the physical symptoms and psychological effects experienced by people with MG. This ‘existential’ concentrates on experiences after people were diagnosed and illustrated a range of symptoms people have experienced that include difficulty breathing, swallowing and communicating, visual disturbances, facial and limb weakness, fatigue, psychological problems and side effects of medication. The experience of these symptoms was individual, unpredictable and exacerbated by fatigue. George described MG as a “violent viper” and shared what the disease meant for him:

“It is invisible most of the time, unless you are absolutely showing symptoms. It is pretty invisible to people who are encountering you, including hospital staff, who can’t understand why you’re there. And what it does to your body when you hit that crisis is terrifying”.

**Difficulty breathing: “I was scared about the breathing”**

Some of the people interviewed experienced shortness of breath or difficulty breathing related to an exacerbation of their disease. George described when he had trouble breathing as “very sudden and alarming”. His wife called the ambulance several times when this happened, but by the time they reached the hospital and had waited in the emergency department, his symptoms had resolved and he was discharged. George recalled what it was like waiting for help to arrive.

“I was down on my knees and trying to force my head up to breathe. I’d lost complete control of myself”.

When Sharon was admitted to hospital she had difficulty breathing and remembered waking up one morning gasping for breath. Sharon and George both were
frightened when they had trouble breathing. George recalled an event in hospital when it was difficult for him to breathe.

“When I started choking and I couldn’t breathe, I pressed the button and everyone just came in and hooked me up. I was terrified. ‘Breathe’, they kept saying, ‘breathe, breathe’. And they kept saying ‘don’t worry, if you can’t we can do something’. I knew a tracheotomy or something was going to come and then I would be in intensive care”.

Usually breathing occurs regularly and without conscious thought. Some of the people in this study experienced episodes where they had difficulty breathing. Words used to describe difficulty breathing included being “frightened”, “scared” or “terrified”. This highlighted the uncertainty and fear that people with MG experienced in relation to this essential bodily function.

**Difficulty swallowing: “I just couldn’t swallow”**

Beth recalled it was hard to swallow the pureed food given to her while she was in hospital. George also remembered how difficult it was to eat and could only tolerate smooth yoghurt.

“All I was doing was liquid. Pureed. I couldn’t even take porridge, you know, because the little tiny bits in it. Fluids, I was terrible with fluids. I couldn’t take liquid. So the only liquid I was getting was with this pureed food”.

Sharon reflected on how difficult it was for her to eat while she was in hospital.

“I mean even drinking orange juice would be quite hard to swallow. It was just using those muscles, in my throat. It would tire me out”.

Swallowing is a complex process of ingesting food in various stages while protecting the airway to prevent aspiration (Hickey, 2009). As noted above, some of the people in this study experienced difficulty with chewing and swallowing. It took longer for people to eat their food, and as a consequence hot food became cold and potentially less enjoyable to eat. Four people experienced significant weight loss and associated fatigue when they were unwell due to difficulties with chewing and swallowing.
Difficulty communicating: “And I couldn’t speak, I was talking all funny”

Some of the people interviewed had difficulty communicating or articulating speech because of their myasthenia. John found the inability to communicate frustrating and had to write things down because hospital staff could not understand what he was trying to say. Sharon also had difficulty communicating when she was in hospital.

“I couldn’t do much, but I could work on my laptop more than I could talk to someone”.

Bunty experienced changes with her voice, including a “lisp”, that she was conscious of when it became obvious to others. Having difficulty speaking was experienced by some people, but was not viewed negatively by the all people in this study.

Visual disturbances: “I thought I was going blind”

Double vision and blurred vision was a problematic symptom for some people in this study, and was most prominent when they were concentrating on a task or activity. Bunty experienced double vision and one of her eyes would close so much she could hardly see. Fred’s wife first noticed his droopy eye, which he initially ignored. He remembered regularly developing double vision, particularly in the evening and described it as being “horrible”. He recalled an experience where his vision suddenly became worse.

“One day I went to work, waiting at the bus stop, looking, and instead of about four people coming, there were eight people coming towards me. And I thought how am I going to get home? That was the worst one. It really was”.

George described his double vision as “if Picasso had made a stained glass window and smashed it”.

“When your eyes are bad, your eyes are bad. You just keep closing them until they get better”.

The visual problems experienced by the people in this study fluctuated, were compounded by fatigue and was a significantly negative experience of MG. Most people recalled times of purposeful concentration, often while driving, when they experienced
either double vision or blurred vision. Whether this was due to having to use their eye muscles more or if it was just when they noticed more was unclear.

**Facial weakness: “Smile for the photo!”**

Sharon’s family noticed she had trouble smiling and expressed their concern, as did her friends who told her that she did not look well. She was aware of it but felt that even though her smile at only 80% it was alright, because she could still smile. When Sharon had “down days”, her facial weakness was reportedly more pronounced and her eyes became sensitive to sunlight and would start to droop. George sometimes felt his face was not his own because of his facial weakness and became self-conscious. He was aware he struggled to show emotion and felt people did not see his true self.

“I think it partly begins with the idea that you can’t smile, that you are not conveying to people what you are and what you are thinking, in the same way that you used to”.

Every person interviewed in this study was affected by facial weakness. People recalled feeling embarrassed because they looked different or were frustrated that they could not portray the emotion they wanted to.

**Limb weakness: “I couldn’t hold a book”**

Most of the people interviewed experienced head and shoulder weakness. Margaret remembered having difficulty washing herself and struggled to write her name. Sharon continued to experience severe limb weakness after she was diagnosed and on some days could not hold her arms up or dress herself. On days when she felt she had no strength, Sharon thought she was just being “lazy”. George remembered how difficult it was to walk after leaving hospital. In addition to double vision, he had neck and shoulder weakness so he would walk a little bit, stop and lift his head up to check the way forward, and then would continue walking. George experienced an extended period of neck muscle weakness.

“It took a long time for my head to come up. I had actually left the hospital, before my head properly came up”.
In talking to her friends retrospectively, Bunty said they had noticed changes in her posture and that her head always went forward. Her family regularly told her to “hold your head up” or “put your shoulders back”. Bunty had difficulty doing this and felt frustrated because she knew her family did not understand the extent of her muscle weakness. Generalised body weakness was distressing for those people who experienced it. It sometimes meant they needed to rely on other people for help: this has been included in ‘lived other’.

**Fatigue: “I would spend most of my time sleeping”**

As mentioned in the previous section of ‘lived time’, every person interviewed experienced fatigue. Sharon played down her symptoms and said she always felt tired or that her strength was gone, so did not really think that was significant. At one stage she reported her body weakness and fatigue was so severe she would have to rest after struggling to dress herself.

“I mean even going to the toilet would take up that much energy that I would just lie there for another couple of hours”.

George remembered being so fatigued and weak that he was on his hands and knees and needed a nurse to crush his medication and feed it to him. Fatigue was an individual experience that affects a person’s body in different ways. For some of the people in this study it was an initial problem, but for others fatigue was a constant daily battle that severely disrupted all aspects of their ‘lifeworld’.

**Psychological effects: “I just wanted to hide away, actually”**

Bunty stated that her vague symptoms, delay in diagnosis and subsequent treatment made her think about all the little things that were “wrong” with her.

“I lost interest in a lot of things. I lost interest in food which is practically unheard of for me. I was often tearful, quite possibly I was depressed. Life just wasn't interesting anymore”.

Margaret said the physical symptoms of MG eventually became overwhelming. The battles with muscle weakness and fatigue, and constant thoughts of uncertainty, for her, felt like fighting to survive. It was her general practitioner (GP) who pinpointed
depression and after a short course of antidepressants she felt a lot better and was pleased she sought help.

“Because after a while you start to think you are going mental. You sort of do start thinking it’s you. When you are better and you look back you realise how low you were and how far you actually have come”.

George experienced a range of psychological symptoms, including euphoria and paranoia, particularly when he started taking steroids. He struggled with fatigue and muscle weakness on a daily basis and took antidepressants for his low mood. The people in this study expressed a variety of emotions when describing their experiences, some found it more difficult than others to manage their symptoms and the effects on their body. Barker (2008) stated that patients can experience periods of frustration and depression intermittently throughout the recovery phase of a chronic illness. The psychological aspects of this disease relate to all four of the ‘existentials’, but have been included here as the mind is part of the ‘lived body’. Benner and Wrubel (1989) suggested emotions have significance in their own right and they alert a person that something important is at stake.

**Side effects of medication: “Prednisone is friend and enemy”**

Several people described their faces looking “puffy” and experienced increased weight gain after commencing steroids to control their symptoms of MG. Steroids made a big difference to Sharon’s symptoms and she felt they quickly had her “up and going” again. However, dramatic side effects she experienced included insomnia, acne, hair growth, weight gain and leg shaking. She endured negative comments from people and became very conscious of her changing appearance.

“I would rather spend four months kind of sickly and weak than do the steroids. Probably, because I am kind of vain, but the side effects were awful”.

Margaret also developed side effects from steroids, mainly facial hair and weight gain. She acknowledged they helped control her symptoms and reluctantly endured the side effects because she did not want to have a relapse. George felt really scared being on prednisone, because of the physical and psychological side effects he experienced.
“And I was going crazy. It’s not just the mood swings, as you don’t have control and you feel so weak and your legs are shaking like jellies”.

All the people interviewed had been prescribed prednisone as part of their treatment for MG. Even though steroids are not directly related to MG, everyone talked about the drug; particularly the side effects they experienced. It was acknowledged that steroids reduced symptoms and there was a general improvement in their condition, however, everyone spoke about the undesirable and unwanted effects which are a significant aspect of the lived experience in people with MG. The symptoms of MG can have a dramatic effect on how a person experiences their body. A body that functions normally can suddenly become prone or gradually altered and different. Symptoms are an interruption in the functioning of the body, and are experienced differently by each person (Benner & Wrubel, 1989). When the people in this study experienced weakness they developed a heightened awareness of their body as it became the centre of attention. Benner and Wrubel (1989) suggested that if there is no disruption of usual body function there is no experience of illness. The ‘corporeality’ dimensions of ‘lived body’ are only one aspect of MG and it is important to examine the other ‘existentials’ in addition to ‘lived time’ to understand the meaning of MG.

4.4 ‘Lived space’ (spatiality)

Van Manen (1990) described ‘lived space’, or ‘spatiality’, as the ‘landscape’ in which a person moves. However, as a landscape changes with the seasons, the fluctuations of MG symptoms can alter a person’s sense of ‘space’. People talked about the concept of ‘space’ in a variety of ways during the interviews. The word ‘space’ can be used in different ways in the English language: it can refer to the dimensions of height, width or depth and can also be used to describe the area beyond the earth’s atmosphere. This ‘existential’ was interpreted as the physical and emotional environment surrounding a person with MG. ‘Restricted space’ referred to people when they were in hospital and had little control over what was happening to them. ‘Improved space’ involved when a person showed signs of improvement, developed determination and a positive outlook. ‘Home space’ involved the challenges of living at home, back in a familiar environment, where adaptation and change were forced to occur.
4.4.1 Restricted space

Mental space: “I wasn't with it really, I was in just another kind of world”

Sharon described her time in hospital as being a bit of a “blur”. She remembered so much being “put into her” and she endured “lots of needles”. Sharon was so fatigued that she just wanted to sleep and did not mind what people did or treatments she had. She remembered being so weak when in hospital she had difficulty performing basic self-care.

“I was showering by myself but only because I didn't want anyone to look at me. It was really, really difficult. I wouldn't say that I was capable of washing myself. (Laughs)”.

Bunty felt in a “bit of a daze”. She remembered feeling anxious and a lot of people being around her. This feeling was echoed by Margaret.

“I just remember feeling so crook. Just so low. Mentally and physically. That whatever they did, I said ‘just do it’. ‘If it’s going to make me better, just do it’”.

George needed help with feeding, dressing and showering when he was in hospital. He described the chaos of emotion in his mind, being aware of things he had not really thought about before. He remembered feeling terrified and feared being dependent on others.

“By now my arms were going as well. I couldn’t get my arms up to feed and all sorts of stuff. And the day when I couldn’t wipe my bottom. And I sat there for fifteen minutes crying in the toilet. I’m not going to ring the bell. I am not going to have someone wipe my bottom. I am just going to sit here until the strength comes back in my hands. I am just going to sit here until the strength comes back”.

Despite being unwell, Bunty enjoyed her time in hospital. She felt she grew from the experience and was reluctant to leave. During the first week of being in hospital, Sharon was really upset when she reflected on all the things she had to give up. She also didn’t know if she would ever get “back to normal”.

“It was nice being in a room with other people because you don't feel so sorry for yourself”.

The experience of restricted space was a significant period for the people in this study and could also be discussed in the dimension of ‘lived time’. The hospital environment places physical and mental restrictions on a person’s ‘space’ when they are
unwell. Sharon, George, Margaret and Bunty all spoke in detail about how they were in hospital, as if in a different world or ‘space’. This could make a person even more vulnerable, if they were also combating fatigue and a weak body.

**Physical space: “I wasn’t allowed out of bed”**

John recalled a time when he became lethargic and had trouble breathing when his nurse was late administering his medication. George also experienced an exacerbation of symptoms when his medication was administered late.

“So there I was, down on the floor again, in the hospital. And my ‘meds’ didn’t come for two and a half hours. And I was a wreck”.

Beth remembers struggling to eat the pureed food when she was in hospital.

“And the thing was they wouldn’t let me out of hospital until I could swallow. I had to get so far before they would let me come home. I had to be able to swallow properly”.

Bunty recalled needing to have a nasogastric tube (NGT) inserted because she had lost weight.

“And when it came to tube feeding I said ‘I am not having one of those. I am not going to have one’. I was adamant. So I fought them for two days”.

She was encouraged by her family to have the NGT. After several nurses attempted to insert the tube, but it was eventually placed under X-ray guidance. John also remembered having a NGT inserted.

“There were three nurses, one on each shoulder and the other one with the tube. Sometimes they couldn’t get them in to the stomach, so then I had to go down to theatre”.

Margaret recalled not being allowed out of bed and had to use a bedpan when she was in hospital. George was restricted to a wheel chair or bed in the first week of his time in hospital. John felt constrained when he tried to mobilise while in hospital.

“Every time I moved around I had to pull this trolley with me, with a bottle on. It was a bit awkward when you went to the toilet and that and had a shower”.
Bunty called her feeding pump “Freddy” and remembered that “he” went everywhere with her.

“No at one stage they said you will have to get rid of Freddy. I was still with Freddy then, he was still feeding me. Then after a while, I was liberated from Freddy for about four hours during the day and I was able to walk around freely and then I was back on him”.

‘Restricted space’ involved physical barriers that a person experienced. This included the constraints of mechanical pumps as experienced by John and Bunty and the restrictions of bed rest that were experienced by Margaret. These are examples of how ‘personal space’ was restricted and limited the autonomy and self-control that each person had. Even a walking frame that assists a person to mobilise interferes with a person’s ‘space’ or ‘landscape’. Having to use a walking frame means a person is restricted to where they can go, with each move requiring care and planning to manoeuvre the frame. Being told what can or cannot be done by health professionals interferes with a person’s ‘space’ as does receiving medication later than normal.

4.4.2 Improved space

Determination: “I've turned the corner”

Bunty knew she would improve when she was really sick in hospital because she was told she would by hospital staff. She remembered what it was like to “feel human again”.

“I did it slowly, but I made progress. It was good to see things returning in my face. My eyes started to open and I could swallow”.

Once the medication started working for George, he felt he started to improve and became stronger every day, despite having fluctuating muscle weakness.

“Well it was great because it gave you determination. It gave you a sense that you were making progress and that you could fight this and that you could overcome this”.

Margaret did not like being different and felt her battle was to get back to “normal” again.

“I still functioned. I still did everything. Just determination will get me through. I don’t like to weaken”.
Beth described her willpower when she was in hospital:

“I was a walking patient. But then I made myself do that. I made myself get out of bed and walk. I made myself get out of my night clothes and into day clothes. I wasn’t just lying around being a sick patient”.

The people interviewed felt mentally and emotionally in a better ‘space’ as their symptoms improved and they started to get stronger. Benner and Wrubel (1989) stated that patients can often overlook improvement because they compare themselves to be their previous fully capable self.

**Positive attitude: “It’s not going to defy me”**

Sharon admitted MG has had a huge effect on her and while remaining positive, she had made significant changes to her life.

“I have had my moments. It's been really tough actually. So it was hard at the time because I just had to do a whole mind shift about what was important and what wasn't”.

Margaret also remained positive. She would rather not have MG, but felt she can manage the disease. Margaret always thinks of new ways to do things around the house and reported feeling more relaxed about what she can’t do.

“I will say to my husband I can’t do it. End of story. It either doesn’t get done or he does it. And, if it’s not done today, I will do it tomorrow. It doesn’t matter. You learn that priorities change. And I’m fortunate with being that wee bit older, I have that luxury. If it’s not today, tomorrow will be fine”.

Bunty always tried to be positive and has learned from her experiences with MG. She felt she is a different person now and has changed her outlook to think more “outside the square”.

“It has had a profound effect on me. It has changed me a lot”.

In this study, reflection on small steps and slow steady improvement appeared to have offered a sense of hope and led to increased determination and a positive outlook. However, it was unclear if the people in this study were naturally like this or if their changed outlook was due to an improvement in their symptoms.
4.4.3 Home space

Being discharged from hospital and returning to the familiar ‘space’ of home was a milestone for many of the people that were interviewed. However, being back in their familiar space did present initial challenges. This next section illustrates some of those changes and adaptations people have made in their ‘home space’. Margaret relied on her husband heavily when she was initially discharged from hospital, not only with personal cares, but with household chores as well. Her weakness restricted her physical ‘space’ at home. She remembered being so weak she got stuck on the toilet and had to wait until her strength returned so she could get up.

“Up and down the back door steps. That was hard. During the day, I would leave two or three things to be done so I could do it all in one trip. But just the door step. Two, three steps – oh it was hard work. That is why I would leave everything in a pile on the floor and he would do it when he got home. And I hated being stuck inside, but I knew it was so hard to get back in”.

Hobbies: “It’s a shame how you give things up”

John stopped a lot of his hobbies when he was diagnosed with MG. He found it frustrating when he wanted to do something and couldn’t. Interestingly, John, Fred, Beth, Margaret and Bunty all referred to their advancing age when reflecting on reasons why they have stopped or changed activities they enjoy.

“I work in the garden for about ten minutes and then I've had it. I've got to sit down”.

Fred struggled with household activities, in particular gardening, although he was not sure if it is related to his MG or another health concern. He did not go out for walks like he used to because of fatigue and weakness in his legs. Beth enjoyed swimming and walking, but since her diagnosis, she has given up both of these activities. Margaret stopped playing tennis due to her symptoms of MG, and justified her decision by saying she was busy with her grandchildren so would not have time. Bunty gave up reading, while George got frustrated because some parts of life he enjoyed were “gone”.

“I can’t read. If you can’t read and you can’t write, and you can’t watch telly. I can’t do simple tasks, look up a phone number”.
Employment: “I could not work”

Margaret’s symptoms of MG affected her ability to work before she was diagnosed. She struggled with fatigue and the physical demands of her job, so she resigned.

“Oh, obviously, it was building up then. Because it was not long after that, that I got really bad. I don’t think it was very long before I was in hospital.”

Fred also had to give up his work due to his symptoms of MG.

“I still went back to work and I was alright then. I packed up because I was getting more cramps in my hands. Twelve, one o’clock I started getting cramp in my hand again. And shakes as well, I had shakes. It’s too delicate work, I can’t do it.”

It was unclear in this study if there was a correlation between a person stopping work as a result of being diagnosed with MG. Sharon was so unwell she could not work for several weeks and was able to return on reduced hours until she could return to full-time employment. From what Margaret and Fred shared in the above statements suggested that the onset of MG symptoms was a factor that prompted them to cease employment or retire earlier than they had planned.

Driving: “I can’t drive anymore”

George felt insecure driving after being in hospital and his wife would not let him drive. After a sudden onset of double vision while driving, Fred’s wife also did not allow him to drive. John could not drive for several months after he was diagnosed with MG.

“It affected my driving, because I had that double vision. Driving down the road you would have two cars coming toward you instead of one”. Margaret’s weakness was so severe she chose not to drive for nine months.

“I was aware of the safety factor. I may not be strong enough to take action. I just felt I would not have been in control. Too weak”.

The visual disturbances that were experienced in this study were generally temporary and did restrict each person’s ability to drive. The decision not to drive was
usually made by the person themselves, and in some instances encouraged by concerned family members.

For some families, going home is highly meaningful because it clearly means that their loved one has survived the illness, regardless of the disability (Benner & Wrubel, 1989). Benner and Wrubel (1989) suggested over time people coping with chronic illness develop habits, practices and knowledge of what it is like to live with illness. The people in this study spoke about adaptations and alterations they have had to make because MG has invaded their ‘home space’. Things affected included: giving up hobbies and social activities, work and driving. With neurological illness the psychological stressors and stress response can be difficult in terms of the person’s ability to cope and adapt (Hickey, 2009). This was especially significant when the person has been discharged from hospital into their ‘home space’. The ‘lived space’ or ‘landscape’ of a person with MG varies and changes depending on the severity of their symptoms. MG can affect a person’s ‘space’ in a variety of ways: it can restrict a person and it can alter what they can do in their life and it can also be viewed positively when a person improves and their symptoms decrease. ‘Lived space’ is a dimension of the ‘lifeworld’ and must not be viewed in isolation because it is closely related to the other ‘existentials’ developed by van Manen (1990).

4.5 ‘Lived other’ (relationality)

Van Manen (1990) referred to ‘lived other’ as ‘relationality’ or ‘communality’ and stated that this ‘existential’ involved the relations maintained with others in their interpersonal space. This ‘existential’ has been interpreted as the experiences of people with MG and the relationships they have with others in their lives. ‘Lived other’ included people’s relationships with their family members, friends, health professionals and faith. Family relationships involved physical and emotional support required, worry and concern expressed by family and times when close relationships became strained. Friendships were talked about during interviews and mainly involved not being able to relate to other people, friends not understanding MG, as well as the forming of new friendships since diagnosis. Relationships with health professionals included the importance of trust, reassurance and communication. Interactions with students was talked about in this study as was the importance of faith.
4.5.1 Family relationships

Family concern: “My son, he seems a bit worried”

Bunty’s family regularly expressed their concern with her symptoms prior to her being diagnosed. When her vision was affected her family intervened and would not let her drive.

“I had to stop. I definitely stopped driving. Because, I could not see with the double vision. The family stopped me”.

Margaret was given a fact sheet about MG that she photocopied and gave to her family to try and get them to understand what she was going through.

“I think family were probably frustrated because they knew how sick I was and they couldn’t do anything about it”.

Family support: “I could not have done without them”

Bunty sold the family home and moved closer to her family for support. She remembers feeling guilty and helpless because she could not contribute towards the house work and valued the support she received from her family.

“I got into the habit of going to spend a fortnight with each daughter. It was kind of the sons-in-laws to put up with me”.

Beth had supportive daughters present during the Tensilon test and several people interviewed said they had family present when they attended appointments with their GP or neurologist. Fred said his wife “looks after” him, while John relied on his wife to give him his medication.

“My wife usually tips it out on the table. She is annoying at times because you can be working on the computer and she comes up with a pill and a glass of water”.

Margaret relied on her husband for personal cares after she was discharged from hospital. She was not confident about showering herself and waited until her husband returned from work so he could help her.

“I mean after I came home, my husband showered me because the facecloth was too heavy. So, I could not really shower on my own”.
Sharon was helped by her father when she was in hospital to communicate, which involved him talking and writing things down so staff knew what her needs were. She also reported that her father would “just sit with me in the day”.

“My dad tried to get me out of my room, because it was quite stuffy and my spirits were quite low. And we walked down the stairs out to the road and I was done. I was absolutely done. He was sort of helping carry me back. That is just how weak it got at its worst”.

Margaret’s limb weakness limits affected her relationship with her grandson.

“Lifting and holding my grandson up. He’s two. I pick him up and then I have to put him down. Too heavy. But he’s alright he has had his cuddles. It’s just not a major, but I can’t hold him for long. And he is happy with that. Well, he has to be, that’s the way it is”.

**Strained relationships: “We do have our words of course”**

George believed the time prior to being hospitalised was awful for his family because was he physically and psychologically unwell. George felt his condition put a stress on the family, in particular his wife, because of the extra effort and time it took to do things. He felt he became “too dependent” and that MG sometimes dominated family discussions.

“Which you can’t, every five minutes you can’t be saying to your partner, or the person you’re living with – something’s happening. You would drive everyone completely balmy. So you just wander off and lie in your bed. They’re used to me now, I just disappear”.

John felt he was more grumpy and miserable and thought his relationship with his wife had changed.

“Hanging around doing nothing. In and out of hospital. You know nothing much to look forward to when you are eighty odd. You know your brain is active and working and you think you can do it, but when you go to do it, you can’t. Very frustrating. And the wife gets it in the neck”.

Hickey (2009) stated that neurological illness not only has serious consequences and challenges for the patient, but for family members and significant others also. In this study family relationships were referred to in a positive way and was a significant experience of MG. It was often a family member who expressed concern or worry about
their initial symptoms. A common theme was the emotional and physical support they needed from family members. Sometimes this resulted in changed roles within the family unit either because the person themselves has to be cared for by another family member, or they struggled to maintain their usual role within the family. Margaret and George, for example experienced significant self-imposed guilt when they felt they could not fulfil their usual family role. Benner and Wrubel (1989) stated there are a variety of emotions that families have to deal with during periods of chronic neurological illness. When interviewed John, Fred and George all experienced “strained” relationships with their spouse at times and felt this was a direct result of their disease.

4.5.2 Friendships

Altered friendships: “I can’t relate to people in the same way that I could”

John felt some people did not truly understand his condition and what he experienced.

“What people say I am doing OK. (Laughs). They can't see the pain and that can they?”

George felt people he knew had trouble interpreting some of the things he did and strategies he adopted to deal with his symptoms. He reported his facial expressions were not always a true reflection of how he felt.

“But this is not simple stuff and here you are looking OK, chatting away and you’ve got a serious disease. And people don’t realise”.

Beth said she couldn’t be bothered with people coming around to visit.

“I think I was tired. I must have been. When I said to them, my friends. I’ve made the cup of tea but you will have to go and get it. And at that stage nothing had been diagnosed”.

John felt that not going out and socialising with friends was more age-related than related to his MG. Bunty thought her social life had slowed down and, like John, also blamed her age. Fred did not go out as much as he used to be because he was concerned about what other people might say.

“He’s got something wrong, but then I would just shut up and I didn’t go anywhere. Really didn’t go anywhere”.

New friendships: “It was a wonderful experience with the patients”

When Beth felt better, she regularly attended Art classes and enjoyed meeting new people and making friends.

“And what’s good about it there, is that there is no mention of health problems. You are doing what everybody is doing. And I actually come home feeling better after the outing. I feel better for it, being with nice people and it’s something totally different”.

Bunty worked hard to build new relationships with people since her diagnosis.

“I had to leave all my friends and make new ones here. Well, I have started to do that. Slowly, but it's not easy because people are in groups here so wherever you go in life you find that. But I have been accepted in quite a few. The street's been very good. We call it that, we do a lot together”.

Bunty enjoyed meeting and interacting with the other patients while she was in hospital. She described some good times and started to write about her experiences. Bunty also recalled a time when she met another patient with MG while she was in hospital.

“He was a tremendous help. He took me through what was going to happen to me, which I had no idea. He said it is not going to be pleasant you may not remember it. But it was a help because I knew where I was going, sort of heading, not conclusively but I did know that I was in for and so I was ready to face it”.

It was not clear in this study if changes in friendships was because the person had been diagnosed with MG or for other reasons. Some put this down to getting older while others felt that friends did not really understand their disease and its effects. Fred and Sharon were particularly concerned about how their friends might treat them or perceive when their symptoms were quite noticeable. Building relationships and making new friends since diagnosis was an interesting finding in this study and was a significant aspect of the lived experience in people with MG.
4.5.3 Health professionals

Trust: “To have someone I was able to trust”

Sharon liked that the neurologist could answer her questions.

“He was amazing when I was in hospital. I didn't know if it was his way or nature, but he actually made me feel like I was going to handle it OK. It didn't matter what the outcome was. And I actually had a lot of respect and trust in him. That was throughout everything. I think that was really important for me to be able to deal with it”.

Margaret took comfort in knowing her neurologist was accessible, despite no longer needing regular outpatient visits. George reflected on the support he received from staff when he was in hospital.

“When I started choking and I couldn’t breathe, I pressed the button and everyone just came in and hooked me up. And I can remember standing there and they were rubbing my back (tearful) and saying “yes you’re getting oxygen” and I was going (demonstrates struggling breaths). “Yes you’re getting oxygen” and “carry on, you’re OK, good”. They were wonderful. I mean they were just wonderful. They saved my life and I could never thank them enough”.

John believed a person with MG should “put all your faith in” neurologists. Bunty mentioned the word “faith” occasionally when talking about her neurologist and, like Margaret, felt reassured that she was able to contact her neurologist if she needed to. She recalled feeling anxious about having her NGT removed by a registered nurse.

“She was very decisive and she knew exactly what she was doing. And she was very calm and collected. So was I and I thought well she knows what she is doing”.

George experienced emotional support and felt the health professionals he encountered understood him and the effects of the disease.

“They were all lovely. All great. Just the individualising, which they did so fast. They would fast latch onto individual things about me, that they could, I mean, that’s training. It’s exceptional. This is trained empathy. It’s brilliant, it’s so reassuring. It’s not false. It’s totally real. But it’s something that you people have learned on the job or it's been actually consciously arrived at, you know. And that was amazing to me. And that is so important for a myasthenic patient, I think. The sense that someone will just sit down with you and just have five minutes conversation and tell you that you are not alone, that this is OK. The things that you are feeling and going through are as they should be. It’s OK. Because you think you are mad”.
The people that were interviewed in this study all felt it was important that the health professionals they encountered knew about their disease. Having questions answered if they were unsure or concerned was reassuring for the people in this study and provided a sense of trust in the health professional that was caring for them. Not only was knowledge important, but the confidence and physical ability to perform certain ‘skills’ instilled a sense of ‘faith’ in the health professional that were encountered.

**Conflicting advice: “But even doctors will all say different things”**

Margaret experienced confusion when told by a nurse she had to remain on bed-rest, while another nurse told her she could mobilise. Sharon also experienced confusion by what some doctors said as she felt information was contradictory.

“I do find the doctors always give me different opinions about myasthenia or a 15 minute doctors session about my sinus thing would end up being half an hour because they find out you have Myasthenia gravis and they get out a book and read things to me about it. And interview me (laughs). I don't mind”.

Conflicting advice was an interesting, but not surprising finding of this study. This may be due to the rare nature of MG: many health professionals may never encounter a patient with MG unless they work in a specialty area.

**Helping others learn: “Students have got to learn and experience it too”**

All seven people interviewed had interactions with students and referred to them in a positive way because they felt they could help others learn. Bunty described how having a nursing student with her provided great comfort and support during invasive procedures and treatments.

“I had a dear little nurse, who took me down for the CT, she was a trainee nurse. I wanted her with me because she held my hand. She was subsequently there with me whenever I had anything. She would come with me and hold my hand”.

George had a student nurse who he experienced as kind and very discreet when helping to showering him. Beth and Fred recalled having medical students present when they had the Tensilon test.
“It was something different and they just sort of more observed”.

Sharon remembered a medical student being involved with her diagnosis and a lot of students seeing her when she was an inpatient.

“I don't know if it was more show and tell because every day I was maybe having five new students come and have a look and a poke. I didn't mind them coming in, I mean it is the only way that they will learn, I suppose, seeing people and learning symptoms”.

Margaret had a positive experience with medical students while in hospital. She liked them because she is aware there are not many opportunities for students to actually see a patient with MG. She felt that she did not benefit that much, but knew they would in the future. Bunty was used as a “case study” by a nursing student and reflected positively about the “entourage” of medical students that would come around with the neurologist when she was in hospital.

“And there were all the trainees, there must have been about eleven to twelve of them. I used to look forward to that”.

People spoke about their interactions and relationships with health professionals in a variety of ways. Despite the person at times having no control over their body or being very unwell, there was an overwhelming feeling of trust, confidence and reassurance in nurses, doctors and other health professionals in all matters related to inpatient and outpatient care. The contradictory advice that Sharon received raises an important issue and requires consideration at all stages from pre-diagnosis to follow up care. One of the interesting aspects in this study was that every person had positive experiences with nursing and medical students. They were happy to be part of a learning environment and felt they were contributing to the development of future health professionals.

4.5.4 Spiritual relationships

Faith: “I had a lot of people praying for me”

Faith was included as an aspect of ‘lived other’ because van Manen (1990) believed that humans search for the experience of other in a social meaningful way, which includes religious experience of an absolute other. Sharon maintained she has
always been positive when managing her illness, tries to remain in control and draws strength from her faith.

“When I was in hospital and it was probably the first week, because I was really upset, really upset. Mainly cause I was thinking about all the stuff that I had to give up and I couldn't do and I actually didn’t know if I would get back to normal and they couldn't tell me that either. It was scary. But then because I do believe in God, so I was praying a lot. And I got my spirits back and right I'm going to be fine”.

Sharon continued to rely on faith, in combination with steroids, to help reduce her thymoma and believed this helped shrink it to a manageable size in preparation for her thymectomy. Fred reiterated that his faith helped him; he considered himself lucky and prayed regularly. Fred and Sharon found spiritual strength and support through their religion which was significant considering the sample size of this study.

Different perspective: “There is a lot worse”

Sharon stated her MG affected her 5% of the time and was extremely grateful for the 95% she was not affected. She had accepted her condition but does think it could be much worse and recalled being in a multi bedded room with a woman that had advanced MS and another woman who had been told she had four months to live.

“And that put things in perspective for me. It was kind of nice being in a room with other people because you don't feel so sorry for yourself”.

George reflected that he has had a good life, but having been diagnosed with MG felt like life had come to an end because he struggled with anxiety and low mood.

“I think that it is something you have to learn to live with, something I have to put up with. There are people out there going through infinitely worse things than I am”.

Margaret always tried to remain positive and knew there were worse conditions than MG and made a reference to MND. Despite having experienced severe limb weakness, she considered herself lucky because she did not have any visual problems.

“Fortunately, I didn’t get that far, fortunately. I was pretty bad, but not that bad”.
The people in this study accepted they had a serious medical condition and experienced an awareness that other people have conditions or diseases that they perceived were worse than their diagnosis. Relationships with others was an important part of the lived experience of MG. It was clear from this study that these relationships become even more important and significant to a person after they have been diagnosed. Relying on others for physical, emotional and spiritual support in whatever form was a meaningful experience in people living with MG. ‘Lived other’ is an important dimension of a person’s ‘lifeworld’ and should be considered with the ‘existentials’ of ‘lived time’, ‘lived body’ and ‘lived space’ to truly understand the meaning of the lived experience of MG.

4.6 The Interrelated Experiences in Adults with Myasthenia Gravis

The findings of this study have been presented using van Manen’s (1990) four dimensions of the ‘lifeworld’. In viewing the results through the dimensions of ‘lived time’, ‘lived body’, ‘lived space’ and ‘lived other’, clear themes related to the phenomenon of MG have emerged and have been illustrated in the following diagram (see fig.1). At different stages of the disease these intertwined circles expand and contract with a sense of fluidity and are always present to some degree. For example when Sharon was unwell with a life threatening exacerbation of MG, uncertainty, weakness and change were all equally enormous experiences. However, while in remission, when she was interviewed, Sharon was not greatly affected by weakness or change because her symptoms were well controlled by medication. But, her experience of uncertainty was overwhelming because she was hoping to have a baby and had concerns about her medication and feared a relapse. George constantly experienced uncertainty and change, but the biggest issue that dominated his experience of MG was his muscle weakness and the associated fatigue which governed his daily existence. The findings of this study were that each person experienced MG in a different way, but the interlinked experiences of living with weakness, living with change and living with uncertainty occur at all stages of the disease and its severity and were unique to each individual. Living with uncertainty, living with weakness and living with change are all meaningful experiences in people with MG and, when interlinked represent the lived experience of this disease.
Each person interviewed in this study recalled where they were in relation to time when they first noticed symptoms and when they were diagnosed. This was significant and had meaning for them. MG is intrusive and alters a person’s sense of time regularly along the disease continuum. A person’s life can be dominated by disease with time spent worrying about weakness, uncertainty and change. The physical symptoms of MG can subtly or severely invade a person’s body. MG is unpredictable and a person may have little or no control during acute exacerbations. As weakness, change and uncertainty overwhelm a person and their body fails them, they experience an array of emotions including fear and anxiety. They may grieve the loss of body function as they come to grips with a body that cannot work like it once did. Even subtle body weakness can have a profound effect on a person’s body, their appearance and self esteem, and it is understandable that the loss of physical function can have a profound effect on a person’s psychological wellbeing.
The experience of MG restricts a person’s dimensions of space, both mentally and physically. A person’s landscape may be cluttered or constricted with equipment and health professionals in the acute phase of illness and then isolated when a person has been discharged home. Relationships with others was a significant finding in this study. No matter what stage of illness whether it was family support or the trust they placed in health professionals, it was an essential that people with MG have relationships with others. This appears to be the most important way of coping with the weakness, change and uncertainty associated with MG. The findings of this study were unique and highlighted the many different ways a person experiences MG. The results have been presented and examined using the four ‘existentials’ of a person’s lifeworld as developed by van Manen (1990). Data analysis has revealed interrelated themes embedded within these experiences which highlight the meaning of MG. The interrelated themes that represent the experiences of MG from this study included living with uncertainty, living with weakness and living with change, and are discussed in the next chapter.
5. Discussion

As outlined in the previous chapter, the people in this study have all had different experiences of MG. The results have been presented using van Manen’s (1990) ‘existentials’ of ‘lived time’, ‘lived body’, ‘lived space’ and ‘lived other’. The analysis of findings identified three main experiences of MG: living with uncertainty, living with weakness and living with change, which will be discussed in this chapter. They are interlinked, relate to the phenomenon of MG and highlight the embedded meaning for people with this disease. Each experience is discussed and explicates the findings further using van Manen’s (1990) ‘existentials’. The implications for nurses and other health professionals are outlined and include nursing assessment, care, patient education and research. The recommendations of this study have also been included in this chapter. Firstly, the limitations of this study and methodological considerations are discussed.

5.1 Limitations of study

The results of this study contribute a qualitative aspect to an existing body of knowledge which is predominately quantitative and medically based. It brings to the fore a unique qualitative NZ perspective that sheds light on experiences of people with MG. Although small, this study does address a gap in the literature for qualitative nurse-led research about people with MG and does highlight numerous potential areas which could be investigated in the future.

The results of this study cannot be generalised for every person with MG, as each person will experience the disease differently. The main limitation of this study is its small sample size. More people in the study may have represented the MG population in a different way. Value may have been added to this study if younger people, and possibly those who had experienced a tracheostomy or an intensive care admission were interviewed. People with more diverse ethnic backgrounds may have also provided a different perspective of MG. The questions asked during the interviews were based on information obtained from the literature review and were relevant to people living with MG.
The collection of structured quantitative data, for example: age at diagnosis, years living with the disease or hospital admissions, in addition to the interviews of people with MG, may have enhanced the results of this study. Most people did refer to these during interviews, but it is something that could be considered when planning this type of research in the future. Finally, this research is the principal researcher’s interpretation only and it should be noted that a different researcher may interpret van Manen’s (1990) methodology, the data obtained and present the results in a different way.

5.2 Methodological considerations

The methodology of van Manen (1990) has been regularly used by researchers in health related fields. However, many nurse researchers restrict van Manen’s (1990) method to data analysis only and do not relate their findings to the ‘existentials’ he developed. This study has used the research methodology of van Manen (1990) as a guide throughout the entire research process. It has allowed some structure for the research process, but also flexibility to enable the lived experiences of people with MG to be presented. Van Manen (1990) believed phenomena in the human ‘lifeworld’, as it is experienced, are multidimensional and multilayered. Hence, this method has been an appropriate approach to examine the experiences in people with MG.

The results of this study could have been analysed and interpreted in a variety of ways. Van Manen’s (1990) highlighting method of data analysis worked well to identify significant aspects of the lived experience. At times, in the current study, it was difficult to separate out excerpts from the transcripts into one particular ‘existential’. Sometimes when people spoke and reflected about a particular experience it could have easily fitted into any of the four ‘existentials’. Bringing all the experiences back to the dimensions of ‘lived time’, ‘lived body’, lived space and ‘lived other’ ensured the research remained on a phenomenological path. Indeed, van Manen (1998) admitted that phenomena are complex, sometimes more than an interpretation can reveal and Crotty (1998) believed that a lot that is not expressed when a concept is investigated.
5.3 Living with uncertainty: alteration in life equilibrium

This study highlighted the uncertainty associated with MG, and is therefore an important aspect of the lived experience in a person with this disease. People with MG experienced symptoms that are constantly changing, which can result in varying degrees of uncertainty that can occur at any time along the disease continuum. Throughout the duration of chronic illness, Hickey (2009) suggested a sense of uncertainty can occur as the level of disability waxes and wanes. Uncertainty has been described as a ‘hallmark characteristic’ of chronic illness (Kaminski, 2009), and this dynamic experience can have a major impact on a person (Hansen, et al., 2012). Kaminski (2009) suggested there are several components to the concept of uncertainty, including ambiguity about the disease, unpredictability surrounding the course and outcomes, complexity of treatment options and lack of information about the disease and treatment. Uncertainty surrounding all of these components was expressed during the interviews in this study and therefore cements this finding.

Hansen et al. (2012) believed the experience of uncertainty has three characteristics: ‘explaining uncertainty’, ‘feeling uncertainty’ and ‘facing uncertainty’. ‘Explaining uncertainty’ was associated with the experience of illness and physical health of a person (Hansen, et al., 2012) which was similar to this study, where every person sought explanation of their initial symptoms because something was not right with their body. ‘Feeling uncertainty’ was described as stressful and an emotional burden, where a person was constantly aware of unusual symptoms (Hansen, et al., 2012). This was very evident in this study, with numerous examples in the previous chapter. ‘Facing uncertainty’ can be a multifaceted, changing problem where a person may experience loss (Hansen, et al., 2012) and was highlighted in this study by how people were restricted in certain activities and how they chose to plan their lives. Living with uncertainty upsets the balance of life and affects every aspect of a person’s ‘lifeworld’. There were two main aspects of how people with MG experienced uncertainty in relation to time: prior to diagnosis, where a person experienced unusual symptoms, and after diagnosis, where people experienced thoughts of worry about the future.

The main period of uncertainty for all of the people interviewed in this study was when they initially experienced abnormal or unusual symptoms they could not explain. Benner and Wrubel (1989) stated that the pre-diagnostic time is rife with ambiguity and
it is only when a person experiences disruption to normal functioning that they will seek help. Unusual symptoms that were experienced became worrisome: Bunty did not know what was wrong with her and Fred “didn’t know what to do”. Some of the emotions surrounding uncertainty experienced by people in this study prior to diagnosis, included feeling anxious, sad, tearful, frustrated, embarrassed, scared and isolated. These are similar to the emotions experienced in people with GBS (Forsberg, et al., 2008) and MS (Barker-Collo, et al., 2006). However, it was noteworthy in this study, that if a person was unable to pinpoint the problem, their worry and concern led them to seek health advice which was similar to the experiences in people with GBS (Forsberg, et al., 2008). Benner and Wrubel (1989) suggested that thinking about multiple outcomes can be distressing for a person, which was a phenomena experienced by people in this study. The time surrounding diagnosis brought feelings of reassurance and relief, especially for Margaret and Fred as noted above. Initially, patients can feel distressed about their symptoms, which includes concern that something may be ‘unfolding’, but Kaminski (2009) reported that some patients experience reduced anxiety and fear after their diagnosis.

For people who had experienced a sudden onset of symptoms, there was a real concern about future time, particularly the unease surrounding relapse which was a similar finding in people with SMA (Lamb & Peden, 2008). Because MG can be unpredictable, and involve rapid onset of weakness that can include respiratory muscles, there was a genuine concern expressed about what may happen in the future. This was highlighted in Margaret’s comment when she used the word “fear” when describing the possibility of relapse. This is pertinent because she had experienced severe muscle weakness in her past and remembered what it was like physically and emotionally. She had legitimate apprehension and was worried about the “lapses” she may experience in the future. Bunty also experienced severe muscle weakness and used the word “worry” when talking about triggers of her fatigue. Because of his past experience of crisis, George was scared that his symptoms would worsen and lived with constant uncertainty regarding future events and what may or could happen. Not knowing when the disease progression was going to slow or stop was also particularly worrying and a concern shared in people with GBS (Forsberg, et al., 2008), MND (Foley, et al., 2007) and stroke (Burton, 2000).
Past experiences of uncertainty and concern regarding the future highlight how uncertainty can impact on a person’s ‘lived time’. Van Manen (2005) suggested with chronic illness the concept of ‘time’ is no longer viewed in terms of seasons, but assessed as priorities because a different awareness prevails. People with MG can become cautious and plan ahead of time to account for multiple outcomes if fatigue and muscle weakness overtake their body. There are no assurances about tomorrow, and time focused on the present with only brief glances ahead, because a person’s future has changed (van Manen, 2005). People with MG may also become hesitant or reluctant to engage in activities due to the uncertainty of their disease and, as a result, personal goals may need to be re-thought.

The experience of uncertainty can affect a person’s body, in particular how they interpreted their initial symptoms. Van Manen (1998) believed that because a person’s body is familiar to them, illness can make a person’s body feel strange. In a normal or healthy state a person is not usually aware of their body, which van Manen (1998) terms an ‘unaware awareness’. When wellness is disturbed, a person ‘discovers’ their body and develops a heightened sense of awareness (van Manen, 1998). If something conspicuous is ‘seen’ this can cause worry and a sense of “un-easiness” (van Manen, 1998, p6). The sudden onset, and slower onset of symptoms that affect a person’s body function with MG are similar to other types of neurological illness. The detailed and continual body awareness described by the people in this study is similar to what King et al. (2009) found in patients with MND.

Prior to diagnosis, some people either played down their symptoms, ignored them or tried to rationalise them in some way, including blaming advancing age. Fred initially ignored a lot of symptoms, but as they became more pronounced, he became increasingly self-conscious, particularly when other people noticed. Sharon also remembered feeling self-conscious about her appearance, but because she was working long hours she thought she was just being “lazy”. Margaret had many excuses for her symptoms including being “tired”, “lazy”, “overweight” and “unfit”. Interestingly, people with GBS also tried to ignore or used excuses for their initial symptoms (Forsberg, et al., 2008), as did people with MS (Barker-Collo, et al., 2006). The experience of uncertainty caused a different personal relationship with their body. Van Manen (2005) suggested this ‘normal relationship’ with the body can no longer be taken for granted.
A person’s ‘lived space’ can be affected by the experience of uncertainty in a variety of ways. Initially, when a person first experienced symptoms and after they are diagnosed, uncertainty affected everyday tasks and activities because their personal space and perceptions of their environment had been invaded and altered by disease. In this study, nearly all the people interviewed recalled times when driving was difficult due to visual problems. This was a problematic time where eyesight was unreliable, in turn affecting their ‘lived space’. The weakness and fatigue of MG, and the associated uncertainty, can limit what a person does in their environment or ‘landscape’. Fred, for example, felt his fatigue and weakness was so unpredictable, it interfered with his work and forced him to retire. The experience of uncertainty can make it difficult for people to plan their life and space, and also closely relates to ‘lived time’, because there can be constant thoughts of ‘What ifs’, ‘What if I am too tired?’ or ‘What if my muscles become weak?’ Some people with MG did not want to get ‘stuck’ in an unfamiliar ‘space’ with an exacerbation of symptoms or combating fatigue, so reduced their activities. Some people chose to isolate themselves, in familiar surroundings, in an attempt to protect their immediate ‘space’. Van Manen (2005) suggested this occurs because there can be a narrower range of possibilities that develop with the onset of disease.

A person’s relationships with others can be affected by the experience of uncertainty. In this study, it was often other people who noticed muscle weakness in a person. They expressed alarm or worry because something was strange or unusual about their loved one. This was not referred to in a negative way, but out of genuine concern for the person’s wellbeing. The people in this study who experienced an acute exacerbation of symptoms experienced enormous amounts of uncertainty, were vulnerable, and had to rely on medical and nursing support during crisis. In these situations there was no alternative to be cared for by others during an uncertain time.

Living with uncertainty was experienced in people with MG. This was where something was not known to a person, their body was unreliable and they were not completely sure or confident managing the symptoms they experienced. Living with uncertainty may be related to previous life experience and can affect all dimensions of a person’s ‘lifeworld’.
5.4 Living with weakness: altered physical strength and energy

Living with weakness was when a person lacked physical strength and energy. This study highlighted the significance of muscle weakness that is caused by MG, and was therefore an important aspect of the lived experience in a person with this disease. The experience of weakness can occur at any stage in people with MG and, as noted, was often the first sign that something was wrong. MG is essentially an invisible disease unless a person exhibits signs of muscle weakness or experiences fatigue. The weakness associated with MG has been well described in the autobiographical literature (Atkins, 2010; Byars, 2007; Cavel-Greant, 2008; Gray, 2011; Gress, 2005; Hill-Putnam, 2010; Smart, 2006) but the meaning of weakness has been elusive. Muscle weakness can be subtle or severe, acute or chronic and can have a profound effect on a person’s body and varied with each individual.

Fatigue is a common subjective experience in people with neurological disorders (Kittiwatanapaisan, et al., 2003) and in this study was strongly linked to the weakness caused by MG. Fatigue can be mental or physical and have the potential to challenge a person’s psychological well-being (Kaminski, 2009). Every person in this study experienced fatigue and developed individual coping strategies to manage it, which is similar to the findings of Grohar-Murray et al. (1998). The way fatigue was described by people in this study was interesting; they all related the experience to everyday tasks, household chores and self-care activities they had difficulty with.

The muscles affected in MG are responsible for important bodily functions including the ability to breathe, swallow, talk, see, control the head and move limbs. Weakness was experienced in different ways for each of the individuals interviewed in this study and as previously mentioned, can fluctuate and have an unpredictable course. Van Manen (1998) believed a person’s body allows them to see, hear, feel and sense things in their world and muscle weakness can mean that the ‘modality’ of the body experience is disturbed. The experience of weakness affected every aspect of a person’s ‘lifeworld’ and it should not be assumed that, because weakness associated with MG mainly effects muscles of the body, it should be restricted to van Manen’s (1990) ‘existential’ of ‘lived body’. In fact, living with weakness also influenced a person’s sense of time, space and the relationships they had with others.
As previously mentioned, the experience of muscle weakness affected a person’s sense of ‘time’ in a variety of ways. For example, Sharon, Bunty and George stated the simple task of eating a meal took longer than usual. Muscle weakness resulted in each person needing more time to chew, before they cautiously swallowed and rested to gain strength to start the process over again. Eating and drinking became a less enjoyable, time-consuming process for some people with MG, which was also found in people with MD (Boström & Ahlström, 2004). The rapid onset of symptoms and associated experience of weakness can affect a person’s ‘lived time’, in particular if they are unprepared for a sudden deterioration which they have no control over. People with MD reported increased time and planning in everyday life for self-care and domestic chores (Boström & Ahlström, 2004).

The experience of muscle weakness associated with MG had an enormous effect on a person’s ‘lived body’. During illness, a person can focus on a part of their body with a “detached curiosity” (van Manen, 1998, p.8): this part of their body can become a target for self-scrutiny. This was evident during this study, because every person was able to talk in depth about particular aspects of weaknesses in relation to their body. It was unclear why some of the people interviewed initially ignored their muscle weakness. Van Manen (1998) suggested people do try and ignore or suppress the symptoms of illness, and stated they can ‘hide’ their body from others, but their body cannot be separated from their sense of self.

A person’s body should not just be observed in the physical sense. Van Manen (1998) believed the body and mind should be viewed together as complex aspects of a person. Noteworthy in this study, is the experience of emotion associated with weakness: emotion regularly emerged during the interviews and appeared to be intertwined with the experiences of uncertainty, weakness and change in people with MG. This finding was similar to people with MD (Boström & Ahlström, 2004) and MND (Hughes, et al., 2005). Forsberg et al. (2008) found that illness can have an overwhelming effect over body and mind in people with GBS. Emotional aspects relating to weakness regularly led to frustration for some people in this study, which was similar to the experiences in people with ALS (King, et al., 2009).

John, Sharon and George all remembered feeling “scared” or “terrified” when they were having trouble breathing due to weakened respiratory muscles. This is similar to a finding in people with GBS who felt frightened, particularly when describing a
sudden onset of muscle weakness when they were losing control of their body (Forsberg, et al., 2008). Visual problems, due to weak ocular muscles, were problematic for some of the people interviewed and were most prominent when they were concentrating on a task or activity. This was similar to the experiences of people with MS (Courts, et al., 2004; Miller & Jezewski, 2006) and stroke (Burton, 2000).

Facial weakness was a distressing experience in this study. It limited some people and caused them to become self-conscious or embarrassed. Weakened facial muscles were the most obvious sign that a person’s body was affected by disease and also meant they could not convey emotion to others. Sharon found her facial weakness particularly upsetting. She felt it affected her self-esteem and wanted to hide herself from others. Facial weakness and changed facial appearance was also found to be distressing for people with MD (Boström & Ahlström, 2004). Body image is concept basic to a person’s sense of identity, security and self-esteem and Hickey (2009) stated that being ill and loosing body function can force a change in body image. In this study, Fred was so concerned about his dysarthria, as a result of muscle weakness, he did not want to go out in case people thought he was intoxicated. King et al. (2009) found that protecting a public image was significant in maintaining self-esteem in people with ALS. Van Manen (1998) suggested the perception of one’s own body, particularly with embarrassing or persistent symptoms, can lead a person thinking that others will judge them negatively. Having MG means a person lived in a different relation to their body than previously experienced: a new bodily awareness develops which is a constant reminder that disease is present.

The experience of weakness affected a person’s sense of ‘space’. When a person’s body was betrayed by MG, it made everyday tasks and activities even more challenging. For example, as highlighted in this study, if a person needed to have nasogastric feeding, they would be bound by the constraints of the feeding tube itself; even mobility was problematic because the feeding pump was always close by, invading the person’s ‘space’. Van Manen (2005) illustrated this and used an example of a wheelchair: prior to illness a wheelchair can be viewed as an object for use by a disabled person, someone who is not well. When illness is present, however, a wheelchair can be viewed as a means to move around in an environment that previously may have been elusive. A wheelchair was viewed in another light, different to what was noted previously. The same can be said about the equipment, including wheelchairs, that
restrict the ‘space’ in a person with MG. A nasogastric feeding pump enables nutrition and ultimately improves the patient’s ‘space’ on a number of levels and a walking frame assists mobility therefore lifting restrictions and increasing the ‘space’ in which a person can move.

At home, a person may be restricted in their own environment due to the constraints of muscle weakness and fatigue. This can result in difficulties and challenges with everyday life activities and potentially more sedentary activities was experienced in people with MD (Nätterlund, et al., 2001). An acute exacerbation of symptoms can suddenly invade and shape a person’s sense of ‘space’ because, for example, there are restrictions on basic bodily functions such as breathing, eating, moving and talking.

The experience of weakness affects a person’s relationship with others in several ways. In this study, on-going muscle weakness affected all aspects of daily life which resulted in reliance or dependence on others for emotional and physical support. Muscle weakness forced a person to be reliant on others, either family members or hospital staff, in different ways, for all activities of daily living and was an important aspect of the lived experience of MG. George recalled not wanting to be dependent on others for personal hygiene which is similar to what Forsberg et al. (2008) found in patients with GBS.

Living with weakness was experienced in people with MG. This was where a person endures fluctuating fatigue and muscle weakness in specific muscle groups to varying degrees. Living with weakness is closely linked to fatigue in MG and can affect all dimensions of a person’s ‘lifeworld’.

5.5 Living with change: altered control, outlook and daily life

This study highlighted the concept of change associated with MG, and is therefore an important aspect of the lived experience in a person with this disease. The people in this study made significant changes to their daily lives as a result of their experiences of MG, although, interestingly, it was not perceived or viewed in a negative manner. Numerous examples of how MG interrupted and changed aspects of a person’s ‘lifeworld’ have been highlighted in the previous chapter. The three main areas of change experienced by people in this study included: ‘change of control’, ‘change of
outlook’ and ‘change to daily life’. ‘Change of control’ involved not having control and being in control. ‘Change of outlook’ involved when people maintained a positive viewpoint and developed determination. ‘Change to daily life’ highlighted the alteration and adaptation people in this study have made in relation to self-care, hobbies, employment and driving.

Issues of control are important in chronic illness and Kaminski (2009) suggested that a person’s sense of control can be challenged with the fluctuating course of MG. All of the people interviewed in this study experienced change related to independence and autonomy, either by not having control or being in control. Although this may seem contradictory, this is similar to the findings in people with CP (Sandström, 2007) and ALS/MND (Foley, et al., 2007; King, et al., 2009). There were times when people had no control over their symptoms and treatment options, particularly when they were acutely unwell. Some people reflected on being in hospital as a time where they did not really know what was going on. Benner and Wrubel (1989) suggested the context for a person in hospital is foreign, meaning a person can feel de-situated. Bunty felt she was in a “bit of a daze”. Margaret’s statement highlighted her change of control. Being so “crook” and “low”, there was no choice: she needed help from others in all aspects of care and decision-making. These experiences are similar to those found in people with GBS, where Forsberg et al. (2008) found that people felt overwhelmingly ‘tired’ or ‘dazed’ when first diagnosed and described their time in hospital as being in a ‘bubble’. Burton (2000) found people living with stroke accepted a passive role in interactions with hospital staff and perceived loss of control over their bodies, similar to the findings of this study. Being in control was also significant in people with SMA who developed an ‘I am in control’ attitude (Lamb & Peden, 2008). Self-management and taking charge over their life and treatment was also an important finding in people with MS (Courts, et al., 2004; Miller & Jezewski, 2006).

People with MG developed a positive attitude, in addition to determination, when their symptoms improved and they started to feel better. Whether people were naturally like this, or if it was related to their MG was unclear. Burton (2000) found that there were significant differences in the way people living with stroke experienced initial recovery, similar to what the people in this study have experienced. A positive outlook and optimistic life view is also significant in people with SMA (Lamb & Peden, 2008) and ALS/MND (Brown & Addington-Hall, 2008; Young & McNicoll, 1998).
and McNicoll (1998) suggested maintaining a positive attitude in people with ALS was a coping mechanism. Forsberg et al. (2008) found people diagnosed with GBS focused on positive prognosis, with half of the people interviewed able to pinpoint a distinct turning point with their symptoms. Boström and Ahlström (2004) reported that people with MD improved psychologically with symptom improvement; which was what some people in this study experienced.

Living with change meant that life has altered significantly for a person diagnosed with MG. The experience of change affected every aspect of their ‘lifeworld’. How a person experiences time, body, space and relations with others will be different as a direct result of having MG. A person’s sense of ‘time’ can be affected due to living with the constant effects of the disease. For example, medication administration can become a dominant part of a person’s life: this process can be ritualised and a person’s day can be structured around medication times. Another effect that change had on a person’s sense of ‘time’ was the allocated ‘time’ to rest or sleep. The sense of freedom and care-freeness can be lost after diagnosis (van Manen, 2005) and a person may glance back at health because the focus of attention becomes the present.

A person’s body can be affected by change, not only in relation to the previously mentioned experiences of weakness and uncertainty, but also through the effects of treatment. Weakness and fatigue are constant reminders that disease is present in the body. In addition to this people experienced side effects from taking steroids, which was noteworthy because of the dramatic side effect they can have. A person’s body can change in size, shape and appearance as a direct result of taking the steroids that control their symptoms of MG. Although this was not directly related to MG, it was a pertinent aspect of the lived experience. While the positive benefits of steroids and a reduction of their symptoms was acknowledged by Sharon, George and Bunty, the side effects of prednisone were problematic for every person in this study, which is similar to autobiographical experiences (Gray, 2011; Hill-Putnam, 2010; Smart, 2006). The effect of other medication, particularly azathioprine, on the body was another concern for some people in this study. In illness, a person learns to develop a new liveable relationship with their body because it is distinctly different (van Manen, 2005).

Kaminski (2009) stated that fatigue associated with MG can interfere with people’s ability to do activities and attend social functions. A person’s altered speech can be problematic during conversation, and facial weakness can induce embarrassment.
due to the inability to display facial expressions, and there is personal discomfort when eating is difficult (Kaminski, 2009). All of these situations were referred to during the interviews and interfere with a person’s sense of ‘space’.

The people in this study have made adaptations that better suit the ‘space’ where they live. Limitations of disease became a natural part of everyday life, people learn to live with their diagnosis and no choice but to adapt (Boström & Ahlström, 2004; Hughes, et al., 2005). Nätterlund et al. (2001) found people with MD found their own coping strategies to avoid being dependant on others. Lamb and Peden (2008) found people with SMA adopt creative and innovative ways to manage their symptoms that involve planning ahead and conserving energy. This does also relate to the concept of ‘time’. This study highlighted how people did household chores: Margaret developed a very structured approach to her housework, while George gave examples of how he struggled to do house hold chores because of his fatigue. People with MS were forced to make lifestyle changes, while others adapted and learned to work around their symptoms (Courts, et al., 2004). This was similar to a study by Wilson, Whitehead and Burrell (2011) who reported people with chronic fatigue managed energy by moderating and avoiding excess in activities.

The concept of ‘space’ can be affected by the experience of change because a diagnosis of MG means a person’s environment changes and home life, hobbies and employment can be affected. Becoming unwell can change daily routines (Greenberg, 2007) and affect quality of life (Kaminski, 2009). The associated changes with illness intrusiveness, can cause lifestyle disruptions which can restrict activities and interests (Kaminski, 2009). This was also found in people with MD (Boström & Ahlström, 2004), ALS (Young & McNicoll, 1998), MND (Hughes, et al., 2005) and stroke (Burton, 2000). This was similar to the experiences in the autobiographical literature that highlights, in particular the impact MG has on employment (Byars, 2007; Gray, 2011; Hill-Putnam, 2010). McCabe et al. (2004) found that neurological illness impacted negatively on employment because people have to make significant changes in work practices because of their illness. Fatigue was noted to be an issue resulting in some people opting to work part time to meet the demands of employment or retire early (McCabe, et al., 2008), which was similar to the reasons why people stopped work in this study.
In a response to change, several people in this study used humour when describing their symptoms. People often laughed or joked when they described significant periods of muscle weakness particularly in relation to the visual changes that occurred when driving. George recalled joking with his friends that he would soon have to wear an eye patch like a pirate. This was like a challenge ‘reframed’ as an adventure as termed by Young and McNicoll (1998) who suggested a sense of humour can be used as a coping mechanism and used to maintain friendships because it can make family and friends feel at ease. King et al. (2009) found that laughter and black humour can become strategies to counteract inner negative feelings, especially the demoralising aspects of MND. Perhaps humour was used by the people in this study because they were comfortable in their own ‘space’, because the interviews were conducted in their own homes.

The experience of change can affect a person’s relationship with others. In this study, the importance of believing in a higher power, God, or faith, was highlighted by Fred and Sharon. A diagnosis of MG meant the relationship they had with their neurologist became more important. People with MG relied on their neurologist and other health professionals in a different way than prior to diagnosis. Friendships with others can change, either diminished friendships due to decreased socialising or increased new friendships as a direct result of being diagnosed with MG and having shared common experiences. Kaminski (2009) suggested that developing a strong social support can provide a ‘buffer’ to some of the challenges people with MG face.

The experience of change was a significant part of the lived experience in people with MG. Living with change can affect every dimension of a person’s ‘lifeworld’ because there are many aspects of life a person with MG must consider, change or adapt to. The experience of change in people with MG was either forced or decided by the person and altered the way they view and live their life, because a diagnosis of MG meant their life was different and would never be the same.

5.6 Implications for nurses and other health professionals

The findings of this study have significance for neuroscience nurses involved in caring for patients with MG because this research adds to the existing body of knowledge, identifies important considerations for nursing practice and fills a gap in the
nursing literature. The results are not only significant for nurses and neuroscience nursing, but for other health professionals who work with this specialist group of patients. MG is disabling, can cause problems with breathing, swallowing, communication, vision, mobility and mood. These symptoms can affect every dimension of a person’s being. Nurses are in a unique position to understand the disease process and its meaning for the patient (Benner & Wrubel, 1989). Van Manen (1998) recommended that people working in health care should be aware of how the body is experienced in various modes of wellness, illness, comfort and discomfort. Investigating a nursing concern allows a better understanding of patient needs and provides a cornerstone for holistic nursing care (Foster, 2010). Nurses have an important and significant role when helping patients with MG adapt and cope with their illness. The implications of this study for nurses involve assessment, care, collaboration, patient education and research.

5.6.1 Nursing Assessment, Care and Collaboration

Taking an accurate history is an essential nursing skill, so nurses should note how patients describe their symptoms and be aware of the significance of these in patients with MG. Nurses should continually assess and reassess their patients, in hospital or community settings, for subtle changes in neurophysiology that may cause an exacerbation of weakness. It is also important to be aware of the symptoms of MG and how they affect each individual person, understanding that fatigue can make a mild symptom worse. Meticulous respiratory assessment is essential when caring for patients with MG in addition to showing sensitivity, calmness and providing timely support to a patient who is experiencing difficulty breathing.

This study highlights several issues surrounding swallowing and nutrition that nurses should be aware of. Firstly, regular on-going swallowing assessments are critical and nurses need to assess for signs of aspiration in their patients. Understanding that eating itself can cause fatigue in patients with MG means that nurses need to support their patients and help develop a plan for eating that maximizes calorie intake while conserving energy. Understanding the difficulty of eating certain types of food is also significant for nurses so they can ensure patients receive appropriate food and adequate nutrition. Nurses also need to accurately document their patient’s food and fluid intake as well as ensuring timely referrals to a speech therapist and dietician if required.
Hickey (2009) stressed the importance of starting nasogastric feeding early because physiological dysfunction and stress can change the requirements of nutrients that are required for cellular function and energy. Early enteral feeding is a critical component of the recovery process and a NGT is vital for the administration of medication used to treat the symptoms, especially if the person is having difficulty swallowing (Hickey, 2009).

Nurses need to be aware how physical weakness of the body and face can have associated stigma and affect a person’s body image. People have differing perceptions of their bodies, therefore it is crucial the nurses identify body image issues promptly and work with the patient to maintain their self-image. Nurses need to be mindful of the patient’s ‘landscape’ when considering weakness or physical barriers, in hospital or at home and provide support accordingly. It is important that nurses regularly assess their patient’s mental health to ensure they receive prompt psychological support. It is essential that nurses assess their patients’ physical and emotional needs if they are unwell in hospital. During this time nurses need to use all their skills in advocacy and respect while maintaining their dignity, because it seems that some people with MG try and appear as though they are coping when they really might need help. Even with the most basic of cares, if patient’s are affected by weakness or fatigue, it is important for nurses to assess each patient and their space and consider these issues when planning care. Ongoing assessment of fatigue is important and nurses need to ensure their patients have realistic coping strategies.

From this study, it was clear that relationships with others are significant in people with MG. It is important that nurses identify these relationships and support them appropriately. Young and McNicoll (1998) found human contact and building social support networks were important for people with ALS. Because faith was a key finding of this study, nurses need to ensure spiritual needs are assessed and supported appropriately at all stages of the disease process. LaDonna (2011) recommended patients with neuromuscular disorders should seek solace in their spirituality. Awareness, insight and understanding the human experience of MG, may help improve, promote and protect the health of Māori and other ethnic groups in NZ when the results of this study are disseminated. Encouragement during rehabilitation is significant and nurses should be involved in acknowledging the improvements their patients make.
5.6.2 Patient Education

Initially, some of the people interviewed in this study expressed a lack of knowledge in relation to MG. O’Brien (2004) recommended that nurses need to identify the information needs of each individual patient and ensure they are provided with sufficient appropriate information. People need practical information about their illness (Hughes, et al., 2005) and nurses should be involved in educating their patients regarding issues relating to symptom management and treatments prior to being discharged.

It is also essential that patients understand what medication they need to take and how medication might exacerbate symptoms. Nurses might need to consult with a pharmacist to provide education or assistance with safely organising patient medication if required. Supporting patients during steroid therapy is important and patients may require education about prednisone and its effects. Nurses may need to work with family members and other health professionals to set up robust support systems for when the patient is discharged back to their own home environment.

Some of the people in this study felt isolated after being diagnosed with MG. The myriad of online websites and social networking sites could address this and may be useful when people are first diagnosed or for health professionals. Social relationships can be maintained with others due to numerous online sites and support chat rooms, which may be particularly useful for people with severe disease or disability. However any information viewed online should be viewed with caution. Information was found to be useful when people with MG were first diagnosed. Sometimes a print out from a website contained technical information was given to a person when they were in hospital. What some people with MG or family members may find easier could be a pamphlet that contains pertinent and easy to understand information relating to the disease.

5.6.3 Nursing Research

Nurses have a privileged place within health care and have the ability to learn from patients to further develop clinical knowledge. The findings of this study will enable nurses and other health professionals involved in caring for people with MG to understand more about this disease, what the experiences mean for each person and why
they are significant. This study promotes nursing research and may hopefully encourage others to engage in research, particularly in the specialist area of neuroscience nursing.

5.7 Recommendations

There were three main gaps identified in the literature reviewed for this study: a lack of nurse-led research about MG, no phenomenological research that addressed the lived experiences in people with MG and limited NZ research. This study addressed all three of these areas, but has also highlighted areas for further development. The following recommendations have been drawn from the findings of this study.

5.7.1 Living with uncertainty

Due to the rare nature of MG, it is important for health professionals involved in diagnosis to include MG as a differential diagnosis. Nurses and other health professionals, need to be aware of the symptoms of MG and understand that the disease can be unpredictable. Patients with MG need regular, ongoing assessments by nurses and other health professionals, and timely treatment, support and reassurance where needed.

5.7.2 Living with weakness

Nurses and other health professionals need to understand the symptoms of MG, in particular muscle weakness and how it can vary among individuals at different times of disease remission and relapse. Patients with MG may need regular assessment of muscle weakness: it is important that nurses are involved with this and support their patients accordingly. Nurses, in particular, need to be aware of muscle weakness that can occur if a patient is not administered anticholinesterase medication at the prescribed time.
5.7.3 Living with change

Nurses and other health professionals need to be aware that a person diagnosed with MG will experience significant change at various stages of disease progression. Change is individual to each person and it is important that nurses and health professionals recognise, support patients appropriately and consult with allied health when necessary.

5.7.4 Supportive relationships

Nurses and other health professionals need to be aware of and support their patients with MG in their relationships with others. This may involve working with the patient to facilitate family meetings, supporting social networks and encouraging spiritual connections where appropriate.

5.7.5 Patient education and support

Advice for patients from health professionals, including nurses, should be consistent and generic. This should include educational pamphlets that explain MG, diagnostic procedures and treatment options. These should be available for people diagnosed with MG and their families. In addition to written material, it is essential that nurses are involved in assessing each patient with MG for their individual learning needs, because nurses need to be involved in every aspect of care. The MDA website is informative and has a link to a five page information sheet that can be printed off. Educational resources on MG can also be requested from the MDA. There are numerous social networking sites and internet based forums where people can share their experiences about MG. Although these have not been explored in this study, they may offer support to people diagnosed with MG that feel isolated or want to share their experiences with others.

5.7.6 Professional development for nurses and health professionals

Health professionals, including nurses, should be educated about MG and have access to regular education updates that relate to all aspects of caring for this patient population. Professional development should include a balance of information that is evidence based and patient focussed.
5.7.7 Data collection
At a national level, data collection of people with MG is very limited in NZ. The Ministry of Health only records discharges from public hospitals. These figures are hard to decipher and it is unclear if they are singular discharges or the same person that may have had multiple discharges. Data collection in NZ should also include the collection of ethnicity data as well as other relevant details that could help with planning resources and care.

5.7.8 Further research areas
There is a lack of nurse led neuroscience research internationally, especially in relation to MG. The importance of nurses conducting research has been stressed by some of the qualitative research articles reviewed in this study and highlighted the need for nurses to not only be involved as primary researchers, but to conduct such research. Nurses working with people with MG should be encouraged and supported to participate in research projects where appropriate. The association between MG and fatigue is established in the nursing literature and this study highlights numerous other avenues that could be explored from a nursing and patient perspective. These could include: thymectomy experience, intensive care experience and tracheostomy experience as they related to people with MG. There is also scope for a nationwide quantitative study in NZ that examines MG, for example, from ethnicity, age, gender and financial impact perspectives of the disease. This would add to the existing body of knowledge, provide an independent understanding of MG with the NZ context and potentially assist with health resource planning.
6. Conclusion

MG is a rare and complex, but well understood disease with many different signs and symptoms that involve fatigue and fluctuating muscle weakness. In nursing, personal accounts are central to understanding the meaning of an illness to a person. There was a great quantity of science based literature about MG. However, there was limited nursing research on MG. Most of the nursing literature was either dated or involved summaries from text books and in some instances, was even poorly written. Medical literature in relation to MG tended to focus on unusual presentations of the disease, historical data or randomised controlled trials about treatment options. There was limited information addressing patient experience for neurological conditions in general and no qualitative studies that examine the lived experience in people with MG. There was a lack of literature that has been conducted in NZ, but research is starting to emerge from other health related disciplines.

The aim of this study was to gain insight and understanding into the experiences of adults living with MG, identify and extract the embedded meaning for people with this disease. This study examined the experiences of seven people living with MG. The findings of the study were unique and provide a platform to view the lived experience using a phenomenological lens so that all of the ‘existentials’ of the ‘lifeworld’ as developed by van Manen (1990) are brought to the fore.

What is the meaning of this disease? From this study, the experiences in people with MG tell us that it is an individual experience with similar aspects that are shared by others with the disease. MG is an intrusive disease that causes physical and psychological challenges differently for each individual affected. The meaning of MG is multifaceted. The experiences of the people interviewed in this study are unique to their ‘lifeworld’. This study has identified that people who have the same diagnosis of MG experience the disease in different ways, but do have common elements that are similar to others types of neurological disease. A person with MG lives in a dynamic equilibrium in their world where the experiences of uncertainty, weakness and change are interlinked and always present in some shape or form. These experiences can be subtle or severe and serve as a constant reminder that disease is present, even if a person is in remission. The experiences of living with uncertainty, living with weakness and
living with change affect every dimension of a person’s ‘lifeworld’, including their sense of time, their body, the space in which they live and their relationships with others.

This unique study raises awareness of MG and brings valuable human insight to the forefront. A review of the literature revealed an international lack of nurse led studies, little inquiry of patient experiences with MG and minimal NZ research. These gaps in the literature shaped this interpretive phenomenological study that has been guided by the research methodology of van Manen (1990). The results demonstrate how changes in a person’s body with MG can also affect the person psychologically and emotionally. The physical symptoms and emotional effects of MG are multifaceted. The findings, although independent, support existing studies in the area of neurological illness and add to the existing body of neuroscience knowledge. This study is significant to nursing and may enhance clinical practice for all health professionals caring for people with MG.

Where to from here? This study was the first of its kind, in that it is a NZ, nurse led phenomenological inquiry into the lived experiences of people with MG. The objective of this study has been achieved because insightful descriptions were provided by people with MG these were, in turn, interpreted in an attempt to understand the lived experience. It has opened the door so that nurses and other health professionals can further examine issues pertinent to people with MG, as there are endless possibilities for future enquiry.
1. References


2. Appendices

2.1 Appendix A - Cultural consultation letter

11 February 2010

Ms Lorraine Ritchie
Centre of Postgraduate Nursing Studies
University of Otago, Christchurch

Mā te rangahau hauora e tautoko te whakapiki ake te hauora Māori
All health research in Aotearoa New Zealand benefits the hauora (health and wellbeing)
of tangata whenua

Tena koe, Lorraine

Thank you to you and Trudy Keer-Keer, for taking the time to meet with me at the University of
Otago, Christchurch on Monday 8th February 2010, to discuss her research study titled:

What is the Lived Experience of a Patient with Myasthenia Gravis

I note that the research is to raise the awareness of myasthenia gravis.

You mentioned that myasthenia gravis is a rare disorder of the neuromuscular junction, with
approximately 50 people in Canterbury living with it. However at this stage it is unclear how
many are Māori.

We discussed the relevance of the research in regard to improving Māori health status and
referred to the HRC’s Ngā Pou Rangahau Hauora Kia Whakapiki Ake Te Hauora Māori 2004-
other reference that is available is Hauora Māori Standards of Health IV: A study of the years
2000-2005 by Bridget Robson and Ricci Harris, Māori Health Research Unit, Wellington School
of Medicine. All provide Māori specific information on a range of health issues.

The recent publication Tatau Kahukura, Ministry of Health, 2006, is an update relating to the
socio economic determinants of health, health status and service utilisation of the Māori
population. Further references are available from the HRC’s Guidelines for Researchers on

There is no mention in the publications of myasthenia gravis in relation to Māori health status.

It is also advisable that researchers review and refer to the District Health Board Annual Plan
and/or the current Health Targets published by the Ministry of Health (1 July 2009).

It was agreed that although there were ten people to be interviewed, there is a need to
acknowledge the issues pertaining to ethnicity and to consider how ethnicity data will be
collected in your study.

Also, given the poor ethnicity data collection in hospital databases this information should be
collected in demographic information as part of the research. Through our discussion the
Census 2006 ethnicity question was considered to be the preferred tool in recording ethnicity.
It is a requirement of the ethics approval process that a final report be submitted when the research is complete. A copy of the report should be provided to me at that time as findings from this project may contribute to the development of future research hypotheses or projects. It is therefore important that appropriate Maori organisations, Maori health professionals and Maori researchers are aware of your findings. The Research Office of the University of Otago, Christchurch and in particular myself as the Research Manager of Maori health would be willing to assist in the dissemination of your findings once your project has reached a successful conclusion.

My suggestions do not necessarily relate to ethical issues with the research, including methodology. Other committees may also provide feedback in these areas. I hope this letter will suffice in terms of the application. Please contact me should you need any other information that may not have been included in the letter relevant to our conversation.

I wish you well in your research.

“Mo tatou a mo ka uri a muri ake nei” Ngai Tahu 2025

Ka nui tonu nga mihi

[Signature]

Elizabeth Cunningham
Research Manager - Maori
## 2.2 Appendix B - Locality approval form

### Locality Assessment by Locality Organisation

Refer to pages 13-15 of Guidelines for Completion of the National Application Form for Ethical Approval of a Research Project (NAFG-2009-v1).

**Locality organisation sign off**

Ethics committees review whether investigators have ensured their studies would meet established ethical standards if conducted at appropriate localities. Each locality organisation is asked to use the locality assessment form to check that the investigator has also made the appropriate local study arrangements.

Ethics approval for study conduct at each site is conditional on favourable locality assessment at that locality.

Please note that the locality organisation may have additional requirements to be met before a study may commence at that locality.

### Part One: General

To be completed by the principal investigator for this locality.

<table>
<thead>
<tr>
<th>Field</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full project title:</td>
<td>What are the Lived Experiences of patients with Myasthenia Gravis?</td>
</tr>
<tr>
<td>Short project title:</td>
<td>What are the experiences of people with Myasthenia Gravis?</td>
</tr>
<tr>
<td>Locality to be assessed:</td>
<td>Canterbury District Health Board (Christchurch Public Hospital).</td>
</tr>
<tr>
<td>Brief outline of study:</td>
<td>This study will explore the experiences of people in New Zealand with myasthenia gravis. Myasthenia gravis is a rare, chronic neurological disorder. The main symptoms are fatigue and fluctuating muscle weakness. Currently, 50 people in Canterbury are living with myasthenia gravis. There are very few studies done by nurses in this area. There is very little information on how people manage their symptoms and the impact that the disorder has on their everyday life. Eight to ten participants will be interviewed about their experiences in hospital and topics related to the disorder. This study hopes to raise awareness of myasthenia gravis and help nurses and other health professionals plan care for these patients in hospital and community settings.</td>
</tr>
<tr>
<td>Principal investigator (for this locality):</td>
<td>Trudy KEER- KEER (Clinical Nurse Educator – Ward 28)</td>
</tr>
<tr>
<td>Contact details:</td>
<td>(03) 364 0640 (ext 89280), <a href="mailto:trudy.keer-keer2@cdhb.govt.nz">trudy.keer-keer2@cdhb.govt.nz</a></td>
</tr>
<tr>
<td></td>
<td>(03) 310 0585 (home), 0274 177667 (Cell), <a href="mailto:hausfrau@xtra.co.nz">hausfrau@xtra.co.nz</a></td>
</tr>
<tr>
<td>Other local investigators (list all at this site):</td>
<td>N/A</td>
</tr>
<tr>
<td>Contact details:</td>
<td>N/A</td>
</tr>
</tbody>
</table>
Part Two: Locality Issues

To be completed by the principal investigator for this locality and signed by the authorised locality representative. (See the Guidelines (NAFO-2009-v1) (pages 13–15) for more information and examples.) Identify any local issues and specify how these issues will be addressed.

1. Suitability of local researcher
For example, are all roles for the investigator(s) at the local site appropriate (for example, has any conflict the investigator might have between her or his local roles in research and in patient care been adequately resolved)?

   X Yes □ No

2. Suitability of the local research environment
   a) Are all the resources (other than funding that is conditional on ethical approval) and/or facilities that the study requires appropriate and available (for example, is staffing adequate? Is this site accessible for mobility-impaired people where necessary)?

   X Yes □ No

   b) Have all potentially affected managers of resources such as patient records or laboratory managers been notified?

   X Yes □ No

3. Have issues such as cultural issues specific to this locality or to people being recruited at this locality been addressed?

   X Yes □ No

4. Have the local investigator contact details and other important contact details been provided to the locality organisation for checking?

   X Yes □ No

Part Three: Declaration by locality organisation

I am authorised to complete locality approval on behalf of this locality organisation. I understand that I may withdraw locality approval if any significant local concerns arise. I agree to advise the principal investigator and then the relevant ethics committee of this occur.

(Questions 1–4 at Part Two above must be completed prior to signing.)

I confirm the organisation has sufficient indemnity insurance to compensate participants for harm that does not qualify for compensation under the Injury Prevention, Rehabilitation and Compensation Act 2001.

Signature: [Signature]
Name: [Name]
Date: [Date]
Position: [Position]

[Name]
[Name]
[Date]
[Position]

General Manager
Medical & Surgical
Christchurch Hospital
2.3 Appendix C - Ethical approval letter

Upper South B Regional Ethics Committee
Ministry of Health
4th Floor, 260 Oxford Tce
PO Box 3877
Christchurch
Phone (03) 372 3019
Fax (03) 372 1015
Email: uppersouth_ethicscommittee@moh.govt.nz

26 April 2010

Ms Trudy Keer-Keer
8 James Drive
Woodend
7610
North Canterbury

Dear Ms Keer-Keer

Ethics ref: URB/10/03/008
Study title: What are the Lived Experiences of patients with Myasthenia Gravis?
Investigators: Ms Trudy Keer-Keer, Ms Lorraine Ritchie, Ms Beverly Burrell
Localities: Christchurch Hospital

The above study has been given ethical approval by the Upper South B Regional Ethics Committee.

Approved Documents
Information Sheet version 2 dated April 2010
Consent Form version 1 dated March 2010
Letter for neurologist version 2 dated April 2010
Expression of interest version 1 dated April 2010
Ethnicity question version 1 dated April 2010
Letter for participants version 2 dated April 2010
Questions for interview schedule

Accreditation
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports
The study is approved until 31 December 2011. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator’s responsibility to forward a progress report covering all sites prior to the ethical review of the project in April 2011. The report form is available at http://www.ethicscommittees.health.govt.nz. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.
Amendments
It is also a condition of approval that the Committee is advised of any adverse events, if the
study does not commence; or the study is altered in any way, including all documentation eg
advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment
or administrative facilitation by any healthcare provider within whose facility the research is to
be carried out. Where applicable, authority for this must be obtained separately from the
appropriate manager within the organisation.

We wish you well with your study.

Yours sincerely

Mrs Diana Whipp
Administrator
Upper South B Regional Ethics Committee
Email: diana_whipp@moh.govt.nz
2.4 Appendix D - Letter to participants

Centre for Postgraduate Nursing Studies
University of Otago, Christchurch
PO Box 4345
CHRISTCHURCH 8140

August 2010

To whom it may concern

I would like to invite you to participate in a unique study about the experiences of people in Canterbury living with myasthenia gravis. Your neurologist has forwarded this letter to you on my behalf. Included is an information sheet that describes the study in more detail. I am a registered nurse working on a thesis for my Master's degree.

If you would like to participate in this study, would like further information or have any questions, please contact me by phone or email as below. Alternatively you may wish to return the expression of interest form in the reply paid envelope and I will contact you.

Yours sincerely

Trudy KEER-KEER - RN BN PGDipHealSc(Nursing)

Phone: (03) 3100 585
Cell phone: 027417 7667
Email: hausfrau@xtra.co.nz

Letter for participants – Version Two (April 2010)
2.5 Appendix E - Information sheet

**Information Sheet**

**What are the experiences of people with Myasthenia Gravis?**

You are invited to take part in a unique study about the experiences of people in New Zealand living with Myasthenia Gravis.

**Participation**

Your participation is entirely voluntary (your choice). If you do agree to take part, you are free to withdraw from the study at any time, without having to give a reason, and this will in no way affect your continuing health care. Participation in this study will be stopped should any harmful effects occur. If you wish to take part in this study you will need to sign a consent form.

**About the study**

This study will explore the experiences of people in New Zealand with myasthenia gravis. It hopes to raise awareness of myasthenia gravis, educate health professionals and help plan care in hospital and the community. Participants have been recommended for this study by their neurologist. Eight to ten participants will be interviewed about life experiences related to myasthenia gravis. The study is based in Christchurch and will end in October 2011. The researcher is working on a thesis for a Master’s degree.

For this study, you will be interviewed once for 60-90 minutes. If fatigue is a problem, you may wish to have two shorter interviews. The interview will be audio recorded and the tapes transcribed. The transcripts will be sent to you to check you are happy it is a correct record of what you have chosen to share. After the study you may keep the tape if you like.

Information Sheet – Version Two (April 2010)
You will be asked which ethnic group you belong to for statistical purposes (The 2006 Census ethnicity question).

**Benefits, risks and safety**
By sharing your experiences you may help health professionals develop a deeper understanding about myasthenia gravis. You must be over 18 and be in good health. There will be no financial cost to you if you wish to be interviewed at home. If you do not want to be interviewed at home, you will be given a small petrol and/or parking voucher to use so you can be interviewed at a place negotiated with the researcher.

**General**
You can get more information about the study from the researcher or supervisors. If you need an interpreter, one will be provided. You may have a friend or whānau support to help you understand the risks and/or benefits of this study and attend the interview if you wish. You do not have to answer all the questions, and you may stop the interview at any time. The Department of Neurology at Christchurch Hospital is aware of this study.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050  
Free fax: 0800 2 SUPPORT (0800 2787 7678)  
Email: advocacy@hdrc.org.nz

**Confidentiality**
Pseudonyms will be used in reports on this study so that no material could personally identify you. Records will be stored securely in accordance with the University of Otago guidelines to ensure information is kept confidential during this study. The researcher and study supervisors will be the only people who have access to the data during

*Information Sheet – Version Two (April 2010)*
the study. After the study, records will be stored at the University of Otago.

**Results**

The results of this research will be published in thesis form. A paper from the thesis will be presented at a conference and published in nursing journals. There will be a delay between the interview and publication of results. A summary of the findings can be sent to you if you wish or the outcomes can be discussed with you individually.

**Statement of approval**

This study has received ethical approval from the Upper South B Regional Ethics Committee, ethics reference number URB/10/03/008.

Please feel free to contact the researcher or supervisors if you have any questions about this study.

**Principal Investigator:** Trudy KEER-KEER - haufrou@xtra.co.nz  
Phone (03) 310 0585 or 027 4177667  
Centre for Postgraduate Nursing Studies  
University of Otago  
PO Box 4345  
CHRISTCHURCH 8140

**Study Supervisors:** Lorraine RITCHIE — lorraine.ritchie@otago.ac.nz  
Phone (03) 364 3850 or 027 5446405

Beverley BURRELL — beverley.burrell@otago.ac.nz  
Phone (03) 364 3850

Information Sheet – Version Two (April 2010)
2.6 Appendix F - Expression of interest form

What are the experiences of people with Myasthenia Gravis?

I am interested in participating in this study.

I am happy for the researcher to contact me.

NAME: ............................................................................................................

CONTACT DETAILS:

Home telephone number: ............................................................................

Cell phone: ....................................................................................................

Email: ...........................................................................................................

PREFERRED METHOD OF CONTACT: .........................................................

Expression of Interest – Version One (April 2010)
2.7 Appendix G - Consent form

**Consent Form**

What are the experiences of people with Myasthenia Gravis?

<table>
<thead>
<tr>
<th>Language</th>
<th>Statement</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>I wish to have an interpreter</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Deaf</td>
<td>I wish to have a NZ sign language interpreter</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Maori</td>
<td>E hiaha ana ahu ki tetahi kaiwhaka Maori/kaiwhaka pakeha korero</td>
<td>Ae</td>
<td>Kao</td>
</tr>
<tr>
<td>Cook Island</td>
<td>Ka inangaro au i tetai tangata uri reo</td>
<td>Ae</td>
<td>Kare</td>
</tr>
<tr>
<td>Fijian</td>
<td>Au gadreva me dua e vakadewa vosa vai au</td>
<td>Io</td>
<td>Sega</td>
</tr>
<tr>
<td>Niuean</td>
<td>Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu</td>
<td>E</td>
<td>Nakai</td>
</tr>
<tr>
<td>Samoan</td>
<td>Ou te mana'o ia i ai se ta'amataia upu</td>
<td>Ioe</td>
<td>Leal</td>
</tr>
<tr>
<td>Tokelauan</td>
<td>Ko au e foufou ki he lino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika</td>
<td>Ioe</td>
<td>Leai</td>
</tr>
<tr>
<td>Tongan</td>
<td>Oku ou tiema'au na fakatonulea</td>
<td>Io</td>
<td>Ikai</td>
</tr>
</tbody>
</table>

I have read and I understand the information sheet dated March 2010 for volunteers taking part in the study designed to explore the experiences of people with myasthenia gravis.

I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whānau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my continuing healthcare.

Consent Form – Version One (March 2010)
<table>
<thead>
<tr>
<th>Statement</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I understand that my participation in this study is confidential and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>that no material that could identify me will be used in any reports on</td>
<td></td>
<td></td>
</tr>
<tr>
<td>this study.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I understand that the interview will be stopped if it should appear</td>
<td></td>
<td></td>
</tr>
<tr>
<td>harmful to me.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have had time to consider whether to take part in the study.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know who to contact if I have any side effects from the study.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know who to contact if I have any questions about the study in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>general.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I understand the only people who will have access to the data during</td>
<td></td>
<td></td>
</tr>
<tr>
<td>the study will be the researcher and study supervisors.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I consent to my interview being audio taped.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I wish to receive a copy of the summary of findings.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

I .............................................. hereby consent to take part in this study.

Date:

Signature:

Full names of researchers: Trudy KEER

Contact phone number for researchers: (03) 310 0585  027 4177967

Project explained by: Trudy KEER

Project role: Researcher

Signature:

Date:

Consent Form – Version One (March 2010)
2.8 Appendix H - Ethnicity question

Which ethnic group do you belong to?
Mark the space or spaces that apply to you.

<table>
<thead>
<tr>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Zealand European</td>
</tr>
<tr>
<td>Māori</td>
</tr>
<tr>
<td>Samoan</td>
</tr>
<tr>
<td>Cook Island Maori</td>
</tr>
<tr>
<td>Tongan</td>
</tr>
<tr>
<td>Niuean</td>
</tr>
<tr>
<td>Chinese</td>
</tr>
<tr>
<td>Indian</td>
</tr>
<tr>
<td>Other (such as Dutch, Japanese, Tokelauan). Please state:</td>
</tr>
</tbody>
</table>

Ethnicity Question – Version One (April 2010)
2.9 Appendix I - Questions for Interview schedule

**Questions for Interview Schedule**

Describe the initial symptoms of myasthenia gravis that you experienced?

Describe how you feel about your myasthenia gravis now compared with when you were first diagnosed?

Describe how myasthenia gravis has affected your relationship with others?
[For example friends, family members, work colleagues]

Describe how myasthenia gravis has affected your activities of daily living?
[For example showering, caring for family members, employment, hobbies]

Explain the treatment(s) you receive for your condition and their effects for you?
[For example medication, surgery, physiotherapy, counseling]

Describe your experiences of being in hospital with myasthenia gravis?

Explain any respiratory problems you have had because of myasthenia gravis?
[For example changes in diet, swallow difficulties, weight loss]

What strategies do you have for managing fatigue?

What strategies do you have for managing muscle weakness?

Describe any pain you experience as a result of myasthenia gravis?
3 April 2012

Trudy Keer-Keer
8 JAMES DRIVE
WOODEND
WAIMAKARIRI 7610

Dear Trudy

Re: application for NERF research grant

Thank you for your application for a NERF research grant. The NERF scholarship committee would like to advise you that your application has been successful and you have been awarded $1000. This has been Direct Credited to your designated bank account. Unfortunately the research grant does not provide funding for fees.

The scholarship committee would like to remind you of the following conditions of receiving funding:

- The Nursing Education and Research Foundation must be acknowledged in all publications and presentations associated with your research (please contact Tessa Cate – tessac@nzone.net.nz – for a copy of the NERF logo for use in presentations);
- A report of your research must be submitted to NERF within six months of completion.

The scholarship committee would like to wish you good luck with your studies and they look forward to receiving your report in due course.

Yours sincerely

Dr Jill Clendon
Secretary, Nursing Education and Research Foundation