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Research Article

**A PROSPECTIVE STUDY OF POST-SURGICAL EPILEPSY  
CARE: A STUDY OF POST-SURGICAL EPILEPSY PATIENTS**<sup>1</sup>Anam Shezadi, <sup>2</sup>Rana Shoaib Akram, <sup>3</sup>Nudrat Hussain<sup>1</sup>Pakistan Institute of Medical Sciences, Islamabad, Pakistan<sup>2</sup>Sargodha Medical College, Sargodha, Pakistan<sup>3</sup>Lugansk State Medical University, Ukraine**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.*

**Keywords:** *Chronic neurological disorder, Post-Surgical Epilepsy***Corresponding author:****Anam Shezadi,***Pakistan Institute of Medical Sciences,  
Islamabad, Pakistan*

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**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 surgeries.

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 worlds 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.

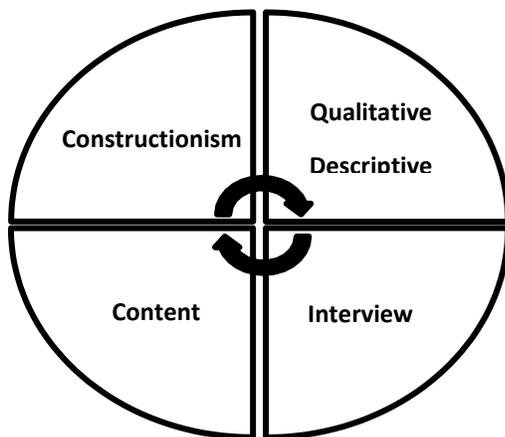
The aetiology of epilepsy is numerous including genetic factors, head trauma, brain tumors, birth complications and brain infections (De Boer 2002). Furthermore, with time, a range of different epilepsy syndromes and seizure types have been identified, however accurate diagnosis still remains a major 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).

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.

### 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



**Figure 1:** Theoretical framework informing the design of qualitative needs assessment.

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.

### 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 from 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.

## **METHODS:**

### **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.

### **Sampling and Recruitment**

We had access to the National Hospital 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.

### **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.

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 National 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.

### **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.

### **Data Analysis**

#### *Qualitative Analysis*

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



50-59	12 (16)
60+	3 (4)
<b><u>Number of Surgeries</u></b>	
1	70 (96)
2	2 (3)
3+	1 (1)
<b><u>Years Post Surgery</u></b>	
≤ 2 Year	15 (20)
< 2 Year, ≥ 5 Years	23 (32)
5 Years > 10 Years	23 (32)
≥ 10 Years	12 (16)
<b><u>Seizure Status Post-Surgery</u></b>	
Seizure Free	55 (75)
Not Seizure Free	18 (25)
<b><u>Duration of Epilepsy Before Surgery</u></b>	
< 1 Year	2 (3)
1 Year ≥ 5 Years	11 (15)
5 Years > 10 Years	11 (15)
10 Years > 15 Years	9 (12)
≥ 15 Years	40 (55)
<b><u>Age at Seizure Onset</u></b>	
Baby (0-4)	14 (19)
Early Childhood (5-12)	15 (21)
Teenage Years (13-19)	13 (18)
Young Adult (20-35)	19 (26)
Adult (36-55)	11 (15)
Older Adult (55+)	0 (0)

### Results Synopsis

The following sections explain the details of the major categories, 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.

### 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.

### Summary of Information Content and Delivery

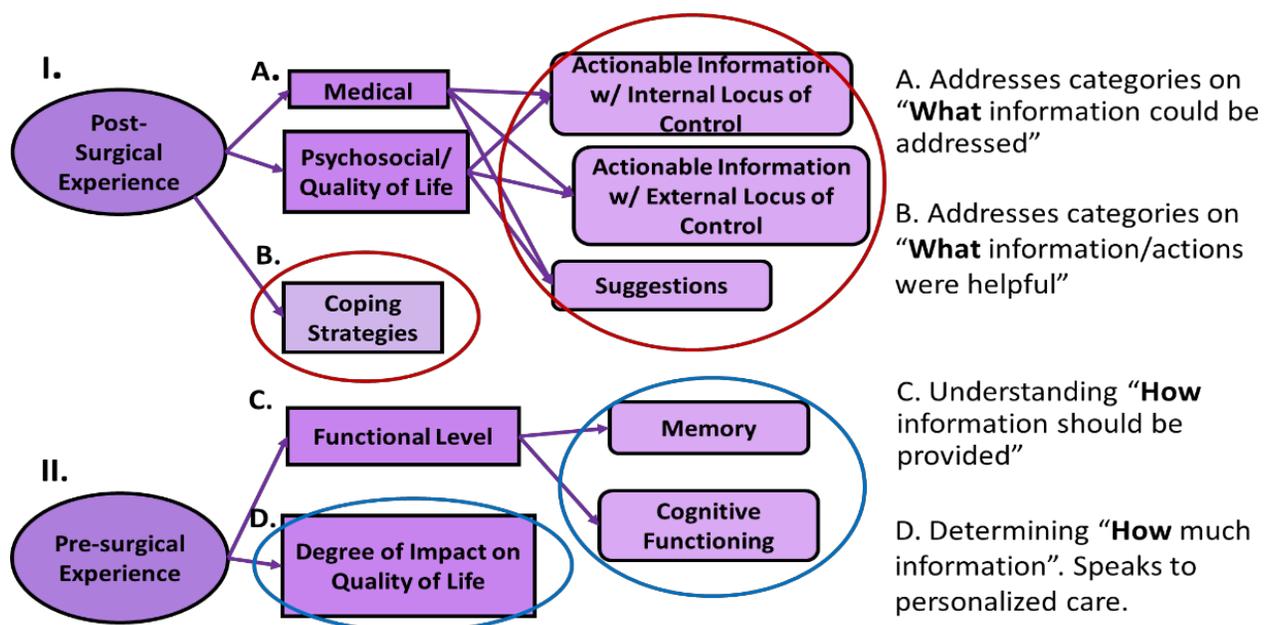
Finally, in addition to obtaining insights into patients' pre-surgical predictions and expectations, and patient identified needs from their post-surgical experiences, and possible coping strategies, this study sheds light on reasons why information might not be permeating and being processed as intended. **Figure 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 2:** Breakdown summary of types and forms of information, identified in needs assessment study.

**DISCUSSION:**

The aim of this thepapersis 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.

**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).

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.**

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.

**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.

#### 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.

#### 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.**

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