Filling the Gap in Post Surgical Epilepsy Care: A Qualitative Needs Assessment Study of Post-Surgical Epilepsy Patients

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science
Institute of Medical Science
University of Toronto

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ABSTRACT

Epilepsy, a chronic neurological disorder, affects over 50 million individuals worldwide. Thirty percent of these have seizures that are not amenable to medications, and of these, at least one-half may be candidates for surgical treatment. While epilepsy surgery maybe an option with high rates of seizure freedom, this does not necessarily guarantee a good psychosocial outcome. Despite well documented issues of post-operative adjustment difficulties, little information exists regarding post-surgical epilepsy patients and what they believe would have benefited them post-surgically, if they had received it pre-surgically. Therefore, the purpose of this study was to explore possible knowledge gaps around the surgical event. This qualitative needs assessment study involved interviewing post-surgical epilepsy patients. The results suggest pre-surgical information and support gaps exist and require change. Furthermore, in conjunction with our recently proposed predictive coding model of post-epilepsy surgery adaptation, our results provide the groundwork for developing a pre-operative intervention to address patient predictions and expectations.
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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AED</td>
<td>Anti-epileptic drugs</td>
</tr>
<tr>
<td>CABG</td>
<td>Coronary artery bypass graft</td>
</tr>
<tr>
<td>CBS</td>
<td>Cardiac bypass surgery</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive behavioral therapy</td>
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<tr>
<td>CNS</td>
<td>Central nervous system</td>
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<tr>
<td>EMU</td>
<td>Epilepsy monitoring unit</td>
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<tr>
<td>ESI-55</td>
<td>Epilepsy surgery inventory</td>
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<tr>
<td>IBE</td>
<td>International bureau for epilepsy</td>
</tr>
<tr>
<td>ICU</td>
<td>Intensive care unit</td>
</tr>
<tr>
<td>iEEG</td>
<td>Intracranial electroencephalography</td>
</tr>
<tr>
<td>ILAE</td>
<td>International league against epilepsy</td>
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<tr>
<td>MEG</td>
<td>Magnetoencephalography</td>
</tr>
<tr>
<td>PE</td>
<td>Prediction error</td>
</tr>
<tr>
<td>PET</td>
<td>Positron emission tomography</td>
</tr>
<tr>
<td>PPEC</td>
<td>Positive prediction error by commission</td>
</tr>
<tr>
<td>PPEO</td>
<td>Positive prediction error by omission</td>
</tr>
<tr>
<td>QOL</td>
<td>Quality of life</td>
</tr>
<tr>
<td>QOLIE-89</td>
<td>Quality of life in epilepsy inventory</td>
</tr>
<tr>
<td>TLS</td>
<td>Temporal lobe surgery</td>
</tr>
<tr>
<td>TWH</td>
<td>Toronto Western hospital</td>
</tr>
<tr>
<td>VNS</td>
<td>Vagus nerve stimulation</td>
</tr>
<tr>
<td>WHO</td>
<td>World health organization</td>
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<tr>
<td>WPSI</td>
<td>Work productivity short inventory</td>
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1. INTRODUCTION

Epilepsy is a chronic neurological disorder that affects over 50 million individuals worldwide. Medical management for epilepsy involves the prescription of one or several anti-epileptic drugs (AED’s). Surgical intervention maybe indicated when medical management fails (Epilepsy Implementation Task Force 2015; Ontario Health Technology Advisory Committee 2012). Despite initial efforts to medically control seizures, approximately a third of individuals with epilepsy develop AED resistance and eventually require assessment for surgical candidacy (Scott Perry & Duchowny 2013) or other forms of therapeutic intervention. The purpose of epilepsy surgery is to alleviate seizures all together, and successful surgical therapy has been largely quantified by measuring the number of post-operative seizures (Rapport et al. 1977; Penfield & Flanigin 1950). Although an individual’s quality of life (QOL) is a multifaceted entity, the ultimate goal of any medical intervention, including epilepsy surgery, is that individuals can undertake their “activities of daily living”, and derive the satisfaction of accomplishment which “is the ultimate outcome of life…” (Pharmaceutical Benefits Advisory Committee 1995). Although intuitively it would seem that by ameliorating seizures, the key problem would be solved for an individual with epilepsy; however years of living with a chronic illness have profound biological, psychological, and social ramifications (Tanriverdi et al. 2008), which we believe impedes an individual from realizing fully the benefits of improved seizure control that may occur as a result of their epilepsy surgery. Thus, measuring surgical efficacy requires looking past the seizure outcomes and towards a more holistic approach to managing an individual’s expectations and preparing for life changes as they proceed through the process of epilepsy surgery. Although we know seizure freedom is a good surgical outcome, we believe
post-operative outcomes can be further improved upon. This study lays out the beginning of developing a strategy towards improving outcomes for those undergoing epilepsy surgery.

2. BACKGROUND AND LITERATURE REVIEW

2.1 What is epilepsy?

Epilepsy is defined as any one of the following; a) the existence of at least two unprovoked seizures occurring > 24 h apart, b) at least one unprovoked seizure where there is high-risk for another or c.) diagnosis of an epilepsy syndrome (Fisher et al. 2014). Furthermore, epileptic seizures are a transient occurrence of signs/symptoms resulting from an abnormal excess or synchronous neuronal activity in the brain (Fisher et al. 2014). According to the world health organization, epilepsy is the most common serious neurological condition and affects 1% of the world's population (Organization n.d.). It is a universal problem, with no geographical, racial or social class boundaries. It is found to impact both sexes, and occur at all ages but most prominently in childhood, adolescence and increasingly in the ageing population (Prilipko et al. 2005). The often dramatic and alarming periodic clinical features of seizures can elicit fear and misunderstandings and has led to much stigma and profound social consequences for those with epilepsy and their loved ones.

The aetiology of epilepsy is numerous including genetic factors, head trauma, brain tumors, birth complications and brain infections (De Boer 2002). Furthermore, with time, a range of different epilepsy syndromes and seizure types have been identified, however accurate diagnosis still remains a major problem, especially in developing countries (Prilipko et al. 2005). In fact, even with the appropriate diagnosis, many may remain untreated or undertreated, for a number of reasons (Meyer et al. 2010).
Treatment and management of seizures often begin with pharmacotherapy, with 70% achieving long-term remission and full seizure control, enabling them to live normal lives. The other 30% are known to have medically refractory epilepsy; patients who continue to have seizures despite “optimal” AED therapy (Prilipko et al. 2005). This population may be assessed for non-pharmacological treatment options including vagus nerve stimulation (VNS), ketogenic diet or epilepsy surgery (Schuele & Lüders 2008).

2.2 Epilepsy Surgery and Surgical Outcomes

For individuals with medically refractory epilepsy, surgery is a significantly beneficial option and aims to remove the seizure-generating region of the brain (epileptogenic zone) in order to eliminate seizures (A. Mansouri et al. 2012; Valiante 2009). The process of surgical candidacy proceeds as follows. Once a patient is deemed to be medically refractory (i.e., continued seizures persist following trying two, first-line medications) (Kwan et al. 2010), they are referred for consideration of epilepsy surgery. To determine surgical candidacy, patients undergo a number of tests, including structural magnetic resonance imaging (MRI), neuropsychological testing and admission to an epilepsy monitoring unit (EMU) (Force 2014; A. Mansouri et al. 2012; Ontario Health Technology Advisory Committee 2012). Other tests may be required following these non-invasive tests, including invasive electroencephalography (iEEG), magnetoencephalography (MEG), and positron emission tomography (PET) (Knowlton 2006). Candidacy for epilepsy surgery requires concordance of information from all sources, such they point to a specific brain region that is safe to remove. As can be appreciated, this is a resource and time intensive process. Once a patient is deemed to be a surgical candidate, they undergo surgery to remove the epileptogenic zone -- the area of the brain that is necessary and sufficient to remove to render a person seizure free (Rosenow & Lüders 2001).
The decision to undergo surgery can be difficult and stressful for epilepsy patients and their families. Furthermore, the large investment towards positive patient outcomes via surgery, is evident. In addition to undergoing a life-changing experience, the pre-surgical evaluation, surgery itself, and the postoperative management involves a high initial expenditure compared to medically-treated therapy (Mikati et al. 2006; Wheelock et al. 1998). However, the Ontario Health Technology Advisory Committee has done extensive research and concluded that epilepsy surgery in Ontario is less costly and provides greater clinical benefits in the long term relative to medically-managed patients (Bowen et al. 2012). Hence, the long-term, high economic feasibility of epilepsy surgery bears emphasis.

Surgical success is measured as an abolition of seizures, achieved almost 80% of the time (Ontario Health Technology Advisory Committee 2012), or a significant reduction in their frequency, and is usually quantified by how many seizures they have according to the Engel classification (Wieser et al. 2001). Despite the benefits of a post-surgical state and long-term cost saving attributes of epilepsy surgery, we believe we lack the necessary tools and intervention for optimizing surgical outcomes. We do not know for certain if epilepsy patients are realizing the full benefits of surgery. This is because it has become increasingly apparent that psychosocial consequences of chronic illness are not automatically removed for patients who have undergone surgery despite seizure freedom (Aydemir et al. 2004). Learned patterns and previously established values, social and family relationships are aspects of life that require attention when considering the overall success of surgery.

In one study, psychological/psychiatric problems, including emotional distress and depression, were indicators of a difficult postoperative adjustment process (Derry & Wiebe 2000). Such studies (Wilson et al. 2001; Wilson et al. 2007; Tanriverdi et al. 2008; Derry &
Wiebe 2000; Wilson et al. 2005; Langfitt et al. 2007; Bladin 1992; Wheelock et al. 1998) conclude that a formal assessment and evaluation of patients’ expectations, aspirations and concerns need to be addressed before surgery in order to reap the full long-term benefits of surgery. In summary, following surgery, psychosocial outcomes are not necessarily contingent on seizure-freedom. Characteristics of the burden of normality and forced normalization, are two phenomenon that are manifestations of post-operative psychosocial distress (Mehmood et al. 2017) that likely underlie failure to maximize on the benefits of surgery.

2.3 Consequences of Epilepsy Surgery

2.3.1 Burden of Normality and Psychosocial Factors

Recent studies have been able to elucidate some potential difficulties that arise for patients in their post-surgical state. One study illustrated that perceived success of surgery goes beyond a seizure-free state, and termed it the burden of normality (Wilson et al. 2001). This model encompasses a collection of psychological, affective, behavioral and sociological features that arise from patient’s adjustment to seizure-free life and having to discard roles associated with epilepsy (Wilson et al. 2007). Interestingly, this adjustment is acutely similar to a long-standing phenomenon of “biographical disruption”, which manifests in individuals initially diagnosed with a chronic illness (Bury 1982); however the burden of normality is the reverse of biological disruption as illness and/or associated symptoms are diminished. This lends to the idea that a significant disruption, such as the introduction or attenuation/cessation of a chronic illness, can have profound effects on an individual's identity and environment with consequent changes.

It has been established that even after complete suppression of seizures following surgery, patients may have difficulties becoming accustomed to a seizure-free life and suffer
social and psychiatric problems, such as stigma, depression and anxiety (Aydemir et al. 2004). Similarly, another study reported that seizure freedom after surgery did not guarantee a good QOL outcome, and patients described a range of psychosocial problems that arose as a direct result of being rendered seizure free (Tanriverdi et al. 2008). Having unrealistic expectations of surgery was one of the primary factors that led to patients having difficulties adjusting to life after surgery, as well as learning to discard roles associated with chronic illness as new intra and interpersonal demands were instigated following seizure freedom (Wilson et al. 2004).

In addition, we know that unusual life events, such as surgery, can create changes in an individual’s evaluation of their current life and their expectations of the future (Wilson et al. 2001). While seizure freedom is the desired outcome following surgery, postoperative cognitive problems, psychological and somatic co-morbidities may manifest unexpectedly (Blumer et al. 1998; Helmstaedter & Kockelmann 2006; Chang et al. 2012). Higher occurrence of co-morbidities have also been associated with epilepsy surgery compared to surgical treatment for other chronic diseases (Chang et al. 2012). A lack of preparedness and skills to handle the new challenges have a high possibility of leaving both patients and family vulnerable to significant postoperative psychosocial distress and difficulties adjusting to life after surgery (Wilson et al. 2004). Other studies have described the same patterns and problems for patients following surgery, despite successful seizure control; patients expressed dissatisfaction due to unrealized or unrealistic expectations held prior to surgery (Bladin 1992; Derry & Wiebe 2000; Wilson et al. 2001; Wilson et al. 1999). These results suggest that in large part, the relative success of surgical outcome is malleable and is based on preoperative expectations.

Similarly, several other studies have highlighted that if preoperative expectations are not realized, the level of psychological distress is likely to increase given the increased expectations
that come along with being seizure free or having reduced seizures (Wilson et al. 2005; Wilson et al. 2004; Wilson et al. 2001; Wilson et al. 2001; Tanriverdi et al. 2008). These findings suggest that we do not fully understand the process around peoples’ pre-surgical expectations and hopes and any attempt at using a pre-surgical intervention to address such issues, will first require investigating patient identified needs around the existing clinical practice. Furthermore, changes in family dynamics, new vocational aspirations, and behavioral changes are common factors among seizure free patients (Wilson et al. 2001), and require attention prior to surgery in order to efficiently improve the QOL for these individuals.

There have been several attempts to determine the best way to approach this problem including longitudinal follow up visits for surgical patients, to assess the evolution and long-term effects of treatment outcomes. The findings showed that patients with otherwise negative features towards post-surgical life, but early family support had a more positive attitude towards adjusting to their new lifestyle (Wilson et al. 2005). These results suggest the need for some form of family involvement and possibly a supportive network beginning in the earliest stages of the surgical process.

While the burden of normality is seen to manifest in seizure-free, post-operative patients, others who experience reduced seizure frequency may face a different set of complications due to unrealistic expectations held prior to surgery (Bladin 1992; Derry & Wiebe 2000).

2.3.2 Forced Normalization

Similarly, the concept of forced normalization pertains to the manifestation of alternative expressions of central nervous system (CNS) dysfunction, predominantly seen as behavioral disorders once seizure control has been established (Krishnamoorthy & Trimble 1999). In other words, behavioral changes and psychosis symptoms including but not limited to depression,
mood changes and agitation are observed in patients as a direct result of improved seizure
control or complete seizure cessation (Krishnamoorthy et al. 2002; Shahani 2012). While this is
a relatively uncommon phenomenon with a prevalence of ~1% of patients with intractable
epilepsy, a number of proposed mechanisms have been elucidated including neuropathology,
genetic predisposition, developmental disturbance etc…. (Mula 2010). Nonetheless, forced
normalization with little consensus on a well-defined mechanism of action, continues to be a
field of ongoing research.

It is not until recently that we published a contemporary view of forced normalization
that centers around the principle of predictive coding particularly emphasizing its manifestation
following epilepsy surgery, explaining the possible mechanism with which this occurs and
further expanding the scope to also explain other behavioral disorders such as the manifestation
of the burden of normality (Mehmood et al. 2017). It should be noted that this is a plausible
mechanism that may contribute to the occurrence of forced normalization and does not undermine
alternative proposed mechanisms or suggest its sole role in the phenomenon.

### 2.4 How other chronic conditions have dealt with adjustment issues following surgery:

It is evident that other chronic conditions following surgery also have their related
adjustment difficulties (Juergens et al. 2010). In fact, research into associated post-surgical
difficulties have prompted these disciplines to create standardized care to address such problems
(Kehlet et al. 2002; Eagle et al. 1999; Lier et al. 2012). Disciplines, such as cardiac bypass
surgery (CBS), have a formalized pre-operative intervention guideline with studies confirming
improved postoperative outcomes (Arthur H M, Daniels C, McKelvie R 2000; Anderson 1987;
Babaee 2007; Mumford et al. 1982). Intervention prior to undergoing CBS are designed to
address patient-specific problems experienced after surgery (Dao et al. 2011; Laferton et al.
A multidimensional preoperative intervention approach was conducted in a study that focused on physical exercise, education and reinforcement, and monthly nurse-initiated telephone calls. The intervention group showed improved QOL 6 months post-surgery and reduced time in the intensive care unit (ICU) compared to the control group. Furthermore, the intervention efficiently used available resources, making it cost efficient and helped patients’ exploit the maximum benefits of CBS (Arthur H M, Daniels C, McKelvie R 2000). Another recent study explored the efficacy of heart surgery by optimizing the preoperative expectations of patients undergoing coronary artery bypass graft surgery (CABG) (Rief et al. 2017). These results illustrate that with an appropriate intervention to guide and address patient-specific difficulties, we can further improve upon the utility of surgery, adjustments needed to achieve realistic goals and an improved QOL is promising for patients in their post-operative state. *Hence, the potential for epilepsy patients to benefit from such a pre-surgical intervention is evident in such processes successfully embedded in other disciplines like cardiac surgery.*

2.5 Why is what we are proposing different from other research:

The existence of poor post-operative outcomes, associated challenges and the subsequent influence on perceived surgical success with epilepsy surgery has prompted the investigation of possible solutions. There have been numerous studies dedicated to understanding post-surgical outcomes by measuring the QOL of surgical patients’ (Baker 2001; Cramer et al. 1999; Gilliam et al. 1997; Meador 1993; Mikati et al. 2006). As such, many factors have been elucidated in an attempt to understand the intricacy of post-surgical life adjustment (Bladin 1992; Bower et al. 2009; Gilliam et al. 1997; Reid et al. 2004; Sperling et al. 1996; Seiam et al. 2011; Taylor et al. 2001; Wheelock et al. 1998). Some of these include determining perceived postoperative patients' QOL, pre-surgical patients' expectations, and factors perceived as significant for
successful surgery outcome. Furthermore, in-depth interviews and standard QOL questionnaires include the epilepsy surgery inventory-55 (ESI-55), quality of life in epilepsy inventory-89 (QOLIE-89), and the work productivity short inventory (WPSI) of pre- and postoperative patients. These measures have allowed researchers to determine individuals' resultant life changes after surgery and their impact (Dupont et al. 2006; Vickrey et al. 1992). These standard QOL guidelines can help assess a patient’s view of their QOL and any improvements that may come out of surgery.

Alternatively, several epilepsy trial studies have demonstrated successful postoperative rehabilitation processes that address surgical complications involving memory decline, psychiatric morbidities and cognitive impairment (Blumer et al. 1998; Koorenhof et al. 2012; Mazur-Mosiewicz et al. 2015). Additionally, having established that many post-surgical epilepsy patients have trouble adjusting to postoperative life despite seizure relief (Aydemir et al. 2004; Tannriverdi et al. 2008; Taylor et al. 2001; Wilson et al. 2001; Wilson et al. 2004), a recent study concerning a postoperative temporal lobe surgery (TLS) rehabilitation trial, focused on improving employment outcomes after surgery (Thorbecke et al. 2014). While postoperative care involves tending to patient-specific, surgery dependent complications, there has been limited or no research in exploring the use of standardized interventions administered prior to epilepsy surgery to optimize post-operative QOL.

Given the preceding evidence, it may be possible to mitigate unrealistic expectations through the provision of targeted information and support in the pre-surgical period. However, resources aligned with patient expectations and desires would first need to be identified. This could allow patients to formulate realistic expectations in all spheres of their existence, provided they are given patient identified education and guidance around epilepsy surgery. Discussions
may also facilitate goal setting, thus in addition to expectation management, provide a roadmap for recovery and reintegration into society (Smith & Kirkpatrick 2015; Simon & Berg 1982).

Therefore, our first step towards developing an intervention is to work with post-surgical patients to conduct a qualitative needs assessment managed through the Epilepsy Program at the Toronto Western Hospital. We hope to use the results from this needs assessment as a prerequisite for future work in designing and developing a novel pre-surgical intervention (program) addressing patient’s concerns, aspirations and perspectives of surgery.

2.6 A ‘model’ to explain poor post-operative outcomes:

To guide the conceptual framework for our work we take from an emerging concept that the brain is not solely a reactive ‘machine’ but a predictive one. We understand the brain to be the device that makes predictions of the external environment and reacts with corresponding actions (Larkum 2013; Bastos et al. 2012). That being said, we have proposed that poor postoperative outcomes of epilepsy surgery, manifesting as the burden of normality and forced normalization, can be explained using the concept of predictive coding (a Mansouri et al. 2012).

Predictive coding begins when sensory inputs from anatomical structures, like the eyes, nose, and ears, are able to collect real data about the outside world and relay unprocessed raw information to the brain (Softky 1996). As one goes through life, certain expectations of the way things should be, are created; these are predictions that are built from past experiences. Broadly speaking, the frontal lobes allow individuals to formulate predictions of what they believe to be true about their external environment. These predictions are relayed back to sensory regions to compare to current data streaming into the brain. The difference in the two is the information that is sent back as the prediction error (PE) to the frontal lobes to be further evaluated by the brain (Bubic et al. 2010). A PE of zero signifies that an individual's expectations match reality.
A nonzero PE suggests that an individual's predictions, or expectations, do not comport with their current representation of reality. When predictions do not comport with the individuals’ perceptions of reality, a number of physiological processes are spawned that lead to emotional distress, depression, conflicts, etc. (Krishnamoorthy et al. 2002; Shahani 2012). Hence, we believe predictive coding is a plausible mechanism to explain the associated poor postoperative outcomes following epilepsy surgery, and we believe it is in association with this mechanism that we can realize change for post operative patients (Mehmood et al. 2017). Following this view, the qualitative needs assessment will be directed to determine patients’ preoperative predictions/expectations and perceived postoperative realities, gaining insights into the types of information that are necessary to deliver, to minimize the PE.

Additionally, we have recently suggested that forced normalization and/or the burden of normality occurs when 1) epilepsy patients form either unrealistic expectations of post-surgical life (positive prediction error by commission-PPEC); and/or 2) they have not contemplated what post-surgical life might entail and the potential problems/opportunities that might arise (positive prediction error by omission- PPEO) (S. Mehmood et al. 2017). Either or both of these criteria can lead to unanticipated outcomes, thus a large prediction error. Furthermore, it is not the uncertainties themselves that result in forced normalization and/or the burden of normality; rather, the inability to cope and manage these uncertainties influence psychological wellbeing of an individual, with their ability to cope being inversely proportional to the magnitude of the prediction error (Mehmood et al. 2017). Hence, emphasizing the need to also determine the presence and extent of coping strategies that post-operative patients’ have.
2.7 Why a qualitative needs assessment will help determine patient predictions

When expectations of the post-surgical state are not congruent with reality, certain individuals are unable to cope with the outcomes: This is reflected in a decreased QOL (Derry & Wiebe 2000; Seiam et al. 2011; Wheelock et al. 1998). This outcome results in the manifestation of forced normalization or other maladjustments following surgery. Therefore, guided by this concept, we hope to conduct a qualitative needs assessment on epilepsy post-surgical patients to capture the major expectation and informational themes, allowing us to understand what post-surgical life predictions, or lack thereof, that pre-surgical candidates have. Additionally, understanding patients’ post-operative realities will provide further insights into determining what types of information can be provided to minimize the occurrence of unrealized or unrealistic expectations and therefore diminish PPEC and/or PPEO.

2.8 Relevance of A Needs Assessment to Clinical Practice

Global Significance

It is only two decades ago that the World Health Organization (WHO), International League Against Epilepsy (ILAE), and International Bureau for Epilepsy (IBE) led the global campaign against epilepsy: “Out of the shadows” (De Boer 2002). The joint project entailed improving acceptability, treatment, services and prevention of epilepsy worldwide. Furthermore, their campaign strategy involved supporting health institutes in identifying needs and promoting education, training, treatment, services, research and prevention in their respective countries (De Boer 2002). With the advents of newer diagnostic tools, improved surgical techniques, and higher probabilities of seizure alleviation, the desire to improve upon and provide greater accessibility and availability of epilepsy surgery also continues to rise (Prilipko et al. 2005). Therefore, following suit, conducting a patient qualitative needs assessment around the surgical
episode will further help to identify any existing knowledge gaps and provide the first step towards developing an intervention aimed at improving upon the benefits achievable through this resource intensive procedure.

Local Significance

Likewise, the management of those with epilepsy has been standardized throughout the province of Ontario. This has led to increased resources to perform epilepsy surgery (Ontario Health Technology Advisory Committee 2012; Health Quality Ontario 2012) and is part of the Provincial Epilepsy Strategy, which was borne out of the realization that individuals with epilepsy are extremely underserviced. In Ontario, less than 2% of eligible patients actually undergo surgery due to infrequent referrals for epilepsy surgery, limited availability and organization of resources, unequal geographical distribution of epilepsy centers, etc. (Ontario Health Technology Advisory Committee 2007). Although Ontario’s efforts in improving the access and availability of epilepsy surgery are incredibly positive steps, we feel obligated to maximize the province's investments, with an estimated $18 million that is spent annually towards improving epilepsy care (Bowen et al. 2012). Hence, conducting a qualitative needs assessment is the crucial first step in determining the necessary information and structure needed to address an important yet often overlooked aspect of epilepsy surgery, which is creating counseling “processes” around the surgical episode of care that maximizes on the societal and personal benefits of being seizure free.

Since 4/5th of the cost of managing those with epilepsy are indirect costs, and epilepsy surgery is itself cost saving (Bowen et al. 2012; Silfvenius 1999), we believe there are many benefits to be had both for the individual and society by looking beyond seizure freedom, and optimizing a person’s response to surgery in all spheres of existence: biological, social, and
psychological. Optimizing post-surgical psychosocial adjustment through a pre-surgical intervention may have economic benefits: The loss of work productivity by the provincial epilepsy population is estimated at 139 million dollars annually, not including high medical care expenditures (Bowen et al. 2012; Ontario Health Technology Advisory Committee 2012). Optimized post-surgical adjustment may further bolster cost-savings that come with being seizure-free (Sperling et al. 1995; Wilson et al. 1998), as improved QOL can potentially decrease both direct and indirect health care costs (Bowen et al. 2012). Therefore, this qualitative needs assessment study aims to lay the fundamental groundwork that will open opportunities to realize these potentialities.

2.9 The Big Picture

This study’s qualitative needs assessment will explore issues/themes/aspects of life post-surgical epilepsy patients feel they would have liked to discuss that would have facilitated their QOL post-surgery. The subsequent extraction of major themes will be derived from patient feedback. Prospectively, the next step beyond this study will potentially involve using these major themes to construct and evaluate the efficacy of a guideline for a pre-surgical intervention. This intervention will be tailored to the circumstances and needs of each patient as informed by this needs assessment around those who have already undergone and experienced the surgical process. The eventual long term goal would be to take a knowledge translation approach, defined as, “the exchange, synthesis, and ethically-sound application of knowledge—within a complex set of interactions among researchers and users—to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system” (Canadian Institute of Health Research 2009). This would involve standardizing a pre-surgical intervention for all surgical candidates and
working towards the transfer of this intervention to other adult and pediatric epilepsy programs worldwide, ultimately aiming to change clinical practice.

### 2.10 Study Summary

Based on published QOL studies and the lack of information and establishment of a clear-cut pre-surgical counselling program, globally for epilepsy patients, we believe that this needs assessment will provide us with new insights. This data will allow us to understand the needs of patients when initiating a pre-surgical counselling and intervention program for patients considering epilepsy surgery. Numerous benefits can be elicited from collecting this information to formulate a pre-surgical assessment intervention. By illuminating the full potential surgery can have on patients with intractable epilepsy, we hope to improve patient QOL and consequently increase societal gains through work productivity gains and decreased health care costs (Langfitt 1997; Silfvenius 1999; Bowen et al. 2012; Ontario Health Technology Advisory Committee 2012).

### 2.11 Study Rationale

#### 2.11.1 Why a qualitative study, why not primarily a quantitative focused approach?

To capture themes that relate to epilepsy patients, specifically those eligible for surgery, we believe the subjective experiences of post-operative epilepsy patients is imperative towards building a solid foundation of themes to create a counseling/intervention program. In addition, our study’s aims seek to answer the questions about ‘what’, ‘how’ and ‘why’ around epilepsy surgery and post-surgical life and gain a more in-depth understanding of this phenomenon rather than measuring the ‘how many’ or ‘how much’ of something (Green & Thorogood 2009). Therefore, a qualitative research design was chosen to address the threefold research objectives
stated below. Furthermore, while taking a quantitative approach by means of surveys and questionnaires would certainly provide a certain depth of understanding around patients’ experiences and choices (i.e., QOL), the opportunity to understand these choices and probe further into specific areas would be lost in the formatting and structure of a quantitative approach. Hence, in qualitative research, the use of an inductive approach to make sense of complex processes, offers the researcher a chance at an attempt to understand the meaning and nature of experience of individuals with problems such as chronic illness (Corbin & Strauss 2008), making qualitative research an appropriate approach for this study.

Finally, a quantitative approach would not be able to encompass and address all that an individual may be feeling or experiences, as a survey or questionnaire is restricted to a set structure and number of questions, thus it does not capture the breadth and depth of an individual’s experience. Therefore, along this understanding, it would be most suitable to take a qualitative approach to explore the various educational themes and expectations patients express to have around the surgical event.

2.11.2 Meaning and Perspective: Theory behind the study

Qualitative research is habitually embedded in a particular theoretical framework which helps to frame and provides justification for specific research objectives, and the methods chosen to address the study aims (Green & Thorogood 2009). Here we lay out the theoretical perspective we chose in understanding what we already know from literature about the experiences of individuals having undergone epilepsy surgery and how it will help to understand what we are trying to achieve through this needs assessment. It will further help to make clear the justification for choosing the particular methodology and method used in conducting this research and finally the analytical approach we took to review the data (Crotty 1998). Figure 2.1
is a visual representation of how each consecutive piece in the theoretical framework informs the subsequent steps in the design of this study.

2.11.2.1 Epistemological View

Epistemology is the theory of knowledge development, a way of understanding and explaining how we know what we know (Crotty 1998). We believe that human beings are seen as constructed frameworks, as opposed to a reflection of some absolute truth, and it is within a specific context that we can understand the meaning that individuals give to the events and circumstances that they experience. Similarly, we believe epilepsy surgery to be experienced and dealt with differently for every individual irrespective of the surgical outcome, and while certain aspects may overlap, creating patterns for researchers to identify, there will also be a number of important variations that we would like to capture, to emphasize the benefits of a patient tailored intervention. Therefore, in order to develop further knowledge around epilepsy surgery, we took a constructivist approach, where knowledge is best developed through interactions with people – a co-creation (Stake 2010).

2.11.2.2 Theoretical Perspective

Constructionism is the view that “all knowledge and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (Maxwell 2013). That being said, we believe given the current clinical practice, anecdotal remarks and literature, that a knowledge gap exists around the epilepsy surgical event, and can be addressed by asking individuals about their personal experiences. We assume that each individual will bring a different experience and from a distinct perspective, that there is no
absolute truth, but rather a compilation of peoples’ experiences and personal held values. As a researcher, my view is situated in the perspective and experience of patients, those of being the important realities that we anticipate to learn and describe in this study. It is imperative that we interview post-surgical epilepsy patients, because in order to design and develop a pre-surgical intervention that meets the needs of this population, we must first understand the meaning that the individual themselves give to the surgical process, capturing important aspects, what may be lacking, and where there is room for improvement. It is with this frame of thought that we base our research aims, in advancing care and mediating suffering around epilepsy surgery.

Figure 2.1: Theoretical framework informing the design of qualitative needs assessment.

2.11.2.3 Qualitative Descriptive Method

The principles of a qualitative descriptive methodology guided this study allowing the use of a needs assessment approach. This method allowed us to provide a comprehensive summary of the every day terms of specific events experienced by post-surgical epilepsy patients (Colorafi & Evans 2016). A qualitative descriptive approach does not require the researcher to move too far form the data, nor the requirement for a conceptual or highly abstract interpretation.
of the data (Lambert 2012). This aligns well with our aims to simply identify and summarize the various important expectational and educational themes that individuals find important to know given their retrospective experience. Although identifying and reporting some interesting overarching themes of patient experiences is also within the boundaries of this approach. Furthermore, a needs assessment makes it easier to fulfill the intent to improve or help individuals through understanding their perspective and determining the needs and knowledge gaps that exist within this population and clinical practice. This approach allows us to study the natural state of the experiences shared by post-surgical epilepsy patients, in that there is no pre-selection or manipulation of study variables, and no prior commitment to any one theoretical view of our target phenomenon (Lambert 2012).

Additionally, qualitative needs assessments have been successfully executed in other health research areas (Pieh-Holder et al. 2012; Rotondi et al. 2007), with some also using content analysis (Rotondi et al. 2007), further supporting our use of this method and analysis.

Finally, following this theoretical perspective of constructionism and methodology of a qualitative descriptive approach, together they provide flexibility in the method with which data can be collected as well as the sampling technique. Furthermore, within this framework we have chosen to use content analysis to process the interview data, where the findings are a co-construction, by the researcher and participant, of what the surgical and post-surgical process was, what was deemed problematic and what actually worked. This permits a level of interpretation to make conclusions without steering far from the real-world experiences of patients’ perspectives around epilepsy surgery.
2.11.2.4 Positionality/Reflexivity

An important practice in qualitative research is recognizing the role of the researcher within the research process and as part of the broader social context within which the research is embedded (Green & Thorogood 2009). Throughout this research study, I was aptly aware of my role as a researcher in co-constructing the experiences and personal accounts of participants and took the necessary measures by: 1) readings transcripts multiple times, and 2) reviewing the interpretations with my program advisory committee (PAC) members and supervisor to ensure that the analyzed data stuck close to the meanings and values that participants gave to the experiences they shared in the interviews. I also recognize that my presence and set of demographics (woman of color, mid twenties, graduate student, not having epilepsy) along with my demeanor set the tone for in-person interviews and influenced the way with which participants interpreted the questions asked and the depth and nature of their answer. The way the questions were delivered with probes, selective of each participant, also inclined study participants to answer in a particular manner, choosing what information to share and in how much depth. The setting (hospital conference room or phone) where the interview was conducted must also be taken into account in shaping the type of information collected and subsequently analyzed. Finally, I reflected on the underlying research assumptions around epilepsy surgery and patients experiences I had initially made, having done an extensive literature review around this subject, going into this study and how this influenced the way in which I approached and analyzed the data.

Reflexivity is sometimes discussed in its absence (Doyle 2013). In this line of thinking, failures of reflexivity offer clarity regarding the importance of the researcher’s influence on the study. This suggests reflexivity is both an awareness and a process. Its aim is to create a
heightened awareness of preconceptions or bias inadvertently influencing the questions, methods and results of a study. I understood this to mean that I had to maintain a strong awareness of the context, purpose, and focus of the research. I also had to account for my prior lack of experience with epilepsy and its treatment which could pose limitations on my comprehension of participants statements and subsequent analysis. This self-understanding contributed to the design of the study including the recruitment of a large number of participants, whereby I would become deeply immersed in the topic and gain an emic perspective. These approaches responded to my reflexive understanding of self and my capacity to develop new knowledge in surgical epilepsy.
3. STUDY OBJECTIVES

The objectives of this qualitative needs assessment study are threefold. Firstly, to identify possible knowledge gaps around the surgical event, by collecting an in-depth understanding of the perceptions and experience of post-surgical epilepsy patients. This study will explore what post-surgical epilepsy patients feel they would have liked to discuss or have known about, that would have facilitated their QOL post-surgery. Once a needs assessment has been conducted, using the information from interviews, a collection of patient identified needs will be established resulting in the identification of major themes derived from patient feedback.

Secondly a focus group will be conducted to validate the study findings and secondarily confirm the need for an epilepsy pre-surgical intervention program. This is to ensure rigor, reliability, trustworthiness and transferability of study results, which is a common practice in qualitative research; establishing a member check on the study findings and results analyzed from interviews (Whittemore et al. 2001; Burnard et al. 2008). This will involve recruiting study participants who have previously participated in the interviews, to provide their feedback and validation of preliminary findings.

Lastly, the third objective of this study is to acquire, through conducting a qualitative needs assessment, the elements and components of a workable framework to inform the design, development and evaluation of a pre-surgical intervention.
4. METHODS

4.1 Research Design

This is a qualitative needs assessment study with a semi-structured interview format for data collection from post-surgical epilepsy participants. Although sample sizes for qualitative studies are subjective, for this study, a sample size of a minimum of 50 participants was sought (Britten 1995). Given the extensive variability in the epilepsy population, a larger sample size was preferential to acquire various perspectives of post-surgical epilepsy patients.

4.1.1 Sampling and Recruitment

We had access to the Toronto Western Hospital (TWH) patient registry, of which a total of 290 patients had undergone a surgical procedure for intractable epilepsy at the time of recruitment. We employed purposeful sampling, a strategy used to deliberately select particular settings, persons, and/or activities to provide information that is particularly relevant to the research question and goals (Maxwell 2013). Therefore, following the objectives of this study and interest in collecting information-rich cases specific to those having experienced epilepsy surgery and the process around it, patient recruitment involved all individuals that had undergone epilepsy surgery at TWH.

4.1.2 Participant Selection and Subject Enrollment

All English speaking, literate epilepsy patients eighteen years of age or older in the registry, who had surgery, were selected for inclusion in this study irrespective of surgical outcome. Only those who refused to or were unable to provide informed consent to the study were excluded. Potential participants were notified and introduced to the study using a study letter (Appendix A) sent via mail as per UHN REB guidelines. They were provided with the
necessary details concerning the study to determine their interest in potentially participating. If and once permission had been obtained via phone call or email, to provide a formal consent form (Appendix D), individuals were mailed the form in a pre-paid envelope to be signed and returned if they chose to participate in the study.

As expected, given the relatively large population size to work with, a range of patients were recruited, encompassing a few months of post-surgery life to several years of post-surgical life experience, among other demographics. This was vital, as it allowed access to a variety of input into what each individual had to say about their experience retrospectively and how it would have been different knowing certain aspects of their life before surgery.

Following the completion and analysis of individual participant interviews, the recruitment of active study participants and support members for a focus group were selected such that they reflected the diversity of the population of interest. This was based on the representation of functionality, age, and gender groups of the population of interest among other criteria. Furthermore, selection was made based on the availability and accessibility to travel to Toronto Western Hospital for the focus group interview. A sample size of eight is found to be optimal for conducting focus group interviews (Stalmeijer et al. 2014), as such eight participants were recruited for this focus group. Selected individuals, with whom prior consent for email communication had been previously established, were contacted by email or phone to determine their interest in participating.
4.1.3 Data Collection Method

Data collection was comprised of a two-part series, each addressing a separate objective. The first part involved semi-structured interviews with individual participants, either by phone or in-person based on personal convenience. The second part involved a single focus group that was conducted towards the end of the study as a form of member checking (Stake 2010) to confirm and validate that the identified themes and information were in fact representative of patient experiences along with clarifying any discrepancies and/or refining specific findings.

Semi-Structured Individual Interviews

Each interested participant was sent a consent form with all the relevant and required information. Informed consent was obtained upon their signing prior to us collecting any further patient history and background. All questions and/or concerns patients had regarding the study were addressed prior to proceeding forward.

Once a participant had read, understood and made an informed decision to participate, they were contacted accordingly to verify their decision and set up an appointment for an interview. 1-2-hour interviews were scheduled at a time most convenient for participants.

The interviews took place, either over the phone or in-person, based on the patient’s preference. Individuals were encouraged to schedule a phone interview if travelling long distances was an issue. If patients had already scheduled an outpatient visit, it was beneficial for them to schedule an in-person interview on the same day to save time and transportation costs. If for any reason, an appointment needed to be rescheduled, participants were required to contact a research staff within a 48-hour notice.
The semi-structured interview was the primary source of data collection and patients’ needs assessment. Our model of predictive coding informed the questions generated for the interview script. Understanding that predictions influence reaction and associated behavior to a said outcome, prompted inquiry of patients’ pre-surgical predictions or lack of in addition to understanding their overall preoperative experience. Moreover, determining information and knowledge gaps around the surgical period with the possibility of informing realistic and realizable predictions, involved asking questions relating to the participant’s life after surgery, difficulties, and adjustments they may have experienced coping with the demands of postoperative life. Finally, participants were also asked to identify any areas for improvement in information or the overall surgical process that they would have wanted to know of, given their experience with surgery (Appendix B). The development of the interview guide was an iterative process, where several iterations of the interview script were created as questions were added and/or refined based on findings from previous interviews. I moderated all interviews, which either took place in the hospital conference rooms in person or by a landline telephone connected to a recording device. All interviews with the assurance of informed consent were audio recorded in addition to note taking in order to capture the full perspectives of patients and to maximize the authenticity of the responses during qualitative analysis (Pope et al. 2007).

Validating Results: Single Semi-Structured Focus Group

This focus group fulfilled the second objective of the study. Once all individual interviews had been completed, transcribed and analyzed, a selected few study participants or individuals from their support circle were contacted to introduce this extension of the study via email or phone call. A consent form outlining details of the extension was sent to participants (Appendix E). Informed consent was obtained, and all questions and/or concerns were addressed.
Upon receiving signed consent from all individuals interested in participating in the focus group, 1-2 dates and time options were made available to choose from using doodle poll. The focus group was scheduled at Toronto Western Hospital, in a private conference room, and was approximately 2 hours in duration. The focus group was audio recorded and involved the presentation of preliminary findings using a power point presentation. These findings were presented as major manifest categories including pre-surgery experience and post-surgery experience (short-term, long-term, coping strategies and suggestions). This was followed by follow-up questions to confirm and validate the information obtained during individual interviews, in addition to questions pertaining to a pre-surgical intervention (Appendix C).

4.1.4 Subject Confidentiality

Subject confidentiality was maintained throughout all steps of this study, including all publications. Data collected was solely used for research purposes. All interviews, individual and focus group, by phone or in person, were audio recorded and precautions were taken to ensure that all individuals remained anonymous for publication purposes and release of research findings. Each participant was given a study number and any information collected for the research objective that linked to the individuals’ identity was stored in a secure location only accessible to the PI. All recordings were stored on a hospital database and will be kept for a maximum of 10 years for analysis before being discarded. The Research Ethics Committee or regulatory bodies may receive copies of the study and may review medical and personal patient records related to the study.
4.1.5 Risk Associated with Interview and Corresponding Precautions

We did not anticipate there to be any potential harm to individuals participating in this study. This needs assessment involved over the phone or in-person interviews that required patients to evaluate their life style and provide feedback on the success of their surgery from a psychosocial perspective. The participants were also required to reflect on their QOL after surgery and provide insight on how different aspects of their current QOL would have improved had these issues been addressed prior to surgery. This potentially entailed examining personal information about the patient, their relationships and their life in general. Such sensitive information was treated with utmost care to avoid any emotional distress to participants. Patients that felt uncomfortable were given the assurance of stopping the interview at any time. If they expressed discomfort with the process, the interview was immediately terminated. No physical risks were involved corresponding to this needs assessment. Several participants were further asked to take part in a focus group. Participation in this study did not hinder or prevent routine standard of care of epilepsy patient population at TWH.

4.2 Data Analysis

Qualitative Analysis Part 1

In order to capture themes that relate to epilepsy patients, specifically those eligible for surgery, we believe the subjective experiences of post-operative epilepsy patients was imperative towards building a solid foundation of themes potentially contributing to the design and develop a pre-surgical intervention program. While qualitative analysis is different from quantitative, there are several steps that are taken to ensure trustworthiness, credibility, validity and authenticity of the analytical process (Golfshani 2003; Fossey et
al. 2002). To ensure this criteria was addressed, triangulation and a member check approach was taken in which the interpretation of other investigators and verification of study findings by study participants themselves in a focus group environment, were used respectively (Thomas 2006; Golfshani 2003).

Based on our primary objective to determine the different categories of information and themes that postoperative patients’ may have wanted to know about prior to surgery, we used an inductive approach in analyzing the data. Firstly, no prior research had been conducted with regards to our angle in interviewing post-surgical patients’, hence an inductive approach that relies on findings that arise directly from the raw data collected and not from priori expectations or models was desired (Thomas 2006). Furthermore, the inductive approach used the actual data to derive the structure of the analysis thereby reducing the potential for bias that was likely inherent in a preplanned coding system as well as reducing the limitations placed on theme and theory development seen more frequently with a deductive approach (Burnard et al. 2008).

More specifically, a content analysis with a thematic analysis embedded within it, most commonly used in health research, was employed for the data collected. Content analysis is commonly used to analytically examine the narrative materials of life stories and experiences. This is done by breaking the text into relatively small units of content and submitting them to a descriptive treatment (Vaismoradi et al. 2013). We chose to capture both manifest (descriptive level) and latent (abstract level) content around patients’ experiences of epilepsy surgery. This involved identifying categories and themes respectively, that emerged from the data collected from post-surgical patient interviews (Burnard et al. 2008). The analysis process began during the data collection phase to allow for any adjustments or refinement of research questions that
may have provided greater depth to the research objective (Pope et al. 2007). The qualitative analysis process involved

1. data collection and management
2. organizing and preparing the data
3. coding and describing the data
4. conceptualization, classifying, categorizing and identifying themes

Data collection and management involved audio-recording all interview sessions and note taking where necessary. All recordings were stored on a secure hospital database to be later used for analysis. During the design of this study, the intended analysis was to occur concurrently with the data compilation in order to gain a better perspective of the research question and further refine it if/when necessary. However, given the large volume of interviews conducted, it was difficult to follow through with a fully iterative process. Nonetheless, as more interviews were conducted, some of the questions were reformatted and rearticulated for better comprehension. Furthermore, in some cases the research questions asked in this study were refined, added onto and evolved in response to the setting, data and its analysis (Fossey et al. 2002). This iterative process of data collection and analysis eventually led to a point where no new codes/categories emerged from further interviews and was a good indication that data collection was complete (DiCicco-Bloom & Crabtree 2006).

All interview recordings were transcribed verbatim with detailed annotations in order to accurately capture what was said and done (Pope et al. 2007; Burnard et al. 2008). NVivo, a qualitative analysis software was used to organize, code and analyze study data. Each transcript was imported into NVivo 11 Pro and read along whilst listening to
audiotapes to ensure its accuracy during interpretation (DiCicco-Bloom & Crabtree 2006). The transcripts were read once in order to get an idea of the responses given and a second time actively looking for words/phrases/statements to develop codes, as the first step towards developing emerging categories and themes that relate back to the research objective and the model of predictive coding. As more codes were generated, revisiting literature around epilepsy surgery and determining what seemed to align and what novelties stood out, provided a sense of direction for the emerging categories and themes. A coding book was created to expand on the codes used. Initially an open coding process was used that involved the examination of data, line for line to identify as many codes as possible. I would meet with my supervisor and a member of the PAC regularly to review and discuss the data, codes, ongoing analysis and possible alternative interpretations to the experiences of individuals from the interview data. As more data was collected, the transcripts were analyzed and placed in the categories formulated until all information had been placed in one or multiple categories. These codes were reviewed by all PAC members to provide further consensus in interpreting the interview data. Memos of each transcript in the form of summaries and specific aspects that resonated with individuals were also documented within NVivo. These memos comprised of the core experiences of the individual that were important to them, including some of the helpful things, some of the gaps, and recommendations.

These accounts provided a chronological history of the analysis process, how the formation of codes, categories and themes evolved with subsequent interviews. Once all data had been organized, the categories were either expanded into sub themes or combined into broader themes (Hsieh & Shannon 2005; Thomas 2006).
Qualitative Analysis Part 2

Qualitative analysis commonly involves the researcher’s interpretation of information provided by participants’ interviews. Therefore, to ensure the credibility and representative interpretation of the population of interests’ results, a second form of analysis of preliminary findings involve conducting a member check (Stalmeijer et al. 2014), by means of a focus group interview and analyzing the data collected. Furthermore, focus groups are also conducted following other research methods (i.e., semi-structured) to further explore the data and refine/interpret previously analysed data (Stalmeijer et al. 2014). The focus group with the assurance of informed consent from all participating parties, was audio recorded in addition to note taking in order to capture the full perspectives of all participants and to maximize the authenticity of the responses during qualitative analysis (Pope et al. 2007).

Both individual interviews and the focus group underwent a content analysis, specifically manifest content analysis, sticking close to real world experiences and identifying themes around the way participants perceived the surgical process. We further performed a latent analysis that explored issues and themes that were not as obvious or apparent as participants verbatim statements. This allowed us to identify and understand complex issues and situations that would have otherwise been left undetected without further inspection.
5. RESULTS

5.1 Semi-Structured Interview Results

Seventy-three individual semi-structured interviews were conducted, capturing the experiences of a diverse group of participants. The interviews spanned an average of 1.5 hours. Table 5.1 shows participants’ demographics, providing a sense of the rich and robust compendium of data collected from this study. Furthermore, people at different time points and stages of their post-surgical life were included. According to Table 5.1, based on the varying time that had expended since their surgery, information was captured from people across various post-operative time points, to talk about their experiences. This provided a unique opportunity to determine the types of information and possible gaps that exist at various stages of the recovery and post-surgical period, potentially helping to narrow down the types of information and resources that need to be provided at different points in the epilepsy pre-surgical and post-surgical periods. Finally, out of the total participants interviewed, seventy- the vast majority of participants- were fairly happy with having undergone the surgery, some with an easier time adjusting than others. There were a few outliers; individuals who were not happy and did not anticipate their post-surgical outcome, but both groups had very helpful things to say about their experience which has been coalesced as follows.

Table 5.1: Participant Demographics (n = 73)

<table>
<thead>
<tr>
<th>Demographics</th>
<th>N (%)</th>
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<tbody>
<tr>
<td><strong>Age Range</strong></td>
<td></td>
</tr>
<tr>
<td>20-30</td>
<td>12 (17)</td>
</tr>
<tr>
<td>31-40</td>
<td>20 (27)</td>
</tr>
<tr>
<td>41-50</td>
<td>17 (23)</td>
</tr>
<tr>
<td>51-70</td>
<td>24 (33)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>26 (36)</td>
</tr>
<tr>
<td>Female</td>
<td>47 (64)</td>
</tr>
<tr>
<td><strong>Type of Surgery</strong></td>
<td></td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>Temporal</td>
<td>65 (89)</td>
</tr>
<tr>
<td>Left</td>
<td>30 (46)</td>
</tr>
<tr>
<td>Right</td>
<td>35 (54)</td>
</tr>
<tr>
<td>Extratemporal</td>
<td>8 (11)</td>
</tr>
<tr>
<td>Left</td>
<td>2 (25)</td>
</tr>
<tr>
<td>Right</td>
<td>6 (75)</td>
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<table>
<thead>
<tr>
<th><strong>Age at Surgery</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>20-29</td>
<td>23 (32)</td>
</tr>
<tr>
<td>30-39</td>
<td>21 (29)</td>
</tr>
<tr>
<td>40-49</td>
<td>14 (19)</td>
</tr>
<tr>
<td>50-59</td>
<td>12 (16)</td>
</tr>
<tr>
<td>60+</td>
<td>3 (4)</td>
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<table>
<thead>
<tr>
<th><strong>Number of Surgeries</strong></th>
<th></th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td>70 (96)</td>
</tr>
<tr>
<td>2</td>
<td>2 (3)</td>
</tr>
<tr>
<td>3+</td>
<td>1 (1)</td>
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<table>
<thead>
<tr>
<th><strong>Years Post Surgery</strong></th>
<th></th>
</tr>
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<tbody>
<tr>
<td>≤ 2 Year</td>
<td>15 (20)</td>
</tr>
<tr>
<td>&lt; 2 Year, ≥ 5 Years</td>
<td>23 (32)</td>
</tr>
<tr>
<td>5 Years &gt; 10 Years</td>
<td>23 (32)</td>
</tr>
<tr>
<td>≥ 10 Years</td>
<td>12 (16)</td>
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<table>
<thead>
<tr>
<th><strong>Seizure Status Post-Surgery</strong></th>
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<tbody>
<tr>
<td>Seizure Free</td>
<td>55 (75)</td>
</tr>
<tr>
<td>Not Seizure Free</td>
<td>18 (25)</td>
</tr>
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<table>
<thead>
<tr>
<th><strong>Duration of Epilepsy Before Surgery</strong></th>
<th></th>
</tr>
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<tbody>
<tr>
<td>&lt; 1 Year</td>
<td>2 (3)</td>
</tr>
<tr>
<td>1 Year ≥ 5 Years</td>
<td>11 (15)</td>
</tr>
<tr>
<td>5 Years &gt; 10 Years</td>
<td>11 (15)</td>
</tr>
<tr>
<td>10 Years &gt; 15 Years</td>
<td>9 (12)</td>
</tr>
<tr>
<td>≥ 15 Years</td>
<td>40 (55)</td>
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<table>
<thead>
<tr>
<th><strong>Age at Seizure Onset</strong></th>
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<tbody>
<tr>
<td>Baby (0-4)</td>
<td>14 (19)</td>
</tr>
<tr>
<td>Early Childhood (5-12)</td>
<td>15 (21)</td>
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<tr>
<td>Teenage Years (13-19)</td>
<td>13 (18)</td>
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<tr>
<td>Young Adult (20-35)</td>
<td>19 (26)</td>
</tr>
<tr>
<td>Adult (36-55)</td>
<td>11 (15)</td>
</tr>
<tr>
<td>Older Adult (55+)</td>
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</tr>
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</table>
5.1.1 Results Synopsis

The study findings are presented in two components. The first is a content list of participants’ experiential accounts that is a result of the manifest analysis of interview data (Figure 5.1). These major categories are a direct manifestation of what individuals found to be helpful, what was lacking or a concern in the post-surgical period, and what they perceived would have been helpful to know in advance. The identified information was found to fit into either medically related factors, psychosocial factors or coping strategies surrounding epilepsy surgery, along with some existing overlap in information.

Figure 5.1: Summary chart of major categories identified from needs assessment study on post-surgical epilepsy patients.

Furthermore, our qualitative needs assessment study has revealed the need to address two information types around epilepsy surgery. We have identified actionable factors that can be placed into the following categories; A. Essential information, and B. Help-Seeking
**Information.** Essentially, the first type of information is within the realm of self-management and links to individuals’ internal locus of control, this is information that will allow patients to be self-sufficient, given the resources at hand, in some aspects of their post-operative care and recovery. This is “essential information” to be provided to all pre-surgical candidates. On the other hand, help seeking information has the ability to inform individuals of the potentiality of scenarios that may require further assistance and resources from the health care provider or other means of support, and thus promotes help-seeking behavior. It is the action of identifying the issue to require further external help, proactively looking for it and reaching that help. This last category addresses experience and outcomes with an external locus of control and can be tailored to patient specific needs.

The following sections explain the details of the major categories presented in Figure 5.1, providing descriptive summaries and associated relevant quotes from participants’ experience. Within some of these major categories of manifest analysis, further latent analysis was undertaken, the second component of study findings, providing more in-depth understanding and interpretation, further tying together various categories leading to the emergence of major themes that surfaced from patient interviews.

### 5.1.2 Identified Descriptive Content

The following descriptive content revolves around participants experiences based on the narratives of what happened to these individuals in their pre-surgical, and post-surgical accounts of their epilepsy surgery. These experiences and feedback have been organized into different contextual categories and anticipatory guidance that may have helped the patients along their surgical journey. These are aspects that are a manifestation of what really came through that were
key aspects of the patient’s recovery, what went well and what did not around patients’ experiences and what they foresaw to be helpful or recommendations for future epilepsy surgical candidates. Therefore, the following categories guided our understanding of the different types of issues and information that others, both clinicians and the patients, need to know about or may find helpful.

Pre-Surgery:

Initially our focus was on post-surgery, because it is experience of participants’ post-surgical life that we wanted to understand. However, it became clear after interviewing several participants, that their pre-surgical accounts of their experience were equally important in providing a comprehensive understanding of the surgical process and informing the types of information and knowledge that could help to improve clinical practice.

Level of Impact of Epilepsy

Participants provided a varying degree of need for information or help, pre- and post-surgery, depending on the degree to which epilepsy was and had impacted their daily life. In general, those who had been diagnosed relatively recently or had low frequency seizures prior to surgery, shared clear and concise descriptions of their perceived ‘normal’ life post-surgery and expressed little difficulty adjusting to long-term post-surgical life. Those who also retained high level cognitive functioning and manageable impact on their memory post-surgery, attested to a similar adjustment around their daily life.

“…it was speaking with people and getting help to make sure I was ready to live with whatever the life after surgery was in the event that it was worse, then it had been before surgery. In the event that it had been better, and it is better because I do have slightly better control there wasn’t anything I felt I needed to do to prepare for that because it’s not like my seizures significantly impacted my life before the surgery. I generally lived a pretty average life and a pretty okay life and yes I’ve always had limitations, but I still do.”
On the other hand, participants highly impacted by epilepsy or having been diagnosed at an early age and living with the condition all these years seemed to be a more vulnerable group and requested for a distinct set of information to be available, albeit with some overlap, and more support pre- and post-surgery.

“I mean I didn't even know I was having them. I had to quit my job because of that, and I lost my license because of that. My husband actually-- they were actually even questioning his job of taking his car away, because it was an employer car, because they didn't know if I was going to go out there and take it. It was just frustrating like that. I find my life really changed. I wasn't basically allowed to do nothing, and I was saying, "Why the hell am I still here?"

Nonetheless, there were exceptions to both these cases, emphasizing the importance of providing tailored information to address the specific circumstances and needs of each patient.

State of Mind

Participants recalled from their pre-surgical experience of either being ready to face the outcomes of surgery and being in a good state of mind or not knowing what to expect and thus had feelings of being in the dark of what post-surgical life would entail. Of those who were more confident, some of these participants had taken time to organize their thoughts and feel comfortable with their decisions. This involved but was not limited to talking to family members, meeting with a psychiatrist, and speaking with others having undergone epilepsy surgery. Many of these accounts were initiated by the participants themselves and recommended to be resources to be provided for all those going through epilepsy surgery.

“I asked for it pre-surgery to my neurologist because I---like I said I was just not in a good headspace to be calm about that piece in terms of being able to live with whatever came with it. I was petrified of impact on memory language, and how it could impact my job, and that was the one little piece that was keeping me from saying, "Yes. Let's go with this." And I knew I wanted to go with it, but I just wasn't in the right headspace to be calm about that piece. And I knew I had to be or I wouldn't be able to deal with what could of surgery if it wasn't what I wanted.”
Of those less prepared, it was merely wanting to see any changes in their current condition of seizures and quality of life that urged them to move forward with their decision and at that time post-surgical life and adjustments were not priority. While these circumstances did not change their decision to undergo surgery, in hindsight wanting to have known more and having made more inquiries was something that participants encouraged.

“See, that's where my attitude came in. It didn't matter. I just, I wanted this done. My life after surgery, well, I would deal with that when the surgery was done. I did not set myself up for anything. I just, I made sure my bills were paid up to date, I gave my wife my security code, numbers and I went through the surgery.”

Information Processing: Retaining Information

Epilepsy is shown to impact memory in varying degrees and many participants acknowledged that given their level of memory deficits, provided that they were given the necessary information about epilepsy surgery, many fine details were lost to time, especially having this information provided verbally.

“...and it's simple information, but when you're told it verbally in a hospital you don't necessarily retain that information or in a setting a month before your surgery. You don't necessarily retain it, but had I had something to look at later it would've been good and I might have been told that stuff verbally, but I don't know. I don't remember it.”

“I don't recall getting any of that information. Like I said, maybe it's because I have short term memory loss. I don't remember, or maybe I just wasn't provided all that information”

Additionally, one must take into consideration that some aspects may have been addressed prior to surgery, however due to the duration of the discussion as well as the stress and overwhelming feelings that come along with deciding to have brain surgery may have made it difficult to retain all the details of the information and knowledge relayed.
On the other hand, participants acquiring short-term memory deficits post-surgery had difficulty recalling information provided during the pre-surgical period. This was particularly common for those who had surgery several years back. For example, one participant when asked to recall their pre-surgical experiences told us “I don’t remember the surgical team being—providing me [stammering], you know, the information that, uh—I guess, you know, I think they just gave me the basics of what they were gonna do but not re—sorry, it was so long ago that—"

Post-Surgery:

a. Recovery Period/Short-term

There are several important and interesting categories identified from participants post-surgical recovery and short-term experiences that account for information that participants had a) wanted to know about or b) stated their concerns for having experienced yet had not been expecting or having been informed about pre-surgery. These instances provide an opportunity to utilize the information that informs individuals actions and recovery in the post-surgical phase such that they may be prepared for the possibilities of addressing such situations if they were to manifest.

i. Changing Relationships

One very interesting aspect that stood out among the participants experience of epilepsy surgery was the dynamic changes in their personal relationships throughout recovery and its complexity as these individuals began to explore their renewed independency.

Some participants found it difficult to remain as they were prior to surgery and experienced role adjustments or reversals as they became the caregivers, or took on more
responsibilities, now having the ability to do more things since being seizure free or having relatively controlled seizures.

“So I kind of went from you know, getting over my surgery to flipping into caregiver mode for him… and then I had to put him in a retirement facility eventually and then they would call me and say you know he's getting up and he’s falling. Somebody needs to be here.”

“Maybe a little bit I feel like they're not so much caretakers anymore or caregivers its more of an adult relationship now not so much being kind of the parent”

While these were positive steps on their part, some participants expressed feeling friction among their family members, whether this was a parent, sibling or spouse, and needing space to be able to adjust.

“Um and then also, a lot of the time everyone will have their different opinion that they’ll try give you. I’ve had people say, like it was more like my grandparents like, “Oh, come on, just take this whole term off. Just like relax, relax…” And some people are expecting higher of you. And I think that should be spoken about, not letting other people like give their own little opinions and that could be frustrating.”

It is evident that both parties in the relationship had to work at adjusting to this new environment and while this period of volatility brought some relationships together, others were unable to cope with such changes and resulted in estrangement.

“And that, so in that respect it’s getting much better. Um as far as you know my personal relationship, my husband, eh I – he’s always been supportive from the very beginning [chuckle]… so for that to - that changing I don't know if that's particularly changed although he’s basically kinda changed his life a little bit to um to accommodate like doing the, like “okay so you know Monday’s we’re doing pizza” and then you know and to go to my sons um rep baseball games, “okay I'm gonna go this day but I'm only gonna go for three innings””, and so it was almost like he was changing his life a little bit.”

Those individuals who were able to work through their differences expressed wanting to have had some guidance or heads up in experiencing such changes in their personal life. One of the participants expressed, “I think it would have greatly benefited the family members as
opposed to what to expect and use you know, real-life examples of what people have gone through. It took us three years, maybe less than three years but before I fully fall realized that [she’s] her own person and she's just as good as me. She can think just as well as I can.”

Others were relieved to have separated, as epilepsy had left them constrained and vulnerable with feelings of having been taken advantage of and feeling completely dependant on their partners.

“…Yes, they weren’t used to that. Even my ex was saying, “I’m not used to you. I don’t even know who you are. The person I married was not you.” And he would even say, “I told you, you’re just forgetting.” And that was something that I was hearing all the time. Those mind games.”

These accounts of participants dynamic relationships provide further insight into the complexity of surgical outcomes that go beyond seizure status. In fact, these experiential accounts suggest the need to involve families in dealing with the participants newly acquired freedom and to equip both patient and their significant others with the necessary tools and resources in dealing with these changes.

ii. Concerns

Participants voiced several concerns around their post-surgical recovery period, aspects both medical and psychosocial in nature, they felt had not been discussed at all or they could not recall having addressed enough prior to surgery. Once again, these categories had not changed their perception of epilepsy surgery being a life-changing experience, rather experiencing these situations came as a surprise. Participants expressed had they had more information or prior knowledge, the transition may have been easier to accept and subsequently dealt with in a different manner.
“I think if information had been provided then that might’ve been, you know, more of a, you know, look out you might be—this might be something that you might experience. I asked my mom because like I said, I don’t remember a lot. She said there was no telling you, okay, even though you had surgery and you’re a success, you still might go through, you know, in my case it was emotional items that I wasn’t aware that would happen.”

Several participants also felt these occurrences had slowed down their recovery as they felt unsure and anxious not knowing if these incidences were temporary or even common occurrences of post-surgery.

“Um…and my senses I sat on the deck and the cat walked by in a leaf blew and it was overwhelming for me. And I thought I was going crazy and it wasn’t until I looked online to think, “Am I going crazy or is this kind of normal?” And I realized that that’s kind of normal. But why do I have to look online for that?”

Some of the short term medical side effects expressed to have been a concern by participants were: severity of pain, heightened senses (smell, touch, hearing), physical side effects such as weight loss, energy dips, insomnia and temporary incoherence and medication effects including withdrawal and its associated side effects such as constipation.

“Instead of just being- not- not- not surprised, because that’s not how I felt, because I- I just all of a sudden got down and I was just uh… very sensitive to so many things like noise. All of that sort of stuff I wish I did know.”

Some of the psychosocial factors expressed to have been a concern by participants included the length of recovery and its impact on their daily life; their physical condition and the time it took to gain back the energy and confidence to resume their every day activities. Interestingly, others experienced a reversal where they felt invincible after a speedy physical recovery, but overexertion soon after surgery left them with a relapse of seizures.

“I would have slowed down a hell of a lot sooner. I would have because if I maybe, maybe, maybe, just maybe if I would have slowed right down and not worked so hard, it might not have gotten to this point.”
“Um yeah that like was difficult, because like sometimes you don’t know what’s going to happen. I think one of like my issues after was like I got like a little bit too anxious to start doing things like I signed up for a couple of like volunteer hours that I realized I was just still too tired to do.”

Yet others experienced more emotional and psychological effects such as anxiety, mood swings and temporary mood disturbances many times catching them and their loved ones off guard, especially if they had no prior history of these conditions.

“I think it took a bit of patience from my wife’s part to deal with it. My---I was very short tempered there for a little while, partly because I was in a lot of pain, and partly because I was on these medications. And coming off these medications with withdrawal and stuff... So especially coming off several months later, that did take a lot of patience on behalf of my wife.”

“Yeah it wasn’t a physical isolation it was a mental isolation, because I couldn’t- I couldn’t- I couldn’t get people to understand what I was feeling.”

b. Long-term/Chronic Side Effects

Participants also articulated challenges they faced in the long-run and addressed some of the chronic side effects lasting longer than six months that they felt were areas of importance to consider in clinical practice. Once again, these were of medical and psychosocial nature, and participants expressed the need to address these concerns such that individuals were better equipped to deal with such circumstances rather than having no other choice but to explore and cope with the situation independently.

“...and my husband in the same room as me was going to be overwhelming and that that was going to make me cry and that I- I went into a very deep depression after the surgery and it wasn't until my follow-up visit with Dr._ that I sort of learned that that could be a normal part of surgery. And I wish that I had known that, because that felt awful to me and so much so that I was pretty much almost suicidal and I didn't know that that could come with surgery. And if someone had had just told me that it wouldn’t have been so scary...”

Some of the medical concerns included effects on cognition that participants found impacted their concentration, processing of information and completion of daily tasks.
Additionally, while the impact on memory vary considerably from person to person, some participants found it took them sometime to get accustomed to their level of memory difficulties.

“Almost everything seems to take a little longer, and I have to think about almost pretty much everything I was doing even passwords and user names I’d forget pretty much everything. Even my ways of living like I’d forget to brush my teeth sometimes. Simple memories like normal living, it seemed to change almost everything, but it seems like over time that yields”

Other aspects such as continuing medications and post-operative seizure status were handled differently for different participants depending on their expectations and what they could recall having been told prior to surgery.

“...I remember sleeping - resting lots because I was just so tired... from the medication but as I gradually came off the medication I - I began to feel better. Um, the process of coming off of them was very... uh very difficult and..., traumatizing in a couple ways, just as they, they very much caution you that you can have breakthrough seizures and things like that and it was very very hard to accept. But um I came off of them with - with no seizures thankfully and uh it was just a very very difficult process as to – like withdrawal symptoms and the detox feeling so...”

Some of the long-term psychosocial concerns participants expressed to having a hard time with, included adjusting to populated areas, specifically for those who were more isolated due to their epilepsy. Returning to work or school was a big step for many of the participants, for example one participant expressed, “Just getting back into school and working because I think I went back too quickly. And I’m still having troubles at works, so it’s been – I’m still having issues at work, so its almost been two years.”

“Just the part about communicating with other people. I had a bit of a paranoia if people were going to understand. I didn’t know what to say, I was lost on communications.”

Additionally, many experienced long-lasting effects on their mental state that affected their surroundings for which some participants eventually sought help, although expressing being informed of such possibilities would have prompted seeking assistance earlier on.
“I think I would've sought help sooner. Yeah. Because instead, I tried to hide it and I was just ashamed of it yeah. Had I known that it was the result of surgery, or could've been a side effect of the surgery I would've called sooner and said, “Hey, I am in this deep depression and feeling suicidal can you help me?”

5.1.3 Major Themes

In addition to the manifest descriptive content reported above, additional latent analysis resulted in the emergence of several major themes around more in-depth interpretation of participants experience around epilepsy surgery. These themes bring out the complexity of individuals behavior and interaction with the surgical process as well as their adjustment around post-surgery. Five major themes have been identified including; decision making, informational preparation, expectation vs. reality, support and identity.

Decision Making

When it comes to one’s health and determining a suitable treatment option, decision making is a process of making choices based on identifying a decision, gathering information and assessing the alternative resolutions (UMass Dartmouth 2017). Based on societal standards, this would seem like a relatively planned out process, especially when it comes to the well-being of an individual with a chronic condition facing the decision to undergo a major brain surgery, however this study has revealed that participants make the decision to undergo epilepsy surgery for different reasons and it is not always a carful, calculated and logical or rational plan.

Some participants expressed having a very difficult time making a decision, primarily due to not being fully comfortable with possible post-surgical outcomes and thus could not make a decision for some time. It was only after therapy or fully grasping the information and speaking with others, whether this was additional surgical consultations, family and personal support or
epilepsy peer support that they were in a better state of mind to follow through with epilepsy surgery.

“So, you know, we shared information and we sort of went our separate ways. And just by chance, Dr. _ was also doing a talk out here. When I was in the pre-surgical stage. And I went out and I actually listened to him. Which helps, because you know, he answered some of the questions and so like I sort of took any resources I could find. And I also went online and found um, epilepsy.com. And I joined their chat and I got to know some people, you know talked to some people who had gone through it that way too. And so, I sort of pulled in everything I could find.”

“okay, uh brain surgery’s over, go home, everything’s going to be lovely” like I knew that wasn’t going to happen. So um, but that was part of the decision making, was okay “so how can we make this work... afterwards”? And of course, I - like I said, I have a husband, I have a mom whose uh really supportive. So I had a big support group.”

Some other participants based their decisions primarily on calculated risks and benefits provided in surgical consultations and heavily relied on numbers and probabilities of a successful surgical outcome,

“...when I heard like the percentage chance of success and everything, I was happy with the results and signed up for it from there.”

“...that he gave me a 75% chance of success and it was better than no chance and um so I just decided to go for it.”

Interestingly, other participants dealt differently, and it was too easy of a decision to make with little follow up questions. Within this group of decision makers, there was variability in the reasons for moving forward with epilepsy surgery. Some individuals felt they were at a point where they had no other alternatives, that the severity of their condition and seizures were debilitating their quality of life and daily living.

“It took 10 years to find the brain injury. The seizure medicines would work and then they'd stop working. And I begged for surgery because I wanted to die. I didn't want to live because I'd wake up and the seizures would start. So, I was ready for it. I would've rather have died than go through more seizures. So, I was ready for it and my neurologist at (hospital), he referred me to Dr. __ here and then we waited three years for the surgery. That was hard.
Others based their decisions on their emotional state, the well-being of their family and/or having faced a disequilibrium about their health and hoping to see a difference.

“I was on four medications and uh... nothing you know was controlling the seizures was still having a lot of seizures per day... and um in my opinion this... that was something. I didn't do any research or anything on surgery I just figured if it was an option then why not, because I try to be optimistic and think if there's something out there that can help they wouldn't be doing it if it was really dangerous or anything like that so um... I decided that if it was a possibility then um... I would go for it.”

It is evident that many factors and varying combinations of these factors; including personal circumstances, level of support, severity of epilepsy and seizures, perception of the usefulness of information, and confidence and reassurance in the health care system, play a key role in participants decision making. Nonetheless, while the final decisions lie with the patient to make, it is evident that the reasons for choosing to move forward have implications and consequences in how participants deal with the outcomes of surgery and the expectations or lack thereof, they carry with them going into epilepsy surgery.

That being said, it is clear that irrespective of the specific reasons for undergoing surgery at that moment in time, there were participants, now having the foresight of post-surgical life, wanting to have had more information or realistic possibilities that were both medical and psychosocial in nature.

“I don’t know, I guess maybe if- it would have been good even if we were given like um, “What to look for on-line” to “What to anticipate,” just something that- how long- just to be realistic about things.”

“and I wouldn't expect anyone to go through the list of the 250 possible side effects or more, but getting a patient pre-op in the mindset that, “Okay, keep in mind the short-term side effects of this are broad. There are things you might not anticipate. Other places of your body might. But nine times out of ten or whatever, you’ll get through it. Just be prepared to deal with what could be some interesting and significant side effects for the short-term.”
However, given the variability in patient experiences, there were some participants that were satisfied with what information was relayed during pre-surgery and content with the post-surgical outcomes. This variability in findings suggest that, despite participants initial perceptions of sufficient information for decision making and not having the foresight of the challenges patients may face post-surgery, it is pertinent for health care providers to disclose a balanced level of information such that, those who do make the decision to undergo epilepsy surgery and their families, are equipped with information and resources they may find to be of benefit post-surgery.

*Informational Preparation*

The findings from this study suggest that information can be a double-edged sword depending on its utility to the person being given this information. While it is important in any health decision to provide information regarding the treatment option and its associated details, it is evident from this study that participants dealt with information differently throughout their surgical experience. Not only was the preference of the type and amount of information variable among participants during the pre-surgical consultations, participants access to information post-surgery also varied considerably.

“I would've known, “Okay, this is normal.” Or even if I had been in, actually this is going to sound totally ridiculous, but I even wrote a pamphlet, I have a pamphlet on my laptop that I wish I had been given as an outpatient- like as a patient going home, because all I was given as I was sent home from the hospital after my surgery 10 days or something was a yellow piece of paper that said follow-up appointment.”

“More awareness I think is more than anything. It was just knowing that, okay, this might happen and, you know, not to panic and say, “Oh, this is gonna for sure happen,” but it’s just something to look out for. That you’re not just—just because you, you know, your surgery’s gone well, you know, you might have other situations come up, now.”
While some individuals expressed being satisfied with probabilities of risks and benefits associated with the surgical outcomes including rate of seizure freedom, probabilities of physical side effects as well as effects on memory and cognitive functioning;

“For me no, I asked all the questions I needed to ask, I knew that there was risk going in, I knew that part of - Do I want to know anything else? No, no I knew that there was little bit of a risk and the benefits would weigh out that potential risk and it's one of those things were the more questions you asked the more risk you feel so for me I-I got what I needed and stopped”.

Other participants required and requested for additional information, including papers to read or more in-depth details of the surgical process. These individuals also stated having taken initiative to search online for greater details and information.

“As far as my concerns were taken care of; yes..., I was also – I did a bit of digging myself so maybe on the exception and not the rule but I was quite uh..., I was..., rather prepared.”

Yet others felt they required a different perspective of information than that provided by the medical team and in fact were recommended by the clinical team, or had themselves requested or sought out other individuals having undergone epilepsy surgery.

“So I spoke this with ___a couple of times and___ had also connected me with four people who had also undergone surgery themselves. And two of those surgeries had been very similar to the one that I was going to have. So it was great to meet a couple---a couple I met with, and a couple over the phone, but it was really great to hear their---their experience, their different reviews. Some had very positive outcomes, one of them, so-so. So it’s good to hear the different perspectives and get an idea as to what sort of---what people went through; what the process was like, what the pain is like afterwards, how good was the outcome. That was really, really helpful.”

Understandably, some individuals expressed having had the surgery many years ago and were not always able to recall the details of their pre-surgical experience. Furthermore, others expressed memory difficulties prior to or after surgery that made it hard not only to recall certain details but the effects on their cognition made it difficult to process the information at the time.
“...More sensitive, or it could just be because that’s a side effect. I don't recall getting any of that information. Like I said, maybe it’s because I have short term memory loss. I don't remember, or maybe I just wasn't provided all that information...”

“...Maybe if I would have been told-- maybe I was, I just don't remember like I said. Having short term memory loss, I don't remember. Maybe you did tell me. I don't recall being told about that. But remember, I had the surgery in 2005 and I had to do a whole year of testing before the surgery. So technically it was around 2003 which was more than 12 years ago when I was given the information of possibly trying surgery.”

That being said, when asked if participants would have preferred more information before surgery, a variation of answers were provided, some feeling it was already clear and adequate, other felt despite the benefits of knowing additional details, it would have overwhelmed them, and yet others felt that timing was essential in providing information in relevance to both pre- and post-surgery. In fact, there were some participants who felt there was very little follow-up information post-surgery and took steps to do their own research and find strategies to cope with the aftermath of surgery, whatever that entailed.

“...Nothing for him to take home nothing for us to sit here in the living room and say okay why is she having hallucinations and that was from medication. Nothing that we could pick up and say, “Okay, why is she severely constipated? Why am I having vice-gripping headaches?” and we had to look all that up...”

Finally, many participants initially perceived “having adequate information” to be medically related and specific to the surgery. It is evident that most individuals, unless probed about the psychosocial factors and associated challenges, were oblivious to address such aspects as “needing information”. This suggests that patients may not be typically considering or possibly conscious of addressing such issues as information to be consulted on prior to surgery.

“So just know all the other things that can happen, like in life, if things like become complex. Maybe you’re working in a certain job, that makes things a bit more difficult, so just being in your last year of school, so like I think I was so focused on not having seizures I didn’t think about the other things that come into life that made me a little frustrated, or maybe feel a little bit bad. So I think speaking about that and that’s like really a difficult thing, because everyone has their own
different experiences…”

These findings suggest that the matters around information are more complex than solely being able to provide adequate information. The details, timing, length, format and types of information to be delivered are factors that need to be carefully considered when addressing the epilepsy population. Furthermore, steps need to be taken to provide information in a manner that is not misleading and results in presenting realistic expectations of surgery and life after surgery.

Support

The majority of participants expressed support of varying degrees to be a major factor that allowed them to manage through the surgical process and cope with the adjustments they faced post-surgery. Interestingly, different forms of support were critical at different times for different participants around their surgical experience and possibly essential in helping them overcome the challenges and surprises they faced post-surgery.

Many participants sought support from family and/or friends during their decision-making process. In fact, having a support network during the pre-surgical period was evidently something that was expressed by those who did not have one. Other forms of support including epilepsy peer support provided the final push for some participants to finally undergo surgery, albeit this was not the case for everyone, as some expressed not needing or wanting to speak to others having undergone epilepsy surgery.

“Um the doctors so I think (physicians name) said if you want to talk to anyone we can find someone for you, I just never took that option. For me mentally if I was going to do it, I was going to do it and I didn’t need anyone else to give me any guidance on it. that’s what it was for me.”

“okay, uh brain surgery’s over, go home, everything’s going to be lovely” like I knew that wasn’t going to happen. So um, but that was part of the decision making, was okay “so how can we make this work… afterwards”? And of course, I - like I said, I have a husband, I have a mom whose uh really supportive. So I had a big support group.”
In the post-surgical period, some individuals had been dependant on their support for so long, and expressed having grown stronger in their relationship. Furthermore, during the earlier weeks into post-surgery, evidently a period of intense vulnerability, participants emphasized their support being a critical part of their recovery. Others found their support system to be essential in getting them back to their daily life and having the encouragement to heal and overcome their obstacles.

“Um it’s a it's important to know what to expect when you get home and to know um what sort of activities you can or can't do, what you want to, um you know start doing slowly- and to really have that so that, for me anyway, I was so much more comfortable going into surgery knowing that afterwards I didn't have to all the sudden..., think about “what was gonna happen, what was gonna happen now?”. I had a sense of -a more sense of the relaxation that everybody..., knew..., what their part was, because we had discussed it and I wasn’t gonna all of a sudden throw them in and say: “come on over, I need help”, like it was more... they knew their part too, “okay this is what I'm gonna do, this is what I’m gonna do”. [ Clears throat] and so it was a calming..., feeling.”

“I think in hindsight a few people mentioned to me was don’t be too hard on yourself afterwards cause in hindsight I was definitely my worst critic right...sort of expecting a fast come back and whether it was my parents or my friends they'd always have to remind me you just had a part of your brain taken out it's going to take time so try not to be too too hard on yourself”

While the focus is primarily on participants having undergone surgery, it is evident that epilepsy surgery affects a network of people around that individual. Some participants suggested that their families may also require some form of support, primarily information to help them cope with the difficulties and adjustments needed for the patient to get better.

“And my husband even researched all of this stuff and then after he could not tolerate it for a while. So it was him too. When I did go see an OT for example, she said, “Yeah, of course it’s a process and he’ll tolerate it and six months it will get better.” I came out and said, “we’ll probably be separated by that time, he’s not going to tolerate it.” You know, I just wish he knew more.”

It is evident that most participants required short-term support during their recovery period, either finding this with family, friends or their peers. The level as well as length of support varied considerably as everyone recovered at a different pace. Some participants
continued to require support, for transportation or if they had experienced rather severe side
effects from surgery.

“Again everybody was for it. Everybody helped out with my husband coming to visit me. People
took turns watching my son in the house, picking him up from school. Again when we came home,
people came in with food and came and took turns taking care of us. It was all-supportive from
“go, go, go”.”

Interestingly, some individuals having recovered and having adjusted to their post-
surgical life, experienced a role reversal and in fact became support for others, whether this was
through volunteering, helping other family members or becoming part of the epilepsy peer
support group.

“It’s taking care of my family now that they were there for me when I needed them. I'm able to
pr—I'm able to help them provide for them, not just, not financially but emotionally and, you know,
if they need help that I'm there for them and not being always in fear.”

“Well because my surgery was successful till this point, I felt a responsibility to give back. So I’m
on a call list for Toronto Epilepsy, and to speak to surgical candidates who might be fearful to go
through surgery but they are good candidates. So I've been meeting with people face-to-face
andaslo over the phone just to help out.”

Through these experiences, it is important to note that support plays an essential role in a
patient’s experience of epilepsy surgery. Our findings suggest that a strong support network is
necessary around the process of decision making, a patients’ recovery, and reintegration towards
their “normal” lifestyle. Furthermore, some individuals may require more support than others,
suggesting that a system of support such as peer support needs to be made freely available for
those undergoing epilepsy surgery.
Identity

Epilepsy surgery can open a lot of doors for patients looking to gain back their independency, to be free of seizures and to be able to live with what they perceive to be a good quality of life. It is evident through participants accounts of their post-surgical life that epilepsy surgery can lead to alterations in identity in the form of a permanent change in their ability to do things. This is particularly true for participants who initially felt their seizures and epilepsy to impede on their relationships, their work, livelihood and other interpersonal matters.

“I would describe it as a bird that was set free, because I was able to say, “No.” I was able to have control over myself, and, things got worse to the point that if you’d ask me prior to surgery that I was going to take care of my kids, and buy my own home, and have my own independent life, I’d say, “I don’t know what you’re on, but that’s never going to happen.”

Some participants felt confused as to whether they still identified as having epilepsy or not. Furthermore, some individuals expressed having difficulties disclosing their circumstances to others despite being seizure free, primarily when seeking employment or returning to school.

It is evident that adjusting came more naturally for some, only taking a few months to feel comfortable in their environment while others even several years later, still experiencing an inner conflict with their self-identity.

“Like not completely, because I did find it was really difficult to explain to people. It’s like, “Oh, you have epilepsy.” But no, I’m not having seizures anymore. Explaining to people was like overwhelming when you look back on the full year how much had changed so I think just yeah more advice and just how to explain things to people.”

“Just feels like I’m lying to people. It still feels like it’s a huge part of my life and I'm still finding ways of-- I want it to be part of my life. Moving forward, I want to do things for people who are going through a similar process. See, it just feels like I'm lying. It's weird. And I try to be like, "They don't need to know that part about you," but it feels like it's too much a part of me to not share. So, yeah, not that it holds me back from making close friends, but it doesn’t feel like I'm able to share myself with someone until they know that. And I really like it. Takes me years to tell them, so it's very weird.”
The liberating changes that some participants experienced through epilepsy surgery led some individuals to feel a shift in their personality, independency, their ability to do things without fear, and without repercussion of having seizures.

“Like I make new friends and talk more than I used to be because before the surgery I used to be a quiet person and didn’t talk with anyone, but now I’m the opposite...”

“So we’ve got two little boys um never would've been able to do that if I had epilepsy so that I think would be the big thing and that's been life ever since right its too little kids, two very busy little boys- its not a lot of extra hobbies or stuff but I’ve got enough to keep me busy so-”

In cases where participants had become highly dependant on others, experiencing this renewed independence with surgery seem to have also shifted their personal network and the evolution of the roles these individuals played.

“So I think that was probably one of the biggest adjustments for me was in-after surgery I sort of realized who my true friends were and who were just your drinking buddies and associates were-ya know so that was actually one of the more difficult bits I think.”

“Yes, they weren’t used to that. Even my ex was saying, “I’m not used to you. I don’t even know who you are. The person I married was not you.” And he would even say, “I told you, you’re just forgetting.” And that was something that I was hearing all the time. Those mind games.”

What makes us who we are is partly defined by the people around us, so it is understandable that when a patient begins to evolve and adjust to post-surgical life, their relation to others begin to shift as well. Interestingly, this phenomenon is evident among participants who became estranged from their spouses, family and friends.

“I even tell people, you know, this is what I want you to do and this is what I don’t want you to do and I’m not having—people want to look after me and I say, “You know, I can look after myself now.”

“Um I’ll be quite frank. We had some arguments. Mainly it would just be me---well actually it was both ways but more me stepping in and doing it automatically. It took a while for me not to so much trust you, but to understand that __ is capable of making her own decisions. But that was never explained to us or that type of thing, and I think that’s a big one.”
Others experienced an opposite affect, expressing a strengthened relationship with their personal relationships. Needless to say, these findings suggest that while some participants and their associated network were able to adjust to these changes, others were less apt at overcoming such changes.

“One of them, yes, just ended. We live far away from each other. But the other one, yeah, he finally admitted, he was like, "I don't see you as the person I met." And I think that had a lot to do with the surgery, and he was with me through the surgery. And then afterwards it was just downhill from there."

Interestingly, this is acutely similar to a long-standing phenomenon of “biographical disruption” identified to manifest in individuals initially diagnosed with a chronic illness (Bury 1982), however in the case of epilepsy surgery, in reverse order as illness and/or associated symptoms are diminished. This lends to the idea that a significant disruption such as an attenuation/cessation of a chronic illness like epilepsy, can have profound effects on an individual's identity and their environment followed by consequential changes. It is clear from the varying outcomes of separation, difficulties and associated friction between relationships that these changes require instating necessary measures and professional intervention to allow for a smooth and successful adjustment.

*Expectations vs. Reality*

It is evident from literature that expectations or lack of expectations set prior to epilepsy surgery have an impact on the way individuals perceive the outcomes of surgery (Wheelock et al. 1998; Bower et al. 2009). Participants reacted differently to their experience of epilepsy surgery and a spectrum of perspectives was collected. While some participants were modest in
their response to surgery, others were all too happy to have undergone the surgery and yet others were not too keen with the outcomes they faced.

“- it was wonderful I was so happy that I did do the surgery because definitely it’s been a long time and I’ve certainly never had a seizure and I used to be having them speech-wise. I could have them four, five times a day so…”

“My patterns and routines have pretty much stayed the same. I’ve had to manage the same triggers the same way. There isn’t anything significantly different that I’ve had to change in terms of my day to day life.”

“I thought, you know, that maybe things would be good—getting better like, I would be married and have—be able to have kids and things like that, but still nothing’s changed.”

Evidently, for some participants, their expectations matched their reality of post-surgical life, and as such they expressed joy and relief, this was true for both seizure free and non-seizure free post-surgical patients. This is especially true for those participants anticipating for better control and a better quality of life relative to what little control they experienced pre-surgery.

“Yeah, but she’s gaining it slowly. It’s just a long road. All I can say is tell people not to expect an overnight miracle. Sure, the seizures go away, but then you’ve got that emotional bottle adjusting to not having seizures…”

Interestingly, there were seizure free patients that although had expected to be seizure free, experienced a whole other aspect of life that they were not anticipating or even conscious of (the emotional, psychological and adjustment process) so while some of their expectations aligned well, other aspects that they experienced they had a lack of expectation for. Similar to other studies (Tanriverdi et al. 2008), our findings suggest that some individual’s perceptions of a successful surgery may not directly correlate with seizure freedom and factors outside of seizures need to be given attention to.

“Well, that’s it and then, you know, not, you know, not realizing that even though you have this, you know, you’ve cured one area something else might be triggered. And what, you know, what that part of the brain will affect. If you don’t have function of it or if it’s removed.”

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“But when it's done, if there are still problems, one of the big things is just accepting that what created my seizures are gone, I'm still an epileptic but I'm seizure free, but I still have other issues to deal with now, that's a lot to take in, so I think everybody needs to know that you know what, when one thing is done, other things can come out of it, good or bad, which is, be prepared, my husband always tells me you know what, prepare for the best, expect the worst.”

Alternatively, there were a few participants that were inflamed by their surgical outcome and expressed difficulties adjusting to these circumstances especially since their pre-surgical expectations did not match the reality they faced.

“And make sure that the part where I said my advice to people my advice to people that have epilepsy that are going to go through this thing, don't, because it'll wreck your life forever.”

“Well, I basically, I live a really closed life now. Now, I don't really have ambition to do much. You know, my joy is just watching TV, which is not good, but, you know, now it's just a little bit different than it was before.”

While this is to be expected as illustrated by other works around expectations, chronic illness and surgery (Reid et al. 2004), there are some interesting findings around participants having their expectations not align with their perceived reality, yet still pulling through and making efforts to adjust to their post-surgical life. It seems these group of individuals have an inherent resilience or ability to cope because while they didn’t expect to experience what they did, they found ways to adjust and accept their circumstances.

“I think I just accepted that this may not work, but I'm going to make it work [laughter] and my attitude from arthritis-- I've been told I'm going to end up in a wheelchair because the disintegrating in my back. And our youngest son has joked saying, "Oh well, you'll just get one of those armless wheelchairs and continued dancing, that sort of the attitude I have.”

“I think just taking it slowly at that one point when I was like taking - like it’s not really always an option for people, but like taking less courses and um looking into like slowly like oh, summer jobs, volunteer hours, but at the same time, I should have tried not to like push myself that hard, so it’s just about- it’s difficult, but for finding a balance is what I’ve tried to do. What I would-say people should try and do themselves cuz- and it’s impossible to say where you’re going to end up...”
These findings provide new insight around participants’ experience of epilepsy surgery. It is evident that these individuals also initially experience an malignment between their expectations and reality. Our work on predictive coding and the manifestation of the burden of normality and forced normalization lend to the idea that when expectations do not align with reality, a positive prediction error occurs which can lead to problems. However, it is not the error itself but the inability to cope with this reality that can result in the above phenomena. Therefore, it may be these participants’ ability to accept and keep an open mind to adjusting to their circumstances is what allowed them to perceive a modest outcome.

“And we would make goals. Do this. Let’s work at reading because I love to read, but I couldn’t. What happened is I’d read, and then I’d go back later to read some more, and I’d forget what I had read, and I had to start over. So, I started doing crossword puzzles, and so we made a goal that I would read one chapter to try, and get. So we made goals. Like I said, I had a great team my family doctor, my psychiatrist, and my neurologist”

“I just thought I would feel safer but it’s just now it’s- it’s the memory thing, I can't work very much I can’t and I- all I my self-esteem is very low, you know, but I always try to be positive of course I don't want to get depressed, but uh, it’s just the way I look at things I always look at the positive and appreciate everything especially this place here, you know, I feel very lucky to be a part of it.”

Nonetheless, the matter of fact remains that within this group, some participants were able to adjust and cope better and quicker than others. Additionally, we identified various coping strategies that participants found to be useful throughout their post-surgical experience. These include but are not limited to changing routes, accessing information, gaining confidence, support network, giving back, planning ahead, and therapy.

Still, participants made suggestions on how to improve upon the process around epilepsy surgery, factors and information they themselves felt in hindsight would have been useful.

“I don’t know, I guess maybe if- it would have been good even if we were given like um, “What to look for on-line” to “What to anticipate,” just something that- how long- just to be realistic about
“Well, he just doesn't get it. Why I can't remember, or why I can't just focus and pay attention, or why I can't think before I react. I think he needs a little bit of-- I think families need to be informed about things that will be happening, and I don't think it should come from the patient.”

These instances and recommendations from patients’ experience provide the opportunity to optimize the time it takes people to accept, cope and adjust to their reality. Providing realistic and relevant information pre-surgery may help patients’ form realistic expectations and thus minimize the cases of a large prediction error, while providing help-seeking and coping strategies with associated resources could help to address and tackle, from an early stage, possible discords in pre-surgical expectations and post-surgical outcomes.

5.2 Focus Group Results

In order to confirm and validate an accurate representation of study participants’ experience and interpretation of interview data, qualitative research commonly involves doing a member check, a way to corroborate the main research findings (Stake 2010). In this study, a member check was done in the form of a focus group with eight participants, of which five were study participants and three family members. Here we report the results of the focus group.

Participants responded well to the study findings that were presented to them, further emphasizing aspects they felt to have directly related to them in their experience of epilepsy surgery.

“All I will say quickly is that I think the summary of the study findings, I think, is laid out really well. I think it addresses all the key things on my mind. And the big thing, as she mentioned as well too, was the addressing expectations and the psychiatry involvement. And neither of those were things that had been suggested to me. They're both things that I thought about or asked for. And the thought about offering that as an option to people I think is really great.”
One participant acknowledged shifts in identity, associated psychosocial factors and the adjustment for both the patient and family, that came with undergoing a life altering surgery.

“So, in our case, changing our relationships because this gives her the possibility of being seizure-free, it has really changed her attitude. And we've tried to adjust because she's much more assertive.”

“One other thing-- possibly under social-- is self-image. Her awareness of herself has changed and she sees herself as a different person. But she still identifies as an epileptic and belongs to the Epilepsy Toronto group and so on. And that is, I think, for her, is a struggle...”

Other major agreements were on epilepsy peer support, pre-surgical consultations, and availability of resources post-surgery,

“The point on physical therapy really hit home for me when I was in recovery and dealing with insane pain and constipation from the medication. Nothing was helping with the constipation. And so finally, my chiropractor/massage therapist came and made a house call.”

“I feel talking to people who have had surgery, and not just one or two people, because their results and experiences are different, but talking to a variety of people who have had the surgery would be helpful. People who had successful surgeries and people who had maybe complications. Both. My son is part of a support group so I think that was helpful for him. So I think that's really important. I think any kind of support group before, after, during, is really important. People that [inaudible] similar age groups, similar kind of lifestyles, I think that's important. And I also think the psychiatry involvement or psychology involvement is important...”

“So if the surgery person, person who's contemplating surgery speaks to somebody who had a great outcome, no more medication, no more surgeries, in that one person, great but they need to see somebody who had surgery and wasn't successful and then maybe somebody who had some success. So I think they need to see-- people should see three scenarios at least.”

When it came to possible informational gaps in the surgical process, many participants provided their feedback and further confirmed the need to reassess the type and format of information and education provided pre-surgery.

“Oh. The only thing I was going to add is accessibility to the information. Myself and a lot of my family in general, we don't deal well with paper because we just kind of throw it out...If we can
access it electronically then we could constantly refer back to it or show it to different members
of our family pretty easily.”

“The one last problem I had was that there should be some kind of discussion or a little video or
something to show people life before and life after.”

In fact, participants shared their experience of having to cope with many obstacles on their
own and having come upon solutions accidentally. They emphasized the need for health care
providers to encourage help-seeking behavior in patients’, pre-surgery, so that challenges
that may arise post-surgery can be addressed promptly to facilitate a speedier recovery.

“Yes. So we weren’t really aware of kind of worst-case scenario. If this happens, then this. These
are things that may happen, but If this happens, see your doctor. Go back to the hospital…”

“A lot of times, you find things out by chance...Maybe the hospital can provide a list of resources:
psychologists or neuropsychiatrists and massage therapists that people can access.”

“And if you really say, "No, I don't need counseling," or, "I don't need to speak to a psychiatrist,"
then you really hear everything coming at you and you reiterate, "I don't need that." And that's
fine, but at least it was discussed and offered and said why maybe it's there if you need it.”

Moreover, participants provided further insights into what kinds of information and the
timing with which this education could be delivered.

“So, I think there needs to be different forms like one may be what to see and expect right after
surgery. How the head looks, speech, whatever and then maybe long-term outcomes. This person
is seizure free, this person has some-- I don't know how-- this person is the same or worse. I think
people need to know that. That maybe you're not going in with a guarantee and so that there are
no surprises.”

“I was going to say both really because you're state of mind before the surgery could be very
different than your state of mind after. So, I think the more information people have at different
times—”

“No. I agree. To have something like, let's say, a pamphlet or something like that and when
something comes up after the fact, at least you can make that association that, "Oh, yeah. I did
read this at some point," and it's not a surprise to [inaudible]—”
Having family members participate in the focus group, provided new insight in what could help to improve the existing system around epilepsy surgery. Participants emphasized having family present during the information delivery.

“And I think also that a doctor should insist there be a spouse or family member there as well too, to take in the information...”

“In an emotionally charged situation like this is, you would want repetition so that every opportunity for something to get inside a parent or a spouse or anyone that lives with you, but even the patient themselves.”

Interestingly, participants encouraged the availability of a sufficient level of information pre-surgery, irrespective of patient preference, suggesting its potential benefits post-surgery.

“So again, to aggregate the information, provide potential, to look out for that-- Even if it scares them, it's still better to prepare them because I’d rather be scared and prepared than surprised. Something to make sure you’re ready to deal with if it comes up afterwards.”

“...Most people will need some information but a few people will need extra, the one-on-one and so on.”

“You can't make them to do anything, but they're minimal if they're not interested. At least give them a handbook to walk away with, they may choose not to read it.”

Not only does this focus group provide confirmation of the study findings, it justifies the need for a pre-surgical intervention not as a recommendation from a researcher but directly from patients’ account of their own surgical experiences. Participants have provided new insight around educating others planning to undergo epilepsy surgery, through the suggestions of information delivery, its format, type and timing. This provides an opportunity to build off such suggestions and fill in the knowledge gap that has been informed by this study.
5.3 Summary of Information Content and Delivery

Finally, in addition to obtaining insights into patients’ pre-surgical predictions and expectations, and patient identified needs from their post-surgical experiences, and possible coping strategies, this study sheds light on reasons why information might not be permeating and being processed as intended. Figure 5.2 summarizes how participants pre-surgical and post-surgical experiences inform different types of information relevant to informing not only the content of a pre-surgical intervention but its possible structure.

Participants’ post-surgical experiences were important in identifying “what” type of information they may need addressed (A) or was helpful for individuals (B). This comes directly from participants experiences and what information they either found was deficient or could have been beneficial in emphasizing, pre- and/or post-surgically. This informs where information may be lacking and also addresses beneficial information extracted from participants’ misconceptions, and overly generalized understanding of certain concepts and outcomes. Furthermore, the research findings reinforce the need to provide epilepsy peer support as an essential addition to the pre-surgical process.

Alternatively, participants’ pre-surgical experiences clarified “how” information should be delivered, as participants’ retention of information was highly contingent on memory and ability to process the information. This is a very critical factor to consider as it will also determine how effective an intervention is in providing information that is not only informative but can be practically used to prepare for post-surgical life and possible adjustments. The degree of impact of epilepsy on QOL will help to identify highly vulnerable patients and direct tailored information and guidance. Determining the level at which seizures and epilepsy have been
impacting the individual will also help to determine “how” much information needs to be addressed and reiterated.

Figure 5.2: Breakdown summary of types and forms of information, identified in needs assessment study.
6. DISCUSSION

6.1 Overview

The aim of this thesis was to conduct a qualitative needs assessment around the surgical event through the experiential accounts of adults ages 18-70 years who had undergone epilepsy surgery. We specifically wanted to investigate information or knowledge gaps existing around surgery and identify the major categories and themes participants accredited to be important. Participants’ reason for undergoing surgery varied considerably, impacting their perceptions of surgical outcomes. Despite the majority being seizure-free post-surgery, participants shared the challenges they faced both during their short and long-term recovery, aspects of surgery they felt they were unprepared for. Additionally, this study provides insight into the coping strategies and suggestions made, to deal with the challenges and adjustments faced with post-surgery. Taken together, these study findings provide an opportunity to investigate the benefits of offering a comprehensive level of information delivered pre-surgery, and helping patients to form realistic expectations. As such, this research has important implications for clinical practice providing critical insights in informing the development of a pre-surgical intervention to guide patients to form realistic expectations, experience a smoother recovery and to anticipate possible adjustments that may be needed post-surgery.

We will begin by discussing the key findings of the research in the context of the literature. We will discuss the current policies, services and chronic disease management around the epilepsy surgical process currently available in Canada. Along this context, the practical implications of this study will be discussed, followed by its strengths and weaknesses, and finally the future directions for research.
6.2 Contribution of Research to Literature

It has been well established by now that a successful outcome of epilepsy surgery is a combination of post-operative seizure status, expectations, addressing possible post-surgical challenges, and the ability to making appropriate adjustments (Wilson et al. 2007). Furthermore, previous research have identified the burden of normality, forced normalization and other associated psychosocial factors to manifest post-surgery, issues that have been found to significantly undermine the potential benefits associated with a successful seizure free or reduced seizure outcome (Wilson et al. 2004; Wilson et al. 2001; Mula 2010; Derry & Wiebe 2000). Based on these findings, many of these studies have proposed the necessity of a pre-surgical intervention/program to address such issues (Wilson et al. 2007; Derry & Wiebe 2000; Bladin 1992).

While both quantitative and qualitative research has been done to understand the perspectives of surgical epilepsy patients, many of which have provided important insights into understanding patients perspectives of a good surgical outcome along with their experience of both pre- and post-surgery, little knowledge exists around an in depth understanding of the specific factors and variables patients perceived to be important pre-surgically that would have aided them after, given their experience of post-surgical life. Overall this study expands on previous research by adding depth to patients understanding of information, and patient identified expectational and educational themes around pre-surgery and post-surgery. This study further highlights patients as the experts in providing their real-life experiences that helped to determine what aspects of the surgical event worked for them, and where there was room for improvements. These accounts of participants’ experiences and suggestions offered significant contributions to our overall understanding of the gaps that exist in the information, resources and
services provided to patients’ pre-surgery and have important implications for policy and practice.

Our study findings illuminate the various reasons patients undergo epilepsy surgery, and the dynamics that exist between an individual’s severity of epilepsy, their decision-making process, and their perspectives on being provided with sufficient information. Based on the literature reviewed earlier in the thesis, others have identified the major motivational factors for undergoing epilepsy surgery to include employment, independence, driving, socializing and overall improvements in their quality of life (Taylor et al. 2001; Ozanne et al. 2016; Aydemir et al. 2004). Additionally, the decision to undergo epilepsy surgery can be a stressful life event, requiring extensive deliberation and thought (Derry & Wiebe 2000). In this study, while the motivations to undergo epilepsy surgery are consistent with other research findings, we have found that patients’ decision making to not always be careful and calculated. In fact, through this study, we were able to gain new insight around patients’ understanding of pre-surgical information and how this impacted their decision. We found participants final decision to rely on a combination of their perspectives of what a good surgical outcome was, their preference for specific types of information and satisfaction with the information, their attitudes towards associated risks, and also the severity of their epilepsy. It is evident that the attitude with which they made their decision; whether this was after considerable deliberation, support and information, feeling cornered with no other alternative solutions, or somewhere in between, informed the expectations or lack thereof they held going into surgery and the subsequent consequence on their perceptions of post-surgical outcomes (Wheelock et al. 1998; Ozanne et al. 2016; Wilson et al. 1999; Auer et al. 2016).
Participants shared their experience of post-surgery, the unanticipated challenges faced during the recovery period, the adjustments required to get back to their perceived normal life, and the coping strategies associated with this transition. Irrespective of a seizure free outcome, participants expressed medical, psychological and social concerns, aspects they experienced post-surgery not being aware of or having been informed about pre-surgery. These shared post-surgical experiences are consistent with the considerable literature done around the burden of normality and the manifestation of post-operative levels of psychological distress associated with unrealistic or unrealized pre-surgical expectations (Wilson et al. 2001; Wilson et al. 2004; Wheelock et al. 1998; Aydemir et al. 2004; Kemp et al. 2016). Furthermore, several other studies have identified pre-surgical expectations to impact the perceived success of post-surgical outcomes, further warranting the need for a pre-surgical intervention (Langfitt et al. 2007; Bower et al. 2009; Bladin 1992). In fact, based on other chronic disease management studies, optimizing pre-surgical expectations has a high probability of leading to an overall good perceived surgical outcome (Rief et al. 2017). That being said, in order to take these studies into consideration and address the issues around pre-surgical expectations, we needed to understand how patients made expectations around certain issues and why not in other aspects.

Our model of predictive coding helped to guide and make sense of the information and experiential accounts that patients shared in this study (summarized in the results section). We used the concept of expectations and reality (the actual perceived outcomes) to account for what happened around people’s experiences. Our findings suggest that people’s expectations or lack there of, are influenced by the information or gaps in information that exist around the pre-surgical period. Furthermore, based on patients accounts of possibly feeling more prepared if specific information relating to their experience had been addressed, suggests that the surgical
experience can be modified by how patients process pre-surgical information. We can further link patients’ recommendations/suggestions of the need for specific areas of information to their experiences; major informational categories to be advantageous in setting realistic expectations and that can inform a balanced level of information, both medical and psychosocial, to be incorporated in a pre-surgical intervention.

Our study findings further suggest that given that pre-surgical information is primarily delivered verbally, along with participants possible memory deficits and cognitive functioning, in addition to the stress and overwhelming feelings that come along with making a decision to undergo epilepsy surgery, participants perceived understanding of information or recollection of it, may not be aligning with its intended purpose. In fact, some patients and families may not be able to fully process all the information provided given the short duration of the pre-surgical consultation. These findings give credence to the relevance of preparatory information being presented to participants that is reiterated, easily understood and accessible on demand (i.e., on paper and/or online) in the pre-surgical phase.

It is clear that undergoing a life altering treatment like epilepsy surgery can significantly impact how patients’ identify themselves, this is especially true for those with a more severe case of epilepsy (Wilson et al. 2001; Wilson et al. 2007). Interestingly, we can draw a reverse parallel to the concept of biographical disruption as the onset of a chronic illness tends to cause a dynamic shift in the individuals way of life (Bury 1982). It is evident that the reverse, an alleviation of a chronic illness, tends to not only change how patients define themselves, but how their surrounding networks shift and the subsequent need to adjust to these disruptions. While this was true for some participants, their feelings of renewed independence, the ability to pursue new aspirations and their altered or reinstated role as caregiver (i.e., parent, spouse); our research
indicates that some participants did not necessarily feel like a different person or felt a change in their identity or personality, rather they felt they were now able to freely express themselves not being restricted by their seizures. Alternatively, our research suggests that some participants not anticipating these shifts, even after several years post-surgery, felt conflicted facing a conundrum that the surgery had allowed them to be seizure free but still having to take anti-seizure medications and identifying as epileptic. These conflicting issues were further complicated by not knowing what or how to disclose these aspects to friends, employers and new relationships.

Our research also confirms that the alleviation of a chronic illness and the associated adjustment to a patients life can alter the relationships they have with their surrounding environment and personal network (Langfitt et al. 1999; Wilson et al. 2007). In fact, participants expressed the challenges and adjustments they faced with their families, further suggesting the importance of involving family members in the pre-surgical consultation in preparation to address such issues. Caring is a defining feature of family member’ interactions, roles and relationships around those with epilepsy (Webster 2017). Therefore, having established such rooted dependency on others may be why relations break down when epilepsy is controlled post-surgery. Furthermore, it is apparent that following epilepsy surgery, the subsequent struggles between relationships is a result of having to adjust to the new dynamic roles associated with being seizure free or having reduced seizures (Bladin 1992). However, from our study we have established that in some cases it was the family members that adjusted around this new freedom, while other cases participants expressed having strengthened relationship because of this dependency and felt the loyalty and gratitude towards the significant other. These findings lend to the idea that it is the mutual adjustments made on both sides of the relationship, that allow for
a smoother transition. Overall, in order to reduce the burden on the patient and to optimize the adjustments following epilepsy surgery, these findings add depth to the importance of educating both patient and family members around such issues.

In sum, our research sheds light on the perceptions and experiences of adults with epilepsy aged 18-70 years having undergone surgery, highlighting that participants may not always make decisions for the same reasons, that information is processed differently depending on one’s preference and circumstances, all of which have consequences on the expectations made pre-surgery and the perceived success of post-surgical outcomes. Additionally, we suspect that depending on the participants’ optimism, support, ability to accept, cope and adjust to unanticipated post-surgical outcomes, may lead to a stark difference in perceived success or failure, in addition to the length of time to recover and associated psychological and emotional impacts that may occur. However, this observation requires further inquiry and the possibility of conducting a randomized control trial to provide sufficient evidence to support this claim.

Finally, participants conveyed different categories of information and issues that were lacking in their recollection of their pre-surgical consultations, information they felt would benefit others in forming realistic expectations and preparing for post-surgical life. In comparing these findings to the literature, which primarily investigated patients’ experiences of epilepsy surgery, both pre- and post-surgery, many of which were quantitative in method, there were both similarities and differences, as indicated above. Furthermore, our research took on a novel approach to understanding the experiences of post-surgical epilepsy patients, by directly addressing patient’s retrospective accounts of the gaps in knowledge that exist around the surgical episode and investigating patient identified informational categories that will inform the development of a pre-surgical intervention. Overall, the collective findings contribute to our
understanding of the surgical process and existing knowledge gaps around clinical practice from a patient perspective and provide an opportunity to improve upon these issues by addressing patients’ concerns and suggestions through developing a comprehensive education program around epilepsy surgery.

6.3 Current Chronic Disease Management and Implications for Policy and Practice in Canada

Over the last several years, the Ontario government realized that its residents with epilepsy were significantly under-serviced. As of 2006, only 2% of Ontarian’s with surgically amenable epilepsy received epilepsy surgery (Health Quality Ontario 2006). With this realization, a Provincial Epilepsy Implementation Task Force was created to address the lack of services for those with epilepsy, specifically addressing the underutilization of epilepsy surgery. The Provincial Epilepsy Implementation Task Force a committee of Critical Care Services Ontario has increased surgical services through the expansion of existing surgical centers deemed Regional Epilepsy Centers of Excellence. It has also created District Epilepsy Centers to feed Centers of Excellence, of which TWH is one. Furthermore the taskforce has published specific guidelines (Epilepsy Monitoring Unit guidelines, Management of refractory Epilepsy guidelines and four others (Force 2014; Epilepsy Implementation Task Force 2015; Critical Care Services Ontario n.d.) in regards to the management of those with epilepsy in Ontario. At the TWH alone, operational costs of $2.5M are required to run the Surgical Epilepsy Program. Although such investment in the health care of Ontarians with epilepsy has increased the number of patients being offered life altering surgery, our experience and the literature (reviewed in background) bear out the fact that adjusting to a seizure-free/post-surgery life is a difficult process and can compromise the results of surgery. Therefore, our research findings and their
implications for clinical practice align well with the Provincial Epilepsy Strategy and Ontario Ministry of Health and Long-Term Care investment goals, by aiming to optimize the outcomes of surgical patients. Furthermore, these finding sets in place contextual relevance to investigate the design and development of a comprehensive pre-surgical intervention. Poor adaptation and frankly mal-adaptive adjustments to the post-surgical life result in decreased post-surgical QOL and increased healthcare utilization. By translating the combined findings of our research and previously established literature to clinical practice, we have the potential of optimizing post-surgical psychosocial adjustments which can further bolster the cost-savings that come with being seizure-free (Wiebe et al. 1995; Silfvenius 1999; Langfitt 1997; Scott Perry & Duchowny 2013; Bowen et al. 2012) while improving QOL.

6.4 Strengths and Limitations

6.4.1 Strengths of Study

Through extensive research pertaining to psychosocial components involved in patients’ surgical recovery, studies dictate that rehabilitation starts before surgery (Wilson et al. 2001; Wilson et al. 2007; Langfitt et al. 2007; Derry & Wiebe 2000). Despite this, preoperative determinants of QOL have received less attention than postoperative determinants (Seiam et al. 2011). Nonetheless, it has been concluded that a pre-operative assessment is “the” approach in identifying and predicting possible psychosocial complications that may arise, and in turn, give insight into appropriate actions/adjustments that can be made (Derry & Wiebe 2000; Wilson et al. 2007). However, in order to establish and implement a successful pre-surgical intervention program, one designed to address patient specific psychosocial difficulties including
employment, requires determining the necessary factors/variables and information to be incorporated, and this to our knowledge has remained unexplored until now.

Our qualitative needs assessment is the first of its kind and provides considerable data to inform the design of a pre-surgical intervention. In fact, it directly addresses the experiences of 73 post-surgical epilepsy patients and their insight into the gaps that exist around the surgical event. This is pertinent because our study lays out the groundwork for designing an intervention that will remain focused and relevant to patient identified needs. Furthermore, this study is informed by our model of predictive coding, directing data collection to patients’ pre-surgical predictions, post-surgical realities and knowledge gaps around their surgical experience. Therefore, based on Figure 5.1’s major *expectational and informational themes* identified from patient interviews, will allow us to understand what predictions of post-surgical life, or lack thereof, pre-surgical candidates have. Moreover, this in conjunction with accounts of participants post-surgical perceived realities will help to establish patient specific information provided prior to surgery such that: A) realistic and realizable predictions can be made and subsequently B) room for perceived failure is diminished, allowing for individual’s predictions to align with perceived post-surgical outcome and reduce the probability of acquiring a large prediction error.

Furthermore, this needs assessment reveals the depth and complexity associated with patients’ experiences and interaction with information around epilepsy surgery. It is evident from Figure 5.2 that this study provides insights beyond patient identified needs and examines participants capacity to make sense of information. It further exposes the possibility of discords between information presented and its subsequent interpretation and retention, largely influenced by patients’ memory and cognitive function. Hence, these results emphasize the need to educate patients pre-surgery by addressing a number of patient identified needs complemented by the use
of an appropriate form of information/knowledge delivery. These measures will ensure the flexibility of accessing important information both pre- and post-epilepsy surgery.

Additionally, while the qualitative needs assessment pertains to an epilepsy surgical population specific to a single epilepsy centre, likely providing patient identified needs for a particular geographical location, it is important to note that many of the informational categories from the study findings including those associated with memory are consistent with literature and may well be portable across other epilepsy centres. Additionally, other categories can be identified as clinician and patient independent factors, including psychological effects, medical concerns and structure of information delivery that may be transferable and adaptable to other centres. Nonetheless, acquiring a consensus on the major study findings, possibly through a survey across other epilepsy centres is warranted.

We also conducted a focus group interview to confirm and validate the study findings. This focus group further emphasized the need for a pre-surgical intervention and necessity to educate and council both patients and families prior to undergoing the surgical procedure. Furthermore, while we understand the burden of normality and forced normalization to be the two phenomena for cases of poor postoperative outcomes, we believe our paper on predictive coding is a plausible mechanism with which these phenomenon manifest and we believe it is in association with this mechanism along with our research findings that we can realize change (Mehmood et al. 2017).

Finally, Table 5.2 provides a summary of clear and key recommendations coalesced from this study’s findings for the benefits of helping clinicians address the concerns and information identified by people with epilepsy in their own clinical practice.
Table 6.1: Summary of study findings in the format of clear and major recommendation for clinical practice.

<table>
<thead>
<tr>
<th><strong>Key Recommendations</strong></th>
<th><strong>Essential Information</strong></th>
</tr>
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<tbody>
<tr>
<td><strong>1.</strong> Complementing verbal consultation with <strong>written/accessible and reiterated information pre-surgery</strong>. Also encouraging note-taking or recording by patients and support.</td>
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<tr>
<td><strong>2.</strong> Ensuring patients understand the extent and intensity of pain that may be experienced.</td>
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<tr>
<td><strong>3.</strong> Patients’ awareness on the variability in the length of recovery time and adjustment (i.e., encouraging self pacing and weaning into daily personal and vocational activities)</td>
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<td><strong>4.</strong> Possibility of medication and/or physical side effects (i.e., medication withdrawal symptoms, heightened senses, fatigue, loss or gain of memory).</td>
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<tr>
<td><strong>5.</strong> Ensuring patients have (or are provided with) a circle of support, before, during and after the surgical event (i.e., personal, family, peer and medical).</td>
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<tr>
<td><strong>6.</strong> Patients are entering surgery with a <strong>stable and accepting mindset</strong> of the various possible outcomes of their post-surgical state (both of medical and psychosocial nature).</td>
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<tr>
<td><strong>7.</strong> <strong>Mandating Peer Support Groups:</strong> meeting with several individuals having undergone epilepsy surgery of varying post-surgical outcomes (i.e., seizure-free, improved seizure free state, no change) ideally matching patients’ demographics.</td>
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<tr>
<td><strong>8.</strong> <strong>Addressing Patient Expectations:</strong> ensuring realizable and realistic expectations are being formed (guided by the findings of this study).</td>
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<tr>
<td><strong>Information Incentivizing Help Seeking Behavior</strong></td>
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<tr>
<td><strong>9.</strong> Patients’ awareness of possible temporary <strong>emotional and psychological</strong> instability post-surgery (i.e., anxiety, depression, mood swings, behavioral changes).</td>
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<tr>
<td><strong>10.</strong> Dynamics and complexity of <strong>changing relationships</strong> (encouraging <strong>family involvement</strong> and education pre-surgery).</td>
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<tr>
<td><strong>11.</strong> Possible changes in personal identity that may warrant seeking counselling.</td>
<td></td>
</tr>
<tr>
<td><strong>12.</strong> Accessibility and availability of resources and services (psychiatrist, social worker, massage therapist, nurse phone calls) pre- and post-surgery.</td>
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</tbody>
</table>

### 6.4.2 Limitations of Study

Most participants, either by preference or due to commuting difficulties, were interviewed over the phone. This was a limitation because a lot of contextual information was lost, I was not able to perceive their physical sense, and there might also have been concealment when asking questions or probing, aspects that would be more visible in person. Furthermore, the extent of their health and their environment were also not apparent.

Furthermore, given the time limitations and rich composition of seventy-three interviews, it is possible that I was not able to learn everything. Furthermore, not all data was analyzed.
iteratively and many of the transcripts were analyzed after all the interviews had been conducted. From these limitations, it may be beneficial to have two interviewers in the future along with a group of researchers to simultaneously analyze transcript data and discuss major findings to enrich the qualitative analysis.

Finally, there have been some changes in clinical practice in the last decade around epilepsy surgery. Therefore, some experiences of individuals, specifically of those who had surgery several years back (5-10 years ago) may not align or reflect the needs of those with a more recent experience. Irrespective, these participants experience still provide substantial insights into their interaction with the surgical process.

7. CONCLUSION

Findings of this thesis provide novel insights into patient identified needs around the surgical episode. Collectively, this research enhances our understanding of patients’ experiences around epilepsy surgery and further illuminates the expectational and informational categories identified by patients to be addressed pre-surgery, and in doing so lays out the framework in designing a pre-surgical intervention, possibly complemented by resources provided post-surgery. Future research is warranted to build upon the framework provided by this study and to utilize these findings, in conjunction with previous literature, to design, develop, and evaluate a comprehensive pre-surgical intervention.
8. FUTURE DIRECTIONS

There are a number of potential directions for future research, which build on the research findings of this study. Firstly, based on the insights we have gained from this study, some recommendations for clinical practice will be made followed by the next steps in strengthening the theoretical framework to inform the development of a pre-surgical intervention.

8.1 Recommendation for Clinical Practice

Our work from the perspective of post-surgical epilepsy patients and family members has revealed 1) the method of information delivery and 2) ensuring the intended understanding of information, to be two essential criteria in preparing individuals for post-surgical life. Furthermore, our current findings suggest that the content of the information may be difficult to understand or relate to, especially in the context of anxiety provoking information such as risks of medical complications and memory difficulties. We believe that informing patients of essential information that relates to patients’ recovery and adjustment process, will allow these individuals to inform thought-out decisions and understanding of common experiences post-surgery. Therefore, delivering non-verbal and/or printed forms of education to supplement the traditional verbal exchange of information, are warranted.

Along with education, with our understanding and recent publication (Mehmood et al. 2017) on the contemporary view of forced normalization and burden of normality and its associated predictive coding mechanism, we suggest the need to address patient expectations. Essentially, we propose that an intervention designed to educate and thus prompt discussion of expectations specific to each individual prior to surgery will minimize the perception of failure.
and the difficulties faced from unrealized and/or unrealistic expectations. This is realizable since we have recently demonstrated that providing balanced information about surgery can significantly alter an individual's perspective about surgery (Zuccato et al. 2014). In fact, cardiac surgery is one discipline that has identified the significance of preparing individuals for postoperative life and has illustrated the critical role optimizing preoperative expectations plays in contributing to improved postsurgical long-term outcomes (Auer et al. 2016; Laferton et al. 2015). Therefore, along side education, we recommend expectation counselling or other appropriate forms of therapeutic intervention should be incorporated (i.e. cognitive behavior therapy (CBT), that work through developing realistic expectations about the surgical outcomes and the recovery process, potentially providing discussion around management of unpleasant outcomes and ways to positively influence the disease course after surgery (Rief et al. 2017).

Overall, based on our study findings along with recommendations made by previous research (Wilson et al. 2005; Langfitt et al. 2007; Derry & Wiebe 2000; Bladin 1992), we suggest the need to utilize our study findings to design and evaluate a comprehensive pre-surgical intervention. A successful preoperative intervention to enhance postoperative QOL could also result in reduction in healthcare utilization and thus reduce both direct, and indirect medical costs of epilepsy (Mansouri et al. 2015).

Finally, there are quarter yearly epilepsy surgery support group meetings held in Toronto Western Hospital (TWH) to provide surgical candidates with an avenue to interact in open conversation with epilepsy post-surgical patients. Many attendees participate to hear first-hand stories and experience of others having gone through the surgery and their personal decision-making process. While current participation is voluntary, we recommend steps to mandate these sessions and make it a part of the intervention where all candidates will have to attend at least
one session. We further suggest other epilepsy centres to instate such meetings such that pre-
surgical candidates have the opportunity to access epilepsy peer support.

8.2 Validation of a Pre-Surgical Intervention

It is pertinent to focus on enhancing surgical effectiveness. To do this, we propose to
intervene prior to surgery. We firmly believe that realizing pre-operative expectations will
minimize the level of psychosocial distress and difficulties that are seen to arise when sufficient
measures are not taken to address patient specific concerns/expectations. Our recent needs
assessment study and complementary focus group interview confirm and justify the need for a
pre-surgical intervention, specifically delivering sufficient information around various important
“descriptive and expectational categories”, as the initial groundwork for designing a pre-surgical
intervention. Furthermore, seeing as the model of predictive coding guided the types of data
collected from patients accounts of their experience a pre-surgical intervention can potentially
prepare patients for 1) dealing with likely positive PE and/or 2) mitigating the magnitude of the
PE by developing realistic and realizable expectations of surgical outcomes and post-surgical
life.

8.3 Recommendations for Future Research

Our needs assessment study along with our recently published review article, already
provide considerable data to not only confirm and validate the need but also informs the design
of a pre-surgical intervention. Our work provides the initial leg work to inform further
investigation into developing and evaluating a pre-surgical education/counseling epilepsy
program.
One potential step moving forward involves further analysis on the existing data. Given the rich composition of data in the interviews, analysis of patient experiences was not exhaustive. More in-depth analysis of clustering groups and making natural comparisons of experiences is warranted to find further potential correlations in specific themes. This will ultimately help to identify patient specific needs and tailor the information such that it is relevant to a specific demographic. We may also want to analyze further inter and intra relationships among the emerging themes. Finally, we may want to conduct a summative content analysis to determine the frequency/probability of key words, phrases or themes/categories amongst patient responses. This next steps in the analysis may have the potential to clarify the level of significance of each theme/category to the QOL of post-operative patients (Hsieh & Shannon 2005).

In addition, further data collection is warranted in order to provide additional insight to understand: 1) the behaviours that need to change, 2) factors that maintain the current behaviours, 3) barriers and facilitators to change, 4) sex and gender differences and underrepresented groups of individuals in the recovery process, and 5) expertise to develop strategies to achieve change.

If the next step is to design a comprehensive intervention, it is imperative to conduct further interviews with patients, family members, clinicians, and other health care providers. Specifically, conducting focus group interviews will stimulate real-world dynamics and allow us to gain consensus on existing gaps and needs across different stakeholders (Stalmeijer et al. 2014). It will further expand our understanding around the surgical event as it concerns the patient and their interaction with the various stages of the process and the health care system.
Focus groups will provide an avenue to determine and reiterate what important resources and services would be needed and or should be available for post-surgical needs.

Capturing instances and a compilation of individual interviews that provide touch points and issues that resonate with the interviewees will provide further evidence and support to develop a strong pre-surgical intervention. Video clips of patient and family stories is a powerful tool (Abu Abed et al. 2014; Gagliano 1988) that can be further utilized for various forms of information dissemination. Modified version can be presented at conferences, used as a dissemination vehicle or importantly incorporated in the intervention itself to provide patients with tangible experiences and scenarios to look back on.

Finally, systematic reviews on pre-operative education and counselling, and its effects on postoperative patient outcomes will provide further guidelines for designing a high quality, comprehensive intervention (Ronco et al. 2012; Friedman & Cosby 2011).
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APPENDICES

Appendix A. Telephone Script (Interviews)

I: Do you have any questions for me before we begin?

Please note that you are allowed to stop this interview at any time. If you feel uncomfortable with any particular question or topic, please let me know and I will continue on with the next question or stop the interview if requested. Also, take your time to think about the questions and answer in as much detail as you can.

1. To begin can you please guide me through how you were initially introduced to the idea of surgery as a treatment option and your initial thoughts and reaction to this proposal?

2. What made you choose to undergo surgery?
   (use prompts – decision making process – peer support, family discussion)
   (prompt – In what way was your epilepsy affecting your life?)
   - Were you provided with information about Epilepsy Toronto?

3. At the time, did you have any expectations from surgery? What were they and you feel that they were fulfilled?
   - What were the most important expectations of surgery to you personally and do you feel they were satisfied?

4. (What were you looking to achieve from surgery from a quality of life and daily living perspective?)
   (prompts to ask specifically about daily life – expectations/goal setting etc… what actions you took to prepare for life after surgery?? Services you wanted to access etc…)

5. What are some of your short-term or long-term expectations (aspects of daily living or life after) surgery you feel were not addressed prior to surgery?

6. Do you feel you were fully prepared for the adjustments you experienced going from pre-surgery to postoperative life?
   - What were some new responsibilities and demands of post-operative that stood out to you and may have initially took some time to get used to?
95

- Is there anything that you can think of that took some time adjust to in your daily living?

(prompts: How do you know this? What did you do to get through this or cope with this and get to where you are now?

What aspects of life after surgery were unexpected and came to you as a surprise?)

- And have you made any changes to your life, patterns, routines that have helped you adjust to post-surgical life?

7. What are some aspects of life that you believe you would have liked to have discussed prior to surgery that you feel would have helped you adjust more easily to your present life?

- Are there any difficulties in your daily living that you have faced adjusting to post-surgical that you feel could have been avoided or you could have perhaps been more prepared to deal with these issues if you had been given some guidance for these prior to surgery?

- What do you believe would have benefited you post-surgically with respect to your overall daily living if you had the chance to have a pre-surgical evaluation/discussion (being provided more information, one on one discussion about expectations after surgery, talking about the experience of other individuals)?

8. If you were given the chance to have a pre-surgical intervention of some sort, in what format would you have preferred to have been provided with this? (ex. On paper, by phone, in person, through a phone app?)

9. Is there anything else that you would like to add with respect to your experience or if you would recommend anything that should have been incorporated into a pre-surgical intervention that you believe would help individuals to prepare for post-operative life and help them adjust more easily to post-surgical life.

10. Have your relationships changed in anyway going from pre-surgery to post-surgical life?

(Prompts: Is there anything you think could have prepared them more for you undergoing surgery and even life after surgery both short-term and long-term?)
That concludes the end of the interview. Do you have any questions for me? Once again, we greatly appreciate your time and feedback.

Your contribution to this study is invaluable and the data collected will be used towards improving the health care system for epilepsy patients. We hope to improve the QOL of individuals who have undergone surgery, and this is the first step towards achieving our goal.

If you find that you remember any additional information after this interview, please feel free to contact me at 416 603 5460 and I will be more than happy to speak with you. Thank you very much for your participation and time and I hope you have a great day.
## Appendix B. Interview Script (Focus Group)

### Validation of Study Findings: Environmental Scan

#### Semi-Structured Interview Guide (Focus Group)

<table>
<thead>
<tr>
<th>Topic</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Welcome and Introductions</strong></td>
<td>5 minutes</td>
</tr>
<tr>
<td><em>To all participants: Please be advised not to share any personal information discussed in this focus group in order to maintain privacy and confidentiality. Furthermore, because of the nature of this group setting, confidentiality cannot be guaranteed. Brief introductions of participants (particularly post-surgical patients), type of Epilepsy, duration of Epilepsy before surgery, seizure status, overall perceived QOL.</em>*</td>
<td></td>
</tr>
<tr>
<td><strong>Background and Purpose</strong></td>
<td>4 minutes</td>
</tr>
<tr>
<td>Briefly speak to the environmental scan (needs assessment study), the details of the study and purpose for the focus group (ex. For validation of results, getting further insight into developing an intervention – involve patients and families in helping to get a sense of the intervention, ensuring incorporation of patient identified needs etc.….)</td>
<td></td>
</tr>
<tr>
<td><strong>Ground Rules/Confidentiality</strong></td>
<td>2 minutes</td>
</tr>
<tr>
<td><strong>Presentation of Findings (preliminary results) + Time for F/U Questions</strong></td>
<td>35 minutes</td>
</tr>
<tr>
<td><strong>Does the Information Resonate with Participants?</strong></td>
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<tr>
<td>1. What are your thoughts on the information presented?</td>
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<tr>
<td>- what stood out to you?</td>
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<tr>
<td>- Do you agree/disagree with the findings? Does it align with your experience, is it information you would have liked addressed? (How/why, please explain?)</td>
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<tr>
<td><strong>Gaps, additions, retractions?</strong></td>
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<tr>
<td>- In retrospect, from your own experience (of your interactions and what you know about others), is there anything you feel was left out (or unnecessarily included?)</td>
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<tr>
<td>- Speaking to the family/support participants, what is your take on this? (Information from your experience that would further help improve the process? Could have been further addressed or other information that could have been reiterated?</td>
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<tr>
<td><strong>Opening Discussion: Semi-Structured Questions</strong></td>
<td>Total: 75 minutes</td>
</tr>
<tr>
<td>Surgical patients have varied perceived success of surgery and experiences (difficulties, adjustment processes, transitions) post-surgery, in the short term and long term.</td>
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</tr>
<tr>
<td>a. Give the participants few minutes (surgical patients + support member) to think about their experiences, during surgery, right after, through recovery and transitioning back to daily life – the duration, what challenges they faced (physical, psychological, behavioral, social etc.….)</td>
<td>37 minutes</td>
</tr>
<tr>
<td><strong>Concerning Presentation/Findings:</strong></td>
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</tr>
<tr>
<td><strong>Key Questions</strong></td>
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<tr>
<td>Based on what we have learnt, and what you have said today, we believe there is space for improvement.</td>
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<tr>
<td><strong>A Need for an Intervention (Pre-surgical, Post-surgical, both?)</strong></td>
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</table>
2. Having undergone surgery and having the hindsight and experience, do you and/or your circle of support think there is a need for an (supportive) intervention to address the quality of life aspect of post-surgery?
   - If so (if not), what is your reasoning?
   - A need for information at what point in time in the surgical process?

**Utility of an Intervention**

3. What benefits (or not) could this have? Why do you think so?
   - What are we missing? Who is not included? Who might disagree?
   - Need for addressing short and long term concerns or possibilities?
     (Possibly encompasses education, counselling, further preparation for life after surgery?)
   - Possible information on strategies and recommendations?

**Proposed Ideas for Intervention (Structured w/Options):**

**Key Questions**

**Disclaimer:** Every case is different, in the way individuals respond and experience the surgical process (decision making, surgery and post-surgery). Therefore, while the initial step is taking a generalized approach in presenting this “information/education”, further care and details may be refined to address patient specific concerns (Peer support, counselling, extension to online or telephone care)

A. **What should be Essential Components?**
   If we are looking to make changes, we need to study up. We would like you come with us on this hypothetical study journey.

   If you were enrolled in a pre-surgical intervention, based on your experience, challenges and different daily aspects you have dealt with, tell us what you think about the following three questions?

   Intervention (involving common experiences) accompanied by an information booklet?

   1. **(Peer) Support**
      Was peer support or other forms of support important in your post-surgical recovery and adjustment process? Do you think having accessibility to reach others with similar experiences pre- or post-surgery is important? Why, what benefits to you see coming from this opportunity?

   2. **Education**
      Have you experienced post-surgical incidences you feel you would be more prepared for (mentally, emotionally, physically), if further information was provided? Would this have changed how you reacted, felt or dealt with the situation? If so, how? Can you please provide examples?

   3. **Guiding Self-Management/Self-Care?**
      How have you managed your post-surgical life? Do you think it is important to have available the opportunity to discuss information on how to manage your post-surgical life with the health care team?

B. **Menu of Potential Interventions**
   We realize from the interviews that individuals would have liked more information/details based on what they experienced on their own as well as the benefits of support. Based on the study results, from past evidence and taking from
other disciplines relating to chronic illness (ex. Cardiac surgery, pain management) you are provided with a menu of possible ways of delivering information.

**Options below will be presented as visuals in power point**

- a. More information (Booklet and information session, possibly classroom based) – using multimedia (videos, online support system)
- b. Multiple pre-surgical meetings (addressing specific questions)
- c. Telephone outreach
- d. One on one counseling/intervention (pre-habilitation, online cognitive behavioral therapy (CBT), peer support, coaching, educational, expectation counseling)
- e. ...Accompanied by post-surgical rehab/counselling

What do you think about these? Which one of these do you think would be most important and the best in delivering the pre-surgical information/intervention? Why, and what do you think needs to happen here? Are these acceptable? What don’t you like? Why?

### Conclusion, Question and Answer

5 minutes

Before we conclude this session together, we want to make sure that we have noted all points about the needs assessment study and its representability relating to helping to inform and educate pre-surgical candidates about the different possibilities post-surgery and helpful information to know. Please let us know if we missed any points and anything you would like to add or elaborate on?

### Consider Speaking to Selected Participants Individually (maybe after focus group)

A few final remarks. We are planning to devise a patient advisory group for the development of a pre-surgical intervention, we would like to know if any of you would be interested in contributing to writing a grant and advising the planning and dissemination of a pre-surgical intervention? If so, might we contact you again in the future? Thank you.
Appendix C. Consent Form (Interviews)

CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

Study Title: An Environmental Scan of Post-Operative Epilepsy Patients at the Toronto Western Hospital

Investigator/Study Doctor:
Dr. Taufik A Valiante MD, PhD
Dept of Neurosurgery
Toronto Western Hospital
University Health Network

Study Contact Number:
Sumayya Mehmood

Introduction:
You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study doctor or study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

Background/Purpose:
You are being asked to participate in this study because you have been diagnosed with an epilepsy disorder and due to the ineffectiveness of medication and inadequate control of your symptoms you have undergone surgery to treat your intractable epilepsy.

Epilepsy is among the most common chronic neurological condition. In addition to the clear difficulties associated with frequent seizures, patients with epilepsy may suffer a range of psychosocial problems including unemployment, cognitive decline, depression and social isolation, just to name a few. Surgical intervention as an alternative treatment has gained popularity with the advancement in medical technology, improvement in surgical techniques and successful seizure outcomes.

It has become increasingly apparent that seizure frequency is only one benefit realized from surgery. Medical health care teams, researchers and patients alike agree that an improvement in quality of life (QOL) following surgery is a major determinant of a successful surgery.
Currently, there are no standard pre-operative intervention programs in Canada nor globally, to guide patients through difficulties faced by postoperative life. We hope to establish a pre-surgical counseling/intervention program that will address the concerns of patients in the early stages and both improve their QOL after surgery and subsequently eliminate the need for postoperative care.

To realize this goal, we propose to conduct an environmental scan of post-surgical epilepsy patients. This will be the first step to determine what themes/factors need to be addressed prior to surgery that will help patients adjust to post-surgical life. An environmental scan is a collection of data from a population of interest that provides insight into a concept in its early stages of research. As an individual part of the postoperative epilepsy population, your insight will give us an accurate representation of what information we need to incorporate into an intervention program. We hope to revolutionize how surgical patients are counseled and bring change to the attitude and mindset in which patients’ go into surgery using the themes that we will generate from the environmental scan.

**Study Design:**

This study is an open-label study, which means that both you and the investigators will be fully informed of all steps of research.

This is a multiphase study. You will only be participating in phase one of this study. Phase I will involve a quality of life questionnaire and a onetime interview with postoperative epilepsy patients, like you, to collect data for an environmental scan. Once this environmental scan has been compiled using the information from interview/questionnaires with all study participants, major themes will be found from patient feedback.

It is anticipated that about 290 people will be asked participate in this study at the Toronto Western Hospital. The entire study encompassing the environmental scan is expected to take about 3-8 months to complete and the results should be known within a 3-8 month period.

**Study Visits and Procedures:**

This study involves completing a 10-15 minute long online quality of life questionnaire followed by a scheduled one hour interview. You must complete the QOLIE-31 form before proceeding to the interview. A link to the questionnaire will be emailed to you to complete once an interview has been scheduled. Please note that the security of e-mail messages is not guaranteed. Messages may be forged, forwarded, kept indefinitely, or seen by others using the internet. Do not use e-mail to discuss information you think is sensitive. Do not use e-mail in an emergency since e-mail may be delayed. You may choose to complete the questionnaire in paper form. If this is the case, please notify one of the study team members so that it can be arranged to be sent to you by mail in a pre-paid envelope. This QOLIE-31 is a standard questionnaire used to determine how you perceive your quality of life in your present state. The interview will be audio recorded and transcribed within the week for the purpose of
research analysis. No personal identifying information such as your name will be transcribed from the recordings. The interview will involve several questions relating to your life after surgery and any difficulties or adjustments you may have experienced coping with the demands of postoperative life. We encourage you to answer all questions to the best of your ability and with as much details as possible. After the interview, if you feel you remember information that did not come to mind at the time of the interview, feel free to contact Sumayya Mehmood at [Contact Information] - to provide any additional feedback.

**Risks Related to Being in the Study:**

We do not anticipate any risks associated with participating in this study. However, questions asked in the interview and questionnaire may be personal or sensitive for some individuals, as it asks you about your health and surgery. You may choose to not answer any question that you do not want to, or stop the interview at any time.

**Benefits to Being in the Study:**

There is no predicted or hypothesized direct benefit to you for participating in this study. Information learned from this study may have long term benefits for the epilepsy population that include creating a counseling session around the surgical process of care to maximize on the societal and personal benefits of undergoing surgery.

**Confidentiality:**

You have the right to have any information about you that is collected, used or disclosed for this study to be handled in a confidential manner.

**Personal Health Information**

If you decide to participate in this study, the investigator(s) and study staff will look at your personal health information and collect only the information they need for this study. “Personal health information” is health information about you that could identify you because it includes information such as your:

- Address (for mailing purposes)
- Name
- Demographics (ex. Age and gender)
- New or existing medical records, that includes types, dates and results
- Phone number (only applicable if interview is administered over the phone)

You have the right to access, review and request changes to your personal health information.

**Research Information in Shared Clinical Records**

If you participate in this study, information about you from this research project will be stored separately in a locked cabinet in the PI’s office.
The following people may come to the hospital to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study is following proper laws and guidelines:

- Representatives of the University Health Network (UHN) including the UHN Research Ethics Board

Access to your personal health information will take place under the supervision of the Principal Investigator. Information about you relating to the study will not be shared outside of the UHN.

The Principal Investigator will keep any personal health information about you in a secure and confidential location for 10 years and then destroy it according to UHN policy. A list linking your study number with your name will be kept by the PI in a secure place, separate from your study file.

**Study Information that Does Not Identify You**

Your interview, either by phone or in person will also be recorded. This information will be stored in a hospital database. All information recorded will have a code and will not show your name or address, or any information that directly identifies you. Once the data has been collected and analyzed, the recordings and completed QOL questionnaire will be kept for 10 years, locked in a secure location. We would also like to request your permission to use this data for possible future studies possibly involving its use in exploratory, causative and/or correlative analysis that will provide additional information and contribute towards further improving patient-centered health care concerning epilepsy surgery.

All information collected during this study, including your personal health information, will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be named in any reports, publications, or presentations that may come from this study.

You have the right to be informed of the results of this study once the entire study is complete.

**Voluntary Participation:**

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind later. **You may choose to end your participation at any time without affecting your care.** You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.

**Alternative to Being in the Study**

This study is not designed to test new treatment or intervention. Your alternative to participation is not to participate.
Withdrawal from the Study:

If you decide to leave the study, with your permission the information that was collected before you left the study will still be used in order to help answer the research question. If you wish to have your information withdrawn, your decision will be respected. No new information about you will be collected without your permission.

Costs and Reimbursement:

Participation in this study will not involve any additional costs to you. The interview will either be done during an outpatient visit or a scheduled phone interview. You will not be paid to participate in this study.

Rights as a Participant:

If you are harmed as a direct result of taking part in this study, all necessary medical treatment will be made available to you at no cost.

By signing this form, you do not give up any of your legal rights against the investigators or involved institutions for compensation, nor does this form relieve the investigators, or involved institutions of their legal and professional responsibilities.

Conflicts of Interest

The hospital and researchers have an interest in completing this study. Their interests should not influence your decision to participate in this study.

Questions about the Study:

If you have any questions, concerns or would like to speak to the study team for any reason, please call: Dr. Taufik Valiante at 416-603-5460, or Sumayya Mehmood.

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of individuals who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

You will be given an online copy of this consent form.

Consent:

This study has been explained to me and any questions I had have been answered. I know that I may leave this study at any time. I agree to the use of my information as described in this form. I agree to take part in this study.

We would like to use the data collected from you in this study such as your interview responses, for possible future studies. Please indicate below your preference:
☐ Yes, I consent to have my data collected to be used in future studies.
☐ No, I do not give consent to have my data collected to be used in future studies.

__________________________________________  
Print Study Participant’s Name  Signature  Date

My signature means that I have explained the study to the participant named above. I have answered all questions.

__________________________________________  
Print Name of Person Obtaining Consent  Signature  Date

(You will be sent a completed copy of this consent form)
Appendix D. Consent Forms (Focus Groups)

CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Environmental Scan Study of Post-Surgical Epilepsy Patients at Toronto Western Hospital

Investigator/Study Doctor:
Dr. Taufik A Valiante MD, PhD
Dept of Neurosurgery
Toronto Western Hospital
University Health Network
Phone: 

Study Contact Number:
Sumayya Mehmood

Introduction:
You are being asked to take part in a focus group interview because you are a patient with epilepsy who has previously participated in this study or you are within the support circle of a patient with epilepsy. Please read this explanation about the study and its risks and benefits before both of you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study doctor or study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

Background/Purpose:
You are being asked to participate in this focus group as an extension of your previous involvement in the research study, “An Environmental Scan of Post-Operative Epilepsy Patients at the Toronto Western Hospital”. Research findings require your feedback and assessment.

Epilepsy is among the most common chronic neurological condition. Surgical intervention as an alternative treatment has gained popularity with the advancement in medical technology, improvement in surgical techniques and successful seizure outcomes.
It has become increasingly apparent that seizure frequency is only one benefit realized from surgery. Medical health care teams, researchers and patients alike agree that an improvement in quality of life (QOL) following surgery is a major determinant of a successful surgery.

Currently, there are no standard pre-operative intervention programs in Canada nor globally, to guide patients through possible difficulties faced by postoperative life. We hope to establish a pre-surgical counseling/intervention program that will address the concerns of patients in the early stages and both improve their perceived QOL after surgery and subsequently eliminate the potential need for postoperative care.

We have conducted the aforementioned environmental scan, interviewing seventy-three individuals in total. Preliminary findings have been established from the information collected. To further confirm and validate the credibility and trustworthiness of these findings, as an individual having participated in this study or as a member of the support circle, your feedback and confirmation is requested.

**Study Design:**

This study is an open-label study, which means that both the participants and the investigators will be fully informed of all steps of research.

This is an extension of the environmental scan study. Participating will involve your presence, as either an individual having participated in this study or as a selected support circle member, in a focus group interview. It is anticipated that eight people, 4 post-surgical patients and four respective support members, will be asked to participate in this focus group at the Toronto Western Hospital. This is a onetime focus group and is expected to take approximately two hours to complete.

**Study Visits and Procedures:**

This focus group involves a scheduled, approximately one to two-hour session at the hospital site. The interview will be audio recorded and transcribed within the week for the purpose of further research analysis. No personal identifying information such as your names will be transcribed from the recordings. The interview will involve the presentation of preliminary findings followed by several questions to confirm and validate information obtained during individual interviews, in addition to questions pertaining to a pre-surgical intervention. We encourage you to answer all questions to the best of your ability and with as much details as possible. After the focus group, if you feel you remember information that did not come to mind at the time of the interview, feel free to contact Sumayya Mehmood at [contact information] - to provide any additional feedback.

**Risks Related to Being in the Study:**

We do not anticipate any physical risks associated with participating in this focus group. However, questions asked during the interview may be personal or sensitive for some
individuals, as it may ask further questions about your health and experience of surgery. Furthermore, given the nature of the group setting, personal information will be shared and may result in anxiety and/or emotional discomfort. You may choose to not answer any question that you do not want to, or withdraw from the focus group at any time.

**Benefits to Being in the Study:**

There is no predicted or hypothesized direct benefit for participating in this focus group. Information acquired from this focus group will help to confirm and present credible study findings and may have long term benefits for the epilepsy population that include creating a pre-surgical session around the surgical process of care to maximize on the societal and personal benefits of undergoing surgery.

**Confidentiality:**

You have the right to have any information about you that is collected, used or disclosed for this study to be handled in a confidential manner.

**Personal Health Information**

If you decide to participate in this study, the investigator(s) and study staff will look at your personal health information and collect only the information they need for this study. “Personal health information” is health information about you that could identify you because it includes information such as your:

- Address (for mailing purposes)
- Name
- Results
- Phone number

You have the right to access, review and request changes to your personal health information.

**Research Information in Shared Clinical Records**

If you participate in this study, information about you from this research project will be stored separately in a locked cabinet in the PI’s office.

The following people may come to the hospital to look at the study records and at your personal health information to check that the information collected for the study is correct and to make sure the study is following proper laws and guidelines:

- Representatives of the University Health Network (UHN) including the UHN Research Ethics Board
Access to your personal health information will take place under the supervision of the Principal Investigator. Information about you relating to the study will not be shared outside of the UHN.

The Principal Investigator will keep any personal health information about you in a secure and confidential location for 10 years and then destroy it according to UHN policy. A list linking your study number with your name will be kept by the PI in a secure place, separate from your study file.

**Study Information that Does Not Identify You**

The focus group will be audio recorded. This information will be stored in a hospital database. All information recorded will have a code and will not show your name or address, or any information that directly identifies you. Once the data has been collected and analyzed, the recording will be kept for 10 years, locked in a secure location. We would also like to request your permission to use this data for possible future studies possibly involving its use in exploratory, causative and/or correlative analysis that will provide additional information and contribute towards further improving patient-centered health care concerning epilepsy surgery.

All information collected during this study, including your personal health information, will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be named in any reports, publications, or presentations that may come from this study.

You have the right to be informed of the results of this study once the entire study is complete.

**Voluntary Participation:**

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now, and then change your mind later. **You may choose to end your participation at any time without affecting your care.** You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.

**Alternative to Being in the Study**

This study is not designed to test new treatment or intervention. Your alternative to participation is not to participate.

**Withdrawal from the Study:**

If you decide to leave the study, with your permission the information that was collected before you left the study will still be used in order to help validate the research findings. If you wish to have your information withdrawn, your decision will be respected. No new information about you will be collected without your permission.
Costs and Reimbursement:

Participation in this study will not involve any additional costs to you. You will not be paid to participate in this study.

Rights as a Participant:

If you are harmed as a direct result of taking part in this study, all necessary medical treatment will be made available to you at no cost.

By signing this form you do not give up any of your legal rights against the investigators or involved institutions for compensation, nor does this form relieve the investigators, or involved institutions of their legal and professional responsibilities.

Conflicts of Interest

The hospital and researchers have an interest in completing this focus group. Their interests should not influence your decision to participate in this study.

Questions about the Study:

If you have any questions, concerns or would like to speak to the study team for any reason, please call: Dr. Taufik Valiante at [redacted], or Sumayya Mehmood.

If you have any questions about your rights as research participants or have concerns about this focus group, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at [redacted]. The REB is a group of individuals who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

You will be given an online copy of this consent form.
Consent:

This study has been explained to me and any questions I had have been answered. I know that I may leave this study at any time. I agree to the use of my information as described in this form. I agree to take part in this study.

We would like to use the data collected in this study such as your interview responses, for possible future studies. Please indicate below your preference:

☐ Yes, we consent to have our data collected to be used in future studies.
☐ No, we do not give consent to have our data collected to be used in future studies.

_________________________________  
Print Study Participant’s Name  

_________________________________  
Signature  

__________  
Date

My signature means that I have explained the study to the participants named above. I have answered all questions.

_________________________________  
Print Name of Person Obtaining Consent  

_________________________________  
Signature  

__________  
Date
Appendix E. Research Ethics Board Approvals

University Health Network
Research Ethics Board
10th Floor, Room 1056
700 University Ave
Toronto, Ontario, M5G 1Z5

Notification of REB Initial Approval

Date: January 26th, 2016
To: Dr. Taufik Valiante
433, 11, McLaughlin Pavilion, Toronto Western Hospital, 399 Bathurst St.
Toronto, Ontario, Canada, M5T 2S8

Re: 15-9228-BE
An Environmental Scan of Post Operative Epilepsy Patients at the Toronto Western Hospital

REB Review Type: Expedited
REB Initial Approval Date: January 26th, 2016
REB Expiry Date: January 26th, 2017

Documents Approved:
- Protocol
- Consent Form
- Interview Script
- Letter of Appreciation
- Study Introduction Phone Script
- Email to Questionnaire link
- GOLIE-31 Questionnaire

Version date: January 13th, 2016
Version date: January 17th, 2016
Version date: January 22nd, 2016
Version date: January 7th, 2016
Version date: January 7th, 2015
Version date: January 13th, 2016
Version date: November 30th, 2015

The UHN Research Ethics Board operates in compliance with the Tri-Council Policy Statement; ICH Guideline for Good Clinical Practice E6(R1); Ontario Personal Health Information Protection Act (2004); Part C Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations and the Medical Devices Regulations of Health Canada. The approval and the views of the REB have been documented in writing.

Furthermore, members of the Research Ethics Board who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

Best wishes on the successful completion of your project.

Sincerely,

Alan Barolet, MD PhD FRCPC
Co-Chair, University Health Network Research Ethics Board
Notification of REB Amendment Approval

Date: August 26th, 2016
To: Dr. Taufik Valiante
433, 11, McLaughlin Pavilion, Toronto Western Hospital, 399 Bathurst St.
Toronto, Ontario, Canada, M5T 2S8

Re: 15-9228-BE
An Environmental Scan of Post Operative Epilepsy Patients at the Toronto Western Hospital

REB Review Type: Expedited
REB Initial Approval Date: January 26th, 2016
REB Amendment Approval Date: August 26th, 2016
REB Expiry Date: January 26th, 2017

Documents Approved:
Amendment as described in the Amendment form
Consent Form

Version date: August 2nd, 2016
Version date: August 2nd, 2016

The UHN Research Ethics Board operates in compliance with the Tri-Council Policy Statement; ICH Guideline for Good Clinical Practice E6(R1); Ontario Personal Health Information Protection Act (2004); Part C Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations and the Medical Devices Regulations of Health Canada. The approval and the views of the REB have been documented in writing.

Furthermore, members of the Research Ethics Board who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB.

Best wishes for the successful completion of your project.

Sincerely,

Gillian Goulet, MSc
Research Ethics Coordinator

For: Alan Barolet, MD PhD FRCPC
Co-Chair, University Health Network Research Ethics Board
Appendix F. Contributions

Sumayya Mehmood solely prepared this thesis. All aspects of this work, including the planning, execution, data analysis, and write up of all original research and publications were performed in whole or in part by the author. The following individuals are formally acknowledged for their contributions:

Dr. Taufik A. Valiante (supervisor) provided overall mentorship, guidance and assistance in the following: planning and executing the qualitative research study, analysis and interpretation of interview and focus group data and the preparation of the manuscript and thesis.

Dr. Craig Dale (program advisory committee member) provided mentorship, guidance and assistance in the following: planning and executing the qualitative research study, analysis and interpretation of interview and focus group data and the preparation of the manuscript and thesis.

Dr. Monica Parry (program advisory committee member) provided mentorship, guidance and assistance in the following: planning and executing the qualitative research study, analysis and interpretation of interview and focus group data and the preparation of the manuscript and thesis.

Dr. Carter Snead (program advisory committee member) provided mentorship, guidance and assistance in the following: planning and executing the qualitative research study, analysis and interpretation of interview and focus group data and the preparation of the manuscript and thesis.