HEALTH INFORMATION NEEDS OF PATIENTS LIVING WITH MYASTHENIA GRAVIS:

A NARRATIVE INQUIRY

A Thesis Submitted to the College of
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In Partial Fulfillment of the Requirements
For the Degree of Master of Nursing
In the College of Nursing
University of Saskatchewan

By

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ABSTRACT

Myasthenia gravis (MG) is a rare autoimmune disease that affects the neuromuscular junction of voluntary muscles, resulting in muscular dystrophy. The disease is termed the snowflake disease due to the variability of symptoms, disease progression, and effective treatments for each individual. As the implications of the disease are mostly invisible, many individuals living with MG feel misunderstood and marginalized.

The purpose of this study was to explore the stories of individuals living with MG through a narrative inquiry (NI) lens. The aim was to understand the information-seeking practices from the onset and duration of their disease experiences. Research and available studies of information-seeking for patients living with rare diseases was limited, but there was a complete lack of studies exploring the health-information needs of patients living with MG. The available literature also focused on quantitative methods, leaving an absence of qualitative studies. This study addressed the gap in the literature for assessing the health-information needs of patients living with MG and gave these individuals a voice in the system that often left them feeling isolated and stigmatized.

Four participants shared their stories and experiences. Conversations took place online over Zoom to accommodate geographic distance and physical limitations due to the illness. The analysis revealed four resonant threads throughout the participant stories: reasons for seeking information, sources of information, changes in information seeking over time, and satisfaction with information. From the analysis and interpretation, recommendations have been made for nursing practice, education and professional development, and future research.
ACKNOWLEDGEMENTS

First and foremost, I would like to thank the participants of this study for trusting me with your stories. I will remain grateful and appreciative of your time and openness, allowing me to live your experiences alongside you. You have all inspired me to continue advocating for myself and others in the MG community, and to strive for a higher quality of life. I will remain grateful for your friendship, encouragement, and support. You have all improved my life, and I hope I have done the same for you.

I would like to extend a big thank you to my supervisor, Dr. Noelle Rohatinsky. Thank you for your ongoing support, encouragement, and guidance. You have helped me grow in academia and as a writer as I navigated the process of narrative inquiry. You helped me to stay focused and keep my thesis manageable, reminding me to keep the research puzzle at the forefront. Thank you for your mentorship, expertise, and understanding as I pursued my graduate degree within my own health issues and limitations.

Thank you to my committee member Dr. Anthony de Padua. Your expertise in narrative inquiry and willingness to provide ongoing support will not be forgotten. I aspire to reach the level of experience and knowledge of narrative inquiry that you exemplify.

Thank you to my family for their unwavering support as I pursued a master’s degree over the course of the Covid-19 pandemic and throughout my own journey with myasthenia gravis. Nothing other than emotional support and encouraging words were directed my way. Lastly but absolutely not least, a thank you to my beautiful, inspiring, and supportive children. Despite their young age and lack of knowledge and experience with chronic illnesses, they both have been the most empathetic, helpful, and verbally supportive people I have had in my corner during this time.
DEDICATION

I dedicate this study to all individuals living with MG and their families. Every one of you are an inspiration. The disease is unique to every one of us, but together we are strong and unstoppable. Continue to engage in the challenges, strive for an improved quality of life, and never let your hope for the future waver. Life is unpredictable, myasthenia gravis is not what we imagined for ourselves, but we have much to gain from each other and how the illness forces us to grow. Your life may look different, but it will still be wonderful in many ways.

“When we deny our stories, they define us. When we own our stories, we get to write a brave new ending.”

- Brené Brown
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<th>Description</th>
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<tbody>
<tr>
<td>MG</td>
<td>Myasthenia Gravis</td>
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<tr>
<td>NMJ</td>
<td>Neuromuscular Junction</td>
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<td>AChR</td>
<td>Acetylcholine Receptor</td>
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<td>MuSK</td>
<td>Muscle Specific Kinase</td>
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<td>LRP4</td>
<td>Lipoprotein-related protein 4</td>
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<td>IVIG</td>
<td>Intravenous Immunoglobulin</td>
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<tr>
<td>NM</td>
<td>Neuromuscular</td>
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<td>MS</td>
<td>Multiple Sclerosis</td>
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<td>RA</td>
<td>Rheumatoid arthritis</td>
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<td>GP.</td>
<td>General Practitioner</td>
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<td>PLEX</td>
<td>Plasmapheresis</td>
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<td>SNMG</td>
<td>Seronegative Myasthenia Gravis</td>
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<td>ALS</td>
<td>Amyotrophic Lateral Sclerosis</td>
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<tr>
<td>NI</td>
<td>Narrative Inquiry</td>
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<tr>
<td>EMG</td>
<td>Electromyography</td>
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<tr>
<td>ANA</td>
<td>Antinuclear Antibody</td>
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CHAPTER ONE: NARRATIVE BEGINNINGS

My identity within health and illness has always been on the professional side; evidence-based practice and caring for patients. Although my career has focused on a narrowed niche of surgical care, from my training and experiences I believed I had a broad yet comprehensive understanding of chronic illness. I thought I understood the hardships associated with managing a chronic illness and could empathise. It was only once I crossed over to the other side of the healthcare relationship, to becoming a patient with a rare autoimmune disease, were my assumptions of how to live with a chronic illness quickly dispelled. I was faced with the stark realization that one cannot truly understand how chronic illness disrupts everyday living until you become the one living it. The disease becomes not just part of who you are, but ultimately dictates everyday choices and activities, affecting not only careers and livelihoods, but also personal relationships and integration within social norms.

I was diagnosed in my mid-30s with myasthenia gravis (MG); a rare autoimmune disease that disrupts the chemical communication between nerves and voluntary muscles. Although I have cycled through the stages of grief many times, I always come back to the belief that my experience with chronic illness is both simultaneously a gift and personal bane. MG has created physical limitations, associated mental health challenges, threatened the advancement of my career, and challenged my overall motivation to set and achieve goals. However, MG has also allowed me to realize and understand the profound challenges and impact chronic illness can have on a patient’s life, created a deeper sense of empathy, and has allowed me to spend more time with my family leading to strengthened personal relationships. As I have sought disease-related information to learn to cope with and manage the disease, I have come across challenges that would be amplified for non-healthcare professionals. I have scoured the internet, online
community forums, and medical journals seeking answers that do not exist. This study has evolved from my own need to understand and manage my personal disease trajectory, to a desire to help others in their ability to discover, learn, and understand how the available information on MG can influence the management of their disease.

1.1 Introduction and Background

MG is a complex autoimmune disease that significantly affects a patient’s quality of life yet is largely overlooked or misunderstood by the medical community. From Latin and Greek origin, MG translates to “grave muscle weakness” and was often fatal before the adjunct of modern treatment modalities (Myasthenia Gravis Society of Canada [MG of Canada], 2021). Abnormal pathophysiologic processes occur causing the body to mistakenly target receptor sites located in the neuromuscular junction (NMJ) on voluntary muscles, disrupting or even blocking muscle contraction, resulting in muscular dystrophy (Myasthenia Gravis Foundation of America [MGFA], 2021; MG of Canada, 2021; National Organization for Rare Diseases [NORD], 2021).

MG is often referred to as the *snowflake disease* due to the variability of symptoms experienced by each person (Conquer Myasthenia Gravis [Conquer MG], 2022). Just as each snowflake presents a unique pattern, MG patients experience a heterogeneous pattern of clinical presentation requiring a tailored combination of treatments to control the disease (Conquer MG, 2022). The hallmark of MG is fatigability; muscle weakness that worsens with repetitive movement or activity and improves with rest (MG of Canada, 2021; Punga et al., 2022; Spillane et al., 2013). Figure 1 displays the vast range of symptoms related to multiple voluntary muscle systems and affected daily activities that patients with MG may experience. The disease often manifests as primarily ocular but progresses to generalized MG in approximately 80% of patients within a few years (NORD, 2021; Spillane et al., 2013). Due to the fluctuation of symptoms in
terms of frequency, severity, and affected muscle groups, diagnosis can be challenging and is often delayed or results in misdiagnosis and subsequent inappropriate or ineffective treatment (Spillane et al., 2013). The clinical course and prognosis of MG is difficult to determine due to the complexity and variability of the disease for each person (Punga et al., 2022).

Figure 1

Muscle Groups and Associated Symptoms with MG

1.2 MG Pathophysiology

1.2.1 Autoantibodies

Fatiguability of affected muscles in MG is caused by different types of autoantibodies that target specific components of the NMJ (Marx et al., 2013). The most common type is acetylcholine receptor (AChR) autoantibodies that block or destroy the receptor sites on the muscle that receives the chemical message of acetylcholine from the nerve (Li et al., 2021; Meriggioli & Sanders, 2012). With fewer functioning receptor sites, the ability of the muscle to contract is diminished (Li et al. 2021; Meriggioli & Sanders, 2012). Muscle-specific receptor tyrosine kinase (MuSK) autoantibodies block a specific protein involved in the formation of NMJ sites (Li et al., 2021; Meriggioli & Sanders, 2012). Similar to AChR, with fewer sites available, fewer chemical signals for muscle contraction are transmitted (Li et al., 2021; Meriggioli & Sanders, 2012). A small percentage of MG patients have lipoprotein-related protein 4 (LRP4) autoantibodies which also hinders the cascade of muscle contraction, and less than 5% have no detectable autoantibodies and are diagnosed with seronegative MG (Li et al., 2021; Meriggioli & Sanders, 2012). See table 1 for the prevalence and clinical characteristics of autoantibodies for MG. It is widely accepted in the neuronuclear medical community that seronegative MG patients do in fact have autoantibodies, but current diagnostic tests are unable to detect them, or the autoantibody responsible for the disruption at the NMJ has yet to be discovered from a scientific standpoint (Li et al., 2021; Meriggioli & Sanders, 2012).
<table>
<thead>
<tr>
<th>Antibodies status</th>
<th>Prevalence</th>
<th>Clinical characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acetylcholine receptor (AchR-Ab)</td>
<td>70-85%</td>
<td>Fluctuating weakness that is worse with repetitive activity and improves with rest</td>
</tr>
<tr>
<td>Muscle-specific tyrosine kinase (MuSK)</td>
<td>1-10%</td>
<td>Predominantly females</td>
</tr>
<tr>
<td>Lipoprotein related protein 4 (LRP4)</td>
<td>1-5%</td>
<td>High bulbar involvement, less involvement of extremities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Higher incidence of refractory MG</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Often remains ocular</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Generalized symptoms often mild</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Low incidence of myasthenic crisis</td>
</tr>
</tbody>
</table>

*Note.* The prevalence of autoantibodies that cause MG and associated clinical characteristics, adapted from *Serological diagnosis of myasthenia gravis and its clinical significance* by Li et al., (2021). https://doi.org/10.21037/atm.2019.07.86

### 1.2.2 Role of Thymus Gland

Although the cause of MG is largely unknown with a possible link to genetic and environmental factors, abnormal thymic pathology is strongly correlated to the disease (Fujii, 2013; Meriggioli & Sanders, 2012). The thymus gland is located behind the breastbone and plays a pivotal role in the immune system, particularly in childhood but becomes less active once beyond the adolescent years (MGFA, 2021). Research has shown that in MG the thymus gland becomes enlarged or has distinct cellular abnormalities, producing the autoantibodies that block and attack the different components of the NMJ (Fujii, 2013; Meriggioli & Sanders, 2012). Approximately 10% of patients have a tumor of the thymus gland, called a thymoma, that is often benign but can occasionally become malignant (Fujii, 2013; Spillane et al., 2013).
Thymectomy is one of many therapeutic options for managing the symptoms of MG and the best prospect of achieving remission, but there are a variety of other options with efficacy hinging on each individual’s unique disease pattern (Fujii, 2013; Marx et al., 2013).

### 1.3 Epidemiology

The epidemiology of MG follows predictable geographic patterns, with higher incidence correlated to further distance from the equator, similar to other autoimmune diseases (Punga et al., 2022). In Canada, the incidence of MG is 23 per 100 million per year and the prevalence is 263 per 100 million (Punga et al., 2022). The United States displays similar statistics, with 14-40 per 100,000, and on a global scale, the prevalence sits at 29 cases per 1 million people (Punga et al., 2022). As with many autoimmune diseases, MG is underdiagnosed with the true prevalence of the disease believed to be much higher, which in turn affects the quality of epidemiological studies (MGFA, 2021). The incidence of MG is demographically split with a 2:1 ratio of women experiencing symptom onset and diagnosis in their 20s and 30s, and a reversed ratio of men to women in their 50s and 60s (NORD, 2021; Punga et al., 2022). Incidence rates of MG are increasing on a Canadian and global scale, possibly attributed to increased disease awareness leading to increased diagnostic rates (Punga et al., 2022).

### 1.4 Medical Treatments for MG

Adding to the complexity of this condition, numerous medications are deemed cautionary drugs for MG, ranging from antibiotics to calcium channel blockers, as they can cause an exacerbation of the disease (MGFA, 2021). Some medications that are prescribed to treat the disease can paradoxically cause a worsening of symptoms (MGFA, 2021). Prednisone, a corticosteroid, is the most commonly prescribed first line of treatment but is documented to cause a temporary worsening of muscle weakness during the first few weeks of therapy,
requiring close monitoring for those with symptomatic respiratory weakness (MGFA, 2021). The other most prescribed medication, pyridostigmine, is an anti-acetylcholinesterase agent and has a threshold limit (Adeyinka & Kondamudi, 2022). An overabundance of this medication can precipitate a cholinergic crisis; overstimulation of the neuromuscular receptors resulting in muscular weakness, paralysis, muscular fasciculations, and blurry vision (Adeyinka & Kondamudi, 2022). As the symptoms of a cholinergic crisis are congruent with overarching MG symptoms, this can lead a patient to increase their pyridostigmine dose or frequency which then further contributes to the development of a cholinergic crisis.

Other treatment options include steroid-sparing immunosuppressant agents, plasmapheresis, thymectomy, intravenous immunoglobins (IVIG), and complement inhibitors (Adeyinka & Kondamudi, 2022). The efficacy of each treatment option is as variable as the disease itself, according to individual autoantibody status and unique physiology (Adeyinka & Kondamudi, 2022). MG is a chronic condition with no cure, although treatment can ease symptoms and make living with the disease more manageable (MG Canada, 2021).

1.5 MG Complications

MG can result in varied complications that range from difficulty getting the disease and symptoms under control to producing significant long-term consequences. The two most profound complications that can be experienced by a MG patient are treatment-refractory disease and a myasthenic crisis.

1.5.1 Treatment-Refractory Disease

MG can flow through periods of exacerbation and remission but can also be refractory in which an individual does not respond to conventional treatments (Alexion Pharmaceuticals, 2019; Punga et al., 2022; Spillane et al., 2013). Treatment-refractory MG is a subclassification of
the disease in which a patient experiences persistent symptoms of fatigable muscle weakness regardless of alternate and escalating medication regimes (Harris et al., 2020). Certain medications may also have to be discontinued despite therapeutic effect if intolerable side effects are experienced. It is estimated that approximately 5-15% of MG patients are treatment-refractory (Harris et al., 2020). Not only does treatment-refractory MG precipitate a lower quality of life than those with a form of the disease that responds to treatment, but these patients also experience significantly more disease exacerbations, hospitalizations, and incidence of a myasthenic crisis (Harris et al., 2020).

1.5.2 Myasthenic Crisis

Myasthenic crisis is a complication that occurs in 10-20% of people resulting from a profound and life-threatening weakness of the respiratory muscles, more commonly in the first few years following diagnosis, requiring intubation and intense medical therapies (NORD, 2021; Punga et al., 2022; Spillane et al., 2013). This medical emergency is preventable and treatable with a high degree of awareness by both the patient and medical professionals, and quick clinical determination and corresponding aggressive treatment (Chaudhuri & Behan, 2009). A crisis can be triggered by poorly controlled generalized or bulbar disease, or any stress placed on the body such as the introduction or removal of medications, an increase in body temperature due to warm environments or fluctuations in hormones, or even emotional stress (Chaudhuri & Behan, 2009). Medications to treat and reverse a crisis include high dose steroids in conjunction with plasmapheresis or IVIG (Chaudhuri & Behan, 2009). An impeding myasthenic crisis can be further complicated when healthcare professionals are unfamiliar with the pathophysiology of MG and neuromuscular diseases in general. A high reliance on the pulse oximeter reading fails
to accurately assess and recognize failing respiratory muscles as opposed to an oxygen exchange problem at the alveolar level.

1.6 The Burden of Disease

The burden of disease is defined as the impact of illness and disability, quantitatively measured by morbidity and mortality (National Collaborating Centre for Infectious Diseases [NCCID], 2002). The burden of disease is a concept that was initially explored by the World Health Organization, but with a strong focus on the financial burden to the healthcare system rather than the hardships experienced by the patient (Gilhus et al., 2021; Lehnerer et al., 2021; NCCID, 2002). The tribulation of MG patients is significant and influenced by a variety of factors; severity of disease and symptoms, frequency of crisis, comorbidities, age of diagnosis, and intolerable or long-term side effects of medications (Lehnerer et al., 2021). The burden of disease is amplified for treatment-refractory MG patients, who are typically female and diagnosed at a younger age while amid careers and raising a family (Lehnerer et al., 2021).

1.6.1 Psychosocial Wellness

Psychosocial and emotional well-being are diminished in MG patients as compared to the general population (Gilhus et al., 2021; Lehnerer et al., 2021). In addition to an overall reduction in psychological and emotional wellness, MG patients exhibit clinical mental health challenges such as depression and anxiety to a higher degree than those without chronic illness (Lehnerer et al., 2021). Many MG patients feel a tangible loss and grieve their lost abilities and lifestyle, or even grieve for their future selves based on their diminished physical abilities (Gilhus et al., 2021). As a debilitating disease that causes an invisible disability, MG is a significant reason for the breakdown of marital relationships and heavily influences family planning (Gilhus et al., 2021; Lehnerer et al., 2021). The effects of the disease extend beyond impacting family and
spousal relationships, but also into social networks and friendships, as symptoms of the disease often prevent people from spending time with others or engaging in social activities (Gilhus et al., 2021). Additionally, the trial and failure approach to finding an effective medication regime and the uncertainty of the future of living with the disease can take a significant mental toll (Gilhus et al., 2021; Harris et al., 2020).

1.6.2 Financial Wellness

MG patients have a staggering six times increased odds of an inability to work than the general population (Gilhus et al., 2021). Even if a person with MG can continue working while managing the disease, most experience a change in employment in terms of reduced hours or a forced change in profession to accommodate symptom management (Lehnerer et al., 2021). Altered employment impacts financial wellness resulting in a decreased income, breaks in pensionable service creating a lower standard of living in retirement, and obstacles in changing jobs or companies while obtaining or maintaining disability insurance (Gilhus et al., 2021, Lehnerer et al., 2021). A paradoxical effect ensues as MG patients contend with a decreased income confounded with ongoing medical expenses.

1.6.3 Quality of Life

Studies show that quality of life is significantly diminished with muscle weakness that results in disability (Lehnerer et al., 2021). Similar to psychosocial wellness and the ability to maintain employment, the quality of life for MG patients is greatly affected by the frequency and severity of symptoms (Lehnerer et al., 2021). Those with treatment-refractory disease suffer from a lower quality of life than those who can be adequately treated or achieve remission (Lehnerer et al., 2021). MG is comparable in terms of quality of life and daily functioning to other diseases that affect muscle movements such as multiple sclerosis (MS), rheumatoid
arthritis (RA), and Parkinson’s disease (Lehnerer et al., 2021). An under-documented factor that affects the quality of life in up to 60% of MG patients is persistent and significant fatigue (Gilhus et al., 2021; Lehnerer et al., 2021). MG patients’ state that fatigue limits their activities of daily living more so than specific muscle weakness yet is a symptom that is rarely evaluated by doctors (Gilhus et al., 2021). A common misconception within the medical community is that activities of daily living are not compromised with mild or moderate muscle weakness, but only for severe muscle fatiguability (Gilhus et al., 2021). The general fatigue experienced by MG patients is limiting to the extent that energy needs to be rationed throughout the day, creating substantive challenges for employment and participation in family life and social activities (Gilhus et al., 2021). Furthermore, future quality of life is often impacted by the sustained use of medications to treat MG. Long-term effects of medications to treat the disease include diabetes and osteoporosis from steroids, severe infections from suppression of the immune system, and chronic b-cell depletion from Rituximab (Harris et al., 2020).

1.7 Health Literacy

The medical model that has been adopted and entrenched in the Canadian healthcare system is patient-centered care in which patients are not only involved in their care plan but are also expected to be informed and actively engaged in medical decisions (Versteeg & te Molder, 2021; Willis et al., 2016). Patients with rare diseases indicated they feel responsible for being the expert in their disease and have a duty to educate others (Budych et al., 2012). Health literacy is the extent to which an individual understands and can use standard health information and becomes much more complex when faced with an illness that lacks attainable and intelligible information (Barton et al., 2018). Lack of information is problematic as a higher degree of health literacy translates to improved health outcomes (Barton et al., 2018). Additional obstacles arise
for individuals with rare diseases as health literacy then goes beyond finding the information to deconstructing the medical jargon and having a trained specialist to discuss findings. Knowledge leads to patient empowerment, which leads to patients taking responsibility for health and adopting an aggrandized role in health decisions (Barton et al., 2018).

1.8 Health Equity

A glaring yet largely overlooked health disparity exists for individuals with MG and rare diseases to access and utilize health information. The *Canada Health Act* of 1984 serves “to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable and uniform access to insured health services, free from financial and other barriers” (Government of Canada, 2022). People living with MG do not have equal access to resources, namely the basic information on their disease and how it can best be managed to achieve optimal health and quality of life. The lack of available information is exacerbated by disproportionate research funding. *Health literacy* makes information understandable; *health equity* serves to make access to health information inclusive (Barton et al., 2018).

1.9 Accessing Information on Rare Diseases

MG is classified as a rare disease, which is any disease that has the prevalence rate of less than 1 in 2000 people (Genetic and Rare Diseases Information Center [GARD], 2022). Medunik Canada (2022) defines rare diseases as illnesses with a low prevalence, low availability of clinical research, and diminished access to specialists and treatment options. Rare diseases affect 1 in 12 Canadians, or a collective 3 million Canadians (GARD, 2022; Medunik Canada, 2022). With over 7000 documented rare diseases in total, all share similar challenges and obstacles for patients; delays in diagnosis or misdiagnosis resulting in inappropriate medical treatment, limited or no access to organizations, associations or support groups, and limited access to
knowledgeable experts on their rare condition due to geographic and financial obstacles (Litzkendorf et al., 2016; Medunik Canada, 2022). Patients of rare diseases face the challenge of a lack of accessible and comprehensible information on their condition (Medunik Canada, 2022). Incomplete or inaccessible information regarding the disease and viable treatment options can substantially hinder an individual’s ability to take an active role in their health and manage the disease accordingly.

1.10 Accessing Specialist Healthcare Providers

The lack of information on rare diseases not only poses a problem for patients to understand their disease but also for physicians to develop a sufficient knowledge base of the illness to appropriately treat and counsel their patients. There is a lack of evidence-based clinical guidelines (Spring, 2014). The guidelines that are available to treating physicians focus directly on symptom management, neglecting other dimensions of the disease (Spring, 2014). As general practitioners (GP) are often the first line of contact for patients in the medical system, the diminished awareness of rare diseases within the medical community creates a cyclical problem in which patients are unable to obtain basic information from their doctor that would aid in independent information seeking (Litzkendorf et al., 2016, 2020).

Timely referrals to the appropriate specialist are necessary for comprehensive care and management of MG, as a delay in diagnosis and treatment can result in not only a progression of the disease, but also a myasthenic crisis (Howard, 2009). Patients with MG may be seen by a general neurologist, but the most comprehensive care is provided by a neurologist who specializes in neuromuscular disorders. In Alberta, there are only two neuromuscular clinics with neurologists specifically trained in neuromuscular conditions: the Neuromuscular Clinic at South Health Campus in Calgary, and the Neuromuscular and MG Clinic in Edmonton.
1.11 Building Disease-Related Knowledge

The ability to cope with a diagnosis and manage disease is significantly affected by the abundance or lack of information about the illness, yet there have been finite studies on patient information requirements and how patients access important information (Litzkendorf et al., 2016). Patients living with rare diseases have identified the necessity of information when diagnosed, yet surveys have indicated that most patients did not feel that they had been given sufficient information about their disease at the time of diagnosis (Litzkendorf et al., 2016). Patients with rare diseases feel that general practitioners do not have complete knowledge of their disease and that they must seek out information on their own (Litzkendorf et al., 2016). Although these same patients indicated that specialists could give complete information and satisfactorily answer questions, access to specialists remains geographically restricted and hindered by lengthy waitlists (Litzkendorf et al., 2016).

Patients have indicated that the information they would most like to receive is the expected clinical course of the disease and how it will affect their lives, how to manage the disease such as symptom control, and what treatment options are available (Litzkendorf et al., 2016). However, information needs will change over time. When first diagnosed with a disease most patients will want to know what it is and how to live with it, if the disease will impact their life expectancy, their expected ability to maintain employment, and treatment options (Litzkendorf et al., 2016). The longer that an individual lives with a disease, they are more apt to seek increasingly detailed information, research studies, and emerging or alternate therapies (Litzkendorf et al., 2016).
1.11.1 Types of Knowledge

The literature highlights the types of knowledge patients will seek in their quest to understand and manage a diagnosis. An article by Willis et al. (2016) describes the act of gathering information on a health condition as a method to gain control over the situation. These authors state that the primary and most trusted source of knowledge is medical or *scientific knowledge*, or the information that is given to a patient by their care provider. However, due to the limited access to neuromuscular specialists and their expertise, MG patients often seek to supplement their knowledge by additional means. Willis et al. (2016) further find that many patients of rare diseases feel that it is necessary to find additional information from other sources. These authors conclude that in the early stages following a diagnosis, accessing information on the internet serves as the primary method to gain information. These authors also found that most people will use search engines such as Google, with a keen awareness that the credibility of the information presented can be equivocal. Despite this awareness, the lay population do not understand how to access or interpret peer-reviewed studies.

Participants in a survey indicated that their own research online greatly impacted their interactions with healthcare professionals and their *system knowledge*; that is, how to access and navigate the healthcare system concerning their personal health challenges (Willis et al., 2016). It has been noted that not all patients want to take the initiative to find additional health information and would rather trust and rely on their doctor’s advice (Versteeg & te Molder, 2021). Individuals who are more likely to seek additional information online are those who have a higher education level or who have background knowledge in health sciences (Willis et al., 2016). With the use of the internet, patients are also able to tap into *experiential knowledge*: knowledge and advice from others who have lived with the disease (Willis et al., 2016). In
experiential knowledge, people engage and learn from others’ lived experiences. Patients in a study by Litzkendorf et al. (2016) rated sharing experiences and stories with others with the same disease as very important when seeking information and that the knowledge of others with the same health condition helped to form a better understanding of the disease.

In times of illness, people are vulnerable and not always able to make rational choices or health decisions within context, creating a heavier reliance on knowledge and information from practitioners and the advice of others (Willis et al., 2016). As patients living with rare diseases seek to understand and appropriately manage their condition, there appears to be a need for the corroboration of medical and experiential knowledge (Willis et al., 2016). The intersection of these types of knowledge heavily influences each patient’s active role in attuning their decisions, advocating for themselves, and taking responsibility for their own health (Willis et al., 2016).

1.12 Hearing Patient Voices

Research that is focused on MG to date has mostly aligned with quantitative methods to streamline diagnostic criteria and emerging medical treatments. Qualitative studies have been limited and sparse, but the research has shown that patients with a chronic illness have much more to contribute than what can be conveyed in a predetermined checkbox survey or clinical trial (Clayton et al., 1999). This observation is supported by Warms et al. (2005) in a statement that there is a lack of research investigating the subjective experience of living with chronic disabling conditions. Warms et al. states that surveys and data collection tools are sufficient for quantitative data and establishing generalizations, but a sole focus on one type of methodology only presents a segment of the picture, essentially breaking down a person into the sum of their parts. Clayton et al. (1999) state, “people are stripped of their experience, their story, when seen as bodies, symptoms, and disease.” (p. 513). Furthermore, Clayton et al. explain that surveys and
quantitative data collection methods do not offer open-ended questions and present a limited number of choices to choose from. Also, the questions are formulated by the researcher and their view on what is important to assess rather than what is important to the patient.

Qualitative research on the other hand, specifically narrative inquiry, includes rich detailed descriptions and patient explanations in the form of stories to put information into context (Clandinin, 2013; de Padua, 2015; Warms et al., 2005). Individuals living with chronic illness not only have to adapt to physical limitations, but also have to consider psychological effects, which can be managed by telling their stories to others (Clayton et al., 1999). In fact, previous studies indicated that patients living with chronic illness do not feel they can adequately answer questions in a check box format with the absence of an opportunity to explain their answers. In a survey for MS, 25% of respondents wrote narrative comments in the margins (Clayton et al., 1999). Similarly, 54.1% of respondents on a survey for chronic pain added narrative comments, displaying an unexpected but overwhelming desire to have a dialogue with the researcher (Warms et al., 2005). These narrative comments on surveys were wrote with the intention to explain their answers within context or tell the remainder of the story as it related to the question (Clayton et al., 1999). Many comments also indicated suggestions of what questions would be better to ask, what type of information was missing from the survey, or articulated that the survey questions did not cover what is important to them as a chronic illness patient (Warms et al., 2005).

An important consideration when administering a survey for chronic illness with predetermined check boxes is the nature of shifting symptoms. In the study conducted by Clayton et al. (1999), some respondents indicated that their responses to survey questions would vary at different times due to fluctuating symptoms, giving them a stronger desire to explain their
responses. Despite these unexpected yet valuable results, there remains minimal qualitative research that seeks the subjective experience of participants living with chronic illness to allow them to discuss what is important and meaningful to them. Furthermore, as researchers, we consider how the process and results of a study will provide benefit to the participants. Clayton et al. (1999) state that narrative inquiry provides an opportunity for individuals to think about their experiences and tell personal stories, which may facilitate participants’ search for meaning in their circumstances. These authors further explain that the opportunity to tell stories and feel acknowledged is perceived as therapeutic to participants. Hearing the voices of MG patients holds significant weight in the study of chronic illness. Due to the snowflake nature of the disease and uncertain clinical course, many MG patients still feel alone in the management of their illness despite seeking commonality with fellow MG patients.

1.13 From Nurse to Patient

As a registered nurse with fifteen years of experience, I thought I knew the healthcare system inside out and believed we were doing the best for our patients despite system challenges or lack of resources. I strived to live a healthy lifestyle to maintain my overall health but failed to consider the possibility of developing a life-altering chronic illness. I was subsequently diagnosed with MG in early 2021, following the typical pattern experienced by many MG and autoimmune disease patients; I was plagued by vague symptoms that would come and go that resulted in misunderstanding from physicians, misdiagnosis, and delayed treatment. I felt brushed off when I brought my concerns to a general neurologist and came to the point in which I was starting to doubt myself and what I was feeling. Fortunately, with my medical background, I was able to search for information and piece together what was happening to me, ultimately
resulting in a self-diagnosis, and strongly advocating that I be referred to a neuromuscular specialist.

The initial meeting with the neuromuscular specialist resulted in a confirmed diagnosis within half an hour. Immediately following the diagnosis, I remember feeling a mixture of relief to finally have an answer and treatment plan but simultaneous grief for what this meant for my future. As a natural planner and information seeker, I began to research and connect with others online in various national and global MG communities. This is where I first encountered a frustration with finding disease-specific information and connecting how the information I did find aligned with my personal circumstances and disease pattern. Not only was my experience different from fellow MG patients I spoke with, but my experiences often did not even line up with the information I was able to read in medical journals. In discussing the information I found with my neuromuscular specialist, his views were not often in line with what I have read due to the variance of my own disease and his inability to predict my clinical course due to the unique disease pattern. Through these experiences, I have wondered how those without a medical background make sense of their illness and learn to decipher disease-specific information to advocate for themselves.

Further discussion with others living with MG has revealed not only frustration with trying to understand the disease and the relevance of information to their clinical presentation, but also the perceived lack of knowledge from healthcare professionals. Feeling as though they need to be the expert and educate others including general practitioners, the information they have sought and their understanding of the disease from living with the condition greatly impacts interactions within the healthcare system. I understand this frustration from my own experience with a respiratory crisis from the disease as it was targeting my respiratory muscles. In the
emergency room I explained to nurses and physicians that this was not an oxygen exchange problem, but a muscle weakness problem. However, these healthcare providers were unable to look past my perfect oxygen saturation reading on the monitor. Even when my inspiratory and expiratory tests revealed that I was not even suitable to be off a ventilator, I was told that my oxygen saturations were the best in the department and that I no longer needed their medical care. Only when I then traveled down to my specialist an hour and a half away, unable to say more than one or two words on route without gasping for air, was I given the appropriate treatment. This experience is not uncommon for MG patients. Even if we understand the disease ourselves, it is challenging to have healthcare providers who are not trained in neuromuscular conditions listen and understand.

Failing to hear the patient voice is as grave as the disease before modern treatments. The Canadian healthcare system revolves around patient-centered care, yet there is a discrepancy between that term and the follow-through of action. I believe that with more awareness and an increased focus to listen to our patients, with all illnesses and not specifically MG, we can enhance medical care and help to improve the quality of life for many.

1.14 Statement of the Problem and Study Purpose

MG is a chronic autoimmune disease that is misunderstood, underfunded, and understudied. The limited research that has been conducted strongly focuses on quantifiable diagnostic parameters, pathophysiology, and medical treatment. A literature search reveals limited qualitative studies on MG. Personal interactions with patients living with MG have identified a lack of access to not only physicians that understand the disease and can give credible information, but also significant obstacles to increasing health literacy of the disease and associated treatments. The minimal research into knowledge acquisition for rare diseases to date
shows that these patients face heightened challenges in managing their illness more than their commonly known disease counterparts. The purpose of this study is to explore the stories of adults in Western Canada living with MG related to their knowledge construction of the disease over time.

1.15 Research Puzzle

To understand the experiences of people and their individual narratives rather than seeking a definitive conclusion, framing the research question in terms of a puzzle was most appropriate for this study. Narrative inquiry of MG patients will be a process of searching and researching and telling and retelling of stories to determine how all the pieces of information come together and can be rearranged to find meaning and understanding (Clandinin, 2013). From a review of the literature, personal experience, and engagement with others living with MG, one research puzzle has emerged: What are the personal experiences of adults living with MG in their acquisition of knowledge related to the disease?

1.16 Rationale for Study

Stemming from personal experience, conversations with MG patients, and a literature review, the rationale for this study is to bring to focus the challenges of access to health information experienced by people living with MG. This study not only aims to place a heavier emphasis on qualitative research for chronic disease but to bring to the forefront the additional challenges faced by people with rare diseases and how healthcare professionals can advocate for and best support these patients in their quest to achieve optimal health.

1.17 Significance to Nursing

Nurses plays an integral role in patients managing their illnesses; therefore, nurses need to listen to the patient and try to understand their subjective experiences (Niven & Scott, 2003).
Nurses cannot carry out the most basic values and roles of the profession, such as patient advocacy, supporting patient autonomy, and education on health choices if we do not listen to the patient and gain an understanding of their perceptions of what is important to them.

In the case of MG, as with all rare diseases, the lack of general knowledge of the disease and access to expertise makes it of higher stakes to gain the subjective experience of patients and how they make sense of the information to manage the disease and navigate the healthcare system. MG presents an additional challenge for patients in that even if they can access reliable medical and experiential knowledge, the high variability of the disease causes a unique experience for each patient, making them feel more alone rather than connected. In the age of an abundance of accessible information, it is still difficult to find detailed information about MG online, even from the websites of major organizations and associations such as the MG Foundation of America and the MG Society of Canada. An investigation into how MG patients have developed their knowledge of the disease and how they perceive their knowledge gap going forward is a necessary entity for the management of rare chronic diseases. Inaccessible and incomprehensible information on rare chronic diseases can lead to fragmented care and hinder the ability of nurses to adequately support and advocate for their patients (Barton et al., 2018).

Innovation has become ubiquitous in healthcare and in the time of global connectedness with information at our immediate fingertips, nurses need to be the leaders in identifying and addressing gaps in the system that is doing a disservice to our vulnerable patients. The past three decades have marked a drastic increase in the incidence and prevalence of all autoimmune conditions worldwide, with Canada being one of the top three countries leading the new diagnoses of MG (Lerner et al., 2015). As healthcare professionals working to provide quality
care, we need to evolve in our critical thinking, our understanding of emerging diseases and health trends, and our ability to address health information needs.
# DEFINITIONS

## Table 2

### Relevant Definitions

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
<th>Source</th>
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</thead>
<tbody>
<tr>
<td>Autoantibody</td>
<td>An antibody produced by the immune system that attacks healthy tissue rather than foreign invaders.</td>
<td>Meriggioli &amp; Sanders, 2012</td>
</tr>
<tr>
<td>Cholinergic Crisis</td>
<td>An overstimulation of the neuromuscular receptors from the medication pyridostigmine, resulting in muscular weakness, paralysis, muscular fasciculations, and blurry vision.</td>
<td>Adeyinka &amp; Kondamudi, 2022</td>
</tr>
<tr>
<td>Compliment Inhibitors</td>
<td>A type of monoclonal antibody that prevents the immune system from attacking healthy autologous tissue. Example: Rituximab</td>
<td>Adeyinka &amp; Kondamudi, 2022</td>
</tr>
<tr>
<td>Intravenous Immunoglobin (IVIG)</td>
<td>A blood product consisting of donor antibodies given intravenously.</td>
<td>Adeyinka &amp; Kondamudi, 2022</td>
</tr>
<tr>
<td>Myasthenic Crisis</td>
<td>A profound and life-threatening weakness of the respiratory muscles requiring intubation and intense medical therapies.</td>
<td>National Organization of Rare Diseases, 2021</td>
</tr>
<tr>
<td>Myasthenia Gravis (MG)</td>
<td>A chronic autoimmune, neuromuscular disease that causes fatigable weakness of voluntary muscles, resulting in muscular dystrophy.</td>
<td>Li et al., 2021</td>
</tr>
<tr>
<td>Neuromuscular Junction (NMJ)</td>
<td>The space between a nerve ending and muscle fibre for chemical transmission.</td>
<td>Myasthenia Gravis Foundation of America, 2021</td>
</tr>
<tr>
<td>Plasmapheresis (PLEX)</td>
<td>The process of removing blood from the body, filtering out harmful substances and antibodies, and then transfusing back into the bloodstream.</td>
<td>Adeyinka &amp; Kondamudi, 2022</td>
</tr>
<tr>
<td>Rare Disease</td>
<td>Definition</td>
<td>Source</td>
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<td>-------------------------------------------------</td>
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<tr>
<td>Rare Disease</td>
<td>A disease that affects a proportionally small segment of the population, limiting information, research, and treatment options. Also called orphan diseases.</td>
<td>Adeyinka &amp; Kondamudi, 2022</td>
</tr>
<tr>
<td>Seronegative Myasthenia Gravis (SNMG)</td>
<td>A classification of MG in which the patient does not have detectable serum autoantibodies.</td>
<td>Li et al., 2021</td>
</tr>
<tr>
<td>Thymectomy</td>
<td>The surgical removal of the thymus gland.</td>
<td>Fujii, 2012</td>
</tr>
<tr>
<td>Treatment-refractory Myasthenia Gravis</td>
<td>A subclassification of MG in which a patient experiences persistent symptoms of fatigable muscle weakness regardless of alternate and escalating medication regimes.</td>
<td>Harris et al., 2020</td>
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CHAPTER TWO: LITERATURE REVIEW

This narrative review will assess the commonalities and inconsistencies in the experiences of MG patients as they seek to obtain and understand health information related to their disease. Although quantitative research and clinical trials have positively resulted in medical advancements for patients with neuromuscular diseases, there remains a scarcity of qualitative research to understand the patient’s perspective of knowledge acquisition to manage the symptoms and everyday life while living with the disease.

2.1 Search Strategy

An electronic database search was completed using the databases CINAHL, Medline, Web of Science, PsychINFO, and Embase. This combination of databases was selected to ensure a holistic and comprehensive search of articles not only specific to nursing practice, but also encompassing multidisciplinary, pharmacological, and psychosocial aspects. These databases were chosen to present an authoritative, complete, and transparent search of high-quality peer-reviewed articles. Due to limited results, Google Scholar was also utilized along with an audit of references lists of articles for a complete review. Search combinations included the terms ‘myasthenia gravis’, ‘neuromuscular diseases’, and ‘rare diseases’ combined in alternate arrangements with ‘disease-related knowledge’, ‘information seeking’ or ‘information needs’, ‘health literacy’, ‘patient consumers’ or ‘consumer health information’, ‘knowledge’ or ‘attitude’ or ‘belief’ or ‘understanding’ or ‘awareness’, ‘educate’ or ‘learn’, and ‘information seeking behaviour’. Parameters were set on the search for peer-reviewed articles published in the English language between 2010 and 2022. Assistance and advice were sought from a librarian and the University of Saskatchewan to appropriately tailor my search to meet the parameters of the research puzzle.
Inclusion criteria for the literature search were: (a) articles focusing on patient knowledge or information, (b) patients with MG, rare diseases, and neuromuscular diseases, (c) adults, and (d) global distribution. MG lies within the definition of a rare disease and a neuromuscular disease and including these search terms ensured a comprehensive search. Studies that focused on amyotrophic lateral sclerosis (ALS) were included in the search as ALS and MG are both neuromuscular diseases and can mimic the other, which can cause patients with either disease to experience overlapping information-seeking challenges. All geographic locations were included as there is limited research on information provision for rare diseases and MG. Adults were defined as individuals who were 18 years or older. Articles with quantitative, qualitative, and mixed methods articles were reviewed and included.

Exclusion criteria for the literature search were set to: (a) a focus on physician or healthcare provider knowledge acquisition, (b) review of medical databases, (c) information-seeking experiences of others (e.g., friends or family members), (d) knowledge of gene sequencing for rare or neuromuscular disorders, and (e) research focused on chronic illness. Literature that assessed information seeking for others (e.g., pediatric patients or family members) was excluded as patients may search with a different approach when experiencing symptoms themselves and living with the disease as opposed to conducting a search for others. The information presented in medical databases does not address how an individual independently seeks information, and gene sequencing was excluded to focus on autoimmune MG rather than an inherited genetic form of the disease. Research that addresses chronic illness is too generic and broad, often focusing on diseases of affluence such as type 2 diabetes and coronary artery disease, which do not appropriately reflect the information seeking challenges for MG.
2.2 Literature Accessed

Retained articles from the search were read carefully to assess for inclusion and exclusion criteria and critically appraised. Nine articles that met the inclusion criteria were included in this review. Articles that included both patients and caregivers were utilized, but with a focus on the information pertaining to just the patients and not the caregivers. Including articles with caregivers was done to ensure a sufficient number of articles were available to complete a comprehensive literature review. During the literature search, it was revealed that most research that has addressed knowledge acquisition on rare diseases has focused on physician and healthcare provider knowledge. As well, the few studies that do exist for information provision for patients with rare diseases are largely quantitative. Qualitative studies of rare diseases to date have a primary focus on the quality of life.

For this review, five quantitative, two qualitative, and two mixed methods studies were included. Research that has been completed to date on the information needs of rare disease patients has mostly been from Europe; Germany (n = 3), Croatia (n = 2), and Spain (n = 1). The other articles included are from Pakistan (n = 1) and the United States (n = 2). There were no articles located from Canada. The reviewed articles focus on rare diseases in general (n = 5), a combination of scleroderma, lupus, and MG patients (n = 2), neuromuscular diseases (n = 1), and ALS (n = 1). Table 3 displays the articles obtained from the literature search.
<table>
<thead>
<tr>
<th>Authors and Location</th>
<th>Title</th>
<th>Study Aim</th>
<th>Design</th>
<th>Participants</th>
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<tbody>
<tr>
<td>Abdulla et al., 2014</td>
<td>Information needs and information-seeking preferences of ALS patients and their caregivers</td>
<td>“To investigate the information-seeking behaviour of patients with ALS and their caregivers” (p.506).</td>
<td>Quantitative</td>
<td>n = 106 patients n = caregivers</td>
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<td>Germany</td>
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<td>Interview and surveys</td>
<td>ALS patients</td>
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<td>Ahmed et al., 2020</td>
<td>An assessment of the knowledge, attitudes, and specific practices of patients and family with diagnoses of hereditary neuromuscular disorders</td>
<td>“To identify gaps in patient knowledge, attitudes toward the diagnoses, and specific practices to create better awareness among patients and healthcare providers to improve care and overall outcomes” (p. 265).</td>
<td>Quantitative</td>
<td>n = 130</td>
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<td>Pakistan</td>
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<td>Telephone survey</td>
<td>Neuromuscular disease patients</td>
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<tr>
<td>Bryson et al., 2021</td>
<td>Navigating the unknown: A content analysis of the unique challenges faced by adults with rare diseases</td>
<td>“To explore, in participants’ own words, the nature and frequency of challenges experienced by people with rare diseases” (p. 624).</td>
<td>Mixed Methods</td>
<td>n = 1157</td>
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<td>United States</td>
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<td>Online and paper surveys</td>
<td>Rare disease patients</td>
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<td>Carpenter et al., 2011</td>
<td>Use and perceived credibility of medication information sources for patients with rare illness: Differences by gender</td>
<td>“To describe patients’ most frequently used medication information sources, determine which sources patients perceive as credible, and explore gender differences in source use and perceived credibility” (p. 1)</td>
<td>Quantitative</td>
<td>n = 232</td>
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<tr>
<td>United States</td>
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<td></td>
<td>Online surveys</td>
<td>Rare disease patients/ vasculitis</td>
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<tr>
<td>Authors</td>
<td>Title</td>
<td>Methodology</td>
<td>Sample Size</td>
<td>Participants</td>
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<tr>
<td>Katavic et al., 2016</td>
<td>Illness perception and information behaviour of patients with rare chronic diseases</td>
<td>Quantitative, n = 171</td>
<td>Patients with scleroderma, systemic lupus erythematosus, and myasthenia gravis</td>
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<td>Croatia</td>
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<tr>
<td>Katavic, 2019</td>
<td>Health information behaviour of rare disease patients: seeking, finding, and sharing health information</td>
<td>Mixed Methods, n = 146 online questionnaires</td>
<td>Patients with scleroderma, systemic lupus erythematosus, and myasthenia gravis</td>
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<td>Croatia</td>
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<td>Litzkendorf et al., 2016</td>
<td>Information needs of people with rare diseases – What information do patients and their relatives require?</td>
<td>Qualitative, n = 55 patients</td>
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<td>Litzkendorf et al., 2020</td>
<td>Use and importance of different information sources among patients with rare diseases and their relatives over time</td>
<td>Qualitative, n = 55 patients</td>
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<td>Rovira- Moreno et al., 2020</td>
<td>Beyond the disease itself: A cross-cutting educational initiative for patients and families with rare diseases</td>
<td>Mixed Methods, n = 37</td>
<td>Rare disease patients</td>
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2.3 The Challenge of Information Acquisition for MG

Despite the increasing global prevalence of MG, there is an absence of research exploring how these patients seek information to cope with their diagnosis. Only two studies out of Europe from Katavic et al. (2016) and Katavic (2019) included MG patients in the broader scope of rare disease patients. Broadening the literature search to knowledge acquisition of rare disease patients rather than a specific focus on MG subsequently revealed a continual dearth of research. It is acknowledged that patients with varied rare diseases face similar and compounding challenges as compared to those with more commonly known illnesses and most of these additional challenges stem back to the lack of information available to both physicians and patients (Bryson et al., 2021; Litzkendorf et al., 2016, 2020). Challenges collectively faced by rare disease patients not only include limited available disease information, but also delays in diagnosis (Litzkendorf et al., 2016), limited treatment options and lack of peer patient support (Bryson et al., 2021), and lack of public awareness and understanding leading to elevated levels of stigma (Bryson et al., 2021; Carpenter et al., 2011). Although previous research has indicated that there is a heightened need for education and information for patients living with rare diseases, little has changed as a result (Rovira-Moreno et al., 2020). As health information becomes more widely accessible and utilized in the digital era, rare disease patients are left behind and unable to take an active role in the management of their disease to the same extent as other individuals with more well-known conditions (Katavic et al., 2016).

Research that investigates disease knowledge acquisition to date primarily focuses on common chronic diseases; mostly cancer patients and type 2 diabetes (Litzkendorf et al., 2020). An insufficient amount of research has investigated knowledge acquisition for rare diseases and the obstacles that arise when patients seek to understand their disease (Katavic et al., 2016;
Katavic, 2019). Previous studies that do exist are outdated, are based on single sources, and do not acknowledge rare diseases (Litzkendorf et al., 2020). With limited research grants available, resources are dispersed for the results to have the greatest impact on the greatest number of people; therefore, information on rare diseases is almost non-existent and these illnesses have been termed ‘orphan diseases’ (Rovira-Moreno et al., 2020).

2.4 Knowledge of Disease

The availability of credible health information significantly affects an individual’s ability to understand their disease, their attitude towards managing their illness, and their ability to dispel health misinformation (Ahmed et al., 2020). Katavic et al. (2016) found that only 54.9% of patients understood their illness. Respondents of this study also conveyed that a better understanding of their illness correlated with an increased sense of control over the disease. Ahmed et al. (2020) found in a study of patients with neuromuscular disorders that only 60% of participants demonstrated sufficient knowledge of their disease. Ahmed et al. further found that knowledge gaps identified for patients with neuromuscular disorders were pathophysiology, symptoms, prognosis, and potential disease complications. The most glaring insufficiency of patient knowledge was on dysphagia, which is one of the most common symptoms of all neuromuscular disorders (Ahmed et al., 2020).

Noteworthy in the study by Katavic et al. (2016) there is a correlation between the attainability of disease-specific health information and comprehension of the disease. However, the longer an individual lives with a disease, the greater their understanding of the disease and how to manage it (Katavic et al., 2016). Patients who have a more severe form of a disease have a heightened knowledge of the disease and associated symptoms (Ahmed et al., 2020). In the
study by Katavic et al., 69% of participants indicated that they are concerned about their illnesses which in turn influences their information seeking behaviour.

Of great concern in the assessment of knowledge for neuromuscular patients is the prevalence of misinformation. In the study by Ahmed et al. (2020), 80% of participants believed their disease is curable, which leads to a higher engagement in alternate therapies such as ancient remedies and stem cell therapy. Ahmed et al. also found that misinformation often focuses on the benefits of certain treatments or experimental therapies with no mention of potential risks or harm. This study further concluded that other problems arise from misinformation, such as many patients with neuromuscular disease believe that they should abstain from physical activity or that their disease can be cured with nutritional supplements.

2.5 Sources of Information

2.5.1 Physicians

Several information sources are utilized by patients, but information regarding diagnosis and rare diseases is most preferred and trusted to come from a physician (Bryson et al., 2021; Carpenter et al., 2011; Katavic et al., 2016; Litzkendorf et al., 2016, 2020). Medical specialists have been rated as the most valuable resource for obtaining information, but patients would most prefer to get information from their general practitioner (Litzkendorf et al., 2020). This preference is possibly due to a closer relationship that has developed over time. It has also been found that individuals with a more severe form of illness have a heavier reliance on information and medical advice from their physician (Katavic et al., 2016). Despite physicians being the preferred and most trusted source of information, many patients with rare disease feel that they received inadequate information at the time of diagnosis from their physician (Abdulla et al., 2014; Katavic et al., 2016; Litzkendorf et al., 2016, 2020).
2.5.2 Internet

To supplement the perceived lack of disease information provided by a physician at the time of diagnosis, the internet becomes the most heavily utilized source of information, usually in the form of search engines such as Google or Wikipedia (Abdulla et al., 2014, Carpenter et al., 2011, Litzkendorf et al., 2020). The internet is often the first source of information-seeking behaviour following the diagnosis of a rare disease, armed with the name of the disease and key terms to aid in their search (Litzkendorf et al., 2020). However, despite patients using the internet as a primary information source, Rovira-Moreno et al. (2020) found that most individuals prefer getting information face to face rather than online, coming back to the preference of obtaining information from general practitioners.

2.5.3 Frequency of Use of Information Sources

A high number of patients with rare diseases will frequently seek health information specific to their diagnosis: 37.6% often or very often, 44.4% sometimes, and only 18.1% rarely or never (Katavic et al., 2016). Abdulla et al. (2014) found that the most commonly searched topics on the internet for neuromuscular diseases were clinical course of the disease (91%), symptoms (85%), treatments (75%), and current research (60%). Other sources patients use to obtain information are print materials, such as books or brochures, patient organizations, and allied health care professionals such as nurses and pharmacists (Carpenter et al., 2011; Litzkendorf et al., 2020). Immediately following diagnosis information needs are high and patients prefer written sources that they can reference later, and sometimes recruit the help of family and friends to find and understand information about their illness (Litzkendorf et al., 2016). The study by Katavic et al. (2016) determined that medical specialists (71.2%), the
internet (54.1%), and peer patients (54.1%) were the primary means that patients obtain disease specific information.

2.5.4 Support Groups and Associations

Patients with rare diseases prefer to engage in social networks and support groups for information at a higher rate than other disease groups, where they can tap into the experiential knowledge of others living with the same disease (Katavic, 2019). Litzkendorf et al. (2020) uncovered similar findings that patient associations and online groups follow closely behind specialists as the preferred source of information. Interestingly, patients are rarely directed towards patient organizations for their specific rare diseases by healthcare providers, but rather find them in their independent searches online (Litzkendorf et al., 2020). Patients indicated that connecting with individuals with the same diagnosis is a way to understand not just what the disease is, but how to live with it (Katavic, 2019). Often patients with rare diseases merely want to not feel isolated and alone in their journey with the disease or confirm they are experiencing similar symptoms as others (Katavic, 2019). Online social networks are a prominent source of information for rare disease patients as they can access not only experiential knowledge, but also psychological support and advice on how to manage the challenges of daily living (Bryson et al., 2021; Katavic et al., 2016). Connecting with others living with the same disease online can become necessary as most patients with rare diseases do not personally know others with the same diagnosis in close geographic proximity (Katavic et al., 2016; Rovira-Moreno et al., 2020).

Information seeking, particularly on the internet and within social groups, leads to a snowball effect. Each subsequent search leads to further information and connections, such as finding a specialist (Litzkendorf et al., 2020), or patient groups and associations (Abdulla et al., 2014). Some patients experience a form of serendipity when peer patients introduce them to
previously unknown information such as a new medication or patient association group (Katavic, 2019). Respondents in a study by Katavic (2019) discussed a found sense of purpose in the opportunity to share their experiential knowledge with others in support groups, especially those who were newly diagnosed. In contrast, some patients find that sharing experiences with other patients only results in commiseration and perceive it to be an unsatisfactory information exchange (Litzkendorf et al., 2020).

2.6 Reliable and Credible Information

The literature displays mixed results on the perceived credibility and reliability of health information obtained from the internet. Although Carpenter et al. (2011) found that patients with rare diseases believe the internet to be a credible source, many participants in the study by Abdulla et al. (2014) declared that the reliability of the information found online is low. The incongruency carries forward into the perception of credible web sources. Abdulla et al. found that the most trusted sources were university websites, Google, and Wikipedia. However, Litzkendorf et al. (2020) found that although some individuals believed Wikipedia to be a trusted source, others cited the ability of anyone to change the information displayed. Litzkendorf et al. found that although patients question the credibility of the information presented on Wikipedia, it is a preferred source as the information is quick to obtain, presented in a structured format, and easy to understand. These authors found that some patients will determine the credibility of a website by the author or publisher rather than assess the quality of information contained on the webpage. There appears to be a stronger consensus on the reliability of information from patient associations. Some patients feel that the information from patient association websites is the most credible and reliable and do not feel the need to seek information from alternate sources (Abdulla et al., 2014; Litzkendorf et al., 2020).
2.7 Satisfaction with Information

Although online searches can produce quick information, many rare disease patients feel dissatisfied with the results, especially when there is little information available or when the search results are too complicated to understand (Katavic et al., 2016; Litzkendorf et al., 2016, 2020). Patients are often further confused by the information online when presented in an unstructured format with little applicability to their unique disease variability or the stage of their illness (Litzkendorf et al., 2020). The information found online for rare diseases is presented in medical terms, offers little hope, and is presented with a negative connotation (Katavic, 2019). Independent searches sometimes reveal frightening or concerning information about the prognosis or complications of the disease that were not discussed by a physician, often resulting in feelings of anxiety or despair, and more questions than answers (Katavic, 2019; Litzkendorf et al., 2020). Katavic (2019) found that MG patients in the study felt the information online is presented in a way that makes it difficult for their family and friends to understand their daily life and struggles to cope with the illness. In internet searches for rare disease, patients are often disappointed in the experience as most of the information online is too generic and broad for an individual to apply to their personal situation (Katavic, 2019; Litzkendorf et al. 2020). MG patients specifically cited the unsatisfactory results of searching medication information online, as many medications used for MG are off-label and the information they desire does not exist (Katavic, 2019).

There appears to be a small increase in satisfaction with online searches from patients with rare diseases as they become more skilled and structured in their search (Litzkendorf et al., 2016). With more experience, patients also have learned to deconstruct medical jargon and assess how the information applies to them personally (Litzkendorf et al., 2016). Patients with
rare diseases were generally satisfied with printed information as it is quick, easy to understand, and easy to use as a reference, but medical literature remains unsatisfactory as it contains complicated medical terms making it difficult to understand (Katavic, 2019; Litzkendorf et al., 2020).

Patient satisfaction with information from health care providers fairs a bit better. Patients with rare diseases are disappointed when healthcare providers do not understand their disease, but satisfaction increased if these same healthcare providers were forthcoming and transparent about their lack of knowledge regarding the disease (Litzkendorf et al., 2020). Furthermore, satisfaction greatly improves if a general practitioner learns about the disease and expand their knowledge along with the patient (Litzkendorf et al., 2020).

2.8 Information Seeking and Phases of Illness

Information that is primarily sought out by patients immediately following the diagnosis of a rare disease is prognosis and mortality (Katavic, 2019). Patients in a study by Katavic (2019) described information seeking after diagnosis as a great effort and time-consuming venture. Comments from participants in this study included phrases such as “the struggle of gathering information”, “combing through all possible webpages”, “I roamed wherever I could”, and “manic digging around” (p. 344). Patients initially prefer print material, such as patient pamphlets, that are quick and easy to understand (Carpenter et al. 2011), but this information is not as helpful the longer a person lives with a disease (Litzkendorf et al., 2020). The internet can be overwhelming at first with a vast amount of information with little applicability to personal circumstances, but valuable over time as information needs change and patients learn how to efficiently conduct a search (Litzkendorf et al., 2020). As time goes on, online searches focus less on medical terms and symptoms and more on searching to find communities and groups
with which they can relate, and tap into the experiential knowledge of others (Carpenter et al., 2011).

Ongoing information seeking occurs when there is a change in circumstances, for example a new symptom or medication change, or sometimes just out of curiosity for new or previously missed information (Katavic, 2019). Over time, patients with rare diseases tend to become more interested in clinical trials and research studies as a method to increase their knowledge of available treatments and to better communicate with their healthcare team (Katavic, 2019).

2.9 Discrepancies in Information Seeking Behaviour

Although the limited literature highlights many similarities in information seeking among patients with rare diseases, some differences have also been noted. The most glaring dissimilarity that has surfaced is between males and females. It has been found that females are not only more likely to seek health information about a rare disease, but males will heavily rely on their spouses to find and help them comprehend the information (Bryson et al., 2021; Carpenter et al., 2011; Litzkendorf et al., 2020). Although gender was shown as a prominent factor for information seeking, other factors also come into play such as age, education, race, and phase of illness (Carpenter et al., 2011). Patients who are younger with higher comfort level with the internet, and those with a higher education are more likely to seek health information (Abdulla et al., 2014; Carpenter et al., 2011; Litzkendorf et al., 2020). Those with more education or a medical background search in a more structured manner whereas others search haphazardly, simply clicking on what is displayed in the online list first (Litzkendorf et al., 2020). Also, those who have a more severe form of the disease with increased symptoms and a diminished quality of life are more likely to seek information online (Abdulla et al., 2014; Litzkendorf et al., 2020). There
is a small subset of the rare disease population who do not want any extra information than necessary about their disease (Katavic et al., 2016). In a study by Katavic et al. (2016), 6.3% of respondents with rare diseases confirmed that they do not intentionally seek out information about their illness. Those who avoid information often do so to decrease anxiety from reading discouraging information (Katavic et al., 2016).

2.10 Becoming the Expert

Information seeking often begins before diagnosis with a suspicion of what disease the person may be contending with and preparing the individual with information before attending an appointment with a specialist (Abdulla et al., 2014). Those who do not seek information prior often feel that the diagnosis is a shock, but regardless of prior information searching most patients begin to look for supplementary information following their diagnosis (Abdulla et al., 2014). Patients often feel the information provided by the physician at the time of diagnosis is insufficient, often leaving them with more questions than answers, which motivates them to conduct an independent search (Bryson et al., 2021; Katavic, 2019). Patients have described feeling abandoned by healthcare professionals in their search for information and left to seek out information on their own (Katavic et al., 2016). Independent information seeking layered with experiential knowledge of living with the disease enables patients to become the expert and begin to educate others (Bryson et al., 2021).

Some patients feel that the knowledge base of their illness among healthcare professionals is lacking and the only way to gain a good understanding and learn to manage the condition is to become their own expert (Katavic et al., 2016). For these reasons, patients with rare diseases feel that independent searches are a necessity rather than a luxury as with other common diseases (Katavic et al., 2016), but find that the information they discover on their own
is difficult to interpret (Bryson et al., 2021). Patients begin to take the advice and suggestions from others living with the same disease, as experiential knowledge becomes of higher importance than what can be offered by healthcare professionals (Katavic et al., 2016). However, many patients also feel that the information they find online about their disease helps them to prepare for upcoming appointments with their doctor (Abdulla et al., 2014). As a form of self-advocacy, the act of seeking information ensures that people can take a more active and collaborative approach to medical decisions regarding their care plan (Abdulla et al., 2014; Katavic, 2019). Additionally, some patients want to learn more to spread awareness and understanding within their social circle and the medical community, further contributing to their acquired role of the expert (Rovira-Moreno et al., 2020).

### 2.11 Coping, Hope, and Empowerment

Health information seeking is a necessary coping strategy for those facing an illness (Katavic et al., 2016; Litzkendorf et al., 2016, 2020). Clear comprehension of clinical manifestations and associated symptoms can facilitate how a person copes with the illness as it eliminates uncertainty and confusion and directly impacts the person’s overall well-being (Rovira-Moreno et al., 2020). The inability to obtain sufficient information can produce feelings of despair or defeat, and leaves little hope (Litzkendorf et al., 2016). Patients can also find hope and comfort by connecting with others who are successfully managing the illness (Katavic et al., 2016; Katavic, 2019). On the other hand, some individuals can find speaking with others with the same disease discouraging (Litzkendorf et al., 2020). In a study by Ahmed et al. (2020), a correlation was found between knowledge and attitude towards the disease. It was found that 42.3% of participants had negative attitudes regarding neuromuscular diseases (Ahmed et al., 2020). Those who independently seek information have a more positive perception of their
illness which then influences their disease management (Katavic et al., 2016). As knowledge is power, a patient who can obtain sufficient and intelligible information about their illness is empowered to take an active role in managing their health resulting in improved psychosocial and health outcomes (Katavic et al., 2016; Rovira-Moreno et al., 2020).

2.12 Gaps in the Literature

An assessment of the available literature has revealed that patients living with rare diseases, including MG, face increased obstacles in comparison to other patients in the quest for disease information. These patients prefer information to be provided by a physician overseeing their care but feel that the information provided is insufficient and that it is necessary to supplement their knowledge with an independent search, primarily on the internet. Patients with rare diseases heavily rely on experiential information from others and seek information from patient associations and support groups to obtain psychosocial support and a sense of connection. Variances are noted for patients with rare diseases related to perceived reliability and credibility of sources, frequency of information seeking, reasons behind information seeking behaviour, and feelings of hope or discouragement with information obtained. Gaps in knowledge uncovered by the literature review were the information-seeking behaviours of patients living with MG. The studies that encompassed rare diseases overall fail to accurately reflect information acquisition for a disease with high variability between individuals such as MG. Further, the available literature mostly used quantitative and mixed methods, with a focus on surveys. The research methods used in these studies from the literature review fail to capture the patient voice.

Strengths of this literature review are a thorough assessment of available literature on the topic from a global perspective, giving a clear picture of the gaps in knowledge. A limitation is that research specifically focused on information needs of patients with MG does not exist and
the review had to focus on rare diseases and neuromuscular diseases overall. Although MG is classified as both rare and a neuromuscular disease, it is a unique disease with each patient clinically presenting as a snowflake. For these reasons, study focused on the information needs specific to patients living with MG is needed.
CHAPTER THREE: METHODOLOGY

The literature review revealed a need for research specific to MG using a qualitative approach. Chronic illness disrupts an individual’s identity and view of how they perceive and control their daily interactions and their idealized future (Oris et al., 2018). As such, it is imperative that research moves beyond causality and defined truths to gain a deeper understanding of how an individual perceives and interprets their illness experience (Green, 2013; Pinnegar & Daynes, 2007). Narrative inquiry (NI) as a research methodology is gaining traction within the social sciences (Clandinin, 2006; Green, 2013). This methodology is a collaboration between researcher and participant in a cyclical process of sharing and interpreting stories and how those experiences have shaped the participant’s current reality and their circumstances (Clandinin, 2006, 2013).

NI is a unique form of qualitative research that reaches further into the realm of a deeper understanding of the lived experience, collecting information with the participants rather than on them (Clandinin, 2006, 2013). NI also challenges conventional research methodologies by changing the type of relationship between the researcher and the researched, as well as using words rather than numbers as data (Pinnegar & Daynes, 2007). Although NI has no single definition, and no defined boundaries or distinctions, Clandinin (2013) describes NI as the study of individual experience, shaped by multifaced external influences, as both a phenomenon and a distinct methodology. NI is a methodology that considers participant stories relationally; moving past the story itself to understanding how the story has been shaped by context and how the story relates to other stories of the same phenomenon (Clandinin, 2013). NI also illustrates how a phenomenon can be experienced and interpreted differently by different people (Squire et al., 2019).
3.1 The Purpose of NI

At first glance NI presents as mere storytelling, but it is a methodology that utilizes storytelling to uncover the subtle differences or variations that collectively paint a coherent understanding (Wang & Geale, 2015). The events and experiences of our lives feel chaotic and uncertain until we pragmatically put those experiences into a sequential order in storied form (Bleakley, 2005). Making sense of stories and telling these stories to others allows individuals to reflect on and interpret their experiences as they compile events into a meaningful narrative (Wang & Geale, 2015).

It is human nature to be drawn to stories to make an experience cognitively tangible and easier to understand (Squire et al., 2019). Personal narratives have power; they engage us, create a sense of connection and empathy for each other, and make the events feel palpable (Squire et al., 2019). For example, the personal stories of individuals experiencing and surviving seemingly unsurmountable obstacles and events are subsequently crafted into books or movies (Squire et al., 2019). As experiences are multilayered and complex, NI works to explore the influence of context on the meaning of experiences, the importance of relationships on experiences, and to understand social patterns within a particular phenomenon (Clandinin & Caine, 2013).

3.1.1 The Purpose of Illness Narratives

Vougioukalou (2019) describes how although illness narratives have historically been perceived as unscientific knowledge, perspectives have shifted to a belief that narratives provide a link between the individuality of each person and the shared anatomic and physiologic traits. This author indicates that illness narratives help to deconstruct how different individuals perceive their illness, how social structure and context influences that perception, and ultimately how their perception influences the ability to manage and cope with the illness. Although a narrative is
subjective, Vougioukalou suggests that it can offer invaluable insights into the social structure of the healthcare system and how healthcare providers can help individuals manage their illness. Patient and family-centered care can only be enhanced by challenging conventional healthcare practices and research methodology by exploring the narratives of patients. This author also describes how narratives are important in chronic illness research to not only allow room for the grieving process, but also for individuals to make sense of their circumstances and gain a sense of control over otherwise chaotic events.

3.2 The History of NI

NI is a relatively new methodology, especially outside the confines of social sciences, primarily explored in education research (Clandinin & Caine, 2013; Squire et al., 2019). Increasing in popularity for healthcare research since the 1990s, NI evolved from narratology: the study of narrative structure (Clandinin & Caine, 2013). In historical terms, humans used storytelling to pass on information, build relationships and communities, and create a sense of purpose and meaning within their lives (Clandinin, 2006). The act of telling stories is old, but the evolution of narrative methodologies in health science is new (Clandinin, 2006). NI emerged as a methodology when health sciences shifted away from positivist and post positivist paradigms (Clandinin, 2006). Rather than constraining philosophical boundaries, NI contains elements from realist, modernist, postmodern and constructionist paradigms (Clandinin, 2006). NI has developed into a distinct methodology with clearly defined terms separating it from other methodology that may use narratives, such as case studies or phenomenology (Clandinin & Caine, 2013). NI is no longer confined to distinct disciplinary fields but has taken hold as a valuable methodology in any discipline with the goal to understand the human experience (Clandinin, 2006).
3.3 The Philosophical Underpinnings of NI

The methodology of NI holds strong connections to John Dewey’s (1938) theory of experience (Clandinin, 2013; Clandinin & Caine, 2013). Dewey expressed that although it is necessary to understand people as individuals, one cannot understand them as individuals without understanding the larger social context that shapes them as unique individuals (Clandinin, 2006, 2013). Dewey also delineated how personal experiences are a product of prior experiences and the building blocks for future experiences (Clandinin, 2006, 2013). These two pillars of this pragmatic philosophy exemplify how NI is best suited to a research puzzle rather than a research question. The aim is not to structure and generalize the information to thread out a precise answer and causation, but rather to understand how the stories and experiences of people’s lives are arranged and fit together contextually and relationally (Clandinin, 2006, 2013).

The development of NI as a methodology was also influenced by the disciplines of anthropology and psychology. Anthropologist Bateson (1994) focused on participant observation and using self-reflection to learn from past experiences to see things from a different perspective. He described making connections and associations between previous knowledge and new experiences. Anthropologist Geertz (1995) studied the concept of culture and its influence on making events meaningful and understandable. Geertz relied on thick descriptions to explain concepts in as much detail as possible. Social psychiatrist Coles (1989) used a narrative style with his work as a method to be transparent in his own beliefs and perceptions, and to impede the formation of generalizations in his final reports. He did not define a starting and end point in his work, but rather would circle around topics looking for themes and connections. Coles believed that stories must be told by individuals in their own words to have power, and that stories help us to understand ourselves as well as others. Bruner (1986) studied learning theory and believed
that people should be active participants in learning and not merely passive recipients of knowledge (Turner & Bruner, 1986). Bruner subscribed to the constructivist approach; that learners are actively constructing new ideas on past and current experiences. Furthermore, the work of psychotherapist Polkinghorne (1988) regarding narrative knowledge has influenced the development of NI. Polkinghorne believed that narratives give people an understanding of their personal actions, and that practitioners must understand those narratives to understand individual behaviour. Polkinghorne also suggests that a historical narrative gives meaning and significance to past experiences which will then shape and influence future behaviours and choices. The contributions of these anthropologists and psychologists together impacted the NI methodology today as used in the social sciences.

NI has also developed around the concepts of constructivism and subjectivism. Constructivism is the epistemological viewpoint that individuals actively form their knowledge base through interaction and experiences rather than osmotically acquiring information in a passive state (Gray, 2021). The Dewey-inspired model of NI strongly follows constructivism as it explores how past and current experiences influence future experiences and knowledge. Subjectivism refers to the influence of individual cognition; thoughts, beliefs, and perceptions (Gray, 2021). NI is a highly subjective methodology from both the researcher and participant perspectives. Researcher subjectivity can be addressed by using a reflective journal, and participant subjectivity becomes the essence of the stories, providing meaning and detail to the stories that help researchers understand participants’ experiences.
3.4 Theoretical Considerations

3.4.1 Living, Telling, Retelling, Reliving

NI has been subject to scholarly criticism due to the misconception that stories are merely told and transcribed by the researcher. However, NI is a much more complex process, as the researcher engages with the participant in living, telling, retelling, reliving (Clandinin, 2013). Clandinin (2013) describes how researchers come alongside participants as they are living and telling their stories. As the researcher inquires further, participants will retell their stories, and as participants retell their stories, they begin to relive their stories. Clandinin emphasizes that the participant stories that populate NI are not fixed with a defined beginning and end, but rather are woven throughout the past, present, and future of their lives. Clandinin also describes how stories of experience continue to evolve and are retold, and those same stories continue to create and opportunity for both the researcher and participant to learn and grow.

3.4.2 Three-Dimensional Inquiry Space

Dewey’s (1938) two criteria of experience, interaction and continuity, set the stage for the three-dimensional inquiry space that forms the foundation of NI (Clandinin, 2013; Clandinin & Caine, 2013). To begin to understand personal experience, researchers need to consider social structures and how interactions with others shape those personal experiences. The three-dimensional inquiry space includes temporality (interaction), sociality (continuity), and place (situation) (Clandinin, 2013; Clandinin & Caine, 2013). The three-dimensional inquiry space highlights the relationality of NI; how personal experiences are related to external influences and social structures, the relational responsibilities of co-constructing personal narratives, and how living and telling stories leads to reliving and retelling (Clandinin, 2006).
3.4.2.1 Temporality

Temporality represents the telling and living of stories over time (Clandinin & Caine, 2013). Clandinin (2013) describes that stories are told in the midst and contain elements of the past and present while also influencing future decisions, events, and stories. Dewey (1938) described this concept as *continuity*. Events in our lives do not follow a linear pattern and researchers must co-compose field texts with the participant by assessing the past and present, simultaneously looking backwards and forwards (Clandinin, 2013). The researcher must also consider subjective and objective influences, as well as contextual and social factors (Clandinin, 2013).

3.4.2.2 Sociality

Sociality encompasses the relational aspects of NI, between participant and researcher, between the stories and contexts that helped shape those stories (Clandinin, 2013). Sociality is derived from Dewey’s (1938) philosophical underpinning of interaction; that transaction occurs not only between participant and researcher, but also between individuals and the environment (Clandinin, 2013). Interaction also represents the phenomenon of objective influences combining with subjective interpretations of an event (Clandinin, 2013).

3.4.2.3 Place

The third pillar of the three-dimensional inquiry space is *place*, or situation. Place can include where the participant stories and experiences occurred, as well as the locations in which the conversations between participant and researcher occur (Clandinin & Caine, 2013). Place also includes the relational space shared between the researcher and the participant (Clandinin, 2013). The location and context of experiences can have a profound influence on personal thoughts, emotions, and beliefs of an experiences (Clandinin, 2013).
3.4.3 Relational Responsibilities

NI is a methodology marked by collaboration, reciprocity, and co-composition of the field texts (Clandinin & Caine, 2013). There is ongoing engagement featuring multiple touchpoints with the participants where researchers collect the narratives in conjunction with the participants (Clandinin & Caine, 2013). Researchers start with an autobiographical NI to understand how they relate to the phenomenon and the research puzzle and begin to relive and retell their own narratives alongside the participant (Clandinin, 2013). NI is a reflexive methodology; to not only explore the stories of participants, but also for researchers to probe into their own stories and experiences throughout the research process (Clandinin, 2013). Inquiry into personal experiences further develops personal justification for the research (Clandinin, 2013). Furthermore, the relational aspect of NI between researcher and participant, and between researcher and their own personal experiences with the phenomenon integrates into the three-dimensional inquiry space (Clandinin & Caine, 2013).

3.4.4 In the Midst

Researchers and participants enter a mutual and symbiotic relationship as each of their own lives and stories are continuing to unfold around them (Clandinin, 2013, Clandinin & Caine, 2013). Experiences and stories do not halt for collection or observation by the researcher, but rather the researcher enters the participant’s life and becomes a part of their story (Clandinin, 2013). Visually this is akin to entering a traffic circle alongside the participant beside their vehicle, in continual motion with other vehicles continuing to circle around influencing the experience, rather than coming to a complete stop at a traffic light. Stories are always in motion, unfolding in real time and are continually being reshaped by events and external influences.
(Clandinin & Caine, 2013). We enter in the midst of our personal and professional lives, in the midst of participant lives, as well as in the midst of social, cultural, and institutional influences that have an impact on the stories (Clandinin, 2013).

Just as we enter in the midst, we exit in the midst. As a vehicle exits the traffic circle it will continue driving, the story does not end. The story will never be complete. The stories will continue to be retold and relived, with room for new stories to be created, told, and relived (Clandinin & Caine, 2013). Researchers and participants enter the relationship on equal footing, learn from each other, and exit the relationship changed on a metaphorical level (Clandinin, 2013; Clandinin & Caine, 2013). Entering and exiting the research relationship in the midst further requires a commitment to understanding lives in motion: researchers understand that they have temporarily become part of the participant’s life and experience, and that their life and story will continue to unfold following the conclusion of the research relationship (Clandinin & Caine, 2013).

3.4.5 Negotiation of Relationships

Clandinin and Caine (2013) suggest that before entering the field, NI researchers must negotiate relationships with participants in relation to the research puzzle. These authors describe negotiation to include the ways in which the researcher can be helpful to the participant before, during, and after the research. According to Clandinin and Caine, an extended and ongoing engagement with participants leads to close relationships and to the understanding that neither the participant nor the researcher leaves the research relationship unaffected. Both parties learn from each other and change from the encounter.
3.4.6 Negotiating Entry to the Field

Researchers must begin by exploring the three-dimensional inquiry space as it relates to their own experiences in relation to the phenomenon of interest and explore how these personal experiences have led us to the research puzzle (Clandinin & Caine, 2013). Clandinin and Caine (2013) describe how entering the relational space with the participant can take two forms: participants begin to tell their stories or researchers engage with participants as they physically live their lives and the stories naturally come to surface. These authors also suggest that stories take the form of conversations between researcher and participant, and the researcher explores where the story takes the participant and what is important to them within the story.

3.4.7 Moving from Field to Field Texts

Field texts is the term used to describe the data collected with NI methodology, to also document the subjectivity of the information collected rather than merely concrete objective data (Clandinin, 2013). The field texts are co-composed by researcher and participant, and can include field notes, transcripts of conversations, and artifacts (Clandinin & Caine, 2013). Clandinin (2013) describes how artifacts can be photographs, artwork, and journals which do not become part of the field text in their entity, but rather serve to trigger memories and stories. This author defines the field as the relational space shared with the participant by the researcher to recount stories, as well as the physical location in which those stories unfold and are retold. Clandinin terms interviews as conversations and those conversations proceed to where the participant takes the researcher rather than following predetermined interview questions with a set desired outcome. She describes stories to be fluid and dynamic, not expected to be chronological or linear.
3.5 Rationale for Research Approach

The literature search has shown a biomedical focus centered on causative autoantibodies and tailored medical treatments for MG. Although quantitative research is necessary, a stunningly large gap has been identified for qualitative research, leaving MG patients to feel alone and misunderstood with a strong need for their voices to be heard. The rich, detailed narratives of patients navigating the complexities of a difficult illness will serve to enrich and complement the biomedical research, adding depth and consistency with nursing values to provide comprehensive care. MG is a complex and varied illness, misunderstood by both patients and practitioners. Likewise, illness narratives can have lexical ambiguity, containing varied stories and interpretations of experiences that foster a deeper understanding of the issue (Vougioukalou, 2019).

The literature review highlighted variability in information seeking behaviours of patients living with rare diseases, but to understand the reasoning behind these differences, to give significance, we need the complementary qualitative data. Due to the absence of prior research on the phenomenon as well as the snowflake nature of MG, approaching the research in the form of a research puzzle by way of NI is most appropriate. As well, NI is a suitable methodology to explore a phenomenon as it unfolds over time, such as the management of a chronic illness (Bleakley, 2005; Green, 2013). NI research is symbiotic in nature, allowing opportunity for benefit for both the participant and the researcher. The medical community develops a deeper appreciation of a phenomenon, adjusting healthcare treatment to fully complement the nature of evidence-based practice. Participants will benefit from the opportunity to tell their stories as it will help them to find meaning from their experiences and circumstances (Clandinin, 2006, 2013). Wang and Geale (2015) agree that NI gives a confident voice to those who have
previously gone unnoticed. Once people can make sense of their experiences and understand how their stories fit within the larger context, it enables them to have a sense of control over the writing of their future story. Chronic illness has the power to deeply impact an individual and irreversibly alter their health and perception of self (Oris et al., 2018), but untangling the complexities of illness narratives in terms of how individuals experience and interpret their quest for health information can help give individuals a sense of purpose and control over their circumstances.

The relationality of NI is apparent not only in context to other participant’s stories, but also in my own story and experiences. I am personally invested in the study of information acquisition for MG because of my own experiences and the desire to make a difference in how MG patients can manage and cope with the disease. I am intrigued how perspective and information seeking behaviour varies with each individual and how they feel it influences the disease process and ability to navigate the healthcare system. The use of NI to understand health information seeking will benefit beyond MG patients, as commonalities and patterns uncovered undoubtedly reoccur and manifest in other illnesses, particularly in other rare diseases (Bleakley, 2005). The meaning and understanding derived from this study will infiltrate healthcare for many patients.

3.6 Justifications

Researchers must consider the rationale behind their study from personal, practical, and social perspectives. These justifications need to be addressed prior to developing relationships with participants, during the conversations and co-composition of field texts, and again at the conclusion of the study (Clandinin & Caine, 2013).
3.6.1 Personal

Personal justification is the process in which researchers evaluate their own thoughts, beliefs, and emotions related to the research puzzle (Clandinin & Caine, 2013). Beginning with an autobiographical narrative inquiry, researchers consider how they relate to the phenomenon of interest and how the research puzzle is constructed (Clandinin, 2013). Often a personal inquiry will evolve into a research puzzle, creating a passion and dedication to the research (Clandinin & Caine, 2013). This study has developed out of my own experiences living with MG and the quest to seek disease related knowledge. My personal justification is to give a voice to a population that is misunderstood on a topic that lacks research, and to explore ways that patients living with MG can be supported in their search for information to better manage and cope with their illness.

3.6.2 Practical

The practical aspect of justification seeks to answer the questions “so what?” and “who cares?” In nursing the practical justification often looks towards change in current practice (Clandinin, 2013). Researchers look to work together with participants to understand how a phenomenon can be experienced differently in the future, particularly in the realm of social justice and equity (Clandinin & Caine, 2013). Practical justification is presented in the final research texts (Clandinin & Caine, 2013). The literature review revealed that qualitative research to date on MG and rare diseases has centered on quality of life, however, the practical portion of these studies have not addressed how to improve quality of life. As knowledge is power, patients living with MG must have access to reliable, understandable, and applicable information to best manage their disease and improve their quality of life.
3.6.3 Social

Social justification encompasses both theoretical justification and social or policy development (Clandinin, 2013; Clandinin & Caine, 2013). Theoretical justifications are addressed by the methodical rational and the contributions of the research to disciplinary epistemology (Clandinin, 2013). Social or policy justifications work to uncover invisible or silenced inequities embedded within social structures and institutions (Clandinin & Caine, 2013). This study aims to uncover the inequalities that patients with MG face in accessing basic information and resources for their illness.

3.7 Description of Research Methods

3.7.1 Participants and Sampling

The inclusion criteria for this study were participants between eighteen and sixty years old, living in British Columbia, Alberta, Saskatchewan, or Manitoba, with a confirmed diagnosis of MG for at least one year. The age limit eligibility was set to complement the literature review indicating that younger individuals have a higher comfort level using the internet, making them more likely to seek out health-related information. The geographic restriction to the Western Canadian provinces served to keep the sample size small as indicated by NI and allow the possibility to meet in-person with the participants. A minimum duration of one year since the diagnosis of MG was necessary as individuals are often unwell at the time of diagnosis and may be feeling overwhelmed or need to cycle through their own process of grief. Exclusion criteria were a diagnosis of congenital myasthenic syndrome with a genetic etiology which would alter information seeking practices, or an inability to complete an interview in the English language. The use of a translator would fail to capture nonverbal cues and meanings of stories throughout the conversations. The number of participants targeted for this NI study was two to four as to
allow for sufficient time with each participant to gather in-depth information. A small sample size is most appropriate to explore the rich detail in participant’s experiences rather than a goal to generalize the findings (Creswell, 2007). With an emphasis on quality of information over quantity, focusing on a small sample size allowed for researcher-participant negotiations and the relational aspect of NI to evolve (Creswell, 2007). Purposeful sampling was most appropriate for this study as the number of people living with MG is limited and participants needed to be physically able and willing to share their experiences and stories.

3.7.2 Recruitment Strategies

Participants were recruited through a Canadian MG Facebook group page and the MG Association of British Columbia. Although a newer and emerging method of participant recruitment for research over the recent years, social media is a cost-effective method to reach potential participants in difficult to access populations (Topolovec-Vranic & Natarajan, 2016). As MG is a rare disease and individuals are geographically dispersed, social media and a patient association were the most suitable methods to access the population of interest. The use of social media recruitment was ethically responsible as potential participants contacted me in response to the social media post if interested in the study rather than me approaching potential individuals directly, including two of the participants who I had prior contact with before the study. See Appendix A for the social media recruitment post. I am a member of three different MG Facebook groups due to my diagnosis with MG and experience with the illness, however, I did not intentionally reach out to individuals or take information from individual profiles or posts. As I was unable to initially recruit a sufficient number of participants through social media, I employed the additional recruitment strategy of having the MG Association of British Columbia distributing my recruitment poster via their newsletter to all the members. When I was contacted
by interested potential participants, I confirmed they met the inclusion criteria and then started
the process of obtaining informed consent. See Appendix B for consent form. I had a total of
four individuals who met the inclusion criteria and participated in the study.

3.7.3 Ethical Approval and Considerations

Approval from the University of Saskatchewan Human Behavioural Ethics Review Board
was obtained prior to the commencement of this study. Information was provided to potential
participants including the research purpose, process, and potential positive or negative outcomes
of the study to aid in their decision to voluntarily participate. An informed consent form was sent
to each participant prior to the start of the interviews to ensure they were aware that they could
withdrawal their consent at any time without repercussions. Informed consent included the
participant’s willingness to have the conversations digitally audio recorded. Ongoing consent
was verbally obtained prior to the start of each interview. Confidentiality was ensured by using
pseudonyms for direct quotes and removing any identifying features of the participants, dates, or
settings. The benefits of participating in this study included an opportunity to discuss challenges,
a decreased feeling of isolation from realizing that others face similar experiences, and a sense of
empowerment from bringing awareness to the issue and working towards positive change. A
potential risk of participating in this study was an increased awareness of destressing emotional
issues from the disease. The interviews had the potential to surface negative memories or
discomfort around specific topics. The participants were made aware at the start of each
interview they were not required to answer questions that make them feel uncomfortable.
Options were available if a participant is feeling emotionally overwhelmed during the interview
including taking a break or ceasing the conversation.
Conversation audio-recordings and transcripts are stored as electronic data on a password-protected computer with encrypted files for a minimum of five years in accordance with the University of Saskatchewan’s requirements. Participants have been made aware of how they can receive a copy of the study.

3.7.4 Setting

Conversations for personal narratives took place in the natural setting. Semi-structured conversations proceeded in the online environment via Zoom, except for one conversation that occurred over the phone as per participant preference. A virtual format was most appropriate for the conversations due to geographic distribution and mobility limitations of the participants. Gunawan et al. (2022) found that online interviews were increasingly common because of the Covid-19 pandemic and a suitable and complimentary way to gather qualitative interview data. During the online meetings participants were readily able and willing to share their experiences and stories in the comfort and privacy of their own homes. Completing the conversations in virtual format helped to enable control over the environment by both the participant and researcher, which minimized any interruptions or distractions from external influences. Each participant agreed to enable cameras during the interviews which allowed me to assess for non-verbal behaviour and communication. The interpretation and analysis of participant narratives occurred in my city of residence in Alberta.

3.8 Collecting Narratives

Once participants reviewed the consent form and provided their consent, I emailed them a form to collect demographic information (see Appendix C). Once demographic information was received, I contacted the participant to schedule the first online conversation at their convenience. Although I initially planned for four to six conversations with each participant,
each lasting approximately one hour in duration, the participants were all eager to tell their stories and many of our conversations exceeded 60 minutes. One participant completed four conversations and the other three completed two. The conversations were scheduled based on participant preference. Despite fewer meetings than originally planned, the extended interaction time beyond one hour for each conversation allowed data saturation to be achieved. Following two recorded conversations with three of the participants, the stories became repetitive despite alteration in the question format or using prompts. I reached data saturation as no new insights could be gleaned or uncovered related to the research puzzle. NI methodology refrains from indicating a pre-determined number of conversations, but instead focuses on the quality of information and stories relayed to the researcher with the achievement of data saturation (Clandinin, 2013). Data saturation further became evident as I could visualize resonant threads gleaning from the stories. Although I could discern additional topics of interest highlighted in the stories, I remained cognizant to stay focused on the research puzzle.

Entering a negotiated relationship under the premise of NI involves entering in the midst and forming a deep connection that leaves both the participant and research changed (Clandinin & Caine, 2013). I had a pre-existing relationship with two of the participants prior to the study. These relationships have expanded and deepened through our conversations. One of the participants was an acquaintance through the MG Facebook group we both belonged to. The other participant was a former work colleague, who was also a member of the MG Facebook group. Both participants contacted me to participate in the study. I did not contact them directly. Despite our previous experiences, ethically responsible relationships were adhered to without impact on the data collection and analysis. The two other participants entered my study without a previous relationship, but due to the rarity of the illness and the feeling of misunderstanding from
others, I was able to form a quick bond with both of them. As each of the participants and I shared and told our stories, our connections deepened and the feelings of validation and understanding heightened. As we told, retold, lived, and relived our stories, we were living alongside each other in the past, present, and future. The close relationships that formed have continued beyond the study, demonstrating the nature of those relationships that were formed. The participants all affected my life and changed me as a researcher and an individual living with a chronic illness, and I hope I have done the same for each of them.

3.8.1 Semi-Structured Conversations

Each conversation began after confirming ongoing verbal consent from the participant and reiterating that we could stop or take a break if needed to manage muscle weakness and fatigue. To negotiate entry into the participant-researcher relationship, I spent some time at the beginning of the first conversation to get to know the participant outside the confines of MG. The conversations were directed by the conversation guide (see Appendix D), which outlined open-ended questions aimed to explore in-depth participant experiences and stories. Open-ended questions allowed the participant to take the conversation and their stories in the direction they choose rather than being restricted to my research focus (de Padua, 2015). The conversation guide included prompts for the main questions to fully explore each topic from alternate avenues or perspectives, and to encourage detailed stories from the participants. Prompts also served to explore stories as they relate to the three-dimensional inquiry space and determine how the elements of the narratives are relational and contextual (Clandinin, 2013). Questions were asked multiple times in different ways, and I often guided participants back to a story to seek clarification. I utilized pauses and periods of silence to allow the participant to reflect and extend
on their responses and stories. The questions were devoid of directing or influencing language and posed in a clear, accepting, and open-ended manner (Gray, 2021).

As the conversations unfolded, the participant’s focus often deviated from the research puzzle to other topics of importance. The participants described their experiences and stories, but also included rich detail of how they felt or perceived a situation or context. The relationship I developed with each participant became reciprocal as they were often hearing about my experiences and stories as well, helping us to find common ground. The participants were asked about artifacts that became part of their stories or served to generate memories of stories. One participant responded that she kept a journal during the onset of disease and diagnosis but was unsure of its current location. Another participant has accepted her completed narrative account as an artifact and documentation of her story.

The conversations were digitally audio recorded. The recordings were sent to a transcription company, Transcript Heroes, by a secure website format. Upon receipt of the completed transcripts, I read and re-read the transcripts while listening to the audio recording multiple times to ensure accuracy of the transcription. I altered the transcripts to use designated pseudonyms and removed any potential identifiers. The completed transcriptions of the conversations became part of the *field texts*; the documented descriptive and contextual fragments of information that serve to enrich the interpretation of the narratives (Clandinin & Connelly, 2000). Additional conversations provided an opportunity to ask further questions and clarify information, and for the participants to do the same as well as expand on their stories as they felt necessary. I reviewed the conversation transcripts in detail multiple times to immerse myself in the narratives, while engaging in reflexivity and keeping the research puzzle at the forefront. As I reviewed each audio-recording and associated transcript I could begin to see
resonant threads showing through. I began to record the key terms and themes following each interview, arranging the information into a diagram to visually represent the commonalities I was seeing from the stories and to refer to during the analysis.

3.8.2 Field Texts

Field texts were kept throughout my interactions and conversations with participants to document observations, impressions, nonverbal behaviours, and details. Within 24 hours following each conversation, I composed the field texts to include a more detailed description of the interaction and contextual information, as well as personal reflections of the experience. The field texts were also sent to the participants to ensure co-composition and to ensure accuracy in my reflection of their experiences (Clandinin, 2013). The purpose of the field texts was to document rich descriptions, record personal insights of the conversations, and to provide a basis to reflect on the participant experiences as their stories relate to my own experiences (Clandinin & Connelly, 2000). The field texts included key phrases or terms that served as a trigger for myself as the researcher to recall important details of the stories and conversations as I developed the interim research texts. The field texts also encouraged researcher reflexivity to increase the trustworthiness of the study by addressing personal bias, beliefs, and perceptions (Clandinin & Connelly, 2000).

3.8.3 From Field Texts to Interim Texts

To move from field texts towards interim texts, I began to work with the stories and experiences as described by participants as I considered the three-dimensional inquiry space (Clandinin & Caine, 2013). Interim texts are partial accounts that are developed from the field texts, which serve as a starting point to understand or make sense of the information contained in the participant stories (Clandinin, 2013). The field texts were read and re-read, in similar terms to
reliving and retelling stories, to ensure I completely captured all elements of each participant story (Clandinin, 2013). The composition of interim texts was a cyclical process with an emphasis on negotiation with the participant. Following each conversation, I asked the participant to review the interim text and provide feedback, which subsequently lead back to more conversations and additional field texts to aid in the finalization of the narrative accounts (Clandinin, 2013).

3.8.4 From Interim Texts to Narrative Accounts

Moving from interim research texts to the composition of the narrative accounts became an iterative process. Following multiple reviews of the field texts, I composed the narrative account on behalf of each participant. I assessed why the story was told in the sequence it was, points of emphasis, embedded meanings in the stories, missing details, or narrative inconsistencies (Clandinin, 2013). The meanings behind the participant stories assembled from considering how temporality, sociality, and place influenced the context of those experiences. I ensured rich verbatim quotes embedded in the interim research text to capture the participant voice. As I composed each narrative account, I reflected on my personal, practical, and social justifications for the study, and how the participant stories related to the research puzzle (Clandinin, 2013). Considering that the research puzzle establishes an exploration rather than a question searching for an answer, the narrative accounts I composed from the participant stories sought to provoke thought and alternate perspectives for the academic consumer (Clandinin, 2013).

Continual negotiation with the participant ensured that the narrative accounts were representative of their stories with truth and authenticity and served to ensure rigor through member checking. I emailed each participant an unfinished format of their narrative account with
the intention to create a sense of space and ease for alterations (Clandinin, 2013). I engaged the participant in further negotiation with each drafted interim research text to ensure accuracy and appropriate interpretation of their experiences (Clandinin, 2013). I focused on mutuality and encouraged co-composition with each participant as the narrative accounts were developed. The ongoing negotiation and co-composition of the interim research texts opened avenues for further opportunities to re-live and re-tell stories (Clandinin, 2013).

3.9 Narrative Analysis

Clandinin (2013) describes and emphasizes NI as a methodology that uses words as data, devoid of statistical representation but populated by common threads and analogous meanings. Although similarities lie between NI and case-centered research, Clandinin encourages researchers to analytically overlap narrative accounts to thread out commonalities and patterns. She suggests that the analysis of narrative accounts looks beyond the specific language and linguistic qualities spoken by the participants to the sequence of events, the points of emphasis, and why the story is being told. Researchers must look beyond what was said and analyze the purpose of the events recounted in the stories. Clandinin’s description of NI analysis demonstrates that not only has the researcher stretched beyond the particulars of the stories to find a deeper meaning and common threads, but also creates space for the audience to extend beyond the researcher’s interpretation to form their own conclusive discernment. The researcher can prompt their audience to shift their focus from the details of the story to the purpose of the story; how the story was told, in what way, and the meaning behind the words.

3.9.1 Analytic Considerations

Rather than sorting the information to fit within a theoretical framework, Clandinin (2013) suggests the researcher instead determines the significance of the participant’s subjective
experience outside the boundaries of a theory. In the analysis of the participant’s stories, I aimed to analytically represent the interpretations and significance of participant’s experiences.

3.9.1.1 Resonant Threads

To begin the analysis, I took a metaphorical step back from the physical close working relationship with the participant to analyze the accounts. Clandinin (2013) describes this step of the analysis as the process of uncovering “resonant threads or patterns” that are “woven through the narrative accounts” (p. 132). I looked for clues of plotlines that wove in and out of the stories over time and place of the individual narrative accounts. Clandinin describes keeping stories intact while analyzing for similar threads or consistencies maintains the integrity of the experiences as described by the participant. This author suggests that narrative accounts should be considered in a chronological sequence as well as threading out meaningful portions of the story, working in a circular rather than linear manner. She also concludes that the analysis serves to not only make connections between multiple narrative accounts, but also to associate how personal stories are influenced by social structures, such as inequities and social justice. Finding patterns and consistencies in the stories does not serve to form a generalization, but rather to aggregate and relate stories, to raise awareness, and to intrigue further investigation of the phenomenon (Clandinin, 2013). These tenets of narrative analysis as described by Clandinin guided my process of analysis and interpretation.

The beginnings of the analysis began during the data collection stage during the conversations with participants and transitioned into an overlapping and cyclical process. The composition of the field notes following each conversation and the development of the interim texts began to reveal and highlight reoccurring topics and commonalities between participants. Clandinin (2013) describes the commonalities as “threads” rather than themes, as
the researcher can discern how they are “threaded” or “woven over time and place” across the participant accounts (p. 132). The overarching concepts, the “resonances or echoes” across the narrative accounts helped to identify how the experiences of patients living with MG fit within the larger sociocultural context (Clandinin, 2013, p. 132). As I sensed the importance of the repeated emergence of the threads, I began to sketch a working diagram to visualize how the concepts displayed importance across the multiple narrative accounts. The working diagram then became an aid to discern areas of further clarification that was needed from the participant stories and helped to guide the subsequent conversations.

Keeping the research puzzle at the forefront of my mind, I entered the process of attentive familiarization with the semantic data contained within the participant stories. For example, I reviewed the audio recordings of the interviews in conjunction with the transcripts numerous times, and read and re-read the field notes, interim texts, and narrative accounts. The information from each conversation was assessed independently and then as a fragment of a whole to ensure a complete analysis (Fungard & Potts, 2019). From extensive review of the data contained within the documents and consideration of my working diagram, I was able to assign a name to the threads. I then colour-coded each thread and highlighted those threads accordingly in the transcripts and interim texts as I continued my analysis. I considered not only the common threads and how they presented for each participant, but also the inconsistencies throughout the stories to ensure assessment from alternate angles.

As I explored and re-explored the audio recording, transcripts, and texts, I reviewed my working diagram multiple times. The resonant threads represented on my diagram evolved throughout the analysis, sometimes combining threads into a new category, expanding a topic into a bigger concept, or removing a potential thread off the diagram if found to have little
applicability to the research puzzle or across other narrative accounts. Exposing and cohesively assembling the resonant threads became an iterative process as I strived to preserve each individual experience while simultaneously seeking the relational aspects (Clandinin, 2013). The diagram aided to assess the relation of the resonant threads to the research puzzle, and also allowed for the revelation of subcategories embedded within the threads. I further expanded my diagram to include the prominent topics arising from the resonant threads.

3.9.1.2 Interpretations

As I developed and revised the resonant threads weaving throughout the narrative accounts of each participant, I simultaneously considered the meaning beyond the spoken words, and also what was conveyed from what was not said or expressed, such as from periods of silence. I looked past the linguistics to assess how the stories were shaped by context, the three-dimensional inquiry space, and how my voice within the narrative accounts encouraged relationality and deeper meaning. Reviewing the field texts during the analytic process reminded me of the emotions attached to the participant experiences and my impressions of the conversations. The verbatim quotes from participants added power and relatability, humanizing their experiences, drawing the reader into their world. The participant quotes further supported the resonant threads gleaned from the narrative accounts. As I neared the end of my interpretation, in which no further insights arose, I again considered my personal, practical, and social justifications for the study. I met my goal for these justifications by giving participants living with this rare disease a voice, addressing the gaps in the research and literature, and uncovering the invisible inequities related to the access to health-related information.
3.9.2 From Interim Texts to Final Research Texts

The *final research text* is the document that is produced from the interim text for academic or non-academic audiences (Clandinin, 2013; Clandinin & Caine, 2013). The final research texts did not present correlations, causality or final answers, as NI does not seek to answer a concrete question (Clandinin, 2013). Rather, the text revealed how the coalesce of narratives fit together in a completed puzzle of a phenomenon, and how the outcome helped to understand similar populations and influence practical applications (Clandinin, 2013). Direct quotes were used to support participant stories and interpretation of the narrative accounts, as well as to adhere to the tenets of NI research to develop knowledge *alongside* the participant and not *from* them (Clandinin, 2006, 2013). The final research is heavily populated with verbatim quotes to help illustrate the stories and experiences, as well as highlight similarities and differences in perceptions (Clandinin, 2013).

3.10 Rigor

As a branch of qualitative research, this NI study adhered to the properties of trustworthiness to ensure participants’ stories and experiences were accounted for accurately and interpreted in a benevolent manner (Gray, 2021). The goal was not to demonstrate replicability of the study, as different researchers may conduct a different analysis and interpretation (Stahl & King, 2020). As qualitative research is woven with subjectivity, from the participants to the researcher to the audience, the goal was to instill a sense of confidence in the contents of the final report (Stahl & King, 2020). To ensure trustworthiness of this study I adhered to Lincoln and Guba (1985) four factors of criteria: *credibility, transferability, dependability,* and *confirmability.*
3.10.1 Credibility

Credibility in qualitative research is the ability to show that the findings are correct and accurate, and that the audience can have confidence in the truth of the final report (Stahl & King, 2020). Stahl and King (2020) state that credibility aligns with internal validity in quantitative research to show that final outcomes represent the truth and are not due to methodical or researcher error. According to these authors, the challenge with demonstrating credibility is that qualitative research is interwoven with individual perceptions, which are influenced by personal bias, beliefs, and opinions. They also state, that although subjective, researchers strive to maintain an edge of objectivity and seek to demonstrate how the findings fit together to understand the phenomenon under study. For this NI study, credibility was demonstrated by using techniques to show how the information from stories and experiences fit together in the research puzzle. Lincoln and Guba (1985) identified multiple techniques to demonstrate credibility in qualitative research: prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, referential adequacy, and member checks. For this study, I used the techniques of prolonged engagement and member checks.

3.10.1.1 Prolonged Engagement

Prolonged engagement is the act of spending extended time on multiple occasions with participants in their natural settings to gain a better understanding of their lives, experiences, and social and cultural influences (Stahl & King, 2020). Using this technique allowed for an immersive experience to build rapport with the participants, addressed my personal bias and perceptions as it related to the phenomenon under study, and allowed adequate time for the participant to tell, live, retell and relive their stories. Prolonged engagement also offered sufficient time to engage in ongoing negotiation between participant and the researcher. I met
with each of the participants between two and four times over the course of a three-month period. The engagement further extended beyond the conversations to the co-composition of the interim research texts and final narrative accounts, which took place over a following two month period. The establishment of a mutual relationship ensured that the stories and final information presented comprehensively represented the participants’ experiences.

3.10.1.2 Member Checks

Member checks were completed by obtaining participant feedback and validation on the interpretation of the stories in the interim research texts. The participants were provided with the interim research text to validate the accuracy of the information transcribed and to acknowledge any inconsistencies. An invitation was extended to contact me with any concerns or clarifications. Member checking gave the participant an opportunity to ensure their perspective and stories were accurately represented (Clandinin, 2013; Gray, 2021). I then further engaged with the participants to co-compose their final narrative accounts. The co-composition of the final narrative accounts also ensured the accuracy of the participant stories as a form of member checking. As NI is a form of participatory research, member checking with the participants was an important step in the co-construction of research texts and the hallmark of mutual relationships and ongoing negotiation throughout the research process (Clandinin, 2006, 2013).

3.10.2 Transferability

Transferability establishes the trustworthiness of research by demonstrating how the results can be transferred to similar situations or populations for the phenomenon under study (Bomer-Norton, 2021). The results of qualitative research, including NI, are not to proclaim a definitive answer to a specific research question, but rather to create an understanding of the phenomenon and provide insight into how the emerging patterns fit together (Stahl & King,
The transferability in NI comes from providing a vehicle to learn from others’ experiences, to create an awareness of different perspectives, and create a sense of intrigue (Stahl & King, 2020). As transferability looks at how the results can be transferred from one context to another, the concept of the three-dimensional inquiry space plays a key role. Stahl and King (2020) suggest that transferability can be demonstrated by providing “thick descriptions”, accounts in the final research text are detailed enough for the reader to almost tangibility feel and experience the phenomenon alongside the participants (p. 26). I employed this technique by using the information from the interim research texts and verbatim quotes when I composed the final research text. The analysis and interpretation of the overarching concepts and resonant threads enables others to learn from the participant experiences and view MG from an alternate perspective.

3.10.3 Dependability

Dependability in qualitative research is imperative to establish trust in the reported findings and that methodology is repeatable (Stahl & King, 2020). Displaying transparency in the methodological decisions instills trust in the final research report (Stahl & King, 2020). To ensure dependability of this study, I used ongoing debriefing with my supervisor, as well as use the techniques of an audit trail and reflexivity.

3.10.3.1 Audit Trail

To ensure dependability and consistency in my research I created and maintained a clear audit trail: detailed account of how and when information was collected, field notes, methodological decisions, researcher reflections, and advisory committee meeting minutes (Gray, 2021). The audit trail provided transparency as it enumerated sufficient information to demonstrate a timeline of events and how they occurred (Gray, 2021). Meticulous record
keeping throughout the research process further allowed me to ensure the interpretation and emerging patterns were reflective of the participant’s stories and accurately reflected the information enveloped in the narratives. Furthermore, the audit trail maintained that the research process and interpretation of findings were grounded in the stories and remained aligned with the research puzzle.

3.10.3.2 Reflexivity

As I have my own lived experience with knowledge acquisition for MG, it was important to openly acknowledge and explore the potential subjectivity in my study. To accomplish this, I engaged in reflexivity: the critical examination and heightened awareness of my own personal bias and motivations that had the potential to influence my decisions and actions throughout the study (Gray, 2021). The use of field notes throughout the collection of narratives and interpretation highlighted my insights and perceptions which ensured my bias did not influence the research process (Gray, 2021). The field notes included in-depth detail documenting what I observed and experienced, my personal insights during the collection of narratives and any study decisions as to bring awareness to areas of potential bias that had the possibility to influence the interpretation of the stories. The use of a reflexive journal provided ongoing reflection to explore my thoughts and interpretations throughout the research process. Regular reflection on the research puzzle and the rationale for the study helped to remain focused on the participant stories and the meaning behind their lived experiences outside of my own.

3.10.4 Confirmability

Confirmability seeks to ensure objectivity in the research, to show that the results are based on participant narratives as opposed to researcher bias (Stahl & King, 2020). The techniques for confirmability involve checking and rechecking the information throughout the
research process to ensure that fellow researchers could repeat the study with similar findings (Stahl & King, 2020). In this study, I ensured confirmability by reading and re-reading conversation transcripts and confirmed my interpretations with the participants as we co-compose the interim research texts. I was also cognizant to use verbatim quotes throughout the final research text to maintain as much objectivity as possible.

3.10.5 Reflexive Journal

To further adhere to the four criteria of trustworthiness in my study, I used a reflexive journal that included details about methodical decisions and myself as a researcher. The reflexive journal also provided an avenue of self-reflection to assess personal bias, thoughts, beliefs, and perceptions of the phenomenon under study (Gray, 2021; Stahl & King, 2020). I was able to use the reflexive journal to explore how my experiences with MG had the potential to influence my interpretation of the participants’ stories. I evaluated my opinions and thoughts and questioned my interpretations as objectively as possible. Personal reflection focused more on the descriptive information obtained from conversations with the participants and this information was used to provide cognitively palpable descriptions (Stahl & King, 2020). To reflect on the study methods, I documented and assessed the procedural data, the reasons behind methodological decisions, how information was analyzed to determine patterns and consistencies between participant stories, and how my interpretations related to the research puzzle.
CHAPTER FOUR: THOMAS’ STORY

I first met Thomas as an acquaintance though a Canadian MG Facebook group a couple of years ago. When I first received my official diagnosis of MG, he immediately stepped in to offer emotional support, words of wisdom, and a side of humour. Since that time, we stayed in contact and periodically converse over the phone to connect over similarities in our MG journeys and the common daily struggles. He quickly and seamlessly became part of my MG family.

Thomas is one of those individuals who makes you feel at ease and can quickly put a smile on your face if you are having a hard day. He is amiable, confident, and has a defining openness about him. His stories are filled with chronological details, emotion, personal reflections, and highlight the best qualities of his character. From the start of our interactions, I felt a connection with Thomas; talking with him felt like talking to a friend I have known for decades. Our conversations took place in a virtual format due to the geographic distance, but this in no way hampered our ability to connect and engage in a meaningful way. Thomas seemed eager to share his story. He spoke with conviction, but in a unique way that showcased how his disappointments and challenges were intertwined with feelings of gratitude and joy. Reflecting on his journey seemed to offer clarity on situations and complex issues that did not seem to make sense at the time, giving him the ability to piece together how the events have affected and changed him.

I have always appreciated Thomas’ willingness to mentor and support others in the online MG community, but now I also appreciate the insight and detailed window he has provided to me regarding his personal experience with MG. Thomas is resilient and a strong advocate for himself. He has learned to navigate the healthcare system as a patient with precision. Despite having the rarest form of MG and the additional challenges that go along with it, he will not have
his voice minimized and will continue to demand the best medical treatments to support the highest quality of life he can achieve. Thomas is an inspiration; this is the story of his journey with MG.

4.1 Symptoms - “What on earth is going on?”

Consistent with most autoimmune diseases, Thomas was plagued by vague and fluctuating symptoms for numerous years leading up to his diagnosis of MG. As Thomas and I began to discuss his earliest memories of MG symptoms, he quickly cited debilitating fatigue as an initial prominent issue. He recognizes in retrospect that he would often rationalize reasons for the fatigue, such as excessive body weight or a lack of physical fitness. Brushing the exhaustion aside, he carried on throughout his days with as much normalcy as he could. As the details of his story began to materialize, he recalls the first unexplainable indication that something was unequivocally wrong as the inability to maintain his usual fast walking speed, compounded by having to sit down and rest after short periods of exertion.

I noticed that I was getting heaviness in my legs, my calves. And so, I find that you push – keep doing it, walking, and trying to keep and they’re getting heavier and heavier. And then I feel like I’m getting a cramping. It was almost like; you know where you put your - you have a bucket of water, and you hold it out on your side? You can hold it out for a while. And then the more and more you do you get the cramps, it’s harder to keep holding on to it. It was like that was my legs, I’d have to stop and sit down. So, I’d be walking in from the parking lot. And I’d be walking in really fast, fast feet, and then I’d have to stop and sit down. I was like, what on earth is going on?

As Thomas came to grips with this revelation and attempted to mentally unpack the rationale behind this change of pace, the weakness and decelerated movements spread to his
upper extremities. He also noted that his respiration became laboured inappropriately for the intensity of physical exertion.

*I noticed then my arms were getting weaker, writing was getting more difficult. I then found that my arms were heavier, my legs were heavier. My mobility was really decreasing and this fatigue. I noticed then by Christmas that breathing, I’m having to put an effort in.*

Although our conversation was in its infancy at this point, I could immediately emphasize with Thomas. His description of the pernicious symptoms brought back a flood of memories of my own experience, rationalizing away undefinable symptoms, or attributing those symptoms to unrelated causes. I lived in denial for numerous years and continued to push through my professional and home responsibilities. As my symptoms became progressively severe, affecting my ability to climb stairs and causing laboured respiration, I concluded that it must be due to contracting the Covid-19 virus. Only once I was faced with impaired swallowing did I really stop to consider, “what on earth is going on?”

As the initial symptoms progressed and additional symptoms appeared, Thomas was finding it increasingly difficult to maintain full-time employment. After 26 years in the healthcare industry, Thomas’ identity had become intimately interlaced with his career and work ethic. Determined to manage the concerning symptoms yet maintain his reputation as a committed employee, Thomas was forced to decrease his working hours to part-time. With a strong health information base acquired from his education and experience working in healthcare, Thomas began to consider numerous differential diagnoses to explain his symptoms, such as MS or a mitochondrial disease.
I’d do nothing. I’d just do nothing. Lay in bed, rest. And at weekends, I would do nothing. I was resting, saving energy for Monday. I was thinking, “have I got mitochondrial disease?”

4.2 Dismissal from Physicians – “She was talking at me, there was no two way”

The concerning symptoms prompted Thomas to consult with his general practitioner, who referred him to a general neurologist. After a thorough medical history and physical exam, the general neurologist suggested that he may have a rare form of ALS, but he would have to travel to the Mayo Clinic in the United States for a formal diagnosis. Although he did not understand at the time the cause of his symptoms, he recognized that his symptoms improved with rest, which is not a clinical manifestation of ALS. With an inconclusive medical report from the neurologist and further discussion with Thomas regarding his symptoms, Thomas’ general practitioner then sent a referral for him to be seen at the neuromuscular clinic. While waiting in an exam room at the neuromuscular clinic with his wife, Thomas noticed a poster on the wall titled, ‘Do you have Myasthenia Gravis’. Thomas and his wife read over the symptoms listed on the poster.

*I mean, it was all there, textbook. I can’t remember exactly what was written there. And my wife sat next to me. She went, “That’s you!” To which this neurologist came in and my wife said, “Oh, we’ve seen your poster. That’s Thomas.” To which she said, “No, that’s not Thomas.” And she went, “Well, you’ve not spoken to him.” She’s like, “Well, I’ve read his file. That isn’t Thomas.”*

Thomas’ wife timed the interaction with the neurologist at the neuromuscular clinic – six minutes and 42 seconds. He did not have a chance to explain his symptoms or engage as a partner in the conversation. Armed with the name of an illness that appeared to explain his
symptoms, he began to perform independent online searches for information about MG. He had noticed an additional symptom of significant ptosis, particularly later in the day, which is a defining MG symptom. When he found a description online of a diagnostic test for ptosis caused by MG called the ice pack test, he performed the test at home, and it rendered positive. Thomas recorded a video of the results to provide documentation to his physician. I continued to see the similarities in our experiences as I also had discovered the ice pack test online, tested it on myself, and documented the results to bring to my physician. Once I had a referral to a neuromuscular specialist, that documentation was compiled as part of my diagnostic criteria.

Meanwhile for Thomas, the laboratory results ordered by the neurologist were completed, and he received a follow up call from the neuromuscular clinic. As his bloodwork also proved to be indeterminate for any pathologic dysfunction, he was told that what he needed to do was to lose body weight and get a “good psychologist” involved in his care. Thomas describes trying to take in what she was saying, but she was talking fast and talking at him, not with him - “She was talking at me. There was no two way. I’m trying to take it in but she’s talking really fast. And then she’s gone. I’m like, well who’s following up with me now then?”

Disappointed with this interaction, Thomas went to follow up with his family doctor. At his appointment the physician allowed him to read over the consultation report that was sent from the specialist at the neuromuscular clinic. The report evoked significant emotion and disbelief from Thomas as the information presented was a complete disconnect from his circumstances.

*The symptoms weren’t mine, the chronology was incorrect. I mean, she wrote – the arrogance of this woman to write such derogatory comments about me as a morbidly obese man, who needed to see a good psychologist to help him deal with this. These sort
of deep-rooted issues for this man. But she’d written it all based on completely inaccurate, incomplete – I mean, I’ve not spoken to her about anything. I thought, how can she write something about me without a consultation? I thought probably she should be speaking to me. She didn’t speak to me. That’s best practice. Listen to the patient. She didn’t listen to me. I didn’t get a chance to even speak to her. And she wrote this, and I’m left hanging.

4.3 Career Loss – “Staff there thought I had a drinking problem”

As these events were unfolding, employment was becoming increasingly difficult for Thomas. He had an hour’s commute, and by the time he arrived at work in the morning the exhaustion was debilitating; he would go into his office, close the door and resort to sleep. Arriving home at the end of the day he would struggle to get out of the car. Towards the end of his time at work before being forced on disability, Thomas acknowledges that he accomplished very little as his physical limitations had become unmanageable. The staff he oversaw as a manager later told him that they thought he had a problem with alcohol. It was not until later that Thomas realized his speech was affected.

Staff there thought I had a drinking problem. They would see that I’d be holding on to the wall because I was weak trying to support myself. And somebody said that they would see me walk out to my car thinking, “What on earth is this man doing at work?”

I’m then noticing also that my mouth couldn’t keep up with when I was talking. And I have an accent, but I just see this vague look come over people’s face when I’m talking to them that I didn’t realize, as I look now, I was slurring my words. But I didn’t know, I didn’t hear it. I just know that it was just bizarre.
The severity and frequency of symptoms eventually forced Thomas to take a medical leave from work and go on disability. As Thomas told this part of his story, I could feel a real sense of loss. It appeared to be the crux of his journey, the event that separated him from a defining part of his identity and in which he must acknowledge and accept that he was ill.

*It just wasn’t real. I just couldn’t get over that, this is really happening. And then I had to finish work. I was devastated. And I’d say I’m not one to share my emotions or get upset, but I sobbed. I loved my career and I’ve been [in healthcare] for twenty-six years by that time. And I’d been [in a management position] for fifteen years. And I’m really good at being a manager, I loved doing it, love mentoring people, seeing people develop and making things different for the staff and the patients and environment. And it really did devastate me. I felt very guilty that I’d let my boss down, I let my team down. You know, all that stupid stuff that comes into our head about work ethic."

As I reflected on this part of our conversation afterwards, this is the first time I could see the dichotomy of our experiences relating to MG. Although I also love my career, I remember feeling extremely run down, exhausted, and unable to keep up with managing both my professional and home life; I felt relief when I could step back from work and take time to rest and recover. However, I sensed with Thomas that he felt his withdrawal from work was permanent, whereas I felt that my time away would be temporary. I believe now that either Thomas understood the severity of his situation at the time with greater clarity than I did, or that I was in a mental state of denial to the gravity of my situation.

**4.4 Early Information Searching – “I didn’t really know what I was looking for”**

With professional experience in the healthcare industry, Thomas had in passing heard of MG, although he admits that he did not even know how to pronounce the term. His initial
searches were open and vague – typing ‘myasthenia gravis’ into the google search bar. At the time he was not even sure what he was looking for other than an explanation of his symptoms. He describes his early internet searches to learn more about the disease, but also for information on how to manage his symptoms.

_I didn’t know really what I was looking for. I was looking for symptoms. I was looking for treatment, management, skills on how to manage it. Because obviously – I still describe myself as an ultra-short range Tesla. I only have a certain amount of energy and after that I just die. I was – how do I manage that?_

Thomas read anything and everything he could find on MG. Although without a formal diagnosis, the more he learned about MG, the more his symptoms began to make sense and fall into place with his experiences. I asked Thomas what he thought about the information he was finding online at that time.

_I very much kept an open mind because I kept thinking, “Well, everything else has come back negative,” and everything – and this just fitted. It wasn’t like I wanted to fit into that, it just fitted with me. So I was very much like, “I think I really have that.” And then I thought, “Well if I do – if I have [myasthenia gravis], I want the opportunity of treatment to see if I do improve. So, for me it just fitted. It’s not that I wanted to fit that. It was like, that fitted me._

In discussion of early information searching with Thomas I began to recall how I personally approached online searches. I often would search in combination of symptoms to see if a reoccurring set of disease would come up, helping me narrow down a potential cause. I remember it was one defining symptom that I searched that highlighted MG: ptosis. As a distinctive symptom of MG, I was confident I had determined my pathology and proceeded to
request a referral to a neuromuscular specialist to confirm the diagnosis. Thomas’ description of how the disease seemed to fit him resonated with me. For myself, I could almost visually see how the diagnostic pieces fell into place and fit together.

4.5 Connecting with Others – “Validation, she understood all of my symptoms, she GOT it”

Early in the active searching stage, Thomas came across websites for local and global MG Associations. He streamlined his searching to information from those associations and academic papers to ensure he was getting accurate and credible information. Although his searches started broadly for anything he could find related to the disease, he describes how his focus became more narrowed as he continued to identify information sources and increased his understanding of the disease. The information he obtained from these MG Associations proved to be the most helpful and useful to Thomas.

*I looked at the MG Foundation of America, I looked at the MG Association in Australia, and I was just reading about it. And also, being [in healthcare] I was looking at academic research on it, what caused it, what are the symptoms. And also, very much because I’d been tested and I was negative for the antibodies. I was really much looking into that.*

Thomas’ online search for information following his appointment at the neuromuscular clinic quickly led to his provincial MG Association. He proactively contacted the association by email looking to connect with someone he could speak to and find out more information. He was put in touch with the president of the association, and they arranged a phone call. Thomas explained his symptoms and his positive response to the ice pack test: the improvement of ptosis after the application of an ice pack to the upper eyelid, resulting in decreased acetylcholinesterase breakdown in the neuromuscular junction. The president of the association
confirmed that his experiences sounded precisely like MG and suggested that he request a trial of a medication called mestinon from his family physician. Thomas described how he felt after that conversation – “Validation, she understood all of my symptoms, she GOT it. It was like the first person who really did.”

Thomas proceeded to connect with members of the provincial MG Association following the initial interaction with the president. This is where he not only received the first validation that his symptoms were real and that others were experiencing the same thing, but with a smile he recounts the story of how he was congratulated by members of the MG Association for the diagnosis of MG.

*I went to the first association meeting, and they congratulated me for having MG. They said, “Congratulations, you have MG.” And I kind of looked at them, like - what? But obviously compared to ALS or some other – MS or some other thing, this is treatable. [MG] doesn’t scar the nervous system like MS does and ALS destroys it.*

I found this part of Thomas’ story interesting as there is not a provincial chapter of the MG Association where I live, and the national MG Association seems sparse and limited in information and resources. As Thomas was able to quickly link in with others in his home province, have personal conversations and the collaborative emotional support, I could see the necessity of these types of associations for individuals in all stages of the disease, including those who remain undiagnosed. As Thomas heavily relied on the personal connections formed from the association, I alternatively forged ahead to advocate for myself within the healthcare system, using my personal conviction that was assembled from online searches.

Expanding his search, Thomas found numerous MG Facebook groups, giving him an additional avenue to interact directly with other individuals living with the disease. In our
conversation, Thomas consistently and adamantly confirms that the personal sources of information – direct experience from others – was the most helpful. Without intention, Thomas had developed a structured system to search out different types of information for MG. The literature provided him with the basics of the disease – pathophysiology, symptoms, treatments, but the MG Association and Facebook groups connected him with others who could provide information on how to manage the disease and associated symptoms. After he had exhausted his literature search for the basic information such as symptoms and antibodies, and after he had a clear visualization of how the disease ‘fit’ him, he began to learn how to manage the symptoms within his lifestyle. As he spoke about his connection with others living with MG, I could sense how powerful the experiential knowledge of others became for Thomas.

_I found all these ways to manage it, to manage the symptoms, to pace myself, and all these handy hints. I thought, “Oh, that’s useful.” And I found them [the hints] really useful. And so, it was always about – I learned through these websites and people’s stories how – and then also I then joined Facebook groups. I was never on Facebook before, when I worked. I found the MG of Canada Facebook group very useful. And I also found the seronegative MG Facebook group very useful, very supportive._

Although Thomas was deep in his search for information, the type of information that he was seeking could not be found on a standard website. Now as a member of the online MG community, he also took on the role of providing support and sharing information he has found. I can remember seeing posts within the MG Facebook groups from Thomas before we had connected personally, often containing links to research articles on MG related topics. He continues to offer strong emotional support within the online groups. Reflecting on this, Thomas said, “The people in there, you could hear the desperation.”
I found it interesting to hear from Thomas’ experiences and perspective of how he could see the desperation in the posts in MG Facebook groups. After reflecting on that comment, I can see this as well – the frantic search for answers, for a diagnosis, to feel better, to feel a sense of connection that others are experiencing the same thing, a community. I often feel empathetic towards new members of the online MG Facebook groups as they are highly active in their posts, asking about symptoms, what is ‘normal’ for the disease, how to find a physician who understand the disease or is ‘seronegative friendly’, how to manage and cope with symptoms. I get a real sense of the fear and uncertainty the symptoms uncover in people, especially in the absence of a diagnosis. Once these individuals have asked many questions and connected with others in the group, they become less active and seem to be able to engage more in conversations rather than frantically pursuing answers. Thomas explains how connecting with others who share the same diagnosis can be powerful.

*Speaking with people at the MG Association, I found was really useful meeting them, sharing my story, hearing their story, and we’re all the same. Every one of us has been doubted. All the way along. Doesn’t matter who, where, what [we are, our circumstances].*

Thomas eloquently explained the value he has found in the information he has learned from others living with the disease. He stated, “It’s the little nuances. It’s the finer details of the disease I found that was very helpful speaking to people at the MG Association.” He surmised how the practical advice he has learned in conversation with others is much more than he ever found in a simple Google search.

*I found that speaking with some of them was really useful. For example, if I’m having trouble – I didn’t get this from online – I’m having trouble with my swallowing, and I*
can’t swallow, it was a MG Association colleague that said, “Well, put mestinon under your tongue. Just let it dissolve in your mouth. And then try and swallow. Then have a cold drink.” I’d never heard of that. Have a cold [drink] – if you’re swallowing is a bit funny but you still can swallow, have an ice-cold drink because the ice-cold drink cools your esophagus so you can swallow better. But I never thought of that.

4.6 Symptoms Labelled as Psychosomatic - “I was branded”

Thomas describes his general practitioner as “brilliant” and appears to have a mutual and respectful relationship with her built on trust. She accepted his query to try the medication mestinon, which can also be used as a diagnostic tool for MG if it elicits a positive clinical response. Thomas recounted the realization that he had become unaware of how impaired his chewing and swallowing had become until he tried taking mestinon. He described his swallowing before the medication as “clunky,” and with the therapeutic effect of the medication it became “effortless.” Thomas communicated these results back to his general practitioner, who in turn referred him back to the neuromuscular clinic for electromyography (EMG) to assess the health and function of the muscles and nerves.

The test proved to be negative, as it sometimes can be despite the clinical manifestations of MG. However, Thomas realized in hindsight that he had continued taking mestinon before the EMG testing, which affects the ability of the test to discern dysfunction in the neuromuscular junction. Upon interpreting the negative EMG and reviewing the medical notes of the previous neurologist Thomas saw at the neuromuscular clinic, this physician conferred the same recommendations; there is nothing physically wrong and he needed a psychologist, that there is a strong possibility that his symptoms are psychosomatic.
I was just this blind flow of fury, anger, upset and disbelief that I was going through this. Why didn’t they believe me? I am my word. I am known for always being so brutally honest. But I was just a number. I was a patient. I was branded then.

It was interesting to hear Thomas make the association between self-advocacy and subsequently being labelled as psychosomatic. I believe this connection was indicative of how medical professionals had responded to his ongoing symptoms despite his inconclusive test results. I could discern that the events leading up to this point had filled Thomas with doubt and uncertainty despite his strong advocacy skills. I can appreciate how Thomas reached this conclusion from my own experiences. Although it was never suggested that my symptoms were psychosomatic, I often felt skepticism and doubt from a general neurologist in the form of body language or seemingly unwillingness to provide treatment or a referral. She would often shrug her shoulders when I brought up concerning symptoms, such as difficulty swallowing, and eventually only made the referral to a neuromuscular specialist after I involved an optometrist in my care, who then gave a preliminary diagnosis and provided consultation notes for the referral.

As Thomas discussed this difficult time in his journey to a diagnosis of MG, the prominent issue that permeated this story is that he had “no voice” in the healthcare system or in his interactions with healthcare professionals. He had not been offered the chance to have a conversation, explain his symptoms, describe what he was experiencing – the psychosomatic remarks that infiltrated the consultation note became permanently etched into his medical chart. This singular action by two neurologists, who were unwilling to comprehensively understand and explore Thomas’ symptoms, enviably dominated and influenced each and every subsequent healthcare interaction.
4.7 Confirmation of Diagnosis – “I don’t understand why the other neurologists didn’t see this”

With the documentation from both neurologists pointing directly to psychosomatic causation, Thomas’ family doctor was struggling to secure a referral for a subsequent consultation with another specialist. Desperate to find answers, Thomas contacted a former colleague to assist with a referral to another local neurologist that he believed had experience with MG. The appointment was over the phone due to the Covid-19 pandemic, but this was the first appointment with a neurologist in which Thomas had the opportunity to engage in conversation. Following the chance to elucidate his symptoms and circumstances, Thomas was told what he suspected since his first visit to the neuromuscular clinic.

*He said, “Thomas, you’ve got seronegative myasthenia gravis.” And I said, “Well, that’s what I think.” I said, “It’s bizarre, because apparently, I don’t have any antibodies.” He said, “Well, you’ve got a rarer form, Thomas. And quite frankly, I don’t understand why the other neurologists didn’t see this.” I said, “Well, I haven’t got a chance to speak to them. You’re the first one that I’ve actually got to talk to.”*

Thomas speaks of this moment as though it was a relief. A physician listened to his concerns and gave him a preliminary diagnosis. With a diagnosis, he could obtain treatment. I asked Thomas what type of information about MG was provided to him at this time. Reflecting back Thomas said that it was limited.

*He told me about MG and told me about the occurrence of seronegative. I actually on my own volition, I had found information through the MG Association. And there's other support groups online. I have information from Australia, the UK, and also the MG Foundation of America had on a lot of things. So, I was able to get a lot of information*
from there. It would be very useful if his clinic had a nurse or a nurse practitioner to contact but there isn't any.

The feeling of relief that comes from having a diagnosis and an explanation for the symptoms that have plagued Thomas for years is a feeling I know well. Although I was deeply troubled about what the diagnosis meant for my future, I felt a weight had been lifted when a physician took my symptoms seriously, was able to give me a diagnosis, and that there were treatments available. The deviation in my personal story occurs at the point of information sharing at the time of diagnosis. Minutes after the official diagnosis, my neuromuscular specialist took the time to sit beside me, draw out pictures of how MG affects the neuromuscular junction and how the pharmacokinetics of mestinon alleviate symptoms, and discuss the best online resources to find more information. Although I appreciated this gesture at the time, since then I have really begun to grasp how important this step was to lay the foundation of our physician-patient relationship. I felt that the experience created a relationship in which I was comfortable to ask questions, make suggestions regarding treatment options, and become a respected and active member of my own healthcare team.

4.8 Navigating the Healthcare System – “This is not in my head”

From our ongoing conversations, I discerned that Thomas has a multifaceted and complicated relationship with his neurologist. Although he was the first physician to take the time and listen to Thomas explain his symptoms, give him a preliminary diagnosis, and start him on a treatment protocol, Thomas also describes having to justify himself and reiterate the symptoms he was experiencing. Thomas stated, “I have a relationship where he really does grill me at times very much.” Thomas further said, “And so I’d have to really articulate like, this is not in my head. It was really strange.” The neurologist continued to stipulate that Thomas had
seen the top professionals in the area for neuromuscular disease and there was no documented evidence that there was a pathologic cause for his symptoms.

*He would say, “Thomas, you’ve seen the best.”* I said, *“I haven’t seen the best. It was six minutes and 42 seconds with a neuromuscular specialist, who I haven’t actually had a chance to speak to.”*  

Thomas had to keep advocating for himself.

*“He said, “So many symptoms, Thomas, I don’t believe are MG.”* I said, *“Well, I’ve spoken to people in the MG community, and they absolutely categorically agree and identify with every symptom I have.”* He said to me, *“You really want the diagnosis of myasthenia gravis?”* And I said, *“I don’t want the diagnosis of myasthenia gravis, but no one’s given me any alternative. I read the textbook on it. And I’ve spoken to people with it. It’s like a key fitting in a keyhole, it fits. I can’t explain why. This is not in my head.”*  

*He said, “No, I think you really want this.”*

As a former medical professional, Thomas had a good understanding of the variables at play and believes by this point his chart was overflowing with anchoring bias: each subsequent physician relying heavily on the preceding information of him as dictated in his medical records.  

*Luckily, being [in healthcare], I am aware of our research. I’m not skilled, but I realized it was anchoring bias because, ‘I’ve seen the best.’ Even though I would say, “I haven’t spoken to that person” it was written [in my chart] in such a way that somebody who is borderline personality disorder, somebody who’s psychosomatic can really believe the symptoms are real would say that. So, I couldn’t win.*

Continuing until this day, the relationship Thomas has with his neurologist is complex. Thomas describes it as a moving target on how the conversations will unfold. Although this
physician occasionally will actively listen to Thomas and agree to try alternate and escalating treatments, other times he appears to be impressionable from his colleagues and reverts to doubt of Thomas’ symptoms and diagnosis. Thomas described it as, “He’s skeptical. He’s thinking I am going to mimic whatever I’ve read.” I suspect at this point of Thomas’s journey he was on high alert for skepticism or doubt from physicians. The influence of his previous experiences that labelled his symptoms as psychosomatic, coupled with this most recent neurologist’s seemingly lack of confidence in the diagnosis he provided, created a barrier in their ability to proceed forward in a mutual and collaborative relationship. I suspect the tendency of this physician to waver stems from an unfamiliarity of the nuances of the disease due to the extremely low prevalence.

As our conversation continued, Thomas described how his neurologist’s responses vary. His neurologist’s demeanour also seems to fluctuate – at times he is accommodating and enthusiastic, but other times Thomas describes him to be “cool and muted.” I got the sense from Thomas at this point in our discussions that the process of treating his MG was becoming an emotional roller coaster; it was unclear with each encounter with his neurologist if he would receive support and validation or doubt and passivity. I can only imagine the emotions felt during these experiences, as I have personally only ever received acceptance, validation, and trust from my neuromuscular specialist since the day of my diagnosis.

4.9 Information Sharing with Physicians – “Well, that’s not a MG symptom”

Thomas demonstrated during our discussions that he stays current with the latest research related to MG. With a professional background in healthcare, he often would seek out research articles to support treatment options he was requesting from his physician. Thomas stated, “I have brought him research, yes, I have. But in the past. But, I don’t now. Because in his head, all
the time, he’s impressionable by these other guys.” Thomas’ tone and demeanour indicated that although he has attempted to use relevant research as groundwork to discuss alternative treatments with his physician, he has not been met with the same enthusiasm and the physician remains guarded. Thomas gave an example in which he tried to take the information he learned from the MG Association of Australia to his neurologist – the effects of brain fog on those living with MG. Although not a common symptom, Thomas found it to be a documented symptom, and one which he does experience. Thomas described with exasperation how the conversation unfolded with his physician.

“Well, that’s not a MG symptom.” And I said, “Well, the MG Association of Australia’s actually saying that it is and they’re identifying that it is.” And he’s like, “No. No, it’s not. That’s not MG.”

Following this interaction, Thomas sought out the experiential knowledge of others living with the disease in the online MG community. He discovered that numerous others were experiencing the same enervative brain fog that he was, which led him to think, “Oh, so I’m not alone.” Thomas further described an instance in which he discussed the latest research he found on long term scarring of the muscle with MG with his neurologist but was immediately dismissed and told “that’s not true.” Reflecting on these experiences, Thomas acknowledges that with his ongoing in-depth information searches he feels more current on emerging MG research than his neurologist – particularly for seronegative patients.

I found that in some ways I was researching more that maybe I was more up to date than my neurologist. No disrespect to him because he’s in practice. He’s living. He’s doing the work. He doesn’t have time to sit there, and the researching, and doing all these things all the time like I have had, not working.
I hold high regard for Thomas in his ability to reflect on the constraining factors that may limit his neurologist’s time and capacity to engage in the latest research. Although the neurologist treats many patients with different neurological conditions, Thomas acknowledges that he has a myopic focus and available time to uncover and read the latest research. It takes emotional intelligence to consider situations from alternate perspectives, which is precisely what Thomas has been able to accomplish. As I again consider my own experiences, I understand how a neuromuscular physician is more apt to be aware of the specialized MG research over a general neurologist who is required to learn and treat many neurological diseases. I have often brought my research findings to my neuromuscular specialist for discussion. He consistently is not only aware of the research to which I refer but is open to discussion and proceeds to add context and additional information to the topic. As my conversations with Thomas continued, my appreciation for my own physician grew. Although I was not without challenges obtaining the initial referral to his care, my experiences from our first encounter have all been positive.

4.10 Understanding from Others - “It is a lonely, frustrating disease”

Thomas frequently mentioned in our conversations feelings of being discredited by physicians, being misunderstood, and lacking an emotional support system. He highlighted the fact that one does not often come across others who have even heard of the disease, apart from individuals who understand and can have a conversation about it. Thomas said, “It’s very much you're on your own because no one else understands.” When asked about how he feels about the disease he explained how feels alone in his journey.

_They didn't understand because it is an invisible disease. No one can see it. You might look really well. But when I was active, I'd been rested for hours before I was going out_
to do something. So, on the whole, nobody realized what I was doing, dealing with. It's a very lonely journey. It's a lonely frustrating disease.

Even at home Thomas does not feel that he can discuss his symptoms, his illness, or seek emotional support from his spouse. He described that he does feel grateful that his wife immediately stepped in as a physical support, such as moving from part-time work to full-time and taking on the more physical tasks for household chores. Thomas acknowledged a complete role reversal in their relationship in terms of employment and household tasks. However, Thomas still craves the emotional support.

*I feel like I've got another life away from my marriage about MG. There is no support emotionally from my wife on having MG. I just don't discuss it. I don't bring it up because she doesn't want to hear it.*

Despite this, Thomas graciously acknowledges that his wife is frightened by the disease and Thomas’ ability to manage it, and that she is coping in the best manner she can. He knows he is loved, but it is hard to feel the disconnection as MG is a large part of his life and who he is now. Although initiating conversations related to MG with his spouse can be difficult, Thomas knows that she is cognizant of the clinical manifestations and limitations of the disease. Thomas described a list that is kept on the back of the door detailing what she needs to do in the event he has a crisis and is unable to communicate for himself. Thomas jokes that his wife “*saves her compassion for [others].*” He does however acknowledge that he is supported, but in a less overt manner than one would traditionally expect. Nevertheless, as demonstrated from the start of his journey with MG, Thomas exemplifies ongoing resilience and perseverance. He channeled his feelings of loneliness into connecting with others who live with the illness through online MG
groups and his provincial MG association. He continues to develop personable connections and increase his knowledge of the disease in tandem.

Thomas circled back to feeling lonely with the disease a few times during our conversations. Thomas often reiterated – “It’s a lonely disease. That’s the biggest thing.” As I began to think about how I interpreted the concept of loneliness in my own experience with MG, I realized that I viewed it from a different perspective. As with any challenge in my life, my diagnosis was immediately followed by engaging in problem-solving mode. I started by seeking information by any means I could get my hands on, as information is power, and I refused to be powerless to my circumstances. I also quickly reached out to a former colleague who was diagnosed with MG many years prior and worked to establish connections online to others living with the illness. I quickly infiltrated my life with a combination of published literature and experiential knowledge from others. Although I only personally knew one other person with MG, due to the connections I made online, I knew I was not alone. I had at my fingertips the ability to connect and converse with others, ask questions, learn, share stories of struggles and small victories. I have always enjoyed connecting with others beyond a superficial level, and my diagnosis provided an avenue to pursue these types of conversations and relationships.

I also feel that I have consistently had strong family support. My parents and siblings have never questioned my abilities or limitations, but instead have offered a listening ear, words of acceptance and encouragement, intrigue and understanding by the way of questions. My mother once asked me, “What does it feel like?” to help her understand what I was experiencing. My sister has said to me, “It doesn’t matter if it could be worse, you are allowed to feel badly about this” when I was struggling to justify my feelings. Although we are separated by distance,
I know if I am having a hard day, I can call any of them at any time and receive the support I need.

Within my household, I have a strong knit bond with both my sons, now in their preteen and teen years. Once I received my diagnosis, I have discussed with them what it means, and they have observed my struggles and how I often need to manage my limited energy. These two young men have grown into my biggest support system. They display unconditional love, support, and understanding. They are empathetic and consistently offer physical support in terms of household tasks or encourage me to take a break and rest as needed. I could not ask for anything more than I receive from these two amazing young men that I already get both in terms of emotional and physical support. Over time I have witnessed the distress of others in the Facebook MG groups who have unsupportive families, and I am grateful every day for each one of my family members.

4.11 Psychological Effects - “I have severe PTSD”

Thomas described the irony of his circumstances now; he has the firm and concrete evidence of thymic hyperplasia to confirm the diagnosis of MG, yet the psychological implications of his experience leading up to that point are affecting him in ways that he is still uncovering. After years of advocating for himself and rejecting the notion of psychosomatic symptoms with the need to involve a psychologist, he did self-refer to a psychologist to manage the lasting psychological effects stemming from how he has been treated in the healthcare system. Thomas recounted a conversation he had with his neurologist after the pathology report from his thymectomy came back.

*He said, “You have severe PTSD [post-traumatic stress disorder]. You’ve really been through this.” And I said, “yeah...” And so, the irony is I do see a psychologist now*
because I saw [all those different] neurologists. I didn’t need [a psychologist] before I saw them, but I do afterwards. It’s the not being believed. It’s just the way you’re spoken to. I was trash. It was awful. I mean, there was no compassion. There was no caring. They wanted me out. [They thought] I’d hoodwinked my neurologist into giving me an extremely expensive treatment every two weeks that is limited in supply.

As Thomas and I discussed the psychological implications of a chronic illness overarched by disbelief from the medical community, he described how the psychological impact of his experiences continue to affect him. 

Many times, I get intrusive, ruminating thoughts, which in my head, I’m playing over conversations advocating for myself, advising this is what is happening and this is why it’s not a placebo effect from my medication. Because azathioprine, why have I not responded to that? Why the most expensive, intrusive medication IVIG has not been nowhere near as effective as these tiny, little white, cheap tablets called prednisone, which eliminated my disease? At the same time, I got such negative side effects. But if you go through that...The irony is for a neurologist that said I need to see a good psychologist who could solve my issue. Well, actually, I do need to see one now because I saw her, and I saw the others. It’s like the mind and body’s linked. How do you manage that? Yes, I do have PTSD, and I’m recognizing it more, these ruminating intrusive thoughts. I find it difficult to sleep at night. I wake up thinking about these conversations. I dream about these conversations. During the day, it’s just there. It’s exhausting.

From his experience as a patient in the healthcare system leading up to his thymectomy and a firm diagnosis of MG, Thomas finds that he bears a mental burden and that he must approach interactions with healthcare professionals differently than he did before.
I have to say I had ruminating thoughts continuously about how I was going to ask [and] answer certain questions. How I was going to get over this bias that was in my chart, how I was going to articulate in a non-threatening way, in a way that you’re getting the doctors to almost feel like it’s their thought, because doctors don’t like to be told. So, I’m trying to think from my experience [working in healthcare.] What can I get from them, planting seeds all the time. That’s what I’ve been doing for two years about the thymectomy.

Thomas was transparent in his descriptions of his psychological struggles. Although his neurologist identified traits consistent with PTSD in Thomas, he did not proceed to refer Thomas or set him up with any mental health supports. Although a strong self-advocate, I could sense that Thomas feels a bit lost in this part of his illness. His comments exemplified how he feels the healthcare system is fragmented, that the system could better serve patients in a holistic model of care. I agree with Thomas on this point. The diagnosis of MG is filled with uncertainty, fear, and infiltrated with loss – of stability, friends, careers, identity, and the perceived future. Although I have an extremely competent and caring neuromuscular and family physician, I have never been asked if I need mental health support. As Thomas has done, I sought a psychologist on my own to help manage the mental burden associated with chronic disease.

4.12 Moving Forward - “I’m now focused on other things”

Since the removal of his thymus and a confirmatory pathology report to support his symptoms, Thomas has found a sense of ease. He describes how he believes that his thymus was his “smoking gun,” that now with it removed he can start his journey to healing and wellness. A thymectomy was a goal for Thomas from the start – for the best chance at remission and improved quality of life with the use of minimal medications. He no longer carries a constricted
view of continual searching for information related to MG. He has become more relaxed and is starting the process of learning to live with MG without it dominating his life.

*I’m not so obsessed with looking at everything, to be honest now. In fact, I’ve even noticed since I had my thymectomy, I’ll look at the MG Facebook groups, but I’m not so involved now. I’m trying to develop a life. I’m trying to think, OK, for me the goal was a thymectomy. I’ve had it. I’ve just got to be patient. So, I’m now focused on other things and – so that’s what I’m trying to do.*

I personally described this concept putting the MG up on a shelf and living your life with it just off to the side – you know that it is there, but it is not the focus of your day and your decisions. I visualize this as MG being a subset of who I am, but not all that I am. To not be defined by the illness and have the impacts infiltrate all parts of my identity and reality, to not feel that it deserves by constant attention. Thomas seemed to resonate with this analogy; *“I’m trying to live life, trying to get on with it, but I have to look after myself and focus on my body as well.”* We discussed that although having good intentions, this mindset is another step in the MG journey, with ups and downs as people learn to navigate life under new circumstances. Thomas described how he is always thinking and strategizing how to manage his day and the activities he wants to engage in.

*[I am always thinking] how am I going to do this? I want to go with my family. I don’t want to be a killjoy. I don’t want to mention [MG] because they’re sick of hearing about it. I’m just thinking, ‘how am I going to do this?’ You’re thinking of strategies, that’s what you’re thinking about. Strategies of how to deal with things in different situations all the time. That is definitely something. I am always aware of where there is a chair.*
Wherever I go I’m always aware of the seats. How far apart are they? So that I can sit down.

With the thymectomy behind him and a renewed hope for improved quality of life, Thomas has started to consider what that means for a possible return to the workforce. Although he loved working in healthcare and would be eager to return, he is cautious when considering how the stress would exacerbate his symptoms. He aspires to feel productive and contribute to his community through employment, but experiences nagging thoughts of how a stressful environment could initiate a spiral downwards in his ability to manage the disease.

I had a very, very stressful job. I was in healthcare management and operations. I worked 60 hours a week or more. In fact, I was a workaholic and I loved leading my teams, loved doing it. Then obviously I became sick and I couldn’t do it. I want to get well, but when I am well, the idea of going into that stressful environment I find frightening because I don’t want to get as sick as I am now. But at the same time, when I do become well, I want to do something.

Thinking about how stress affects his symptoms and can result in an exacerbation or flare up of the disease, Thomas reflected on his journey to date. He is cautious of entering into circumstances that may cause his symptoms to increase in severity or frequency, and how that would result in negative healthcare experiences in line to what he has already encountered.

My biggest fear, biggest fear is to ever be as sick as I was. Because it was so frightening, not being believed, and not knowing what’s going on. Feeling my body turn off. And I never want to be that sick [again].

As Thomas spoke these words, I acutely felt their weight. I never want to be that sick again. My reflections brought forward the same realization – my biggest fear is to be as sick as I
was at my nadir, to struggle to breath while trying to explain to a physician why my oxygen saturation is not consistent with my present experience. I think of that situation often, mentally force myself to move past the reoccurring thought patterns and fear, and hope that I remain well and never have to live that experience again.

4.13 Reciprocation – “How do I give back?”

Despite the prior negative experiences and the pressing fear in the back of his mind about a deterioration in his health, Thomas maintains an optimistic view – “even when it’s something that’s very painful, you learn from it.” With the thymectomy behind him, the confirmatory pathology results, and a sanguine outlook on the future, Thomas is looking to give back and help others.

*How do I give back? Because I [have healthcare experience.] And I just think to myself volunteering or you know. It’s – I’ll keep thinking about that. [I think] what do I want to do? And how am I going to do it? I don’t know. It’s going to be very interesting to see. I am very hopeful for a good future, and I know I’m going to be well.*

As Thomas has developed an understanding of the disease through seeking information and learning from others living with MG, his approach has shifted. He claimed with a sense of ease that he does not login to the Facebook groups as often as he did previously when seeking answers, but now when he does it is more to engage in conversation and share information rather than seeking answers. Documenting his experiences to help others in MG Facebook groups is one way in which Thomas has started to give back. In a more formal manner he is working with the board of directors for the provincial MG Association to spread awareness of the disease, especially throughout the medical community.
I’m working with the MG Association and we are very much trying to get more spreading of information about myasthenia gravis, because I do not believe….There are more people out there that have MG that don’t know what it is. They’re possibly even dying of some strange, weird disease that’s never diagnosed, and I do think it needs…We’re trying to spread that information out more.

Despite the evolution of Thomas’ focus from obtaining information and understanding the disease to creating awareness and spreading information, he believes the research is still just in its infancy, especially for seronegative patients. He believes medical progress and access to improved therapies will only come to fruition if research expands to investigate the nuances of the disease.

The one thing being seronegative they say maybe – is it 5 to 10 per cent [of MG patients]? I don’t know. I am sure there’s way more than that out there, but it’s just they’re not – as it’s a snowflake disease, they’re being dismissed as psychological, like I was by several. How many more are out there? I am sure there’s way more out there that we do not know. Also, is seronegative MG a different kind of MG? As you have MuSK [antibodies], you have the acetylcholine receptor positive, the MuSK positive...What else is going on with these people with seronegative, you know? What disease mechanism is it? I don’t know. Maybe some time they might say, “Well, it’s kind of like myasthenia gravis but it’s actually a separate disease.” Modern science just [does not] know yet.

I admire how Thomas has shifted his focus to now spreading awareness and helping others. He is determined to not let the disease define him and is looking to make something positive from his experiences. Thomas and I are alike in this way. After moving beyond the initial information-seeking phase and learning to live with the disease, I have become involved in
the MG community in an alternate role – increasing awareness and providing information. I have become an advisor for the MG Society of Canada and entertaining the possibility of forming a MG Association in my home province. MG may have altered my path, but it will not arrest my spirit and drive.

4.14 Conclusion

Thomas spoke with grace and conviction as he recalled the emotions and perceptions that entwined the events of his journey living with MG. His story perceptibly demonstrated the loss he endured in each domain of his life. His internal strength, determination, and refusal to retreat when seeking information and medical care are admirable. Discovery of the provincial MG Association early in his independent information search proved to be a considerable asset to develop his knowledge and social connections. Despite his aptitude to persevere and advocate for information and his healthcare needs, Thomas has experienced fractured relationships within the healthcare system. His experiences have left a considerable detriment in his mental health and ability to proceed forward in future healthcare relationships. However, his mental fortitude persists, and Thomas looks towards the future with optimism and a desire to help others. He strives to spread awareness of MG through his work with the provincial MG Association and frequently considers the type of work or volunteerism he will engage in as his thymectomy leads to improved health and quality of life.
CHAPTER FIVE: ELLIE’S STORY

I have known Ellie as an acquaintance and colleague since 2008. From the first time I met her and continuing throughout our interactions, she was genuine, empathetic, and genial. Ellie and I often were scheduled to work evening shifts together, which is when there were significantly fewer colleagues around, and the environment was calm, relaxed, and conducive to conversation. I have fond memories of this time – I enjoyed working with Ellie, conversing over similarities in our families and personal lives as we shared our work. Although we spent this time together, I do not recall when Ellie began to experience health issues and the associated challenges she was experiencing at work. As staff come and go, and the work schedule is often changed creating dealignment from the previous schedule, I did not note when our paths no longer converged. I later learned that Ellie had been diagnosed with a rare illness called MG and that she would be having major thoracic surgery to help control the illness, but at the time did not understand what this meant or the implications. As we were not close personal friends, we did not keep in touch during this time. I often would hear from other colleagues about how she was doing, that she was trying a return to work in another setting. I remember feeling a sense of empathetic pain for Ellie – I had connected with her on a personal level during our previous time together and understood she was struggling; I just did not understand how or why.

Many years later when I received my diagnosis of MG, Ellie immediately came to mind. I reached out to her through another colleague who is a friend of hers, and Ellie immediately was there for me to provide emotional support and tell me that it was all going to be okay. Most people who are diagnosed with MG have not heard of the disease, let alone know another individual who has also been diagnosed. I considered myself extremely lucky on both fronts; I was previously aware of the illness and had someone to contact as soon as I had my diagnosis.
Since that time, Ellie and I have reconnected, kindled a friendship, and continued to provide emotional and physical support to each other. Ellie commented that although she does not wish the diagnosis on anyone, she is thankful to personally know another individual living with MG, to have someone to talk to about the disease who understands. I value the support and knowledge she has brought to my journey from the beginning, and now highly regard her openness and willingness to contribute her experiences as I explore the stories of individuals living with MG.

Having a conversation with Ellie never fails to highlight her admirable qualities – she is honest, passionate in her belief system, and extends empathy to others. With a diagnosis extending back fourteen years, Ellie did her best to recall events and her associated perceptions of the experiences during the time of her diagnosis and going forward. Although her story is mixed with positive and negative emotions, she displays a strong appreciation for those who have contributed favourably to her experiences.

Our conversations took place in person and over the phone, in a relaxed environment in which we could speak easily and connect emotionally. I appreciate Ellie taking the time to share her story with me, as she is currently experiencing additional health issues that make her days challenging. It enabled me to see her and her life from a different perspective and shift my mindset from my previous assumptions. She is a valuable member of the MG community and can provide emotional support and encouragement to others struggling with the disease. Although I have my own experiences living with MG, through our conversations I learned a great amount from Ellie; this is the story of her journey with MG.

5.1 Symptoms - “Somebody turned the gravity up”

Ellie’s story of receiving a diagnosis of MG begins in the same way that it does for most – she began to experience increasingly prevalent and concerning symptoms that were
unexplainable by her primary care physician. Although the initial symptoms of MG are often vague and difficult to quantify, Ellie specifically remembers the development of notable muscle weakness in her proximal extremities and the inability to maintain ocular muscle control of her right eye. She described her ocular challenges as “my right eye would wander.” Initially, she was unaware that her eye was failing to maintain muscle control until she began to receive comments from family and colleagues. With employment in a physical setting, work was becoming increasingly difficult, and Ellie felt that her muscles just did not seem to be functioning appropriately. She said the best way she could describe how she felt physically is that “somebody turned the gravity up.” To cope with the unexplainable fatigue and muscle weakness, Ellie’s sick time from work accumulated leading to conflict with management and her colleagues. At this time, she also began to experience shortness of breath that was inappropriate to her activity level, an increased response of physical symptoms in response to extraneous stress, and an overall feeling of increased effort to meet the demands of daily activities.

*I just felt really overwhelmed and everything was harder. So, it wasn’t even just the arms and legs, but everything. Like stairs, I found if I was [going up] 10 stairs, it felt like I went up 10 flights [of stairs].*

As these symptoms increased in frequency and severity over time and continued to affect her personal and professional life, it became increasingly difficult to emotionally cope with the unknown and uncertainty. Ellie continued to push herself and try to persevere through work and home responsibilities despite the physical challenges. I could sense when Ellie was speaking of this time in her life that it was stressful, the confusion and lack of answers began to dominate her mind. When Ellie reflected on that time, she explained how she was feeling.
Most of it was not understanding what was going on with my body and nobody being able to tell me what’s going on with my body. [It was] making me crazy because nobody could find anything. I knew I was not functioning, and I couldn’t seem to get any answers as to why.

She described being on the “verge of a nervous breakdown” and developed a mistrust of herself, the symptoms she was experiencing, and overall, how she was feeling. Despite returning to her general practitioner on numerous occasions with the increasing prevalence and severity of the same symptoms, her physician remained unable to relate those symptoms to a particular cause. I could strongly relate to Ellie at this point in her story as it brought me back to my initial symptoms that were unexplainable but concerning. As I reflected on my own experience and the conversations I have since had with others living with the disease, this appears to be a typical scenario for those who have the disease but have yet to be diagnosed. I could relate to Ellie in the feelings of confusion, disbelief, mistrust of self, and perceived helplessness. As Ellie explained this time of her life to me, I felt a connection to her experience. In addition to developing a lack of trust in herself to discern her symptoms, Ellie began to feel that her physician and colleagues believed she was exaggerating or deceitful. She was aware that despite how she was feeling, outwardly she appeared fine to others with no obvious limitations.

I started to the feeling of people thinking that it was me and not something wrong with me, but me, myself, in my head because I looked good. I still had makeup on and my hair done and tried to be at work – I tried to do everything but I didn’t look like I felt and I think that made it really hard for people to grasp how sick I was.

As I reflected on my own experience before diagnosis, I also recall managerial concern over increasing sick time from work, particularly towards the end of the week as the fatigue
became unmanageable. Memories of animosity from colleagues have also dominated my recollections as I became increasingly unable to perform physical tasks. In a team-based environment, I was failing to pull my weight. Interestingly, I can relate to the misunderstanding and lack of awareness from my coworkers about the situation, as I was unable to understand it myself at the time. I could feel that there was something wrong but kept pushing through my days and responsibilities while my productivity and physical capabilities diminished.

5.2 Diagnosis – “My life would never be normal again”

Following numerous appointments with her family physician and unabated symptoms, Ellie was ultimately referred to an internal medicine practitioner. Despite the rarity of MG, this practitioner became Ellie’s ticket to an explanation for her symptoms.

I had been complaining about these symptoms, nobody could really figure it out. I was sent to internal medicine and I explained the weakness and what was happening. I was basically on the verge of a nervous breakdown because nobody could figure out what was going on and why I felt the way I did. And I thought maybe I was going crazy.... And when I saw that doctor of internal medicine he said, “I think you’ve got something that I haven’t seen in a long time.”

With specialized knowledge and medical experience to assess and rule out differential diagnoses, the internal medicine physician immediately suspected that Ellie was suffering from MG. A chest CT was ordered to assess for an enlarged thymus gland. The results revealed an undefinable mass, and Ellie was immediately referred to a thoracic surgeon to perform a thymectomy. I asked Ellie if at the time she was provided with information or reasoning as to why she needed the thymectomy or how it would treat the disease.
No, it was, “Your thymus is enlarged. It has to come out.” That was my explanation. And it was cancerous but they didn’t know that at the time. It was enlarged. And I think 90-some percent of the time it’s actually a benign growth. But a week after my surgery I got a phone call from the surgeon. Pathology had come back and mine was actually cancer.

A concurrent diagnosis of a rare disease and a cancerous growth would be shocking and distressing for most individuals. As Ellie discussed this time in her life, I could sense that it was difficult, that she suffered from the psychological effects as much as from the physical aspects of the disease and circumstances. I asked Ellie if she could remember how she felt at the time of the thymoma diagnosis. She recalls it as an extremely challenging point in her life. The recovery from surgery was slow and strenuous, overlapped with aggressive MG symptoms that were exacerbated by the stress of the surgery. Ellie commented that she felt that her life was over.

[I felt] it was going to kill me and that I – especially after that first surgery – I couldn’t even walk like ten steps so I thought I was going to die with that and it was going to be – that my life would never be normal again.

Despite her medical team’s hope for a remission from the disease with a thymectomy, Ellie’s symptoms continued to be persistent and severe. At this time, Ellie described her symptoms “with a vengeance up and down.” Although I did not experience a thymectomy and diagnosis of thymoma myself, I nonetheless understand the mental impact of hope and disappointment of failed treatments, the feeling that life will not be the same. Numerous times I have felt well, full of energy, with an optimistic view of the future. Unfortunately, despite my practitioner’s goal for achieving remission, I often find the newest treatments that were working well wear off and no longer hold the same efficacy for keeping my symptoms at bay. The emotional ups and downs, infiltrated with hope and dismay, are mentally exhausting.
5.3 Preliminary Searches – “There was no information back then”

I asked Ellie if she had attempted to search out information related to her symptoms before the diagnosis, if she had a hypothesis of the cause. She explained how she began to search key terms and specific symptoms online, which ultimately led to the suspicion of the wrong diagnosis.

*I tried looking into muscle fatigue, I looked into chronic fatigue, I looked into muscle fatigue and weakness. I looked into diseases that would cause muscle – you see I thought they were going to tell me that I had MS. So what I had basically thought, from my research at the time was, ‘Oh my God, they’re going to tell me that I have MS.’ So that’s what I researched.*

The cancerous thymus, or thymoma, officially confirmed the diagnosis of MG for Ellie, which occurred in 2009. Ellie described receiving this information with resignation. It felt as though this was an extremely difficult time of her life - she received not only the diagnosis of MG, a disease she had not heard of before but also the corresponding diagnosis of cancer. I asked Ellie if she could describe the type of information or support that was provided to her at the time of diagnosis. Reflecting on the time of diagnosis fourteen years prior, Ellie described the lack of awareness and information about the disease from physicians.

*I did most of the research myself. [He] just basically told me that I had [MG] and that it was an autoimmune disease that affected my neuromuscular function. And yes, that was about it. They didn’t really explain to me about the disease. Nobody really knew what it was or how it affected people. It was really most – you know, 95 percent of medical staff had never even heard of it. So, I didn’t get a lot of information, at all. Pretty much none.*
Although the diagnosis of MG was concerning, Ellie felt grateful that she did not have MS and hopeful that her illness could be treated. I remember at the time of my diagnosis feeling a mixture of relief to have an answer that provided a route to treatment, but also a feeling of dread as I began to comprehend what the diagnosis meant for my life moving forward. I asked Ellie if she could remember how she was feeling at the time.

_At least they found what was going on and I was just happy it was – I hate to say it, but you’re almost happy when they find something because you’ve been in such a bad way for a couple of years, and then all of a sudden it’s almost a relief because you’re not crazy._

**5.4 Learning About MG - “I tried everything”**

Prior to her diagnosis of MG, Ellie had not heard of the disease or met anyone who was living with MG. Armed with the name of the disease but limited information from her physician, she embarked on an independent search to increase her understanding of the illness and what was going on with her body. Ellie strived for an increased understanding of the illness to aid her in learning to manage the symptoms. Ellie primarily turned to online searches during the early time following her diagnosis and thymectomy. She described how she approached her independent searches for information: a broad search with general or basic key terms to assess whatever information she could find related to MG, then subsequently started to narrow her focus on specific symptoms and particular entities of the disease process. However, her initial searches left her almost as empty handed as when she began. She quickly discovered that any accessible information available at the time was broad and vague.

_Oh gosh, I tried everything. I searched, and a lot of it was online, obviously. I searched through all the [pathophysiology] books [I have] at home to find stuff. I found little_
tidbits here and there about, it’s just the same basic [information] – it’s an autoimmune disease and it affects your muscular function. And they talked a little bit about, the acetylcholine, that chemical that is in our muscles that helps it contract. The antibodies that were involved. [The physician] tried to kind of explain that to me, but not in a very good or thorough way. Back then there was pretty much nil for good information out there on this.

5.5 Information from Physicians – “She was just really intelligent and helpful”

Disappointed with the quantity and quality of information she could find online at the time, Ellie turned her quest for information back to the physician managing her care. Following the thymectomy, the internal medicine physician referred Ellie to a neuromuscular specialist with a practice in a larger urban center. Although Ellie feels that the specialist has been a good resource for information and can adequately answer her questions, it is difficult to remain in contact with him regularly. To give Ellie consistent and local care, she was also referred to a local general neurologist who was familiar with MG. This neurologist quickly became a prominent and significant part of Ellie’s medical team. As Ellie described her relationship with this neurologist, I could palpably feel the appreciation she has for this physician and the ensuing quality of their interactions.

She had lots of suggestions of – a lot more knowledge that she was willing to share. She was very – she was just really intelligent and helpful and she could tell you in a way that you understood and she took the time to do it. She was by far my favourite person, the person in my corner. My GP was wonderful too, but she couldn’t do [what] I needed. [The neurologist] could deal with a lot of the actual problem.
Ellie’s appreciation for the local neurologist grew as she attended subsequent appointments and continued to discuss the disease in more detail. Ellie describes how this physician had a comprehensive understanding of MG and the challenges associated with living with the disease.

*She actually studied under my [neuromuscular specialist]. And she is who explained to me exactly what was going on. The chemicals that are in my muscles, why they don’t work, and what is happening. And that was actually where I found out the most, was from a neurologist [who] knew what was going on.*

With the addition of the neurologist to her medical team, Ellie felt that she finally had a quality explanation of the disease and an understanding of the pathological reasons why her voluntary muscles were failing on exertion. With the support and information supplied by the neurologist, Ellie proceeded with her independent quest for more information related to MG. Although her independent searches continued to provide supplementary information, her primary source became her neurologist as their relationship continued to develop and deepen over time.

*Initially [the information I searched] was broad, and then it was symptom specific. But that pretty much came when [the neurologist] started to explain what was going on chemically. Because I didn’t really know. I had managed to find out what it was, what it kind of means for a patient. But I didn’t get a really good explanation of what it was actually doing inside there, whey it was happening, until I had [this neurologist].*

I can relate to how the information supplied by a healthcare professional supersedes what can be found by way of online searches. Shortly following my diagnosis, a nurse practitioner with a specialized focus on MG was assigned to my healthcare team. She has become my primary and most trusted source of information. I will often discuss the information I have found
online with her, ask for her opinion, and have her help discern how that information applies to my specific circumstances. Although I continue to engage in independent online searches, I value the information from my nurse practitioner above all other sources. I believe that she will have not only the most current and relevant information at her disposal, but that she also has experience with many other individuals living with MG and how that information has been applied across the patient population.

5.6 Dissatisfaction with Online Search Results – “A lot of the information is missing”

Aside from validating her symptoms, Ellie has not found the information available online to be of much assistance. After she learned the rudimentary list of symptoms and treatments, she was seeking the type of information that cannot be found online or in an academic journal – how to manage those symptoms and live day to day with her physical limitations. When talking about her satisfaction with the information found online, she reiterates that the results of her searches were just too broad and vague.

They talk about the muscle weakness, the fatigue, what it is as far as it being autoimmune and neuromuscular, but they don’t get into the dirt of it, what you are living with every day.

The information Ellie found to be most accessible in her early independent searches was rote lists of symptoms. Although she acknowledged that this information helped validate her symptoms and understand what other symptoms she may experience while living with the disease, she felt that these standard lists were too basic. She believes that those living with the disease need more detailed and practical information to learn not only what the disease is, but how to manage the symptoms and live within the limitations imposed by the illness. Ellie acknowledged that individuals living with MG can all greatly vary in the type of symptoms they
experience and how those symptoms present themselves. Discussing how the disease is different for all those who live with it, Ellie is alluding to the snowflake nature of the disease – information that cannot be found in an online search. I could sense that at this time in Ellie’s journey there was confusion, as some of her symptoms could fit neatly into the predetermined list, yet other symptoms still did not quite seem to make sense. Ellie explained how she has yet to find in information sources how symptoms can vary or present differently in different people living with MG.

*I think a lot of the information is missing. I think a lot of it is basic things people know for sure like muscle weakness or difficulty breathing, but I think there is a whole subset that we suffer from that is not understood or acknowledged.*

I could understand Ellie’s perspective of how symptoms can vary from person to person and not completely align with a list. Although I experience ocular symptoms, some are not classic symptoms as presented in a MG symptom list. One of my first symptoms, and continuing to this day, is that my eyelids will start to feel extremely heavy as though I have not slept for days. I was initially confused by this symptom as I could not find this symptom anywhere in writing or on a symptom list. MG symptom lists will typically only include ptosis and double vision as ocular symptoms. To understand my symptoms, I sent out a message on a MG Facebook group asking if any others have the same experience. The result was surprising. I received many responses that, yes, others would experience the same type of eyelid heaviness. I agree with Ellie that rote symptom lists are too vague and do not adequately cover the variation of those symptoms between individuals.

In our conversations, Ellie often referred to her energy status in terms of battery life – draining or charging. I felt that this was an interesting way to describe how muscle weakness
feels to those who don’t experience it. This type of information and description is useful for living day to day with MG, but ultimately will not be found in a list of MG symptoms or be accurately reflected by the term ‘muscle weakness.’ Ellie also indicated how her searches to date have yet to reveal the significant effects of environmental or other factors, such as heat or stress, on the symptoms despite being well-known by physicians and within online MG communities to affect symptoms.

*I don’t think I’ve ever seen in writing where heat affects it. And heat affects it big time. Like, it kicks it into high gear for me, big time. I end up just completely fatigued. I’ve never seen that in writing.*

**5.7 Quality Information – “It was very, very basic”**

Ellie did not perceive the information found by way of independent searches to be difficult to understand as it was “very, very basic to begin with.” She was unable to locate any in-depth information that could help her visually comprehend the pathophysiology of the disease. She indicated that the most useful part of the information she found early in her diagnosis was a validation of her symptoms. Ellie was assured that at that time the information was difficult to find as it just was not available; that even medical professionals had a limited understanding of the disease process and how symptoms affected patients.

Fortunately for Ellie with a professional healthcare background and strong clinical knowledge, she felt confident in her ability to determine the quality of information that she did find. She feels that there are diverse sources of health information online with varying degrees of credibility, and she makes a personal assessment of what information is worth her attention. She described the information she has found online as a “mixed bag” and that it takes time and patience to sift through and determine the applicability or usefulness of the information.
To determine the reliability and credibility of information she has found, Ellie narrows in on where the information has been published, affiliations, and the authors that are credited for the publication. She tends to steer toward medical journals for the most accurate and current information, citing her professional background for knowledge of how to interpret and incorporate this information into her lexicon. Ellie also acknowledged the importance of finding quality information from rigorous studies if she intends to bring the information to her doctor for discussion.

*If you’ve got good ideas and you want your doctor to be on your team with it, you can’t bring them those ideas that are from somebody’s opinion somewhere. They want the science backing.*

In this sense, Ellie has learned to ensure she is relying on quality information sources not only for her benefit and interest but to use the information she finds as supporting evidence in her discussions with her physicians. I got the impression that although Ellie started on her information-seeking journey diffident and uncertain, the perseverance to develop and enhance her knowledge of the disease increased her confidence, information sources, and medical relationships.

### 5.8 Learning by Living – “I just know because I live it”

Ellie described how one of her biggest hurdles was learning how to manage the fatigue stemming from MG and ration her energy throughout the day. The manifestation of fatigue is another major implication of living with the disease yet is not accurately reflected in the literature. Ellie indicated that the fatigue resulting from the disease is a significant disabling variable that is inconsistently and inaccurately described in the information sources online. She has learned to manage this part of the disease through experiential knowledge, living with the
disease, and learning from her own experiences. By trial and error, Ellie has learned what works for her unique situation and managing fatigue.

*I can go for an hour or two and then I sit for an hour, go for an hour or two, sit for an hour, and then pretty much have to stop at some point for longer. It’s never described how you have to ration, and how you have to understand that when somebody [with MG] is spent, they’re spent, and they can’t do anything about it.*

Ellie further clarified how symptom lists do not accurately reflect the disease with the term ‘muscle weakness.’ She described how she will experience a loss of coordination as her muscles begin to tire; it is not just feeling tired or weak, it is that the muscles slide into a state of physical malfunction with prolonged activity.

*When I’m spent and I keep trying to go, that’s when I start dropping things. I start tripping on things. I start bumping into things. And I start getting a little more, I don’t know, stressed or something where I start to notice all these things are happening. And then I’m like, I need to stop. And that’s where work got really tough.*

Information sources that can be found also state that muscle fatigue improves with rest, which is also broad and vague, and does not give readers a real sense of understanding of how the muscle weakness will apply to them. Ellie was transparent when she described how she felt when trying to learn about the illness of her own volition. She indicated that she would often doubt herself and the symptoms she was experiencing. Ellie stated, “you question yourself sometimes, when you’re good and then you’re not”. She feels that it would have been of great benefit to not only her physical capacity to manage the disease but also her mental aptitude, to been provided more information and support at the time of diagnosis. In retrospect, more of the knowledge she has was acquired along the way.
I figured things out on my own, especially symptom-wise, and what I feel I could and I couldn’t [do] – what worked, what didn’t. I very much was on my own with all of that, trial by fire.

Like Ellie, I have also learned by living and figuring out what works for my personal circumstances. I have tried different rest periods and medication combinations or timing, but it has been a frustrating exercise as my physical needs keep shifting. Although talking with others and learning from their experiences can help, the most valuable knowledge has come from experience and learning what works best for myself. After my initial information searches trying to find all available information, I quickly shifted to living each day as my health would allow.

5.9 Social Support - “I was very, very, very lonely”

When Ellie was diagnosed with MG, in addition to the challenges of finding disease-related information, she had never encountered another person who was living with MG. Without a social support network to help her understand the illness, learn to live with it, and share the mutual daily struggles, Ellie felt an intense loneliness. She stated, “I didn’t know anybody else with it. I was very, very, very lonely. It was very lonely.” Lacking a thorough understanding of the disease herself was a challenge, but even more so was how those around her reacted to her new reality.

They see you and you don’t look – they can’t see a tumour hanging off the side of you. Your hair might be up and you don’t look like you’re falling apart, but you’re having a good hour. You’re having a good hour and you’re trying to get some stuff done. They don’t see you trying to drag those groceries in and leave them there [as you must rest]. And then you’ve got to wait for a bit before you can put them away. And then you’re like,
“Ok, I need a nap.” They don’t see all that. I find people are very judgemental of this disease.

I agree with Ellie that others can make a sweeping generalization of the illness based on a snapshot of time. I often have been told “you look fine” or “you look well” by others based on limited interaction. It creates a sense of disconnect, as those around you view your circumstances in a different way than you perceive them yourself. I can see how a misunderstanding or unawareness translates into a feeling of judgement. Often those who comment on how you look are well-meaning and do not understand what it takes to go out and accomplish those small tasks.

Despite these challenges, Ellie feels lucky that her immediate family is supportive and take the time to understand her illness and how it affects her daily life. Her son was pursuing a kinesiology degree and completed an assignment on MG as part of his educational requirements. Her son had the distinct advantage of having Ellie as an information source as he was also limited to the broad and basic information found online. Ellie was able to give him an insider’s view of not just the symptoms of the disease, but how to live with those symptoms and manage them. Following the completion of his project, she feels that he is one of the only people in her personal life who has a sufficient understanding of the illness, without having personally lived through it.

My son wrote a paper. He did a huge research paper on MG. He is probably the one who understands the best about how rationing works and why I sometimes can’t, and why it’s like, yeah, you just came up the stairs and you can’t breathe, but you know – he is – and over time – I’ve been really lucky. My family really does understand. It’s everybody outside of the house that doesn’t.
5.10 Connecting with Others - “Thank God I am not the only one”

Ellie has found comfort in the awareness that many others are living with the same illness and experiencing the challenges that she does. Often those living with a chronic illness feel they can truly only be understood by others physically experiencing the same circumstances. Ellie highlighted in her narrative how support groups matter: emotional support, acceptance, and understanding can make a world of difference to those who feel alone in their illness.

You’re like, “Thank God I am not the only one.” You know? So, yes, it was lonely. And that’s why you seek [information]. You’re seeking to understand because you’re living in this little world that’s a little bit different than everybody else’s and you stand out from everybody else too because you can’t do certain things like they can anymore.

In retrospect, Ellie feels that it would have been helpful to have a connection to someone else living with the disease at the time of diagnosis. With a lack of knowledge and understanding from those around her, she feels that having someone to discuss the disease and associated challenges would have made a difference in her mental health and ability to cope with the diagnosis.

I think it would have been a huge difference in support, and knowledge. I think it would have made a big difference. Even the depression of it where your life just seems over and you’re not feeling well and you know you’ve had – I sometimes felt that the disease took my life away. [For example], I used to love to hike, and I liked to do all these things and I couldn’t do them anymore.

Alone in her journey without any social connections to others living with MG, Ellie learned to rely on herself to figure out the illness and how it affected her personally as opposed to the lists of symptoms she found in her early information seeking. The lack of a supportive
community increased the feelings of loneliness and despair. Her family has always been supportive but cannot replace the social impetus of connecting with other individuals who have the same physical experiences. Ellie strongly conveyed a feeling of social isolation and disappointment in the understanding of others throughout her journey. I asked Ellie if she had ever sought support groups or other MG communities to engage with. From her descriptions, it appears that at the time she was diagnosed, these options were not readily available. As she reflected on this, Ellie stated that she has lived with this illness now for fourteen years and that she feels much farther along in her knowledge and journey with MG than what she believes she would find in support groups. I could empathize with Ellie and see her point of view, as many MG communities and support groups are infiltrated with newly diagnosed individuals or people in the process of identifying an explanation for their symptoms. Ellie described how she is just farther along in the MG journey and has found more value in her experiential knowledge.

*I think I’m so much farther in, maybe, that I mean I’ve had a lot of time to learn what works, what doesn’t, understanding my energy, how I have to ration it to function. And that’s what makes it hard.*

Despite not seeking out support groups for MG, Ellie did indicate that she is interested in continuing to learn about the illness as clinical trials progress and new treatments evolve. She has shifted in focus from learning about the disease to a strong interest in emerging treatments – medications and therapies that can ameliorate her symptoms and improve her quality of life. Ellie described how although she engaged in independent searches previously, she also felt a sense of hopelessness that impaired her information-seeking efforts. She hoped the disease and associated symptoms would dissipate and that she could revert her life to what it was previously. As time with the diagnosis has unfolded and she feels that she is in a more positive mental space,
she is eager to engage in more information opportunities, such as an annual MG conference in a
city close to where she resides.

I haven’t [gone to the conference], but I really am planning on trying to do more of that
kind of thing. You know, for a lot of years I just really hoped this would go away. I still
hope that. And I guess I kind of resigned myself after a while to just – you do that after a
while, and then you try to get back on. But yes, sometimes I was just not super keen.

5.11 Changes Over Time – “Now I’m in a management stage as opposed to a learning
stage”

With time and experience, Ellie developed a more targeted method of independent
information-seeking rather than a haphazard and unstructured search for any piece of information
as it related to MG. When conducting an online search, she will use specific key terms or topics.
Although a methodical and strategic search yielded more distinct information, the results still did
not compare to what she learned on her own as she had to learn to navigate the world with an
invisible and restricting disability.

As Ellie reflected on her information-seeking since her time of diagnosis, she identified
that the frequency has decreased considerably. Her early searches centered on an attempt to
thoroughly understand and visualize the dysfunctional pathophysiology and why her muscles
were failing her. As time elapsed, Ellie progressively realized that living the experience of MG
and acknowledging how symptoms affected her were much more complex and varied than
described in the literature. She then understood that her experiential knowledge was more
beneficial to her than what she could read in an information source.

When you’re new to this you’re looking for anything and everything and then over time,
you start to learn it and know it and understand yourself better. So yes, there’s a lot less
of it that goes on now [information seeking]. Now I’m kind of in a management stage as opposed to a learning stage.

Ellie described that although she relies on the knowledge gained from her lived experience, she will still occasionally conduct an information search online to uncover newer treatment options that may be of benefit to her. If she discovers a new or modified treatment that she would like to consider, she will bring that information to her doctor and initiate a discussion. She describes following through on this process when she discovered online that she could receive subcutaneous immunoglobulin at home rather than having to go to the hospital to receive the immunoglobulin intravenously. In this case, her information searching enabled her to receive her current treatment in a more convenient and less invasive manner. She has seen the treatments for MG change significantly since her diagnosis in 2009, which keeps her coming back to searching for the most current and effective treatments for the illness. Ellie feels that now when she looks there is much more information available than when she started seeking after diagnosis.

I still look occasionally at treatments to see if there are any bright ideas that have developed. Because honestly, when I first started, the only medication for myasthenia gravis was mestinon. And that was it.

Although the information Ellie has found online regarding treatment options for MG has been beneficial to bring to her neurologist, finding information on how to live with the illness daily remains elusive. I could sense during our conversations that although Ellie initially would seek this type of information, she resigned the notion that it could be found and shifted her focus to learning through trial and error.
That was something I figured out on my own based on how I felt. Because I would be like, “Oh my God, I’ve got to stop.” And then I would sit for a bit and then I’d be like, “Ok, I feel better. I can go again.” And that was happening a lot. That’s how it taught me to start rationing [my energy] because also if you’re still half tired before you start again, that affects it too. I find you die quicker. So, it does compound itself. A lot of the stuff I’ve learned over the years, like the heat and the rationing [of energy] and all those sorts of little tidbits that get me through my day, that’s all just experience.

5.12 Healthcare Relationships - “I talk to more doctors now”

As Ellie accumulated more information along the way and juxtaposed that with her experiential knowledge, Ellie described how she expanded her information sources to involve others – namely healthcare professionals and physicians that she feels understand the disease and whom she can trust.

I talk to more doctors now. I have a wider base of people that sort of know what’s going on, you know? Like, or even one in particular runs a MG specialty clinic, and so yes. I guess – I don’t know if I have changed how I find it [the information] as much as now I know where to look.

In our discussions, Ellie repeatedly highlighted the necessity of having the support of the right healthcare professionals and an extended healthcare team. I could sense in our conversations that Ellie feels when she has difficulty obtaining MG-related information, it is largely tied to physicians and their knowledge of MG rather than barriers for independent searches. She describes her local general neurologist as a significant positive entity in her care. Her reflections on the capability of this physician centered on how Ellie perceived her knowledge of MG, and her willingness to listen to her as a patient and work together to find the
best healthcare solutions. From the way Ellie described this neurologist and her knowledge, I could feel how much of Ellie’s satisfaction with the disease information was tied to the type of relationship she was able to develop with this physician.

Following her positive description of her local neurologist and the value she contributed to Ellie’s experience, I asked Ellie about her relationship with her neuromuscular specialist who she sees and speaks to much less frequently. In her response, Ellie appeared to have neutral feelings about this physician. She indicated that she had a precarious start with this physician, but their relationship has evolved. She describes that she now has a good relationship with her neuromuscular specialist and feels that she can involve him in her quest for reliable and credible information. Although she does not necessarily get the responses she desires from this physician, she feels like a valuable member of her healthcare team.

He’s really good. And we’ve come a long way over the years because he’s been with me the whole time. And yes, I know I can call there when I need to, and he will help me.

Ellie described her relationship with her primary care physician as “amazing.” Although her family doctor did not always have the latest information on the illness, Ellie had developed a trusting relationship with her and felt like a valued member of the healthcare interactions. She felt that this physician would actively listen to her concerns and suggestions, and that she would learn about MG alongside her. Ellie even described how she became an information source for her doctor regarding MG.

I brought her some sheets, and said, “I really think this is the problem.” And she read it, agreed, understood, and then called me on another patient she thought probably had it and wanted to ask me some questions.
Ellie described how her independent information searches have not only increased her knowledge of the disease but also helped her to be more confident and assertive in discussions with healthcare practitioners. Although Ellie may not always get the response she desires from physicians, she values her ability to approach the topics of conversation when her requests are backed by reliable research.

*I guess the knowledge has helped me be more forthright in what I need. When I get that information I think it’s easier for me to, “Oh, OK, this is it. Here you go.” Right? This is it [the information behind what I am asking for], here you go. And so, I try to encourage changes that I think are beneficial to me. Some [physicians] accept them, some don’t.*

5.13 Conclusion

Ellie’s story exemplifies the advancements that have been made over the recent years in MG knowledge and awareness. Without disease-related information, a support system, or a well-versed healthcare team, Ellie initially was reluctant to accept the diagnosis. She later transitioned to learning by experience. She highly values her experiential knowledge and feels that it supersedes the available literature online, to move beyond basic lists of symptoms and develop an understanding of how to manage the disease and integrate the limitations within the context of her life. Ellie has combated intense feelings of isolation and loneliness in learning to live with MG but has persevered with the strong support of her immediate family. She has experienced loss in a multitude of ways, yet with determination she continues to maintain her career despite the associated challenges. Despite challenges and setbacks, her resoluteness powers her passion and aptitude to have her healthcare needs met. In the process, Ellie has learned not only how and where to find the information she desires, but also how to surround herself with the right
healthcare team. As she looks towards the future, Ellie will not let MG dampen her spirits and will continue to strive for all that is important to her in life.
CHAPTER SIX: OLIVIA’S STORY

Olivia discovered my study when the recruitment poster was distributed through her provincial MG Association. She contacted me by email indicating her interest, and after a few emails back and forth, we set up a Zoom call to discuss her potential involvement as a participant. Olivia was eager to participate as she places high importance on MG research. As a rare disease with limited awareness, she believes that any research focused on MG is worth the extra time and attention. She also enjoys connecting with others living with MG who share similar experiences and challenges.

I enjoyed speaking with Olivia, getting to know her as an individual and her story of living with MG. As I asked her about her diagnosis and information-seeking, she was thoughtful and discerning, often pausing to think about her responses before she verbalized them. Olivia seems soft-spoken by nature but expressed her story in a way that made it come alive in our discussions. As our conversations unfolded, Olivia seemed to become more comfortable and at ease, which led to a more rich and detailed discussion about how MG has affected our lives. We began to laugh and joke about our circumstances, were able to smile as we discussed challenges and shared in our concerns over the future.

As Olivia began to tell her story, I was surprised to learn that her symptoms traced back prior to adulthood, which is a variation not typical for those with autoimmune MG. I appreciate the expanded perspective Olivia provided me in understanding the disease further and showing me yet another way in which MG truly is a snowflake disease. Olivia’s experience living with MG has been interwoven with struggles and disappointment, but also small victories and acceptance. Although she has experienced multifaceted loss much in the same way as others living with the disease, she has also been able to achieve disease stability with the right treatment.
plan. Olivia was a pleasure to get to know on a personal level through her experiences; this is Olivia’s story of living with MG.

6.1 Childhood Memories – “I remember not being able to bike”

Olivia took me by surprise right from the start of our conversation when I asked her to tell me the story about her diagnosis with MG. In contrast to others who present with their first symptoms in adulthood, Olivia reminded me of the individual nature of the disease when she started off by saying she recalls her first symptoms beginning at age 7. She described how her primary symptom was leg weakness, that she was unable to get on and off the school bus.

*My first symptoms started when I was 7 and my problem was that I could no longer get into the school bus, my legs were weak. And they got weaker and weaker until finally the bus driver was carrying me into the school bus. Then at the end of the school day my legs were so tired that I was sitting on the floor, and I could no longer get up. Then the teacher called my parents, and they picked me up.*

Olivia also remembers struggling to ride her bike as a child; after a short distance her legs would be too weak to keep going. Although weakness in her legs was the main symptom, she does also remember the weakness moving to her arms and having trouble with her vision. During this time, she ended up in hospital due to the severity of her symptoms. She recalls a physician suggesting that she may have a virus and wanted to proceed with diagnostic testing. However, her parents were immigrants with a language barrier and did not subscribe to western medicine or have health insurance. Due to these obstacles, her parents turned down the suggestion from the physician. Interestingly, Olivia’s symptoms then started to improve and completely resolved for many years following, leading her and her parents to forget these staggering health issues had occurred.
6.2 Returning Symptoms – “It was utterly terrifying”

Olivia had put her childhood experiences and memories of weakness to the back of her mind. She went through her teenage years and early adulthood symptom-free and those memories of her limitations as a child slowly faded away. Unfortunately for Olivia, the resolution of her symptoms was not permanent. As a young adult, after giving birth to her third child, the symptoms aggressively returned – she was unable to walk, chew, or swallow. She recalls it as a terrifying experience.

*It completely went away for my teen years until [my 20s], and then suddenly, I had just had my third child and it hit me like a truck, it was so bad. Within a week my legs got weak, my arms got weak and then I started not being able to chew and swallow and it was utterly terrifying.*

Olivia felt blindsided by the sudden re-emergence of the symptoms she had experienced as a child. Memories of the weakness flooded her mind, as well as the limitations that weakness had imposed. As her symptoms had dissipated once before, she was hopeful that would happen again.

*It was really interesting [the] memories of when I was a kid and had symptoms. I had somehow put them out of my mind and then when the [symptoms] re-emerged they all came flooding back. So that was a double whammy. So, it was like, I’ve had this before. It went away so hopefully it’ll go away again.*

The severity of her symptoms led her to seek help at the hospital in the emergency department. She recalls it being a stressful experience, not only because she was concerned about what was happening, but also, she had to keep her emotions under control as she knew she would not be able to manage the secretions if she was to cry or get upset.
Knowing if you choke you won’t be able to cough it up, that was terrifying. I made myself not cry because I knew I wouldn’t be able to deal with the saliva. I knew if I choked, I wouldn’t be able to cough. I couldn’t really cough.

Despite the concern and feeling terrified, not having the ability to swallow or clear secretions, the emergency room physician told her, “There’s nothing to be concerned about, see your family doctor.” As Olivia was telling me this part of her story, she laughed a little, as we both knew that many physicians do not understand MG, that her circumstances were urgent, yet this physician sent her away telling her that she was fine. I have heard this type of reoccurring story from many others within online MG groups – presenting to the emergency room with severe and limiting symptoms yet told by the attending physician that those symptoms are unremarkable. Olivia followed up with her family doctor, who then referred her to a neurologist. By this time, Olivia’s mobility was harshly affected.

They were kind of stumped. And finally my family doctor sent me to a neurologist and that was when I was really weak, I couldn’t walk hardly anymore.

6.3 Diagnosis – “If he would have sent me home, I wouldn’t have made it”

The neurologist suspected Olivia was presenting with MG and ordered an EMG. The EMG was positive and confirmed the diagnosis. Around the same time, Olivia’s disease process had reached the tipping point and aggressive symptoms resulted in a hospital admission. During the hospitalization Olivia received rescue treatments and narrowly escaped a myasthenic crisis.

They did the EMG and that gave the diagnosis. Then I landed straight in the hospital for IVIG. I couldn’t swallow. I had to be in the hospital for fluids, IV fluids and I couldn’t take deep breaths, it was really close to a full-blown crisis. But the IVIG kind of
stabilized it and as soon as I was able to swallow, I got sent home with a huge load of prednisone.

Olivia was then referred to a specialist at the neuromuscular clinic, who told Olivia that the diagnosing neurologist was on the ball as it is not typical for general neurologist to recognize and diagnosis MG. Olivia is aware that her case was a difficult diagnosis as she did not exhibit the discerning MG symptom of ptosis. She remains thankful to the neurologist for taking her symptoms seriously and having the awareness to confirm a diagnosis.

I really owe him my life because yeah, if he would have sent me home, I wouldn’t have made it. I couldn’t even take deep breaths and it seems like they don’t really take you seriously at first. I was young and I don’t know, the doctor in the local hospital here, he didn’t take it seriously at all. He was just thought, “It’s nothing to be worried about.”

With a diagnosis confirmed and a preliminary understanding of what the disease entailed, Olivia was able to gain clarity on her experiences as a child. She remembers articulating that “it doesn’t feel like a message is going through.” The diagnosis allowed her to put the pieces together and understand her childhood experiences, giving her a sense of closure.

When I got the diagnosis and the symptoms, that’s exactly what I had as a kid, just fatigable weakness, as the end of the day I would be so tired. It was exactly. And I remember when I was a kid even saying, “It doesn’t feel like a message is going through.” Because I knew I wanted to do stuff and I remember thinking the message wasn’t getting through and in the end that’s what kind of happened. It turns out that’s what it really was.
6.4 Information Provided at Diagnosis – “What is my future going to look like?”

Olivia remembers her main concerns at the time of diagnosis was if the disease was fatal and what her future would look like while living with MG. She perceived the diagnosing neurologist as knowledgeable regarding the disease and he was able to calm some of her fears. She recalls that much of the information provided at this time was around the treatments available to manage the disease. Although she does not remember clear, specific answers, she does remember that the neurologist discouraged her from seeking information online as he felt she would be inundated by misinformation.

My first question was, “Am I going to die?” He said, “No, there are treatments.” And then it was all about what is my future going to look like? I don’t remember clear answers. I remember what he did tell me was don’t go on the internet because he thought there was a lot of misinformation out there. He said if you have questions ask me. He was very knowledgeable I would say.

Despite the discouragement, Olivia immediately looked online to see what she could learn about the disease. She understandably stated, “How could you not?” At the time Olivia did not have a personal computer at home and relied on family members who did to aid in her information search. A few of her siblings had computers at the time and were looking up information for her. Her parents also had a computer which she would use from time to time.

During her hospital admission shortly after diagnosis, Olivia would ask the nurses and attending physicians if they had heard of MG or knew anything about the disease. She reminded me that this was during a time before smartphones and the ability and ease to look up information at any time, regardless of location. The information she received did not ease her fears, but instead increased them.
When I was hospitalized, I would ask the nurses, “Do you know anybody that’s been in this condition?” Nobody had except one nurse who said, “Yeah, I saw someone in the ICU years and years ago with this.” And I thought, oh dear, I am going to end up in the ICU.

However, Olivia came across one nurse who did not have a good understanding of the disease but provided her with the best advice she can remember – learn as much as possible.

There was this one nurse and she told me, “Because this is a rare disease, as you’re able, find out as much information as you can about it.” And that was such good advice – educate yourself as much as possible about it. I always remember the nurse telling me that.

I found it interesting to speak with Olivia about receiving a diagnosis of a rare disease at a time prior to smartphones and limited internet accessibility. I find it is common now for most people to immediately search the internet when faced with a new diagnosis or health problem. Without that option, people would be limited to the information provided by their physician or would have to seek written information at a library. I think I often forget how fortunate we are now to have vast amounts of information constantly at our fingertips.

6.5 Early Independent Information Searching – “Could I be normal?”

I was interested to know if Olivia had tried to search information prior to the diagnosis of MG, to gain an understanding of the symptoms that were affecting her. She recounts how this occurred at a time when computers and the internet were not always readily available, but also her symptoms appeared quickly and were severe leaving little time to mentally process the experience or try to find a cause.
At that time, I don’t know that we had internet at our house because this was 20 years ago. The symptoms came on so quickly. They came on within a week of me first actually noticing. I just was kind of in denial, but when they suddenly go a lot worse, I don’t think I even really...No, I don’t think I really looked up anything because I didn’t have a computer and we had three little kids, so I didn’t go to the library.

After the confirmed diagnosis and access to the internet through her parents and siblings, Olivia started to search online and see what she could find. She started with a general search of typing ‘myasthenia gravis’ into a search bar. Additionally, a focus of her early information searching centered on her future and trying to understand the whole picture. Olivia said, “To start off, I just wanted to get kind of a clear picture of what this actually was. My big thing was could I be normal?” Olivia found that the information she started finding was too vague or generic, and many of the personal story articles did not line up with her personal experience which could sometimes lead to confusion.

I found there was a lot of just really general information articles – just really general articles where they say, “The prognosis is pretty good” and list some treatment options. But I felt like mine was different than them. I didn’t have the eye symptoms, I was antibody negative, and I had a horrible time on prednisone, it was so horrible. I was very desperate to get another treatment.

Experiencing unpleasant side effects from prednisone, her initial broad and general search to learn about the disease transitioned to looking into specific topics, including antibodies, alternate treatments, and pregnancy.
Once I knew I was seronegative, I remember trying to find information on that. And at the time also I was desperate to come off prednisone, so I was researching a lot of different treatment options. And then later I guess my research was more into pregnancy and MG.

Olivia remembers that her main and trusted source of information early in her diagnosis was from physicians at the neuromuscular clinic. She said, “Then once I started seeing the doctors at the [neuromuscular clinic], that’s when they gave me a lot of information.”

Although Olivia’s information search seemed to follow the common trajectory of a general search of the disease progressing to more specific topics, she also wanted to have a big picture understanding of her life going forward while living with the disease. Her description of the results she found indicate that she was less than satisfied, that most of what she found was either too generalized or contradictory. I explored how Olivia felt about the information she found later in our conversations.

6.6 Pregnancy – “There were no answers, there’s just not enough information”

When discussing the challenges of finding information about MG, the topic of pregnancy immediately came to mind for Olivia. She recalls not only the difficulty she experienced as she searched for information on pregnancy while living with MG, but also how her physicians at the time did not know what to tell her or have any information to provide her.

I really wanted another child, but it was really hard to find information about pregnancy and MG. That was really hard. I finally connected with someone in the States, [although] her MG was MuSK positive. She went through a pregnancy, and she gave me quite a bit of information. That was kind of encouraging because her MG was a lot worse than mine. She even ended up with a trach put in because she was intubated so many times.
Despite not finding much online about pregnancy and MG, the provincial MG Association was able to provide Olivia with a pamphlet. Although the pamphlet was helpful in terms of generic information, it still did not provide answers to specific questions about the pregnancy that Olivia was looking for.

The MG Association had a pamphlet on it. I remember at the time there wasn’t much information on that at all, I guess it’s just too rare. And then a lot of questions I had, like if [the baby] would have neonatal MG, would [the baby] present with the similar symptoms as I do? There were no answers to that, there’s just not enough information out there about that.

Information regarding pregnancy and MG was not a topic I had previously considered making it interesting to hear about Olivia’s experience. Although I had not actively sought this specific topic, I also reflected on my own information seeking and failed to remember coming across any source that provided pregnancy related information. I would personally find it frightening if my physician was unable to either support or discourage pregnancy due to lack of medical knowledge. As Olivia described, this was an instance where again she benefited from the personal experience and story of another individual who went through the same circumstance, who was able to provide experiential knowledge and emotional support along the journey. But even with this support, Olivia still had fears related to the pregnancy that she mentally battled despite making sure she felt physically ready for the pregnancy.

I was basically in remission. It was all very well planned. I had this high-risk maternal fetal specialist. I was fine until about seven months and then suddenly my arms got weak. And that was really weird because it always was my legs first pattern. It came quite suddenly; it was also really scary. Then we had to add prednisone and then the specialist
wanted to deliver my baby and my neurologist suggested no, let's wait and see if the prednisone improves [the symptoms]. We decided to wait and thankfully I was able to make it to 38 weeks and my daughter was healthy thankfully. She had no neonatal symptoms because that was another big scary thing is if she would have temporary symptoms. But she didn’t, she was furious when she was born. She was crying right away so that was such a relief.

6.7 Sources of Information – “I really wanted a book”

Although physicians and online sources were Olivia’s primary means of obtaining information related to MG, along the way she has discovered other sources that have become highly valuable. Shortly after her diagnosis, Olivia came across the provincial MG Association. She speaks highly of the support and the amount of information she received from the association. I asked Olivia if her doctor had directed her to the MG Association, but she confirmed that she had found it on her own volition.

*I just found it online. I remember calling them and they mailed me a bunch of information and I went to some of their meetings. That’s where I got the most of my information, so that was extremely helpful.*

Although she found the information from both her physician and the MG Association helpful, the MG Association added value and context in ways that her physician could not provide. She discussed how she felt the information from her physician was broad and generic, strongly correlated to the pathophysiology of the disease and treatments, whereas the information from the MG association was more functional and personal.
At the MG Association you would talk to people and had personal stories whereas from the doctor you would hear the regular [information] and what they think. It’s not personalized, that’s the difference.

Olivia also has subscribed to a MG newsletter from an association that provides regular information. She finds this to be one of her most current helpful sources of information as it lands right in her inbox. She describes the newsletters as containing information on new treatments and medications, as well as personal MG stories, giving her a good mix of scientific and experiential information. However, she finds that even within these newsletters information on seronegative MG remains elusive.

That’s really handy and I can kind of skim out what interests me and what doesn’t, but it’s still always about antibody positive [not seronegative]. I like to keep up with the new medications and also just people’s experiences. People write articles or even just tips on how to manage it and how it impacted their life. There was one article that the burden of having MG is higher than what’s typically thought.

The one source of information that is missing and Olivia would really like to see is books. She has searched but has been unable to find published books on the topic. She said, “I really wanted a book. I’m a book person. I like to have a book and I was so shocked. There was no book about it.” I agree with Olivia on this point. I also highly value books and would like to obtain information from written literature. I have been able to find one book on MG, containing a mix of medical information and personal stories, which I then suggested to Olivia as a fellow book enthusiast.
6.8 Dissatisfaction with Search Results – “It was really hard to get a clear picture of what to expect”

With the question about her future weighing heavy on her mind, Olivia was dissatisfied with the information she had been able to obtain regarding MG. Although her physician encouraged questions and was knowledgeable, the information he provided became limited to treatment options. Olivia was seeking more – how was she going to live with this disease? What would her life look like? Was there hope?

The information and articles of personal stories that Olivia found online were broad and varied, exhibiting a lack of consistency that could provide her with reasonable expectations. She said, “it was really hard to get a clear picture of what to expect.” She found published as well as anecdotal stories of some individuals doing well and living a normal life with a tailored medication regimen, but then also stories of others who were doing poorly despite medical intervention.

*I found a lot of the articles were kind of vague-ish. They were, “Yes, the prognosis is usually pretty good. Treatments are usually effective, a pretty normal life or near-normal.” But every so often you read a little story about some person who definitely did not have a normal life.*

I feel Olivia’s frustration when reading other’s stories and trying to piece together what I could expect or what my future with the disease may become. Terms such as ‘usually effective’ or ‘near normal’ seem to add to the uncertainty and leave me feeling more confused than where I started. Olivia explained further.

*I always felt like I needed more because it was kind of the prognosis was good but then some sites said, “But it’s not so good.” I was always like, what is my future going to look
like? Well, that was always my big question. And so that was really hard, I just couldn’t really understand at the time that it wasn’t really going to go away and how much I would be able to do over the years, what is it going to look like? I guess nobody really knows the answer to that.

The dichotomy in the personal stories she read started to make sense to Olivia when she discovered why MG has been termed the snowflake disease. Although she remained unsatisfied with the information she found in trying to discern her future, it helped her to understand the variation of information. Olivia said, “I guess it kind of helped when I came across that ‘as a snowflake disease,’ that kind of helped a little bit. But in a way it didn’t because then you really still don’t know what to expect.”

I discussed with Olivia how I felt about accepting that MG is the snowflake disease yet still craving a sense of stability and certainty, knowing what to expect. Seeking information and increasing personal knowledge is often a tool to calm fears, to gain a sense of control, and to provide a basic framework to plan for the future. The complexity and variation of the disease between individuals and lack of specific information leaves people in a lingering state of uncertainty and trepidation.

6.9 Misinformation – “People try to cash in on sick people’s desperation by selling them quack products”

From my involvement in online MG groups, in particular Facebook groups, I have experienced numerous occasions of misinformation. One instance will be an individual who is elated to have found relief with a certain medication or product, extending their review of the indisputable benefit it would have for all others living with MG. The following comments reflect that some people are “desperate and will try anything,” but there will usually also be a high
influx of comments reminding everyone that this is the snowflake disease, we are all different as to what will work for individual situations.

The other instance I have witnessed in the online groups is people looking for financial gain from others’ desperation and suffering. In conversations revolving around how to find relief or manage a specific symptom, comments will occasionally pop up from someone claiming a certain product, such as an herbal mix, “cured” their MG and they are now living a fulfilling and care-free life. Within the same comment will be a link to the website to purchase the curative and life-changing product. These interactions are predatory and discouraging for those seeking the support and advice of others navigating the same circumstances.

I was curious if Olivia had come across misinformation when she was seeking to understand the disease, especially with her diagnosing neurologist discouraging her from seeking information online due to his perception of a high prevalence of misinformation. Olivia confirmed that she had come across some interesting claims online.

_I’ve heard on social media of an ion foot bath which some people were convinced improved their symptoms. I found a CBC Marketplace documentary about foot baths, and they are basically a scam. It’s so frustrating that people try to cash in on sick people’s desperation by selling them quack products._

Early in her diagnosis, Olivia also experienced misinformation from family members and acquaintances. Although Olivia grew up in an environment that rejected western medicine, as an adult she could see the value of medications in the management of her illness. Family friends and a naturopathic physician encouraged Olivia to try an alternative treatment that she immediately rejected.
Most of it I came across during the first several years post diagnosis. I was told that bee pollen was able to improve symptoms by friends of my parents who had friends with muscular dystrophy and used bee pollen as an alternative treatment. A naturopath even suggested a treatment involving bee stings which was supposed to help MS patients. No thank you!

6. 10 Connecting with Others – “Speaking to real people who have gone though it is helpful”

Early in her diagnosis Olivia sought support and experiential knowledge from online groups. In the pre-Facebook era, she connected through Yahoo chat groups that centered on MG. Thinking back to these online conversations, Olivia said, “It was really helpful because people would post their stories and you could interact with them.” Olivia found these conversations to be validating – there were others who were experiencing the same thing and could empathize and understand her situation. The conversations with others opened her perspective to the variety of ways in which different people experienced the symptoms of the disease and helped her gain clarity on what her life may look like going forward. She found that the individual stories were more helpful to fully understand the implications of the disease rather than broad statements published in the literature and websites.

Over time Olivia switched to using Facebook MG groups. She is not overly active in posting within the groups, but often will keep up reading posts and information from others. She finds it easier to keep up and connect with others using Facebook rather than the Yahoo groups, as it pops up easily on the feed rather than having to purposely login to the Yahoo groups. She commented, “Facebook, it’s right there, you don’t really have to look for it if you’re in a group, it just shows up on your feed, whereas Yahoo groups you had to look for it a little more.”
Olivia also appreciates that online groups can have limitations, such as drawing a high participation rate from newly diagnosed individuals or those not responding well to treatment. The perceptible disease outlook can be skewed without the participation of those who have lived with MG long-term or have found effective treatments.

_I remember someone pointing that out to me once, the people that are on these forums or in the groups, they usually are the ones that are struggling. The ones that are doing well, they don’t want to think about it anymore._

Despite this limitation, Olivia reiterated that she finds connecting with others living with MG to be highly valuable, both as an information source and as an emotional support. She was able to articulate how hearing other’s personal experiences provides a separate degree of information than what a physician can provide.

_I think speaking to real people that have gone through it is more helpful. Once you know the general process of the disease from specialists, then speaking to other people that have gone through it I think helps more._

At this point of our conversation, I mentioned to Olivia that I had uncovered the same finding, that those who seemed to dominate the online groups were those without a diagnosis but seeking validation of their symptoms, or those who were struggling physically and looking for the mental and emotional support. I have also witnessed certain individuals become less active in the groups as their symptoms improve and they can resume their daily life with more normalcy. Olivia discussed how she had a similar experience when attending an in-person support group. She found that those attending the meetings were not doing well in the management of their disease and it felt discouraging to her.
I remember going to the support meetings and it was not very helpful because at the time I was a younger person, and it was all older people. I remember asking the lady that ran it. She said, “Yes, there’s quite a few young people, but they’re probably just living their life. They’re not coming to [the meetings] anymore because they are doing well.” Now that I have been doing better, I actually haven’t gone either.

Olivia also found it difficult to relate to those who were attending the in-person support meetings due to the age difference. Many of the attendees were older and retired, and she felt isolated in her stage of life with young children while managing the disease. She explained further.

It was just hard. It was all older people, people that are kind of retirement age, so for me being not yet 30 and having a young family, they had a whole different life circumstance than I did. It seemed easier for them because a lot of them were retiring, but then they’d be like, “Yes, but we are just retired, and we want to do some fun stuff and now we can’t.” I couldn’t really feel sorry for them, to be honest. You know, I’m trying to raise a family and do this.

6.11 Invisible Illness – “I find it very lonely”

While Olivia has been working through understanding the disease and how it affects her body, she has felt the added challenge of having those around approach her with disbelief or lack of understanding. As the implications and limitations of the disease cannot always be seen and are not felt by others, Olivia often felt disassociated from her friends and family, saying “I find it very lonely, it’s very lonely.” Only able to describe to her family what she was feeling and experiencing, she found they had a hard time accepting that she was ill and wanted to believe that she was merely tired or overwhelmed.
It was really hard for my family around me, for various reasons I guess, to really believe that there was something wrong. They just wanted it to be like I was just kind of burnt out and overtired. It was a sense of denial maybe; they didn’t want me to really have a disease.

Olivia further feels judgement from those around her, even outside her family, on what her capabilities should be. As she does not outwardly look sick to others, they can be quick to comment on what they think she should be doing.

My daughter is [now a teenager] and they’re like, maybe I should go get a job. People think I should be getting a job now. They just don’t really get that all my energy goes to maintaining my household, my daughter’s silly pets and getting her everywhere she needs to be and being a parent. I’m done, that’s all I can do.

The invisibility of the disease to others puts considerable strain and stress on those who live with the disease and symptoms every day. I personally find the fatigue to be the most debilitating but unseen symptom of MG, and therefore the most misunderstood. Judgement and suggestions from others of what you should be able to accomplish can only add to the mental toll of living with the illness. The conversation with Olivia uncovered that she agrees and that it is nice to speak with others living with MG, as they are truly the only other people who can really understand – “It’s one of those things you have to experience to understand.” Olivia then brought up an interesting concept I had not yet considered. She has found that although people may be in remission from the disease according to physical standards or medical checklist, the disease can still affect them in ways that others, including specialists, may not realize. I agree with Olivia on this point – physical abilities and fatigability seem like a sperate issue from the overall autoimmune fatigue and managing energy.
If they go by what specialists [write in articles and publications], yes, this person is physically in remission, just taking medication but in remission. But they’re still affected in a lot of ways that aren’t very obvious.

Olivia also talked about how her level of functioning can be difficult to convey to her doctor. Although her clinical exam can show she is doing well, she remains impacted trying to engage in activities she enjoys and struggles with the cumulative fatigue.

My specialized MG doctor, showing up in her office she can’t really notice a lot of clinical symptoms, so to them I’m doing good. Which I am doing good, I really can’t complain. But when I do to out into my world and try and go for a hike or something it’s definitely there. And I go to bed at 8:30[pm] because I’m exhausted.

6.12 Social Support – “They just didn’t want it to be an illness”

Olivia’s quest to learn about MG, understand the illness and have the knowledge to integrate her life with the symptoms was conflicted by the advice and views of her family. At a time of high frequency information seeking early in her diagnosis, her family offered her suggestions that were not in line with her doctor’s advice.

My family was really into alternative health, don’t really believe in Western medicine. They were always trying to get me to come off my medication. Then if I would get bad side effects from the prednisone, they kind of thought it was my fault because I was taking the stuff. But they just didn’t understand that if I stop taking it, well, how am I supposed to breath?

After a while Olivia stopped trying to explain the disease and treatments to her family as they refused to accept her diagnosis or to learn the information alongside her. As she remembers her parents being in denial about her symptoms as a child, and the disapproval of her medical
treatment shortly after diagnosis, I asked Olivia how the relationship with her parents regarding her illness has changed over time.

*It was a bit complicated. My mom does believe [it now]. [My parents] knew it was the same thing [as when I was a child] they just didn’t really believe it at first that it was an actual illness. They just didn’t want it to be an illness. But their way of remembering is that they don’t remember that I had years of symptoms. They just remember the time around when I was hospitalized when I was 7 [years old]. But I remember years of symptoms and they’re like, “We don’t remember that.” It’s very upsetting.*

I could tell that reflecting on her relationship with her parents regarding her illness was difficult. It seems to be a tangled and multifaceted experience, and the lack of belief would cause a break down in the social and emotional support that is typically provided by parents. I unfortunately have witnessed the emotional challenges stemming from a lack of family support in social media groups. Individuals will post about the reaction of their family members in response to their struggles and physical limitations. As often limitations and the effects of the disease are often invisible, especially fatigue, individuals will comment that their family has told them they are lazy or just not trying hard enough. These comments can be discouraging and damaging, leaving people nowhere to turn for support and understanding but to strangers in social media groups. The emotional challenges and lack of social support in turn can affect how individuals perceive their disease and subsequently seeking additional disease-related information.

Fortunately for Olivia, she acknowledges that her mother has come to accept her diagnosis over time and the support structure of their relationship has changed – *“It took [my parents] quite a while to actually acknowledge it was a specific disease. But my mom, she’s very*
supportive now.” With her other children grown up, Olivia currently lives with her one daughter, who appears to be understanding and supportive. Olivia says that her daughter has only ever known her mom to live with MG, citing the use of the battery analogy to convey disease-related information in an age-appropriate manner.

She’s pretty good. The battery analogy seems to work. At the evening she is still full of energy and I’m just exhausted, and it’s like, “Yes, I’m just done. Sorry. I just can’t go anymore. Batteries are dead.”

6.13 Learning by Living – “It’s a harsh reality check”

Despite the information Olivia has been able to learn from her online searches and from speaking with others who live with the disease, she acknowledges that there is a whole entity that can only be learned from experience. She learned over time, from trial and error, from becoming in tune with the small nuances of her body and how it reacts to certain events or situations. She described it as a learning experience early in her diagnosis, reflecting now that she clearly did not understand the fatigability component of the disease.

When I first came [home] from the hospital – because I had a really hard time getting off the couch because my legs were that weak. And foolishly what I did is, I just kept trying, said, “I’ve got to be getting better.” So, I’d keep trying, keep trying. Of course, it would get worse and worse and then I find out later that is not a good thing to do. I’d try because I just wanted it to go away so bad.

Olivia feels that a main component of learning to live with the disease cannot be found in an information search – that she had to learn to pace herself and ration her energy. Learning to ration energy is an individual experience. Although others living with MG can describe the concept to you, it can only be learned and make sense when you start to figure it out individually.
Olivia commented, “The whole pacing thing, I had to learn that.” I understood what Olivia meant by this without much explanation, as I have also had to learn by experience to understand this part of the disease. Although I often still like to push and overdo it, I get a draining feeling when I need to slow down or stop, much like a battery at the end of its charge. I find that often those living with MG describe their energy in terms of battery life, it is an analogy that makes sense when trying to explain to others. Olivia also talks about the fatigue in terms of battery life.

   I just get really, really tired. I tell my daughter, my batteries have died, I just kind of hit a wall. And it’s just – my batteries are done. It’s not specific weakness really, it’s just such fatigue that you just can’t – I just got to go to bed.

   Olivia and I went on to discuss how the disease seems fragile, that small changes or stressors can impact the re-emergence or severity of symptoms, which creates a feeling of living on edge. A large part of learning about how the disease affects you personally extends to knowing what will trigger the disease. Olivia stated, “It’s always the beast looking over your shoulder, right? You never know when it’s going to wake up and make noises.” I feel that even in a state of physical wellness with the illness, the mental impacts continue each day creating an uneasy sensation. Olivia said often she will feel good, that the disease seems to be well under control, but then she will suddenly feel the effects again if she pushes her physical capabilities too far. She described it as a reality check – “It’s like this harsh reality check, it’s like, no you’re not normal.”

6.14 Changes Over Time – “It wasn’t the center of my life anymore; it was more on the edges”

   After living with MG for numerous years, experiencing the highs and lows of the illness, Olivia has come to a place in which her symptoms are well managed, and she can shift her focus
away from MG. As she reflected on how things have changed for her over time, she realized that she is now able to live her life without MG at the forefront of her attention.

Looking back, I kind of saw about three years of my life that kind of was really devoted to [learning about and managing MG]. Then after that it got more routine. It wasn’t the center of my life anymore; it was more on the edges. It wasn’t the focus or such a big deal that it consumed everything. After that I was stable enough to know what to expect.

I found it interesting for Olivia to describe the disease to be more around the edges of her life now, as that is where I aspire to be in terms of my illness. Olivia has more experience than I do learning to live with the disease and has found a treatment protocol that keeps her disease process stable. I believe information seeking would slow down and change for people once the initial uncertainty and fear subside. After having the lived experience and feeling more confident in how to manage life moving forward, the intense seeking would slow, and people would engage in occasional seeking for new treatments or therapies. People would be able to live more freely with the disease once stable, even if still managing minor symptoms or physical limitations. Less weight on the mind would result in less desperation to find answers.

When I asked Olivia how her information seeking has changed over time, she acknowledged she rarely purposely seeks out information now. She previously would actively search, including looking up specific topics related to MG, but now mostly relies on the ongoing emails she receives. The emails contain all updated and current MG information and comes to her without an active search. Olivia said, “It just lands in my inbox, so that’s very convenient.” Olivia will still use social media to read of other’s experiences related to MG when a new or unknown situation comes up, such as Covid-19.
During Covid I was on Facebook a lot because that was really scary being immunocompromised. That was really scary. I was on Facebook quite a bit, reading [other people’s] stories. At the time there was people dying from Covid that had MG. There were actually quite a few people, I’m in quite a few groups, that died from it. It was terrifying.

I do not personally recall seeing this type of information in social media groups, but at the time I was just in the process of getting a diagnosis. I was seeking general information on MG at the time rather than how it would be impacted by the Covid-19 virus. Olivia’s story is an example of the uptick in information searching when a situation presents a new unknown and corresponding concern related to a health issue believed to be under control. I asked Olivia if she also sought out more formal sources of information regarding Covid-19 and MG. She recalled that she tried, but she was unable to find what she was looking for. She remembers finding just one small study well into the pandemic, and the only takeaway was that it was just riskier for MG patients due to a compromised immune system.

6.15 Conclusion

Olivia’s story of living with and learning about MG opened new views and perspectives that I had not previously considered. She was plagued by atypical symptom presentation during her childhood, followed by a long-term remission, and a devastating rapid awakening of the disease as an adult. Olivia brought my attention to the lack of information on pregnancy and MG which had not previously been on my radar. Olivia’s stories and experiences caused me to stop and reflect; to consider concepts and details about the disease I have previously overlooked. She also created an awareness for me that although she has reached stability with her disease, her life is still affected by MG in ways that are not obvious or can be fully comprehended by others or
even her physician. Her description of the beast always looking over your shoulder made me consider how living with MG will always be overshadowed by uncertainty. Considering this perspective, I began to reflect how ongoing information seeking can help those living with chronic illness be at peace with that uncertainty. We cannot know or control the future, but we can learn to adapt and embrace change. I enjoyed getting to know Olivia on a personal level, to connect over our shared challenges and small victories, to know that we will both move forward with our lives using our acquired knowledge and information to live the highest quality of life we can attain.
CHAPTER SEVEN: KATHERINE’S STORY

Katherine and I began to communicate by email shortly after she received my recruitment poster distributed by the MG Association. From her first email to me I could feel her passion and the importance she bestowed on MG research, and she was eager to be involved. Although our initial conversation was delayed due to additional medical challenges, Katherine and I were able to connect. I was immediately impressed by her resourcefulness and personal drive to find supports and a community despite initial obstacles.

From the beginning of our first conversation, I was inspired by Katherine. Devoid of formal medical training, she has not allowed that to deter her from becoming proficient in increasing her medical lexicon, understanding a disease fraught with inconsistencies and variability, and becoming the strongest self-advocate I have met. She is unapologetically direct in ensuring she receives both the information and care she needs and holds her opinions and convictions firm. She will not hesitate to speak up for what she believes and describes her ability to challenge physicians as a badge of honor. Katherine will use the information she independently gains to dispute the medical system, never accepting less than she knows she deserves. Although constantly striving for the best medical care can be exhausting, especially while managing a chronic illness, Katherine has been able to use her knowledge and advocacy to get herself to remission, independent of the opinions and perspectives of healthcare providers. She is honest, forthright, and will never back down from a challenge.

Our conversations took place online via Zoom, both of us joining the calls from our homes. Katherine is personable, a great conversationalist, and creates ease in a conversation mixed with a dose of humour. She articulately explained her circumstances and events in detail. I immediately felt a connection to Katherine, not just because of sharing the same diagnosis, but in
our ability to converse and connect effortlessly. Katherine was open with her stories, and I appreciated her willingness to welcome me into her experiences as she described her challenges and successes. In our conversations, Katherine demonstrated that she has a clear understanding of not only how to find information on MG, but also how to integrate that information together to get a clear understanding of her holistic circumstances. She has a comprehensive understanding of how the healthcare system is organized and can navigate through obstacles as an expert. Katherine and I have formed a friendship beyond this study, and continue to converse – to share our struggles, discuss commonalities, and to provide support to one another. I will always remain grateful to Katherine for reaching out to participate in this research, to share her story and her friendship – this is her story of living with MG.

7.1 Symptoms – “You’re getting weaker, not stronger”

Katherine’s story begins similar to many others who are diagnosed with MG, but also varies as expected with the snowflake nature of the disease. Reflecting on the start of her symptoms, she remembers seeking answers from her general practitioner (GP) when she began to feel extremely fatigued, but also for persistent neck pain. The severity of the neck pain prompted Katherine’s GP to order an x-ray, which revealed a herniated disk. On surface value, Katherine believed the cause of her pain had been identified and began working with a physiotherapist to improve her pain by strengthening the musculature. Surprising to Katherine, the therapy was increasing her pain and weakness rather than resulting in strength and improvement. Her physiotherapist came to the same realization and referred Katherine back to her GP for further investigation.

*I had a really good physiotherapist, and he said, “Something is wrong here, you’re getting weaker, not stronger.” The more I went the worse I got. He sent me back to my*
GP for a neurological assessment, which is crazy to me. I’ve never heard of a physiotherapist doing something like that.

The weakness began to spread and present in other parts of her body and began to limit Katherine from physical activities she enjoyed. Although she did not have an explanation at the time, intuitively she could sense something was wrong and consulted again with her GP.

I continually went back to my GP for answers. I used to be a runner and I would run 10km a day. I felt my body slowly fading away until I was just able to walk. I knew something was wrong. I was tired all the time. Not tired but fatigued. I was fatigued all the time, my legs were fatigued, my neck was fatigued, everything.

Katherine’s GP started the process to investigate further for a cause of her symptoms, but in the meantime, Katherine experienced a devastating consequence – the herniated disc in her neck ruptured.

The disc in my neck ruptured. I had to have spine surgery. And to this day I still believe it’s from the weakness that MG caused in my neck. I was never in a car accident; I had no other explanation for what happened. I think it was because I had undiagnosed MG and they kept pushing me to do physiotherapy, fatiguing the muscles even more. We all know now that the more you use your muscles with MG, the weaker they get. The spine will have to start compensating when the muscles are weak around it. I had to have spine surgery in March of 2018. And then that’s when I actually hit rock bottom with the MG, everything got a lot worse right after that.

Looking back on the situation is difficult for Katherine. In retrospect she could see the sequence of events that led to her diagnosis, how the pieces now all fit together but could not be discerned at the time. The events of her surgery also provided a clue to her diagnosis.
Classic – I mean I didn’t stop breathing when they put me under anesthesia, but I wouldn’t wake up. It took forever for them to wake me up. Looking back, you realize all these signs are a clue that something more was going on.

7.2 Acetylcholine Antibodies – “There should never be a positive amount of them in your blood”

To investigate the cause of Katherine’s symptoms, numerous blood tests were ordered by her GP. The results revealed an extremely high antinuclear antibody (ANA), which is non-specific but can be indicative of lupus, but then the level of her AChR antibodies came back borderline positive. Katherine describes herself as “analytical and logical” and immediately began to learn as much as she could about these blood tests and what the results mean.

*I have a very analytical and logical mind, and I started to research and understand completely what it meant to be borderline positive. My research showed me that a healthy person would never have those antibodies in their blood. I like to be armed with knowledge so that when you do see a doctor you can ask the appropriate questions. You have to be your own advocate. People think [the doctors] have your best interest at heart, but let’s be honest, they are too busy to do that.*

At this point early in our conversation, I was immediately captivated and in awe of Katherine. I was thinking, she does not have a medical background or training, yet she had already determined how to learn and understand antibodies, the value of acquiring knowledge before conversations with physicians, and the necessity of advocating for herself. Impressed beyond belief, I thought back to my initial attempts to learn about the antibodies involved in causing MG, and I believe that Katherine went significantly above and beyond the information seeking I engaged in.
7.3 General Neurologists – “General neurologists know very little about MG”

Katherine was then referred by her GP for an urgent general neurology consult due to concern related to her symptoms and preliminary bloodwork results. The urgent referral secured an appointment within 48 hours. Katherine went to the appointment with the knowledge that AChR antibodies should be zero and that even a borderline positive result was strongly indicative of MG. Despite that knowledge, she was also aware that although some of her symptoms could be explainable with a diagnosis of MG, she also did not exhibit the classic symptoms, such as ptosis. Katherine explains how she felt, having the knowledge she did from independent research, and conversing with a general neurologist.

* I had done all of this research and I went armed with information when I saw the urgent neurologist. In healthcare, I consider a neurologist as the GP of neurology. Yes, you are a specialist, but we also have subspecialties of subspecialties. And although neurologists have a general idea of MG, they know very little about the actual disease.

I had not personally considered the overall role of neurologists in the treatment of MG before Katherine described it to me as the “GP of neurology.” That distinction makes sense to me, as there are neurologic specialties beyond a general neurologist. It takes a keenly aware general neurologist to recognize MG and make the appropriate referral to a neuromuscular specialist, but unfortunately that was not Katherine’s experience. Katherine explained, “*she just essentially told me that I needed to take vitamins, that I didn’t have MG, that I just have IBS. I just had to take some vitamins, and all would be well.*”

From her independent research on AChR antibodies, Katherine refused to accept what the neurologist was telling her and knew that she should be investigated for MG. Held strong in her convictions and knowledge, Katherine challenged the neurologist. As MG is a disqualifying
disease for her profession, she told the neurologist that she needed written confirmation that she under no circumstances had MG.

*I called her out after she dismissed me and I said, “Ok, if you truly believe that [I don’t have MG] I need a letter from you with your name, your doctor ID, stating that I do not have this disease. Once I have that I will be out of here and you’ll never see me again.” She wouldn’t write that; she wouldn’t write that letter. As you’re aware, they won’t take that accountability. She’ll dismiss you in a moment’s notice but to actually write that on a piece of paper, she wouldn’t do that. So that’s how I got the referral to the neuromuscular clinic.*

I was smiling as Katherine told me this part of her story. She takes self-advocacy to a level that I have yet to approach. She is strong, will not back down, and demands answers or further referral if a physician cannot determine a cause of her symptoms. She takes her health into her own hands and is aware that the healthcare system is set up in a way that results in people floundering or get lost in the process. Her knowledge from her information-seeking gave her power. It gave her the confidence to reject the neurologist telling her that her symptoms were caused by IBS and could be remedied by vitamins. With each new segment of the stories Katherine relays to me, I am continually inspired by her passion and persistence.

**7.4 Neuromuscular Clinic – “There’s nothing wrong with you; it’s anxiety”**

Katherine continued to experience progressive and debilitating symptoms. Despite her persistence and subsequent referral to the neuromuscular clinic, Katherine was again met with skepticism and generalized explanations for her symptoms.

*They did the EMG, and it was negative. I was told I did not have MG again, but also, that my symptoms were the result of anxiety. I now had two specialists telling me that I have*
anxiety and implying that my symptoms weren’t real. Before I left, I asked him to explain the positive antibody test. He said that he doesn’t trust the local lab services for acetylcholine antibodies and that he needed to take a new test and send it to BC and London, England. I left there feeling completely defeated.

New blood tests were ordered and sent to the labs indicated by the physician at the neuromuscular clinic. Those tests came back negative, and Katherine was told, “There’s nothing wrong with you neurology wise. It’s anxiety.” At this point of the story Katherine became emotional, despite telling herself beforehand that she would avoid the emotion and just tell her story. I could sense a feeling of defeat, confusion, and medical abandonment. Katherine expressed that the upsetting part was not the lack of diagnosis at the time, but the dismissal to a generalized causation of anxiety, which is unfortunately all too common for those undergoing investigation for vague symptoms that can overlap numerous diseases. Anxiety or stress seems to become a catch all “diagnosis” when physicians cannot determine symptom causation but seem to lack the understanding of how brushing off a patient as having anxiety can cause irreputable harm, as I will learn further along in Katherine’s story.

7.5 Diagnosis – “It seems like the most likely cause”

Following the appointment at the neuromuscular clinic and negative EMG, Katherine’s symptoms continued to progress, along with the appearance of new symptoms. She recalls not being able to move her tongue which resulted in slurred speech and then an inability to move her facial muscles leaving her with a stoic expression. The continued health challenges resulted in an emergency room admission and consultation with the chief of the neuromuscular (NM) clinic. With a high suspicion of MG, the NM specialist ordered a single fiber EMG (SFEMG), which has a much higher sensitivity than a standard EMG. The test was positive. Katherine described
the interaction that followed. “He was the head of the neuromuscular program. And he said, “you have MG.” And I said, “That’s interesting [laughs] because I was told many times I didn’t.”

As Katherine is discussing this part of her story it brings me to reflect on my own experiences and the stories of others I have encountered about how they are treated in the healthcare system. With non-specific symptoms and negative testing, it seems people are made to feel small, dismissed, pushed out, and told there is nothing wrong or it is anxiety. However, once a diagnostic test proves positive or people are connected with the one physician who will consider the whole diagnostic picture, the demeanour changes and the patient is no longer treated as though they are wasting time or resources.

Following the positive SFEMG, Katherine returned to the neuromuscular clinic. Despite the positive test, the NM specialist she had seen before with the standard EMG still seemed hesitant on the diagnosis, but nonetheless started Katherine on treatment.

I showed up for my next NM appointment and he handed me these pamphlets about Imuran, Prednisone and then an accompanying prescription for those drugs. I asked, “So, is this a diagnosis?” To which he replied, “It seems like the most likely cause.” This felt very uncomfortable for me because I had been dismissed so much up until this point and then all of a sudden, I walk in and he’s just writing scripts and handing me these pamphlets.

I took note at this point of Katherine’s story that at the pivotal point of a life-changing diagnosis, the information she was provided from the physician was pamphlets on medications. Katherine did not mention any other type of information provided to her at the time, which I would circle back to later in our conversations. Katherine did mention she found it strange that
he was not fully convinced on the diagnosis, termed it as a most likely cause, but then started her on aggressive treatments that can have significant side effects.

7.6 Missing Information – “You should be given those drugs in a hospital setting”

Although Katherine was given generic pamphlets on the medications she was prescribed at diagnosis, information that was pertinent to her situation regarding those medications was overlooked and not conveyed. Unknown to Katherine at the time, the initiation of prednisone to treat MG can temporarily cause an increase in weakness for a couple of weeks before improvement begins. Not addressed by the prescribing physician, this lack of information laid the groundwork for a potentially deadly situation. It was only after this event that Katherine found the information on her own that could have prevented a medical emergency.

_I have bulbar myasthenia gravis, so all of my symptoms are in the bulbar region. I was prescribed high dose prednisone without any thought or education on worsening of symptoms. I learned after the fact that bulbar MG patients should be given the initial high dose prednisone in a hospital setting._

The initiation of the high dose prednisone treatment caused a sudden and severe increase in her bulbar symptoms. She called 911 for help, but without the knowledge at the time of how prednisone can have this initial paradoxical effect, she had a hard time communicating with the paramedics her circumstances and was subsequently nearly treated for the wrong medical emergency.

_I fill my prescription and take the first dose. Within an hour I couldn’t breathe, I couldn’t swallow, I had to call 911. Within minutes there are paramedics and firefighters everywhere in my home. They state, “You’re having an allergic reaction.” I say, “No, I’m not, this is myasthenia gravis.” They continue, “But you’re just starting these drugs,
an allergic reaction is likely." So, I could see where they were coming from but I insist, “Don’t give me epinephrine yet, please.”

Katherine’s analytical and logical nature became the basis that prevented the wrong treatment. She was aware of the thought process of the paramedics in determining a cause for her breathing difficulties and associated treatment, how it appears that starting a new medication could cause an allergic reaction but putting the information together in her mind she knew that this was not the case.

I was slurring my speech and I likely looked like someone that was having an allergic reaction, I just started a new drug for the first time, right? But my throat wasn’t closing, so I continued to advocate for myself, “Don’t give me epinephrine because I don’t think I need it.” They transported me to [the hospital] and that’s when I was hospitalized for a week and I had to have IVIG every single day while I was there to manage my worsening symptoms. After I was released, I did some research and found out that patients with bulbar prominent MG should be given high dose prednisone in a hospital setting because of the high likelihood of worsening symptoms. After I was released from hospital, then I had anxiety. Can you imagine what it was like to come home and take these drugs and not know if I was going to stop breathing again?

As Katherine told me this part of her story, I tried to remember my own experience starting prednisone. Although my physician provided information on the disease at the time of diagnosis and prescribing prednisone, he also did not mention to me that symptoms would temporarily get worse before better. I do however remember being aware of this information, so when my weakness increased, I was not surprised. I believe I had read this information online or heard about it from within a social media group and knew what to expect. Katherine’s experience
is an example of how lack of information can have extreme consequences, and how patient education can prevent poor health outcomes.

7.7 Searching for Information Before Diagnosis – “I definitely went into Doctor Google”

As Katherine explained the situations that brought her to a diagnosis and her present circumstances, I considered the symptoms she was initially experiencing, the span of years of uncertainty and dismissal, and what her thought process was during that time. Although I suspected I knew the answer to my question from what Katherine had told me thusfar, I asked her if she took any steps to determine possible causes for her health concerns before the diagnosis. Katherine confirmed what I suspected – she was constantly searching online trying to find answers. She described herself as the type of person who needs to know what is going on.

That’s just how my brain works. I have to find out why something is happening. And I definitely went into Doctor Google, which is never a good thing, but what other source is there for anybody when they’re looking for information? You have the internet, and that’s really it.

Katherine tried multiple search combinations and used websites that employed a symptom checker to determine possible diseases, but she quickly became frustrated when the vague symptoms produced endless lists of possible causes. Her search led her to the possibility of MS, as it does for many who are eventually diagnosed with MG, but she discerned that MS did not make sense for her situation.

I used the WebMD symptom checker and entered all of my symptoms. What was so difficult at the time is that the disease is so non-specific. Fatigue is listed for most of the diseases out there. When you look into neurological-type symptoms, the likely culprit is MS. MS is way more common than MG, but I knew deep down that MS didn’t fit.
Katherine did not exhibit the distinguishing symptom for MG of ptosis, which made piecing together a cause for her symptoms more difficult. As she was describing her process of early information searching, she recalled a previous event in which MG did surface, but at the time she had never heard of it and did not seem like a likely cause.

*I did a 24-hour urine test and it had come back positive for something. And at the time when I was googling causes of why that would be positive, weirdly enough MG was listed in there. That test hadn’t sent me down the MG road just yet because I had never heard of it, and I didn’t know anything about it. It wasn’t until I saw my GP that following November and she had done the antibody blood test that was borderline positive that I really dove into the research of what the disease is.*

Katherine described how most of her research came from the internet. I agree with her when she stated that you do not have any other options when you are initially investigating a cause for symptoms. I believe that it is fortunate to have quick, easy, and instant access to information, and Katherine seems to be proficient at sifting through her findings to logically piece together the information as it pertains to her situation. I do not believe that most people would be able to approach the information search and make sense of the results in the same way that Katherine has been able to, but I believe her thirst for knowledge and desire to gain a comprehensive understanding of her body served her well in the process of diagnosis.

**7.8 Lack of information at Diagnosis – “No information from my doctors, zero”**

As Katherine had described the medication pamphlets she was given at the time of diagnosis and then sent on her way, I was curious if any information was provided to her on the disease itself outside of the treatments. I asked Katherine if she could remember what was told to
her during that appointment. Katherine was quick to respond, “No information from my doctors, zero.” She then elaborated.

There was nothing told to me. You know, I was given handouts from my specialist, and it was on the drugs I was taking. There was no real support about living with a chronic illness or what to expect throughout the process.

Thinking about the experience, Katherine believes that the reason she was not given any disease-specific information at the time was that the NM specialist was not fully convinced that he should be giving her the MG diagnosis, as demonstrated from his comment of it is the “most likely cause.”

When I eventually got my diagnosis, I even said, “Is this a diagnosis?” He said, “Well, it’s the most likely thing that’s happening.” To which I replied, “Ok. But these are some serious drugs for a not sure.”

Despite her doctor’s reservations, Katherine was firm in her belief that she had received the correct diagnosis, that her ongoing symptoms for years were caused by MG. From our conversation, I believe that Katherine was confident in the diagnosis due to her information seeking, learning about the antibody tests, symptoms, and ruling out other possible causes.

At that point in my mind, I knew it’s what I had. I don’t know why, I just knew. I knew 100 percent even though I didn’t have the positive blood tests or positive EMG. As soon as I saw the positive SFEMG, which they say is the most sensitive test for MG, I was convinced it was enough for me. If it had been negative, I would have pushed for other answers. I don’t know where I would be if that had been negative.
7.9 Lasting Psychological Effects – “Everybody is so quick to tell you that you have anxiety”

The process of diagnosis with an autoimmune disease can be trying. The physical effects take a toll and are compounded by the mental exhaustion of managing unexplainable symptoms, trying to mentally sort through what is happening, and then not having the compassion or support of medical professionals when seeking help. Feeling dismissed and told her symptoms were merely due to anxiety had a lasting effect on Katherine.

*It was crippling. I was having panic attacks daily about taking the prednisone because of how I reacted initially. There is no support. I got a couple of pamphlets and was told, “See you later” and then I end up in the emergency room and admitted for a week. So, I just continued on those drugs and obviously had to work on the mental emotional side as I was going through living with a chronic illness.*

Thinking back to the lack of emotional support and lack of belief or empathy from physicians, Katherine continues to feel upset and believes that more can be done to support patients in the process. She said, “I was a wreck. And the one thing I find so frustrating is that everybody is so quick to tell you that you have anxiety, but nobody helps you with it.” Katherine went on to further explain the conversations she has had with her family regarding her circumstances, and how the experience of feeling dismissed by physicians and told she just had anxiety have now affected her in a way that could have proved to be deadly.

*My mom and my sister, they say to me all the time they would have given up. Because this wasn’t a short timeline, this was years of suffering and saying that something is wrong and just continually being told it’s in my head. That damages a person so much so that when I just recently had a pulmonary embolism, I didn’t seek medical care for five days. I*
was worried that they would say it’s anxiety. I could have died on the floor of my house alone. I was laying there, couldn’t breathe and I wouldn’t go to the hospital. That’s the damage this had done to me from constantly being told that things are in my head.

During the pulmonary embolism my sister said, “There’s never been a time when you have experienced symptoms and there hasn’t been a cause or something wrong.” She stated, “It’s never been anxiety.”

I could emphasize with Katherine as she told me this part of her story. Although I was never directly told my symptoms were attributed to anxiety, I intuitively felt that the general neurologist I was seeing prior to my referral to the NM clinic did not believe what I was telling her. The simple body language of shrugging her shoulders as I explained my difficulties swallowing was enough to make me doubt myself, to question what I was experiencing, and to think twice before seeking medical help or second opinions. It is unfortunate that many patients later diagnosed with an autoimmune disease have similar stories of how they were made to feel psychosomatic by physicians and now have a fear of seeking medical help.

7.10 The Informed Patient – “You can’t advocate for yourself if you don’t have the information and the knowledge”

As I was fascinated with Katherine’s story and the steps she took to figure out what was happening to her body and independently learn enough to feel secure in her diagnosis, despite her NM doctor’s hesitation, I wanted to know more about her motivations to seek information. Katherine’s first response was, “I always like to research why things are happening within my body, and it correlates with what I am finding.” I further probed if this quality came from her professional training.
[My job is] very logical. Similar to being a doctor it’s logical. There’re steps and there’s processes. It’s very process-oriented type of work. But I am not sure I would say that everyone I work with is the same.

She described her work as logical with a step-by-step process, but also commented that it is not a consistent personality trait across her profession, that her training did not necessarily instill those types of qualities. She further went on to state that she believes that it is just her specific personality, that she always strives to learn and know as much as possible. She further correlated how her research helps her as a patient.

I love to research. Even if I’m going to buy a new coffee machine, I’m going to research what type of coffee machine is best for me. It’s part of my personality, and I want to be the most informed person I possibly can be whenever it comes to something I want to talk about because you can’t advocate for yourself if you don’t have the information and the knowledge.

As Katherine began to talk about advocating for herself, she immediately sounded like a healthcare professional. She uses the appropriate terms and has in-depth knowledge of how the system operates. She mentioned that she has been asked “over a dozen” times if she is a nurse. I believe with the knowledge she has acquired Katherine can have extensive and all-inclusive medical conversations with physicians. From her years of experiences as a patient, Katherine had learned the value of becoming an informed patient, how her confidence in her knowledge and ability to engage in a medical discussion benefits her care and treatment.

I just felt that if I went into an appointment and I didn’t know what was going to be discussed, then you can get bulldozed pretty quickly by these specialists about what they think and feel is right. And I have learned that you can’t blindly trust doctors. I’m sure
the intent is always to help but from my experience about medicine over the years, receiving a diagnosis from a doctor usually comes from them following some sort of flow chart and that doesn’t always help you in the moment.

Considering the comment about a flow-chart, I was interested to hear more of what Katherine had to say on the topic.

There’s a flowchart for everything in medicine and if you don’t fit into the boxes or the checklists you are dismissed – like you have X, X leads to test Y, we can’t go to this step until we’ve done this step – it’s a flowchart. I’ve actually seen my GP pull out a flowchart once. She stated, “This is what I have to follow.”

I found this concept interesting as I had not considered it before, but as I thought more on this, I could understand Katherine’s point of view. I have discovered as a patient rather than a nurse that our healthcare in this country is rationed and care plans pre-determined. My NM specialist explained to me on numerous occasions when I would request specific treatments that I had to go through the process and fail one treatment before moving on to the next one. There seems to be rules and regulations around what treatments can be offered to patients based on where they fit on a chart or in a checklist. Katherine made the comment that she has even told her doctor to stop trying to fit her into a checklist that she does not fit into, to treat her as an individual.

I just find it so frustrating. And I’ve said to my specialist, “This disease is known as a snowflake disease. Why are you constantly trying to put me into a box that I don’t fit into?” I said flat out, “I don’t fit into your flowcharts so stop trying to treat me as if I do.”
Katherine then elaborated on how she feels about continual information searching, always striving to understand more.

*With each new symptom, it opens up new information and new medical terms, new understanding for me how it all works together. I don’t know if it’s the research or the knowledge of trying to figure out what’s going on that allows me to have that gut instinct to know when to push harder.*

I have great respect for Katherine in her continual quest to learn, to acquire new information, to grow as an informed patient. She understands that value of having the ability to engage in medical conversations and how the information gives her the confidence to advocate for herself.

### 7.11 Conversations with Physicians – “I went armed with supported documentation”

When Katherine mentioned that she has been asked many times if she was a nurse, it shows that others also believe her level of knowledge would indicate someone with a health care background. Katherine demonstrated through her stories of information-seeking that she understands how to find credible information, often citing research studies and clinical trials. Although she described it as “a steep learning curve, learning the medical terms and understanding and comprehending,” she seemed less than satisfied with her physician’s inability to keep up with her on the latest research and information on MG. She explained how she felt about her ability to find information in comparison to what she receives from her doctor and finding credible sources of information.

*I look at my specialist and I say, “You’re the specialist here. It took me two seconds to find this case study on the internet.” I don’t read non-reputable sites. I always read*
actual case studies and findings with controlled outcomes. I’m not just reading what Joanne posted on Facebook.

Impressed with Katherine’s motivation to learn about her health in a way that extends beyond basic knowledge, I was curious to know if she presented the information she found to her physician in their discussions. Katherine described to me one instance in which she printed off research studies to bring to a physician.

I once went armed with documents printed off on case studies about how thymectomy results are just as good in seronegative patients as in seropositive. That was the one time I went armed with supported documentation to a specialist, and it was the cardiothoracic surgeon. I was relentless even though he said, “Yeah it doesn’t work.” I said, “Well I think it does.” He said, “The risk of the surgery outweighs the potential benefits.” I said, “No. It doesn’t. Not for me. I’m willing to take the risk.”

Katherine and I felt a connection again at this part of her story as I explained I did the same thing in the case of the surgical consult for a thymectomy. I had the referral from my specialist, although he was uncertain it would be accepted, just that I could go and “have the discussion.” I came to the appointment with over 10 research papers on thymectomy for seronegative patients and the International Guidelines for the Management of MG to present my case. After some deliberation and consultation with colleagues and my NM specialist, the surgeon agreed to book the surgery.

Continuing with the topic of presenting information to physicians, Katherine explained that she will never go into an appointment without having acquired information and written notes to refer to during the appointment. She finds that with her complex health issues it can be too easy to miss something or forget to ask a question. Katherine said, “I don’t go into any doctor
appointment without notes on my phone.” I personally do the same as I find otherwise, I will forget to ask a question or address a topic, with an extended time frame before I speak to my specialist again. I create a checklist to ensure all my questions and concerns have been addressed before the end of the appointment.

7.12 Self-Advocacy – “My doctors didn’t get me to remission, I did that”

As our conversations progressed, Katherine began to describe to me the ways in which she had to advocate for herself. Her relentless self-advocacy is awe-inspiring. It is amazing how she advocated for herself, stood up to doctors and told them she disagreed with them, and pushed to the point of finally receiving the treatments that led to remission. After many failed medications due to ineffectiveness or intolerable side effects, Katherine started to inquire about a medication called Rituximab and a thymectomy. She explained her circumstances at the time and the discussions she was having with her physician.

It was two years of failed drugs and me saying, “I’m losing my life.” And he would sit there and say I wasn’t a candidate [for a thymectomy] and I wasn’t stable enough for surgery. I was up to 220 plasma exchanges by this point. I had been asking too about Rituximab. We’ve given these other drugs time and they continue to fail. I don’t have a life, I can’t do anything, this is clearly not working.

Katherine mentioned the comment a few times that she had lost years of her life. I had not previously thought of my circumstances in that way, but when she would make that comment it struck a chord for me. I instantly felt what she was describing. It can be devastating to spend years upon years of attempting to find the right treatment, all the while losing your career, social life, identity – just waiting and waiting to find the ‘right’ treatment and be able to live again.
Katherine’s persistence paid off and she was finally able to receive Rituximab, however, she was still not happy with her health circumstances.

*I was pushing, pushing and then finally he said yes to Rituximab. And Rituximab actually worked for me and got me stable, but I was still doing plasmapheresis. [I was] continually asking for a thymectomy. I would tell every specialist, “We’re putting band-aids on broken arms here, and I feel like we’re not getting in front of the actual disease.”

Katherine was adamant that a thymectomy would help manage her disease and knew from her information searching that it was her best chance at remission. Unfortunately, due to the classification of her MG as seronegative, there is insufficient research for surgeons to believe the surgery would be beneficial. However, she did have the support and recommendation of the apheresis specialist for the surgery. Katherine was elated to finally have convinced her doctor to refer her to the surgeon, but then was quickly let down and disappointed upon the initial consultation.

*He said, “There’s nothing on your x-ray, there’s nothing on your CT scan, you’re not seropositive, there’s no reason for me to do this.” You take one step forward with your MG and then you take five back, that’s literally been my life for the last six years. One forward, five back. And just when you think, “Oh my god I’m finally going to get this surgery that I felt I needed all along” only to have your hopes crushed when the surgeon says, “No, and I’ve consulted with my colleague, and both of us think it is a no.”

Katherine refused to accept no as an answer. From her extensive information seeking and conversations with others that revealed anecdotal evidence of the benefit for a thymectomy regardless of seronegative MG, she was confident in her knowledge giving her the determination to push back.
I was obviously upset, [but] said, “I disagree with you. I disagree with you completely. The specialists who are treating me disagree with you.” His argument was the risk of the full sternotomy and undergoing anesthesia with MG. He felt going under was a greater risk than the potential reward of surgery. [However, there is a surgeon] in Toronto that does the minimally invasive thymectomy for MG patients. And he said, “If you’re stuck on this, I’ll refer you to him.”

Katherine was passionate as she told this part of her story. I could feel the distress she felt during the appointment, being told there is no benefit for her when she strongly believed otherwise. She explained further how she was feeling at the time and how she continued to communicate with the surgeon.

I’m [in my 30s] and I’m in a hospital bed three times a week. I have no life. I can’t travel anywhere, I can’t go to work, I can’t do anything. And nobody is willing to do the work to get me out of that situation, everything we have tried hasn’t worked. So, I had nothing to lose at this point. What’s the worst thing to happen – this guy says no. I don’t care, it’s my life. And I just said, “I don’t agree with you.” And that pushed him to say, “Well, if you really think you need this, I can refer you.” I said, “Yes, I’ll take that referral.”

I feel those words are powerful on their own – I don’t agree with you. Many patients may think that statement, but few will verbalize it to physicians. Katherine took the referral and left that appointment with a sense of relief and satisfaction that she was a strong advocate for herself. She did not immediately get what she was seeking but had another referral in hand to continue pushing for what he believed would improve her disease. The consultation with the surgeon in Toronto was a positive experience.
He said, “We believe that seronegative patients can benefit from this surgery, we have had a lot of positive outcomes from this surgery in these patients.” He also said, “I do believe that you are a candidate.” It was just so validating.

I could see from the change in how Katherine spoke about each surgeon the contrast in how she was treated and correspondingly how she felt. The initial surgeon did not seem open to the conversation about surgery and made her feel out of line for pursuing the option. The surgeon in Toronto was open to the option and provided Katherine a sense of validation. It was only through Katherine’s persistence, backed by the knowledge she had acquired, that led her to the right physician to manage this aspect of her treatment. Katherine admitted that it was extremely difficult to go through this process and have the confidence to stand her ground and be firm in her belief of the potential benefit of the surgery.

The first step in getting the surgery was the apheresis specialist believing that I needed the surgery too. And me pushing back when I didn’t agree with the first surgeon – can you imagine – to go up against a cardiothoracic surgeon and say, “No, I don’t think you’re right and I’m not taking no as an answer.” People don’t do that.

In this part of our discussion, I was beyond impressed with Katherine and what she had accomplished to get the care she felt she deserved. Although I have strongly advocated for myself for treatments as well, Katherine seemed to go to the next level. I have also had to really push for treatment with Rituximab, which ultimately made a substantial difference in symptom resolution, and then had to push for the correct dose of Rituximab due to government funding restraints on the drug. I also have advocated and pushed for a thymectomy. I convinced my specialist for a referral, showed up to the initial consultation with an armful of research studies. Despite the comment from the surgeon after meeting me for three minutes “you seem to be doing
okay,” I explained to him how “doing okay” is not compatible with a good quality of life, and my limitations on work, travel, and social life. I refused to give up and did tell him that I disagree that it should not be considered an option. After many months and a discussion between my specialist and the surgeon, the surgeon has agreed to proceed with the surgery.

It was interesting for me to speak with Katherine and hear her story of self-advocacy to get a thymectomy, as it closely aligned with mine. It filled me with hope to see that someone without a professional medical background could be an informed patient and stand up to physicians for what they believe they need. From the thymectomy, Katherine achieved remission. As she told me this, I felt elated for her, I felt joy, and I felt hope for the potential outcome when I have my thymectomy. Katherine made it clear at this point that her doctors did not get her to remission, she takes full credit for getting herself there by pushing and advocating, by refusing to take no for an answer. She acknowledged that she most likely has been labelled as a difficult patient for how she advocates for herself, but she is fearless and does not regret a moment of her strength. She now sees her tenacity as a patient to be a strength and said, “That used to bother me and now I almost wear it as a badge of honour.”

7.13 Transparency with Information – “You have no right to keep that information from me”

As an informed patient, Katherine always made sure to request a copy of her medical reports and testing, to review results and further learn about her health status. She described this process as labour-intensive and frequently was met with resistance when obtaining her own health information. When the province transitioned to an online health reporting system that is accessible by the patient, Katherine said it was the best thing to have happened to review and manage her healthcare. I agreed with Katherine on this point. Previously if I had bloodwork
done, I was told it was all fine unless I received a phone call from the physician, but that never sat well with me. I wanted to monitor the results, decipher what was abnormal and causing a problem, and proactively address issues before they could turn into a bigger challenge. With the online reporting, I can review and assess, then make an appointment with my physician if I feel there is something that needs to be addressed. Katherine, however, gave me an example that I found to be shocking and indisputably demonstrated the need for patient access to health information. She was hospitalized for a pulmonary embolism and had an echocardiogram to assess her heart and lung function. She was able to pull up the results of the test on her phone and review before the physician came to see her.

I read my echocardiogram and saw that I had pulmonary hypertension. A few minutes later I had a resident walk in the room and tell me my echocardiogram was normal. I ask how that can be the case when three of the four valves have regurgitation, which is not normal. Blood flowing backwards through a valve in your heart is not a normal thing and having pulmonary hypertension is also not normal. I just said, “I don’t want a resident here telling me something that I know is not true when I can read it, it’s in black and white. I want to see a specialist.”

A pulmonary specialist came in to see Katherine the next day to discuss the test results. This story stirred up disbelief in me, that Katherine could be told the test was normal when there were significant abnormalities. I asked Katherine what happened with the resident.

The resident came in later to apologize and admitted it was her second day at that hospital. She said, “We’re really trying to figure out how much we inform the patient.” I looked at her and I said, “You tell the patient everything. It is not your place to decide
how much information I should have about my own body. You have no right to keep that information from me.”

It is frightening to think what could have happened for Katherine if she did not have access to her health records online. She would have accepted that her echocardiogram was normal, would have not have a consultation with a pulmonary specialist and would have been devoid of follow up for her heart and lungs. The online health records have created a transparency that is valuable to patients who want to be informed and learn about their health and wellness. Katherine explained how the transparency of the system helps her to be an informed patient.

That’s the best thing, I get the report first so I can be informed. I can figure out what it says so I can ask the right questions. With each new scan or test I learn a whole new part of my body.

Katherine’s resourcefulness and ability to engage in continual learning is admirable and benefits her as she continues as a patient in the healthcare system. However, she is keenly aware that being an informed patient is not always appreciated from a physician perspective. She said, “They don’t like informed patients. They don’t like patients that advocate for themselves. You get pegged as the difficult patient.”

7.14 Connecting with Others – “Information from other MG patients incredibly helpful”

Moving forward in our discussion on information-seeking, I asked Katherine if she had joined any online MG groups or support groups. She indicated that in her search for local groups left her empty handed, but she found the MG Association in a neighbouring province.

I went searching for support groups and that’s when I found the MG Association. And when I signed up, the president at the time would call me and talk to me about everything
I was going through – I’m so grateful for her. We talked about what my symptoms were, what her story was, what she went through. That was the first person I ever met with MG.

Impressed again with Katherine’s resourcefulness, I thought back to my own searches for groups or associations for MG. I recall seeing the website for the same MG Association chapter but did not think to call and ask if I could join despite residing in a different province. Katherine spoke highly of the association and the support she was given, along with the type and amount of information she received.

When I became a member, I received a comprehensive package in the mail with a booklet on MG, all the recent drugs, thymectomies, plasmapheresis, and IVIG. I got all of my information from them and they were such a great support group.

Katherine became the third participant to speak about the same MG Association, how valuable a resource it was, the amount of information provided, and the level of emotional support provided. It gives me the sense that I was at a disadvantage during my diagnosis, not having connected with an association. It seems like a resource that provides not only complete, succinct, and tangible information, but also a type of mentorship and personal connection that cannot be found elsewhere. Katherine and I discussed how she feels about connecting with others who are also living with MG.

I find information from other MG patients incredibly helpful. Online information is black and white, similar to how our doctors treat us. Real life MG patients don’t fit into that black and white box and through their experiences and medical outcomes, they can share what worked for them – which in turn could potentially work for me too. They also provide a level of support and understanding that I’ve not been able to find in any other person.
Katherine feels strongly about the value of the MG Association, how she felt supported and the information they were able to provide at a time of high uncertainty. She remains an involved member and even provides financial support as she knows how her monetary gift will be used to help others who find themselves in the same situation.

_I still support them by offering a donation, because there’s no fee to be a member. They operate off donations. So even to this day I still send what I can to be part of that association and support their work. They continue to send out newsletters on upcoming treatments options and the different trials that are happening for MG._

7.15 Dissatisfaction with Information – “My biggest hurdle has been lack of information and transparency from doctors”

Katherine shows through her stories that she is tenacious; she quickly became proficient in her search for information and used the knowledge gained to support her ability to advocate for herself. With a detailed understanding of the disease and treatment options, I asked Katherine how she felt about the information she has been able to find about MG. It seemed to me that she was able to sort through and compartmentalize the information she found to how it made sense for her and her situation. She thought back to her early information searching.

_It's hard to sort through it all and there's so many overlapping symptoms with other diseases. I would research and try to determine what seems like the best fit? And then once I had found what I thought was the best fit, I would have this gut feeling that I found the diagnosis._

I had heard this type of explanation from one of the other participants as well. That after they sorted through all the information and considered the symptoms, MG just seemed to fit. In this way, much like the research puzzle that overarches the study, I can see how others, like
myself, had to treat their health and symptoms like a puzzle. Learning what the symptoms could indicate, exploring the results of diagnostic tests, and using the knowledge acquired to slot together their experience so the pieces fit and the image clears. I also recall that I got to the point where I just knew. From reading, learning, talking to others – I was confident I knew I was afflicted with MG and expected the diagnosis during my appointment with the NM specialist. The information searching had led to clarity and confidence.

Katherine does not recall ever coming across misinformation in her searches, but I suspect that is in part to her knowledge of credible sources. In further discussing if she was satisfied with the information she was able to obtain, Katherine cited lack of transparency as a major obstacle to being an informed patient.

*I think my biggest hurdle has been lack of information and transparency from doctors on predicated outcomes or potential side effects of the drugs they start you on or even what to expect through the healing process.*

From listening to Katherine’s story, I can understand how the events she experienced have led to feeling a lack of transparency. Starting from the lack of communication of the paradoxical worsening of symptoms on the start of prednisone, to the resident conferring that her echocardiogram was normal despite significant abnormalities, Katherine has often felt that she has been kept in the dark regarding her health information.

7.16 Conclusion

I value the relationship Katherine and I formed as we discussed MG and her story of learning to navigate the disease. From the start of our conversations, she inspired me. Although met with continual challenges and setbacks, Katherine uses her ability to seek information to her advantage; to understand her health, to prepare for medical appointments, and to advocate for
herself. Katherine will not remain silent when she disagrees with a physician and will push for the highest quality of life. Learning about the disease led Katherine to remission. Although she has recently experienced a regression, she is hopeful with her continued advocacy that she can push the disease into remission once again. Moving forward Katherine will take the knowledge she has gained and use it to not only support others living with MG, but to address her other health issues as they arise. I am confident her future is bright and will always appreciate the friendship she has extended to me during these conversations and beyond.
CHAPTER EIGHT: OVERARCHING ANALYTICAL INTERPRETATIONS

Each of the four participants were gracious and open while discussing their stories of knowledge acquisition related to MG. The conversations focused on the information-seeking practices that ensued to understand MG and to learn how to live with the disease. The detailed review and interpretation of each narrative account revealed “resonances” and “threads” interwoven through each story (Clandinin, 2013). Throughout this section, I explore the overarching analytical interpretations that have enabled their stories to come alive; reasons for seeking information, sources of information, changes in information seeking over time, and the relevance and perceived satisfaction of the information found. These four aspects represent the resonate threads that weave throughout the plotlines of the participants narrative accounts, over time and place, echoing across the stories from each participant (Clandinin, 2013). Each participant had unique stories with varying emphasis, however, the four resonant threads discussed in this section emerged when I considered the figurative overlapping of the narrative accounts (Clandinin, 2013).

8.1 Reasons for Information Seeking

Although the snowflake nature of MG became increasingly evident as I explored each participant’s story, the reasons and motivations for seeking disease-related information aligned across participants. The type, severity, and frequency of initial symptoms varied for each of the four participants, but their reasons for searching for information presented similarities and overlapping features. From these four participant stories, I uncovered that the reasons behind information seeking were uncertainty and worry, self-advocacy, and a desire to improve their quality of life.
8.1.1 Uncertainty and Worry

As I explored each narrative account, I could perceive how the initial vague and non-specific symptoms were concerning and worrisome for the participants. Searching specific symptoms online before a diagnosis was often futile and increased anxiety or worry as search results produced a collection of calamitous diseases such as MS or ALS. Although participants could discern how their symptoms did not entirely fit with these alternate diagnoses, the ruminating electronic suggestion pointing to these diseases only served to increase concern and worry. Thomas described the feelings associated with the start of searching for answers as desperation. Although the other participants did not directly elucidate feelings of desperation, I could sense from their stories that these feelings dominated their initial searches for information. Health concerns that have the potential to alter perceptions and certainty of the future will lead individuals to seek information to regain a sense of control (Lee & Hawkins, 2016). I recognized the need to stabilize against a loss of control from the participants. Information seeking also appeared to serve as a method to legitimize the symptoms participants were experiencing.

It seems appropriate that the first reaction of people experiencing a health issue would be to seek information, to gain understanding and clarity. Lee and Hawkins (2016) found that worry increases when people feel uncertain about a situation, which leads to higher engagement in information-seeking as an attempt to alleviate that fear. Each participant I had conversations with described their feelings of fear, often recalling circumstances that they could only describe as terrifying. The driving factor behind information searching was to understand their prognosis and what could be expected in the future while living with MG. Information searches seemed to quickly move from basic disease information to more complex topics such as how to manage symptoms and continue living their lives while managing the disease. This observation mirrors
the findings of Rovira-Moreno et al. (2020) and Spring (2014) that identified seeking disease-related information was a coping mechanism, to decrease uncertainty and improve overall well-being.

Reflection on the research puzzle brought to my awareness that the participants were constructing their own puzzles. I realized how each participant unknowingly assembled their own puzzle when they spoke of the clarity gained by reflection on their early symptoms and experiences. As participants considered their early experiences with MG, it appeared to provide an avenue for the participants to make sense of the chronological events. They could then mentally organize the events and the picture became clear, as though slotting together the pieces of a puzzle. Thomas described how the more he learned about MG the more it fit him, like a lock and key. For Olivia, she gained clarity on her childhood health experiences that had remained unresolved. Katherine understood how her information searches brought her to the point where she was confident the pieces fit, and that she had the right diagnosis despite hesitation from her physician. Ellie was able to understand the pathophysiology of the disease and why she felt her muscles were failing her. Each participant gained lucidity of their symptoms and corresponding diagnosis as they recalled their earlier memories of MG manifestations. Understanding how the pieces fit together then influenced their present disease status or where they strive to be in the future. Thomas and Katherine further expressed how their interactions with healthcare providers in the past influenced their current and future perceptions of healthcare interactions, altering their motivations and desire to engage.

8.1.2 Self-Advocacy

Self-advocacy, the ability to verbalize needs or promote one’s own best interests, is an essential skill when living with a chronic illness (Ruggiano et al., 2016). Advocacy was a
common thread that appeared to dominate many of the participant stories. Abdulla et al. (2014) and Katavic (2019) found that information searching as a form of self-advocacy led to patients becoming more active in decision-making for treatment plans. This finding was demonstrated by the participants in the current study. Each participant described the dissatisfaction they felt with their care and treatment plans, citing limited information or resources provided. Subsequently, participants were left with the responsibility of engaging in information searching and taking on the task of self-management of their disease.

The participants described many instances of self-advocacy throughout their stories. Katherine was the strongest self-advocate I have met, and summated her experiences when she commented, “My doctors didn’t get me to remission. I did that.” Self-advocacy was a skill that the participants developed over time as they gained confidence with additional knowledge. Thomas had to justify himself, reiterate his symptoms on multiple occasions, and remain firm when he was labeled as psychosomatic. Refusing to give up, Thomas had a thymectomy, and in a follow up conversation he shared that he was doing well and experiencing improvement in his health with decreased symptoms. Ellie advocated for herself to receive alternate treatments after learning about those treatments from her information searches. Olivia also advocated for herself when the side effects of a treatment were unbearable, and when she wanted to have another child despite her chronic illness.

Information searching and self-advocacy also became a means for the participants to assert their place in the world living with a chronic illness, to ensure their needs were met, and to influence the social structure around their circumstances. Plackowski and Bogart (2023) corroborated that individuals living with rare diseases face social and internalized stigma related to their disease. Lack of awareness of rare diseases within the medical community influenced
healthcare provider perceptions, attitudes, and behaviours, which in turn conjured feelings of animosity towards providers and altered social interactions (Plackowski & Bogart, 2023). Participants in this study exemplified need to advocate for themselves to not only improve their circumstances and quality of life, but also to improve the social and cultural fabric that encases rare diseases and chronic illness. Plackowski and Bogart (2023) found that increasing disease awareness combined with a desire to improve personal and other’s circumstances became the driving force behind advocacy engagement. For example, personal advocacy often leads to advocacy for the rare disease community as a whole and becomes a cyclical process around improving circumstances and addressing the lack of societal and healthcare awareness (Plackowski & Bogart, 2023). All four participants discussed stories and experiences that revolved around self-advocacy to improve their circumstances. Thomas and Katherine both spoke of advocacy that extended beyond their personal circumstances and giving back or using their acquired knowledge to advocate for others within the MG community.

8.1.3 Improve Quality of Life

Each story of living with MG from the participants was overshadowed with loss; loss of career, identity, activities once enjoyed, relationships and social interaction. The prevalence and magnitude of cumulative and reoccurring loss are well documented in the literature. Ahlstrom (2007) completed an inductive analysis detailing numerous categories and subcategories of loss experienced by individuals with chronic illness. The findings of the analysis included loss of autonomy, identity, perceived future, relationships, family and professional roles, recreational activities, and manageable emotions and mental health. The physical limitations experienced by each participant contributed to intense feelings of loneliness and social isolation. The participants in the current study also described the deep loneliness they felt while living with MG. Loneliness
increased mental health challenges that resulted from living with a rare chronic illness and little emotional support. Thomas and Katherine spoke more strongly about their mental health challenges, that there was no support, resources, or referrals provided to manage and cope with the diagnosis. Loss, loneliness, and emotional distress all became significant factors in the quality of life for the participants.

Information seeking also became a means for participants to improve their quality of life. Connecting with others living with MG in the online setting, in chat forums or social media groups, was cited as highly valuable. A common comment was that connecting with others helped with the feelings of validation, that their symptoms were real, and others were experiencing the same circumstances. Hearing other’s stories and connecting over a shared diagnosis helped alleviate some of the feelings of loneliness and feeling misunderstood by others in the physical world. The concept of MG as an invisible illness was discussed by all four participants. Participants believed that others did not understand the disease, including the physicians who were treating them. The literature reveals that it is not uncommon for individuals to feel stigmatized and marginalized while living with symptoms that are not easily discernable to others. Armentor (2017) identified that invisible illness created tension in personal and social relationships due to a lack of understanding and knowledge. Disbelief of symptoms or physical limitations from personal or medical relationships quickly lead to tension, avoidance, and social isolation (Armentor, 2017). The strain on relationships from the invisible nature of MG lead the participants of this study to seek understanding and emotional support online. Although each participant found a supportive community online, the diminished in-person relationships resulted in a decreased quality of life.
One of the top reasons for information searching discussed was for treatment options. All four participants indicated that learning about available treatments for MG was part of their initial searches, as well as the cornerstone of their ongoing searches as time elapsed and they lived longer with the disease. The motivation behind searching for new available treatments was to further improve the quality of their lives – to lessen the symptom burden and to increase their ability to actively engage in activities and their communities. Abdulla et al. (2014) also discussed that current clinical research and treatment options were two of the most searched topics for patients living with a rare disease. These most searched topics were reflected by the participants in the current study as they all confirmed the focus of their information searching was how to live with the disease and maximize their quality of life.

8.2 Sources of Information

Identifying the sources of information most preferred or trusted by the participants helped to understand the process of gaining knowledge about MG as I considered the research puzzle. The literature search revealed that the most preferred and utilized sources of information were physician specialists, online sources, and support groups or associations (Katavic et al., 2016). The prevalence of these three information sources was seen in the participants stories as they navigated the healthcare system and learned about this rare disease.

8.2.1 Physicians

Litzkendorf et al. (2020) found that patients with rare diseases most trusted health information received from specialists, although they preferred to get the information from their family doctor. I saw this preference for information sources mirrored in the participants experiences, but recognized that it was also dependent on the type of relationship the participant had with the physician - whether the relationship was reciprocal or partisan. A commonality
uncovered throughout the narrative accounts was the lack of information provided to participants at the time of diagnosis. Thomas and Ellie described not receiving any information at all, and Olivia and Katherine only received information on treatment options. Interestingly the literature review revealed that although specialists were the preferred and most trusted source of disease-related information, patients felt that they receive inadequate information at the time of diagnosis (Abdulla et al., 2014; Katavic et al., 2016; Litzkendorf et al., 2016; Litzkendorf et al., 2020).

Reflecting on the role of physicians as an information source, a common finding that materialized across participant’s narratives was a feeling of dismissal when seeking help or information. When seeking answers regarding symptoms before a diagnosis, Thomas and Katherine both experienced disbelief and dismissal from physicians and were told their symptoms were attributed to anxiety or psychosomatic issues. Olivia had a similar experience in the emergency room. The careless comments and sweeping generalizations experienced by all the participants caused emotional distress and resulted in a mistrust of the healthcare system. Future medical encounters were influenced by these experiences, resulting in Thomas and Katherine to independently seek out psychological services. Olivia also spoke of her mental health struggles exacerbated by a medication, but also confirmed that her physician did not offer support or resources.

Although physicians were the preferred sources of information, participants in this study were dissatisfied with their knowledge of MG. Thomas and Katherine found that their knowledge of MG surpassed that of their physicians, and that their physicians did not remain current on the newest research. Ellie spoke of finding new research from independent searches and bringing that information to her physician as a point of discussion or to support her requests for a change in treatment. Olivia’s physician was unable to provide her with any type of
information or guidance on pregnancy and MG, turning her to seek this information from experiential knowledge from another member of a MG social media group.

As documented by Dinneen and McMorrow (2022), it was not uncommon for people living with a chronic illness to transcend into a phase of feeling more knowledgeable than their physician. Contrasted to an acute illness, people living with a chronic illness become more invested in developing a knowledge base to actively engage in self-care management, often feeling their knowledge supersedes their physician’s (Dinneen & McMorrow, 2022). As each participant relayed their stories, I identified the point at which they felt their knowledge of the disease, including not only the management but also the new and emerging treatments, had excelled beyond the perceived knowledge level of their physician.

8.2.2 Internet

With dissatisfaction with the type and quality of information provided by physicians, all four participants turned to the internet to find the information they desired. Resorting to the internet was a behaviour supported by Abdulla et al. (2014) and Carpenter et al. (2011). The internet was the most heavily utilized source of information for patients, especially when they felt the need to supplement the information received from physicians or lack thereof (Abdulla et al., 2014; Carpenter et al., 2011). Li et al. (2014) identified that 40% of patients sought information online due to inadequate information from doctors or were dissatisfied with the quality of information they were provided. Reflected in participants experiences, Li et al. (2014) further discovered that physicians with specialized training, such as a neuromuscular specialist, provided less holistic care which increased the likelihood of patients turning to the internet.

The participants in this study also quickly took to the internet to gain information and understanding of their symptoms and then subsequent diagnosis as it was fast, easy, and readily
accessible regardless of time or place. All four participants accessed formal and written literature online, including current research and academic papers, indicating their knowledge and desire for accurate and credible information. Although Litzkendorf et al. (2020) found Wikipedia to be a highly trafficked website for people seeking health information, the participants in this study all described how they gravitated towards generic Google searches and association websites. Thomas, Ellie, Olivia, and Katherine all confirmed that the internet was their primary and ongoing source of information.

Each participant also described how their online searches started broadly, then narrowed and became more focused, as also described by Litzkendorf et al. (2020). Thomas and Katherine both stated how their first information search started by typing MG into the Google search bar. This type of generic search produced top results from hospital-affiliated medical centers such as Johns Hopkins Medicine, Mayo Clinic, and Cleveland Clinic, which provide standardized and structured lists of symptoms and treatments. Further down the search results were Wikipedia, National Organization for Rare Disease, the Muscular Dystrophy Association, and finally towards the bottom, the MG Foundation of America. Quickly tiring of lists of symptoms that seemed to only be partially applicable to their situation, participants then narrowed their searches to specific topics. For example, Ellie and Katherine began to tease out more information on antibody types, and Olivia searched for pregnancy-related information. Consistent with the literature review, each participant moved from a haphazard and generic search to a more structured and focused search strategy (Katavic, 2019).

Unfortunately for each participant, their internet searches also failed to provide consistent and relatable information. Thomas, Ellie, and Katherine all described how their initial search results produced an assemblage of potentially serious or fatal diseases, such as MS or ALS.
Katherine cited her struggles with searching symptoms as fatigue could be experienced with numerous acute and chronic illnesses. All four participants expressed their discontentment with the information found, citing a lack of applicability to their own circumstances. Dissatisfaction with the applicability of available information was well documented in the study of other rare diseases (Katavic, 2019; Litzkendorf et al. 2020; Spring, 2014). As a result of the disease variability for each participant, the available information only partially explained their symptoms and left them confused and in doubt.

8.2.3 Support Groups and Associations

It became clear in my discussions with the participants that MG Associations were the most valued source of not only information but also emotional and social support. Thomas, Olivia, and Katherine all spoke highly of the MG Association, speaking of the relief and validation they felt when connecting with members who also lived with MG. Katherine described how connecting with others provided a level of support and understanding that she failed to find elsewhere. Olivia and Katherine both described the type and quantity of information the MG Association mailed to them, citing it as the most helpful and relevant information source. The MG Association provided these participants a unique combination of reliable and credible printed information along with discussion and personal conversations that provided validation and emotional support, offering a holistic approach.

Thomas and Katherine found comfort and attestation of their symptoms after speaking to the president of the association following dismissal by their physicians and the healthcare system. The mentorship, support, and experiential knowledge of others living with MG became a cornerstone of learning to understand and live with the disease for Thomas, Olivia, and Katherine. Olivia and Katherine both described how the information provided by the MG
Association differed from the information found online or from physicians. Katherine stated that the information outside the MG Association was black and white, similar to how physicians treat patients and their symptoms. Katherine was referring to the snowflake nature of the disease with her black and white comment – that the information available online and from physicians fails to address the variability of the disease. Connecting and learning from others living with MG provided information with greater applicability. Experiential knowledge from others provided context, gave an avenue to understand the variations and nuances of the disease and symptoms, acknowledged the variability of the disease, and provided tips or suggestions on how to manage specific symptoms.

My observations of the profound effect of the MG Association on the lives of the participants were supported by Pulciani et al. (2018). Rare diseases historically have been overlooked in terms of medical research and information sharing due to a low prevalence of the disease and lack of public awareness (Pulciani et al., 2018). However, patient associations for rare diseases have come to fruition to fill the void; to raise public awareness, secure research funding, and allow patients to connect with others living with the disease (Pulciani et al., 2018). The success of patient organizations was embedded in the unique manner of creating a culture and community in which individuals could seek refuge from stigma, isolation, uncertainty, and lack of reliable information (Pulciani et al., 2018).

Thomas, Olivia, and Katherine have lived with MG for many years but continue to engage with the association and its members regularly through information sharing, support meetings, and newsletters. As the importance of the MG Association came to the surface while speaking with these participants, I considered Ellie and how her frustrations, isolation, and emotional struggles could have been partially alleviated had she found an association to connect
with early in her diagnosis. Unfortunately, the province in which Ellie resides does not currently have a local MG chapter.

8.3 Change in Information Seeking Over Time

For each of the participants, the evolution of their information-seeking behaviours over time mirrored patterns described in the literature review and as reflected in other chronic disease processes (Katavic, 2019). As each participant gained experience living with the disease, their focus continued to shift to accommodate new approaches and perspectives. As I considered the process of change for each participant, I could visualize a pattern that began to emerge. Three phases of information seeking surfaced as I evaluated overlapping commonalities and threads – onset to diagnosis, expanding resources, and disease management.

8.3.1 Onset to Diagnosis

Before a confirmed diagnosis but when experiencing persistent and concerning symptoms, Thomas, Ellie, and Katherine all engaged in intense and time-consuming information-seeking online. Motivated to find answers and alleviate concerns, these participants described initial searches as broad and frantic – attempting to piece together any piece of information they could find. Thomas, Ellie, and Katherine also described early searches focusing on symptoms, often using a symptom checker website, to find a possible diagnosis. Chen (2016) identified similar search patterns in fibromyalgia patients, a difficult to diagnose condition that also presents with vague and overlapping symptoms to other diseases. Olivia varied in this phase of illness as she was hit suddenly with intense symptoms as an adult, was hospitalized, and lacked internet access. She did however try to obtain as much information as she could from nurses and physicians during her hospitalization. The participants in the study by Katavic (2019) also described this intense and unstructured searching phase early in the disease process.
Participants in the current study as well as those in the study by Katavic (2019) initially sought information related to prognosis and mortality. Olivia stated that one of the first questions she posed to her physician at the time of diagnosis was, am “I going to die?” Olivia then further discussed, in parallel with Thomas, Ellie, and Katherine, how many searches centered on prognosis and how to live with the disease.

Once armed with the name of the disease after diagnosis, each participant then developed a narrowed focus and more structured search strategy. Ellie spoke many times of searching for information to help her understand what was happening on a physiological level. All the participants spoke about looking for specific symptoms, information on antibodies, and available treatments. Although obtaining a formal diagnosis was lengthy and mentally challenging for these participants, it eventually enabled them to focus their information searching in a more structured manner. Chen (2016) also found that once patients received an official diagnosis, information seeking then transitioned to more detailed searches. A similar pattern was observed from each of the four participants in the current study. A focused search on the specific disease enables them to move forward in their active information-seeking.

8.3.2 Expanding Resources

Once the preliminary searches were completed and participants had acquired basic disease-related information, they moved to find groups and communities to which they could relate, as also described by Spring (2014). Thomas, Olivia, and Katherine all spoke about the MG Association and the emotional support they received from connecting with other members. This connection had not previously been possible for them due to the rarity of the illness. Connecting with other individuals then shifted these participants more into an information-sharing phase, a reciprocal relationship of giving and receiving information related to MG.
Learning from others and the gained experience of living with the disease provided a different and more holistic type of information, filling the knowledge gaps left by physicians and the internet.

Chen (2016) found that in the information-sharing phase some patients feel empowered, which further encourages information seeking, connecting with others, and sharing of experiences as a form of giving back. Katherine and Thomas both described their desire to give back to the MG community, citing the financial and administrative avenues they were using to accomplish this goal. For example, Katherine often contributes financial support to the MG Association to continue helping others, and Thomas assumed a top role within the organization. Both of these participants felt that membership with the MG Association drastically improved their access to information and emotional support when they needed it the most. Feeling confident in their knowledge of the disease and having experiential knowledge, Thomas and Katherine felt they had much to offer others who were newly diagnosed or seeking information and support.

8.3.3 Disease Management

As time unfolded and each participant began to appreciate the experiential knowledge gained from living with the disease, their information-seeking practices shifted and slowed. The participants moved into a phase of direct problem-solving related to the disease and monitoring. As described by Katavic (2019), all the participants moved to a phase of only engaging in information seeking if they experienced a change in circumstances related to their disease or to seek out new or advanced medical treatments. In the current study, Katherine described how each new health issue she experienced lead her to keep searching and learning. Olivia described her change of information searching patterns when she spoke about re-entering a frantic search
mode during the beginning of the COVID-19 pandemic and how COVID-19 could affect those living with autoimmune disease. Ellie stated that she was now in a management stage as opposed to a learning stage. Thomas, Ellie, and Olivia each described how now, after living with the disease for many years, they only occasionally searched for information, and the search primarily focused on finding new treatments to manage the illness.

A commonality that appeared to weave throughout the participant stories as they spoke of the evolution of information-seeking behaviours was shifting their focus away from MG. In the acute and uncertain phase, information seeking was time-consuming and frequent. After many years of living with the disease and learning to manage their unique snowflake variation, all the participants described how they did not want the disease to be at the forefront of their attention anymore. Olivia described her chronic illness as being removed to “around the edges.” Thomas described his illness as being off to the side. It appeared that although participants had not achieved remission, the management of their symptoms had stabilized. The increased daily functioning had led to acceptance and a courage to move forward in their lives without a constant focus on MG. Chen (2016) similarly described that once patients had a diagnosis and acceptance of how that diagnosis changes their lives, they approach moving forward with the disease as part of their lives and not the dominating factor.

**8.4 Satisfaction with Information**

As I explored information seeking related to MG with each participant, their stories reflected their feelings about the information found or received. The most common sources of information were from physicians and healthcare workers, the MG Association, and internet searches. Although the participants expressed varying degrees of satisfaction or dissatisfaction, similarities could be seen in their reasoning. Satisfaction appeared to hinge on the degree of
availability, applicability, and usefulness of information. Three common threads that surfaced related to the relevance or helpfulness of information were dissatisfaction with formal information from the medical establishment, satisfaction with experiential information from others living with the disease, and becoming the expert on the illness.

8.4.1 Formal Information from the Medical Establishment

As the common thread of dissatisfaction with information from published sources and physicians began to surface through the participant stories, a comment from Katherine brought the intensity of dissatisfaction into perspective. Katherine stated that the information was organized into checklists, and that all patients living with MG were slotted into a pre-determined list rather than treated individually. This perspective was echoed through the other participants’ narratives as well – Ellie quickly tired of the available information only consisting of standardized lists of symptoms or medications. Also, Thomas explained how he felt there was a whole entity to the disease that physicians did not understand or address, such as how to live with the disease. Thomas felt that physicians only focused on clinical parameters and quantifiable symptoms. Finally, Olivia discussed how the burden of disease was higher than perceived by healthcare professionals. With each participant, there became an understanding that the information that was published and disseminated in the medical field, and then subsequently distributed by physicians to patients, was assembled by those who did not have the experience of living with the disease. The facts and figures were based on biomarkers and clinical findings. Ellie often circled back to her feelings that the information was too broad or vague, that the information scratched the surface and failed to give people an accurate perception of what they would experience while living with the disease. The superficial lists of symptoms and treatments also lacked an explanation of how the snowflake nature of the disease would impact the
variations in which those symptoms would be experienced. I believe that the healthcare model was developed to serve the masses, and to provide a standard of care across a patient population. Unfortunately for patients living with MG, a personalized approach to care and health-related information is required and remains missing.

Katherine provided a visual to the concept of generalizing patients into categories when she discussed her experience of the healthcare system and providers following flowcharts. She found that as a patient she was slotted into a predetermined list and associated flowchart, and her physician could not proceed to the next step in diagnosis or treatment until the previous step was completed. She went as far as to tell her physician that MG was a snowflake disease, and to stop trying to fit her into a checkbox that she did not fit into. This experience emulated the stories of the other participants as well. Thomas, Ellie, and Olivia all discussed how their symptoms and experiences did not fit within the published literature on the disease. They felt that some pieces lined up, but overall, their situations seemed much different from the information available. These findings were supported by Litzkendorf et al. (2020), citing the dissatisfaction with information to address the unique disease variability between patients.

Although unintentional during recruitment, all four participants had a diagnosis of seronegative MG. Each participant in turn spoke to how their information-seeking results were further impacted by their seronegative status. Most of the information available focuses on AcHR and MuSK antibodies, but with seronegative comprising only 5% of these rare disease patients, there remains extremely limited research and consequently an absence of information. Overall, the participants each confirmed that the published information from physicians was limited, vague, and did not alleviate their concerns. Budych et al. (2012) found that a lack of information from physicians regarding rare diseases stemmed from low prevalence of the disease.
resulting in physician inexperience, and lack of awareness of the illness. MG is a poorly
understood disease overall, but the rarest form of the rare disease, seronegative MG, presents
further challenges for physician awareness and experience, and ultimately information
dissemination.

8.4.2 Experiential Knowledge

Each participant had expressed their dissatisfaction with the information available online
and from physicians, mainly citing that the type of information did not give them a sense of how
to manage and live with the disease. All four participants discussed that they learned the most
about MG by living the experience, by trial and error, by figuring out what works for them, and
how to minimize debilitating symptoms. Ellie pointed out that the written literature stated muscle
weakness gets worse with activity and improves with rest, but Ellie mentioned that one cannot
understand the concept until one has experience living it. Fatigue was listed symptom but does
not convey how the fatigue is different from merely feeling tired. Each person must individually
experience the fatigue and learn how to manage it. Ellie and Olivia both discussed learning to
pace themselves to manage the fatigue and muscle weakness and that the only way they could
learn this was by living with the disease and experimenting with what worked for them. Both
Olivia and Ellie spoke of the analogy of a battery – to pace and recharge their battery throughout
the day as not to end up in a negative energy balance by the end of the day. Learning how factors
such as stress or heat affect symptoms was also highlighted as a part of the disease that can only
be learned by experience. All four participants valued their experiential knowledge, and once
they had a better understanding of their unique disease process and how to manage it, decreased
their search for information.
The topic of mental health support surfaced as a key thread frequently and with each participant. Each participant struggled emotionally and mentally with this life-altering diagnosis, yet no one had been asked by their physician how they were doing or if they needed support. It has been well documented that individuals living with a chronic illness suffer from higher rates of clinical depression than others without an illness (Fernandez, 2021). Despite the increased risk for concurrent physical and mental health disorders, the emotional well-being of patients was overlooked or not addressed (Fernandez, 2021). Lack of mental health supports was experienced by each participant in this study. Two of the participants sought out therapists on their own to help manage the mental aspects of living with the disease. However, psychological resources are costly and may not be financially feasible for those who are uninsured. The MG Association appeared to fill the mental and emotional support gap related to connecting, sharing, and learning with others.

8.4.3 Becoming the Expert

As each of the participants has lived with MG for numerous years, they came to a phase in their illness in which they felt they were an expert. Patients living with rare diseases often felt that their physician lacked comprehensive knowledge related to the disease and felt it necessary to find alternate methods to be an informed patient and self-manage (Katavic et al., 2016). Olivia described how she felt about physician knowledge of MG when she stated that the disease affected her in ways that her physician could not understand. She explained that although a physical exam may show good results the disease still hindered her in her day-to-day life that the physician did not see in the exam room. Thomas and Katherine also discussed how they have come across research related to MG that their physicians were unaware of, and sometimes rejected when presented to them.
For acute and more prevalent diseases, information dissemination typically flowed from physician to patient (Budychk et al., 2012). With rare diseases, patients were often left with no choice but to become well-versed in the disease and associated treatments, changing the nature of the physician-patient relationship (Budychk et al., 2012). The low prevalence of a rare disease and corresponding lack of knowledge or awareness from healthcare professionals led patients to become the driving force behind their care plans and therapies (Budychk et al., 2012). I could see this pattern developing through the participant’s stories. Each participant reached a point in their knowledge acquisition where they felt more educated on the treatment of MG and strongly advocated for the therapies that they perceived made a difference. This trend opposes the traditional medical model of care delivery and can be met with resistance from physicians, as seen with Thomas and Katherine. The shift in relationship dynamics is counterintuitive to the physician’s previous experiences and can often lead to communication breakdown and impaired physician-patient relationships (Budychk et al., 2012). Thomas and Katherine further expressed how negative experiences with physicians continued to impact how they engaged in current and perceived future healthcare interactions.

The findings from this study are represented in Figure 2. The left-sided column represents the resonant threads woven throughout the stories. The colour blue within the boxes of the column is intended to represent reflection, knowledge, and wisdom. The participants reflected on their experiences and how they gained knowledge, leading to the wisdom of how to live with MG. The middle column represents the categories that emerged from within each thread. The boxes in the middle column have a smaller blue surface area with a white boarder to represent the categories as smaller pieces of the whole resonant thread. Finally, the right-sided column represents the subcategories that emerged from the categories in the middle column, further
reducing the colour to white, to represent an even smaller piece of the puzzle. Each thread, category and subcategory are concepts that flow through the participants stories. The arrows flow from one column to the next to represent the smaller subcategories building into the categories and the categories building into the resonant threads. Figure 2 is the final copy produced from my working diagram created during the data collection and analysis stages.

**Figure 2**

*Analysis and Interpretation: Resonant Threads*

<table>
<thead>
<tr>
<th>Resonant Threads</th>
<th>Categories within Threads</th>
<th>Subcategories of Threads</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reasons for Information Seeking</td>
<td>Uncertainty and Worry</td>
<td>Regaining control, Coping mechanism, Puzzle</td>
</tr>
<tr>
<td></td>
<td>Self-Advocacy</td>
<td>Necessity, Advocate for MG community</td>
</tr>
<tr>
<td></td>
<td>Improve Quality of Life</td>
<td>Loss, Social connections, Effective treatments</td>
</tr>
<tr>
<td>Sources of Information</td>
<td>Physicians</td>
<td>Limited information, Healthcare relationships</td>
</tr>
<tr>
<td></td>
<td>Internet</td>
<td>Supplement, Accessibility, Applicability</td>
</tr>
<tr>
<td></td>
<td>Support Groups and Associations</td>
<td>Validation, Holistic model, Emotional support</td>
</tr>
<tr>
<td>Changes in Information Seeking</td>
<td>Onset to Diagnosis</td>
<td>Active searching, Broad search to structured</td>
</tr>
<tr>
<td>Over Time</td>
<td>Expanding Resources</td>
<td>Experiential knowledge, Community, Giving back</td>
</tr>
<tr>
<td></td>
<td>Disease Management</td>
<td>Problem solving, Management, Re-focusing</td>
</tr>
<tr>
<td>Satisfaction with Information</td>
<td>Formal Information</td>
<td>Applicability, Flowcharts, Seronegative</td>
</tr>
<tr>
<td></td>
<td>Experiential Knowledge</td>
<td>Learning by living, Peer support, Mental health</td>
</tr>
<tr>
<td></td>
<td>Becoming the Expert</td>
<td>Informed patient, Relationship dynamics</td>
</tr>
</tbody>
</table>
8.5 Summary of Findings

The research puzzle was kept at the forefront during the data interpretation and analysis, to understand how individuals living with MG learned about the disease while also navigating the healthcare system and the diagnosis. Although each participant displayed different variations of the disease, overarching concepts, and common threads surfaced. The participants shared many differences, but also many similarities in their journeys to uncover and understand MG-related information. The stories not only share similar experiences and situations but also similar emotional dimensions. As the resonant threads became evident, I then went back to the literature to determine how the information supported existing literature and extended it to fill the research gaps.

The participant stories explored not only identified how information was sought but also why the participants were seeking information. From a coping mechanism to a feeling of regaining control, each story led down the same path of easing worry or fear. A life-altering and incurable diagnosis provoked feelings of uncertainty and dismay, leading the participants to want to act and manage what was within their control. Many participants also spoke of self-advocacy; becoming a well-informed patient to take an active role in their care. Each participant learned to manage their disease outside the confines of healthcare relationships. The overarching concept that became clear was information seeking to improve the quality of life – by addressing loss, forming new social connections, and trialing alternate treatments to help manage the disease and symptoms.

Although the experiences of the participants in finding MG information aligned with the literature regarding other rare diseases, participants faced the additional challenge of the snowflake nature of the disease with high variability between individuals. They all agreed that
available information was too broad with little applicability to their situation and did not give a sense of how to live with and manage the disease, or what the future may look like. Lack of information resulted in feelings of isolation and loneliness, as each participant learned to navigate the disease on their own, through trial and error.

A consensus was also seen in the relevance or usefulness of information. The participants overwhelmingly expressed dissatisfaction with the lack of information provided by physicians, as well as their general unsatisfactory experiences in the physician-patient relationship. It was felt that physicians did not understand MG, and that lack of understanding often became an additional obstacle in obtaining a diagnosis and effective treatments. In this case, the participants became well-informed, seeking information from alternative sources, and felt they became more of an expert on the disease than the physicians treating them.

The most valued information unequivocally came from the MG Association. All but one participant sought out the MG Association early in the onset of the disease and spoke with passion and conviction about what the association was able to provide. Printed information that was easy to read and understand was mailed upon joining the association, and the participants received a level of emotional support and understanding they were unable to obtain elsewhere. The MG Association offered the opportunity to connect with others living with the disease, mentorship, dissemination of experiential knowledge from others, and a sense of community to ease loneliness and isolation. The information and social support from the association came to the participants holistically, addressing informational, psychosocial, and physical well-being.

It quickly became clear that each participant had a story to tell and a desire to share. The stories were filled with loss and disappointment, struggles and challenges, but also victories and gratitude. One participant voiced afterward the therapeutic effect experienced by telling the
stories and then reading the narrative account. With narrative inquiry, it gave the participants a chance to discuss their journey with another who they felt understood and could relate. It created a sense of connection, validation, understanding, emotional support, and lasting friendships. The participants were able to find meaning in their illnesses and experiences, and their experiences will continue to transcend the three-dimensional inquiry space as they move through time and engage in further social and healthcare relationships.
CHAPTER NINE: DISCUSSION

The discussion of the results of this study includes strengths and implications, limitations, and future direction. The study sought to explore the stories of adults living with MG as they navigated the process of obtaining knowledge and learning about the disease. Each participant’s story was as unique as the disease itself, offering varied insights, but also presenting resonant threads and overlapping similarities. As I reflected on each story, I relived the stories again, gaining a deeper understanding of the struggles and challenges each participant faced. Each of the four participants opened up private parts of their lives to me, offering a detailed view of how they faced adversity by seeking information and becoming active members in their care. The insights amassed from the analysis and interpretation are not only supported by the existing literature on rare diseases but also expand on that literature to address the lack of MG information.

9.1 Three-Dimensional Inquiry Space

As I considered the participant’s experiences through the lens of NI, the three-dimensional inquiry space became evident throughout their stories. Components of temporality, sociality, and spatiality can be found woven through the stories and my insights in the analysis and interpretation. I contemplated not only how each dimension presented in the participant stories, but also how each dimension interacted and influenced the inquiry space overall.

9.1.1 Temporality

The final narrative accounts each in turn depicted elements of the past, present, and future. Each participant recalled their story of the onset of disease and diagnosis, reflecting on the chronological events. Recapturing these memories allowed the participants to consider how they perceived the event or the information they held at the time, and what they now thought of
those circumstances. The participants spoke of looking back on symptoms and situations, and
that with increased knowledge and experience they could now piece together how it all made
sense despite a lack of understanding at the time. Reflecting on past experiences seemed to
become a form of closure on the past, a supporting validation of their experiences. The
participants also articulated how their early experiences living with MG and searching for
information affected their present disease status and what they could hope for in the future.
Temporality can be seen throughout the reasons for information seeking, mainly in the worry or
concern over the future and the hopes for an improved quality of life. Temporality also was
evident as I explored the changes in information seeking over time, including developing
personal experiential knowledge and becoming an expert on the disease. It was interesting to
witness how each participant would move back and forth between the past, present, and future.
They understood how past events influenced their present and perceived future, and how their
hope for the future impacts their present choices and decisions.

9.1.2 Sociality

As I assessed how the dimension of sociality arose throughout the participant stories, I
noticed how interpretations of an experience became clouded or influenced by the type of
relationship that surrounded it. Social structures and the demeanor of healthcare professionals
were highlighted as significantly important. In many stories, I could palpably feel the tensions
that complicated participant experiences within the healthcare system, and how those
experiences then influenced the narrative of that experience. The stories also highlighted how the
participants felt when engaging in self-advocacy, how it was received by physicians, and how
they ultimately felt more informed and current on MG research than their physicians. Tensions in
personal relationships also became evident, as the participants described the loneliness they felt,
the effects of an invisible illness, and the loss of careers, identities, roles, and activities once enjoyed. Some of the participants described how living with MG requires them to live in a separate world from those they love and care about.

In contrast, sociality also appeared as the participants described how connecting with others living with the disease significantly influenced feelings of validation and emotional support. The participants believed that only those living with MG could understand the disease and could relate to them, and that formal information from physicians and the medical establishment failed to comprehensively provide disease information. The mentorship, support, and information sharing provided by connecting with others through online groups and associations became vital in learning about the disease and establishing a new social support network. The information provided by the MG Association supplemented the minimal information provided by the medical establishment and published online literature.

9.1.3 Place

The participant stories occurred in numerous locations at different times. Common locations included hospitals, clinics, physician offices, and at home. The prominent site for information sourcing was in the online environment – webpages, research articles, support groups, and disease communities. The conversations between participants and myself mostly took place in the online environment due to the geographic distance, as well as health implications that limited mobility and travel. One participant was able to meet in person for the first interview but subsequently had to continue our conversations over the phone to accommodate physical limitations. The location and environment described by the participants set the stage for each story, gave it context and meaning, and integrated with temporality and sociality.
9.2 Research Significance

The participants in this study unanimously emphasized the lack of information available related to MG and the associated detriments. The type of information provided by physicians and found online lacked applicability and relatability, resulting in overall dissatisfaction. Even as the participants developed proficient knowledge of the disease and how to manage the symptoms and daily challenges on their own, it was reported that physicians continued to dismiss that acquired knowledge and maintain a hierarchical position in the relationship. The power dynamics that influence healthcare interactions became evident through the participants’ stories. For example, the uniform treatment of all patients living with MG despite the variability of the disease was highlighted in this current study. The stories and experiences expressed by these participants should serve as a catalyst for healthcare professionals to provide individualized care to patients as opposed to merely following prescribed treatment algorithms.

The only satisfactory information source identified was the MG Association, which provided a holistic model of information and support. But the results of this study extend much beyond the research puzzle, highlighting issues of significance including lack of emotional support or mental health resources, tensions in relationships, and the need for a community and sense of belonging after experiencing many losses. By giving these individuals with rare disease a voice and exploring their journey with MG, new insights were gleaned that can incur positive change. The weaving resonant threads that emerged from the narrative accounts add context and transparency to the hidden challenges of individuals living with MG.

The stories, personal experiences, and negotiated narrative accounts detailed in chapters four to seven provide a basis to increase awareness and uncover new knowledge. With a patient-centered care model in Canada, patients need to be heard and involved in their care to have
successful clinical outcomes. The first step is listening, next is taking action. The information revealed from this study remains futile unless it is implemented. The threads that weave throughout the stories unveiled the need to increase awareness of MG, increase access to information, incorporate mental health supports, and to remove obstacles for individuals to find new social connections within disease associations. As I lived and relived the participants experiences and stories alongside them, I could not only relate and empathetically understand, but I could also visualize where the healthcare system is failing those with MG and how we need to progress forward.

9.3 Research Strengths

I chose NI for this study as there was a gap in the research for qualitative studies related to rare diseases, and also to give a voice to individuals who feel misunderstood, isolated, and stigmatized. Each participant told their stories in detail and mixed with emotion, which extended much beyond basic questionnaires and quality of life scales. The participants voice comes alive off the page, drawing the reader into their experiences, tangibility expressing the struggles and transitions they experienced. Telling their stories became therapeutic for some participants, to engage with and explain to someone else living with the disease who could relate. One participant told me after her narrative account was complete that she shared it with her family, that they were in tears, and forever grateful for me to document her story. I believe the insights aggregated from this study, analyzing resonant threads across the stories, could not have transpired from an alternate research method. The power of the patient’s voice cannot be ignored.

Further, as I was able to explore the stories of the four participants, I was able to uncover information from a varied demographic mix. Two of the participants were former healthcare
professionals, which gave them an advantage by having background health knowledge when being diagnosed. Two other participants did not have a formal background in healthcare, giving a good basis to assess how these participants sought information and navigated the healthcare system in comparison. I was fortunate to include a male participant in the study, as MG often does not develop in males until older adulthood. Including participants from two western provinces helped to assess differences in healthcare systems and available resources, as well as created personal awareness of a provincial MG Association. Although each participant had their own unique background, experience, and disease variability, I was able to determine how overlapping elements gave rise to the key insights.

9.4 Limitations

Due to the rarity of MG and the limited accessibility to reach individuals living with the disease, I was unable to obtain a sufficient sample size with my initial inclusion and exclusion criteria. A revision to the geographic location of participants, as well as increasing the age range resulted in a total of four participants. The inability to recruit participants from the same province may pose a limitation in assessing how the key insights and recommendations can be applied to different provincial healthcare systems.

Although I was able to develop deep personal relationships with each of the participants, all but one interview took place in an online setting. Due to the geographic distribution of the participants, as well as energy and mobility limitations, in-person interviews were not feasible. Online conversations with the participants presented a variation to the typical NI methodology and may be viewed as a limitation. Despite the lack of face-to-face conversations, I was able to develop deep and sustaining relationships with each participant. We were able to form an instant bond due to the shared diagnosis and mutual understanding. I remain in contact with many of the
participants following the finalized narrative accounts, as we continue to offer each other encouragement and support.

9.5 Recommendations

Nurses are a significant entity of the healthcare system, operating within the pivotal roles of patient advocate and educator. Patients with MG should not be an exception to the standard of care provided and should have equal access to disease-related information. Nurses can support patients to become well-informed self-advocates, as well as promote health within illness. Increasing patient access to information and the ability to self-advocate all begins with knowledge and empowerment.

9.5.1 Nursing practice

The participant stories conveyed an absence of MG-related information provided by nurses. The Canadian Nurses Association outlines one of the roles of the nurse as a health educator. Educating patients regarding health conditions involves assessing current knowledge and understanding of an illness, identifying barriers or challenges to increasing the patient’s health literacy, and providing supports and resources to meet and enhance the patient’s healthcare goals (Canadian Nurses Association, 2024). Despite the critical role that nurses play as health educators, the role of nurses other than organizers for physicians were silent. The results of this study suggest that nurses employed in neurosciences should create informational resources to supply to newly diagnosed patients. The participants in this current study spoke highly of the information package sent to them by the MG Association. Nurses working in neuromuscular clinics could provide the same access to information, which could include reputable websites, contact information for support groups or associations, and key disease-related information. Supplying newly diagnosed individuals with credible information and
resources would help to eliminate sources of misinformation, as experienced by one of the participants in this current study.

The implementation of nurse liaisons for patients with chronic, complex, or rare illnesses would address patient feelings of isolation, confusion, and uncertainty (McNab et al., 2016). The current care model within the Alberta neuromuscular clinic utilizes nurses as physician’s assistants, communicating messages between the patient and physician. Transitioning the role of nurses employed in these clinics to that of a liaison between not only the patient and physician, but also between the patient and resources would have a significant impact. A nurse liaison could streamline care and supporting resources, including an assessment of mental health status and appropriate referrals (McNab et al., 2016). Persons living with MG, and others living with any rare disease, should be referred to a patient association to ensure holistic care involving information, emotional support, and a sense of community (Harrison et al., 2023). The peer support provided by disease associations has been shown by this current study to have a notable impact on coping and mental health. A nurse liaison or other healthcare professionals, such as physicians, nurse practitioners, or nurses working in neuromuscular clinics, can help connect patients to patient associations and disease communities.

Nurses working in any speciality can also learn about rare diseases alongside their patients and strive to empower the patient to become a strong self-advocate. Self-advocacy was highlighted by the participants as a necessary skill while living with MG, to get the appropriate referrals, care, and treatment. The participants clarified how increasing knowledge of the disease gave them more confidence to speak up to physicians and strive for a higher quality of life. Nurses can work with patients to uncover barriers preventing them from self-advocating and provide support for patients to become involved in their own care.
9.5.2 Physicians

The participant stories detailed numerous issues navigating the healthcare system and the challenges within healthcare relationships. As physicians were deemed as the most trusted and preferred source of health information from the literature review, and are also the most responsible healthcare provider, the lack of information provided to patients living with MG and the indifference or dismissal of concerning symptoms is unacceptable. Karademas et al. (2016) state that the quantity and quality of health-related information provided to patients has a significant impact on patient health perceptions, including a sense of control within a chronic illness, which directly influences patient health-related behaviours. Providing timely, comprehensive, and relevant information to patients regarding rare diseases is an essential component of the patient-physician relationship and associated healthcare outcomes.

Thomas et al. (2005) evaluated the contributing factors that affect the patient-physician relationship. Physician characteristics that had a negative impact on the healthcare relationship were a perceived lack of empathy, a disinterest or dismissal of concerns raised by the patient, displays of superiority or arrogance, and a perceived limited knowledge from the physician on the disease (Thomas et al., 2005). Factors that encouraged positive relationships were the provision of thorough explanations, admittance of a lack of knowledge coupled by seeking colleague opinions, displays of compassion and concern, and showing respect for the patient as an individual with personalized needs (Thomas et al., 2005). The stories told by participants of this current study all contained elements of the physician attributes that cause a negative impact on the healthcare relationship. Thomas et al. (2005) further explained that patients caught in a patriarchal healthcare relationship have a higher rate of mental health effects including anxiety and depression. Some patients who are dissatisfied with the care received by their physician will
take it upon themselves to learn about the disease and manage their own care plans, but find it to be a time and energy consuming process that does not alleviate their anxiety (Thomas et al., 2005). The study by Thomas et al. (2005) and the experiences described by the participants of this current study call for physicians to be aware of and strive to ameliorate the barriers to a therapeutic healthcare relationship. Improved patient-physician relationships would decrease negative mental health effects of patients, enhance health outcomes, and improve overall patient quality of life.

Two of the participants in this current study bravely stated how their treatment from physicians has profoundly affected their trust in the healthcare system and their likelihood of seeking medical care in the future. The experiences Thomas had with numerous general neurologists and emergency room physicians has resulted in a diagnosis of PTSD. The system Thomas sought help from during one of the most challenging periods of his life caused irreversible harm and lasting mental health effects. Katherine was told repeatedly that her symptoms were merely due to anxiety causing her to avoid seeking further medical care. She suffered alone at home for five days with a pulmonary embolism, refusing to present to the emergency room, with a deep fear of disbelief and dismissal from attending physicians. Unfortunately, this situation is not rare, and has exploded on social media platforms, termed ‘medical gaslighting’ (Barnes, 2023). Patients with invisible illnesses, such as chronic fatigue syndrome, Lyme disease, and long COVID described how their symptoms and concerns were attributed to anxiety or stress by physicians (Barnes, 2023). The dismissal and disbelief of patient experiences by physicians is harmful to patients, creating lasting psychological effects (Barnes, 2023). The stories and experiences of Thomas and Katherine call for change in the patient-
physician relationship. Particular attention is warranted in the treatment of patients experiencing undiagnosed but concerning symptoms, and diseases that lack a visible presentation.

9.5.3 Education and Professional Development

Nurses working in all sectors, including acute and chronic care, need to be vigilant in their own ongoing education regarding rare and emerging diseases. Medical research, knowledge, and associated healthcare evolves continuously, making it necessary for nurses to rise above stagnation, to engage and learn on an ongoing basis. This study revealed that patients highly trust and value information from healthcare professionals but feel the quantity and quality of the information is lacking. It was also revealed that patients living with MG appreciate and reform their opinion of their healthcare provider if that provider is willing to learn alongside them. Nurses from every field can fill this void. Nurses can provide care, emotional support, and information and links to community resources. Nurses can provide patient awareness of patient associations and encourage them to seek out these groups, as a holistic means of information and support. In the case of each participant, they found the MG Association on their own. Awareness of rare diseases can spread as nurses continue to engage in knowledge development, and subsequently share their findings and new knowledge with colleagues, either informally or in a structured method such as education sessions or in-service presentations.

Nursing education programs would benefit their students by including neuromuscular disease information in pathophysiology and chronic illness course content. Lack of awareness of MG surfaced as an obstacle to obtaining information by the participants in this current study. Exposing future healthcare professionals to neuromuscular diseases in their formal training would help the patients as well as the nurses to provide the most comprehensive care. Also, an
increased availability of neuroscience nursing would help to spread awareness of MG and prepare nurses for employment in the specialized field.

9.5.4 Future Research

Although the focus of this study was on knowledge acquisition of MG, other topics of importance were identified that warranted further examination. One finding was the tension experienced in relationships due to the illness – with friends, family, and healthcare providers. The tension or conflict in relationships affected not only the acquisition of knowledge, but also significantly affected the participants personal lives and ability to receive what they deem as the most appropriate care from the healthcare system (Robinson, 2016). At a time of high loss and perceptions of being misunderstood or dismissed by others, relationships seemed to break down causing further social isolation rather than relationships serving as a support and resource (Niedling & Hämel, 2023). Further exploration into the effect of personal and professional relationships on the ability of an individual to manage their illness and care would fill this gap.

A second topic of influence that dominated many of the participant stories was mental health. Despite the knowledge that individuals with chronic illness experience higher rates of clinical depression and that chronic illness leads to a multitude of loss (Fernandez, 2021), there remains a lack of research, acknowledgment by medical professionals, or support and resources for mental health. Each participant in this study discussed how the illness and associated experiences affected their mental health, yet they identified the complete absence of assessment or referrals to the appropriate mental health professionals to manage this dimension of the illness. Research into the mental health effects of MG, particularly due to the snowflake nature of the disease and ongoing feelings of confusion and uncertainty, would provide an avenue forward to support patients. Tereke et al. (2022) indicated that individuals living with chronic
disease experience mental health challenges to a significantly higher degree than the general population. An assessment of mental health status from healthcare professionals could connect patients with the appropriate resources leading to improved health outcomes overall (Tereke et al., 2022). Two of the participants sought psychological support independently, but the other two appeared restricted in their ability to engage in this resource.

This study revealed that one of the most challenging aspects of learning to live with MG is learning to manage fatigue and ration energy. Although there has been research into energy conservation for conditions such as fibromyalgia and myalgic encephalomyelitis/chronic fatigue syndrome, energy rationing or conservation has yet to be explored for MG. MG combines the unique features of not only fatigue, but also muscle fatigability. Participants described energy rationing as the most difficult part of the disease to understand and manage, but have come up with analogies to describe it, such as the charging and depletion of a battery. Research into the cumulative burden of fatigue and fatigability, as well as methods for individuals living with MG to learn to manage the fatigue and incorporate rest and recovery into their daily habits is warranted.

**9.6 Conclusion**

I set out in this study to understand how individuals living with MG learned about the disease through their stories and experiences. The outcomes of the study align with the generalized published research on rare diseases, filled a gap in knowledge regarding information-seeking for MG, and uncovered further areas of research and study. The participants allowed me to explore their stories of learning about MG alongside them, but also highlighted other areas of importance that necessitate further research.
As I began to wrap up the final pieces of the research puzzle for this study, I once again reflected on the participant experiences and stories. I reviewed not only the resonant threads, but also how each person is unique with their own path and journey. Once again, I felt gracious and appreciative to each participant for taking the time to share a part of their lives with me. As I considered my own experiences with MG and how those experiences reflected in the participant stories, I continued to feel the bond and connection I had established with each participant. A common perspective for individuals living with MG is that it can only be understood by another who has experienced the disease. The mutual feeling of understanding and relatability between myself as the research and participants strengthened each relationship and allowed me to live alongside them, to live and relive the experiences we have had, and the challenges endured. Exploring and understanding alternate perspectives brought definition and transparency to my own feelings and perceptions of MG.

Each of these participants demonstrated the need to have a voice, particularly within the healthcare system. The participants of this current study also had the desire to talk about what is important in their daily lives as they navigate the disease and plan for the future. I am honoured to have given each participant the opportunity to have a voice, to speak up, and to display their knowledge of MG and how it was acquired. I appreciate the opportunity to develop a relationship with each of the participants and witness their perseverance and incredible spirit, never giving up and always striving for more. The participants’ stories are not complete. As I exit the researcher-participant relationship with each participant, we will continue living our lives with MG and strive to learn more about MG in order to improve our lives. More stories are to come, and I hope I can continue to explore these future stories with the participants as we move forward in our enduring friendships.
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PARTICIPANTS NEEDED FOR RESEARCH IN *Myasthenia Gravis*

We are looking for volunteers to take part in a study of *experiences of individuals living with Myasthenia Gravis in seeking disease-related information.*

As a participant in this study, you would be asked to: participate in in-person or online interviews via Zoom.

Your participation would involve *four to six* sessions, each of which is approximately 60 minutes.

For this study participants will need to be between eighteen and sixty years old, living in British Columbia, Alberta, Saskatchewan, or Manitoba, and have a confirmed diagnosis of MG for at least one year.

For more information about this study, or to volunteer for this study, please contact:

*April Fox, RN, Graduate Student*
*College of Nursing, University of Saskatchewan*
*Email: apf002@usask.ca*

*Noelle Rohatinsky, RN, PhD, Associate Professor*
*College of Nursing, University of Saskatchewan*
*Email: noelle.rohatinsky@usask.ca*

This study has been approved by the University of Saskatchewan Behavioural Research Ethics Board.
**Participant Consent Form**

You are invited to participate in a research study entitled: *Health Information Needs of Patients Living with Myasthenia Gravis: A Narrative Inquiry*

**Student Researcher:** April Fox, RN, Master of Nursing, Graduate Student, College of Nursing, University of Saskatchewan  
Email: [apf002@usask.ca](mailto:apf002@usask.ca)

**Supervisor:** Noelle Rohatinsky, RN, PhD, Associate Professor, College of Nursing, University of Saskatchewan  
Email: [noelle.rohatinsky@usask.ca](mailto:noelle.rohatinsky@usask.ca)

**Purpose and Objective of the Research:**  
The purpose of this study is to explore the stories of adult Albertans living with myasthenia gravis (MG) related to their knowledge construction of the disease over time. The objective of this study is to:  
- To explore how and why people living with MG access health information related to the disease.

**Procedures:**  
- Enrollment of two to three participants for the study.  
- Participants will need to be between eighteen and sixty years old, living in British Columbia, Alberta, Saskatchewan, or Manitoba, and have a confirmed diagnosis of MG for at least one year.  
- Completion of a brief demographic form by participant via a OneDrive link.  
- Each participant will engage in four to six semi-structured interviews, each approximately 60 minutes in duration. Interviews will take place in-person or using the communication platform Zoom. Interview dates and times will be at your discretion. Information on the privacy policy for Zoom can be accessed at [https://explore.zoom.us/en/privacy/](https://explore.zoom.us/en/privacy/). Accommodation can be provided for participants who would rather complete the interviews via phone call. In-person interviews will occur at a location as per participant preference such as a public space (e.g., coffee shop), outside space (e.g., park), or in a private meeting space (e.g., booked meeting room at the library).
• Interviews will ask you questions about your information seeking for disease-related knowledge for MG. Questions will be open-ended and encourage you to tell stories about your experiences.
• Interviews will use audio and video settings within Zoom and be digitally recorded to enable transcription. You may ask to have the recording turned off and end the interview at any time without giving a reason. You can choose not to be video recorded by turning off your device’s camera.
• The recordings will be uploaded to a secure, encrypted folder for transcription with Transcript Heroes (https://transcriptheroes.ca/). The privacy policy for Transcript Heroes can be found at https://transcriptheroes.ca/privacy-policy/. A confidentiality agreement will be signed with the transcript service. The completed transcriptions will be accessed by the student researcher from the same encrypted, password-protected folder.
• Interview transcriptions will be documented in an interim research text and provided to participants to review. Participants will be encouraged to contact the researcher with any additional clarifications, questions, or concerns. At this time participants will also be given the opportunity to add, alter, or delete information as they see fit. If the researcher is not contacted within two weeks after providing the interim research text to the participant, the researcher will proceed to draft the final research report using all provided information from the interviews.
• Participants will be made aware of how they can obtain the final research report.
• Participants are encouraged to ask questions regarding the procedures and goals of the study, or their role in the study as a participant.

Funded by:
This study does not hold funding.

Potential Risks:
• Discussing personal experiences as related to illness can sometimes be emotionally upsetting. This risk will be addressed by: participants encouraged to answer only the interview questions that they are comfortable discussing or stop the interview at any time without giving a reason.
• Nonetheless, should you become emotionally upset during the interview and need professional assistance, please refer to an appropriate health professional in your local area or please call Crisis Services Canada at 1-833-456-4566 (toll free) or visit their website for more information at www.crisisservicescanada.ca, or connect on the Crisis Text Line by sending a text CONNECT to 741741.

Potential Benefits:
• The benefits of participating in this study include an opportunity to discuss challenges, a decreased feeling of isolation from the knowledge that others face similar challenges, and a sense of empowerment from the opportunity to share your stories and experiences.
Compensation:
- No compensation available for this study.

Confidentiality:
- Confidentiality of information will be a priority. Please note that although we will make every effort to safeguard your data, we cannot guarantee the privacy of your data, due to the technical vulnerabilities inherent to all online video conferencing platforms.
- Participants will agree to not make any unauthorized recordings of the content of the online interviews.
- For in-person interviews, confidentiality will be maintained by seeking a quiet space in public or outdoor spaces that allows a sufficient distance from others. If a participant chooses a public or outdoor space, maintaining confidentiality will be discussed at the start of the interview as part of the on-going consent.
- The student researcher confirms that she will conduct the videoconference in a private home office that will not be accessible by individuals outside of the research team during the data collection. It is recommended that the participants do likewise.
- The data collected will be disseminated in a final thesis project and publication.
- Participant identities will be kept confidential. Although direct quotations will be part of the final research document, you will be given a pseudonym, and all identifying information such as names, ages, geographic location, and names of your care providers will be removed from the report. Named facilities, healthcare practitioners, and landmarks will not be used. Participants will have the opportunity to review their stories and be able to remove any perceived identifying information.
- Consent forms will be stored separately from the data so that it will not be possible to associate a name with any given set of responses.
- A secure file will be established with each participant through OneDrive to securely transfer transcripts and narrative accounts.
- If participants choose to not be recorded during the interviews, the student researcher will take notes during the conversations to record the data.

Please put a check mark on the corresponding line(s) to grant or deny permission:

<table>
<thead>
<tr>
<th>I grant permission to be audio recorded</th>
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<tbody>
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<td>I grant permission to be video recorded</td>
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Please only select one option below:

| I wish for my identity to be confidential |  |
| I wish for my identity to be confidential but you may refer to me by a pseudonym |  |
| You may quote me and use my name |  |
Storage of Data:
- Zoom servers are located in Canada and no data will be transmitted through, or stored on, any servers outside Canada.
  - The University of Saskatchewan has an agreement with Zoom to ensure that all data transmitted using their software will only be routed through Canadian servers.
- Electronic data will be stored by the Principal Investigator on the Usask OneDrive account during data collection and analysis and shared with the student researcher.
- The digital recordings will be saved to a researcher-managed computer rather than to the videoconference platform’s internal cloud storage and will be encrypted.
- The electronic data will be stored for five years post publication.
- Once the data is no longer required and following the five-year storage period, the data will be destroyed beyond recovery.
- A master list connecting participants’ identities to their pseudonym will be kept allowing for the re-identification of data. The master list will be encrypted and stored on a password-protected computer, separately from the study data (i.e., transcripts). Only the principal investigator and student researcher will have access to the master list. The master list will be kept until after all transcripts have been verified for accuracy and participants are satisfied with their narrative account.
- All identifying information, (e.g., consent forms, demographic forms, master list) will be stored separately from the data collected. The master list, consent forms, and demographic information will be kept for five years after the last publication.

Right to Withdraw:
- Your participation is voluntary and you can answer only those questions that you are comfortable with.
- Your right to withdraw will apply until two weeks after the interview transcripts have been provided to you for your review. After this time, it is possible that analysis of our conversations will have impacted the analysis of other participants’ data and it will not be possible to withdraw your data.
- Should you wish to withdraw, the data will be deleted from the research project and destroyed.

Follow up:
- To obtain results from the study, please contact the researcher using the information at the top of page 1. Results will be available in Fall 2024.

Questions or Concerns:
- Contact the researcher(s) using the information at the top of page 1.
This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office: ethics.office@usask.ca; 306-966-2975; out of town participants may call toll free 1-888-966-2975.

Oral Consent:
- Oral consent will be obtained from the participant prior to starting each interview, with a reminder that the participant can end the interview at any time.
- Given the remote data collection, oral consent will be obtained for continued consent instead of signatures.

I read and explained this consent form to the participant before receiving the participant’s consent, and the participant had knowledge of its contents and appeared to understand it.

__________________________________________  ________________________________  _____________
Name of Participant                             Researcher’s Signature           Date
Demographic Survey

Personal Information

Year of birth: ____________________________________________

Gender: __________________________________________________

Marital Status: __________________________________________

City of residence, province: __________________________________

Members of household: ______________________________________

Education and Employment

Highest level of education completed (High school/Bachelor’s degree/Graduate degree):

___________________________________________________________

Occupation: _______________________________________________

Employment status (Full time/Part time/Casual/Retired):

___________________________________________________________

Myasthenia Gravis

Year of diagnosis:

Who primarily manages your care for MG (Family doctor/Neuromuscular specialist/General neurologist):

___________________________________________________________

City of this doctor: _________________________________________

Other diagnosis/medical conditions: _______________________________
APPENDIX D: CONVERSATION GUIDE

Conversation Guide

Can you tell me your story about your MG diagnosis?

What symptoms were you experiencing prior to diagnosis and what did you think of them?

When you were first diagnosed, tell me about the type of information you were provided by your doctor.

Prompt: Can you describe how you felt about the information you were provided at diagnosis? Can you describe your overall satisfaction with the amount and type of information you were provided?

Soon after you were diagnosed, tell me about the steps you went through to find out more about MG.

Prompt: Can you describe the topics related to MG that you searched and the sources of information you used? Can you describe if and how you found the information you found useful?

Describe any journals, calendars, or any other artifacts that you may have to document your journey with MG.

Prompt: How has this item helped you to remember details of your MG journey or information seeking related to the disease?

Can you tell me how your information seeking behaviours have changed now that you have lived with MG for a few years?

Prompt: Can you describe if and how the frequency of information seeking, the sources or the type of information you are looking for has changed?

Can you tell me how and if you have sought MG related information from others living with the disease?

Prompt: Can you describe the steps you took to join support group or patient associations for MG? How have you found connecting with others with MG helpful or not helpful?

Can you describe what source of information you prefer to use for MG and why?

Prompt: Can you tell me how you feel about the reliability of the information you find or how easy it is to understand? Can you describe how you feel the information relates to your personal journey with MG?

How do you feel about the quality of the information you find online?

Prompt: How do you determine what information is accurate? How do you determine accurate information versus misinformation?
Do you have a story about any barriers to information seeking about MG you have experienced? Prompt: Can you tell me about a time in which you found it was easier or harder to obtain the information you were looking for?

How would you describe your overall satisfaction with the information you have found online about MG? Prompt: Can you describe how the information you found on MG has changed the ways in which you manage the disease or your interactions with healthcare practitioners?

Is there anything else you would like to discuss related to your information seeking experiences for MG?