Quality of life after epilepsy surgery

Deepak Lachhwani, MB.BS, MD
Cleveland Clinic

Introduction

For varying length of time, everyone here in this room has lived the “quality of life” after surgery. As members of the medical community our insight on this topic would never be as personal and penetrating as yours is already. In that regard, you are the more correct choice to be up here at the podium, while I should trade places and listen to your thoughts instead. In the next few minutes, I hope that my comments would evoke one or more of the three responses from you:

*I know exactly what you are talking about, I have personal experience
*A...haa...I never quite put my thoughts in such words, but it makes sense
*I feel better informed now, more than before – that while the immediate goal is to stop seizures, epilepsy surgery has far reaching ramifications and I feel comfortable in sharing some of these thoughts with the next family I meet who are contemplating a surgical treatment for their child.

Each one of you has a strong advocate within yourselves, to pursue the option of brain surgery – given the right circumstance of course! For no other reason except that you have ‘been there and done that’. We hope that these last few minutes of today’s morning session would serve you and encourage you to persist in speaking up for our mutually shared belief that every child with seizures deserves a chance.
**Why think about QOL**

For the treating team “seizure control” could be the sole aim of surgical treatment because seizures are bad and they result in morbidity and mortality. However, we know that even though stopping seizures is the looming goal leading up to a consideration for surgery, there is an implicit understanding that achieving this goal would also allow young patients to do some things that they are unable to do. Further more, stopping seizures would allow the caregivers and siblings to do some things they are unable to do. These ‘good effects’ have a seamless impact on the entire unit of family surrounding each child and make up the ‘quality of life, which is a composite of physical, social and mental well being and not merely the absence of disease or infirmity.

The psychosocial repercussions of epilepsy are often of greater significance than seizures themselves. They influence caregivers, siblings, work and other interpersonal relationships of everyone involved in the care of a member with epilepsy\(^1\text{-}^4\). In a prospective study\(^2\) parents were interviewed about the impact of epilepsy in the lives of siblings of children with epilepsy. More than 120 siblings of 78 children with epilepsy had only negative feelings toward disease, mostly sadness and fear. Adolescents perceived epilepsy as much more debilitating than asthma, diabetes, migraine, leukemia and even HIV infection. Children felt responsible for their sibling, saw that the parent gave more attention to the sick child and some of them even wanted to get sick in order to get more attention.

There are several other facets of epilepsy related detrimental effects which may be oblivious at first glance. It becomes important to therefore describe the nature of those
effects before surgical treatment, acknowledge these effects as proper reason(s) for attempting to cure seizures and be able to measure the changes as an indicator of success.

Understanding these detrimental effects is best accomplished when the perspective of the treating team, the patients and families is considered together. Researchers in UK gathered responses from hundreds of patients and families, before epilepsy surgery and they were able to make some broad categories of responses to understand the nature of people’s aims to want epilepsy surgery. It is educative to be able to understand the ways people hope to feel better and at the same time this knowledge is a poignant reminder of what the treating team is liable to overlook.

**How to think about QOL**

The overarching goal which has an impact on QOL with the help of epilepsy surgery is to cure seizures. It is however, illustrative to note that the aims of surgery may be quite diverse and when responses are reviewed across all ages, these may be put in a few categories.

Frequently sought after goals pertain to changes in social process elements such as independence, ability to socialize, removal of restrictions, driving etc. Changes in mental state such as improved behavior, self confidence/self esteem, improved mood, not feeling embarrassed and feeling less irritable – make up another common category of the expressed wish list. Some of the other desired goals to pursue epilepsy surgery are: Improvement from seizure experience such as nasty seizures, feeling washed out, Damocles effect, being able to plan and feeling cured; Work or return to school; Safety
**issues** involving children or personal safety and **Cognitive issues** of memory and learning.

Many tools exist which help to capture the nature of these changes associated with epilepsy surgery. The sociologic research on epilepsy is done using a variety of questionnaires and may include ESI (Epilepsy Surgery Inventory 55), QOLIE 89 and QOLIE 31 (Quality Of Life Inventory In Epilepsy), HASS (Hague Seizure Severity Scale), HARCES (Hague Restrictions in Epilepsy Scale), HAY (How are you) questionnaire, HrQoL (Health related Quality of Life). Some studies use measures of behavioral and emotional functioning such as CBL (Child Behavior Checklist) Emotional Well-being test. Responses obtained with the help of these tools reveal that the outstanding concerns relate to aspects of social process and are certainly not limited to relief of medical symptoms or removal of the need to take daily medications.

**What information is available about QOL**

There are published data from centers within the US and abroad pertaining to QOL and epilepsy. Large studies with sound methodology and extensive follow up specific to pediatric experience with epilepsy surgery are lacking. Some of the more recent data are included here while other references are included in the bibliography.

Dutch study (2005) included prospective follow up data on 21 patients at 6, 12 and 24 months after epilepsy surgery. Two years after surgery 72% of patient remained seizure free. From the point of first surgical follow up, parents and children evaluated the frequency of activities as improved, children had positive emotions more frequently, they
started to feel better about seizure variables in the second year after surgery. At the end of two years children perceived themselves as being socially more competent and having greater self worth. In the adolescent group, several aspects of self perceived competence improved shortly after surgery, where as two years after surgery, athletic competence and romance had improved.

A unique 2008 study from Lebanon\(^6\) included two groups, surgery group and a matched comparison non surgery group. Assessment to compare these groups was made at the end of two years after surgical intervention. Seizure severity, medication side effects, overall quality of life, general health, physical activity and well being were better in surgical patients (71% seizure free vs 8.3%). Cognitive, social and behavioral functioning did not differ. The authors felt that this latter finding was a result of the social fabric and support system in Lebanon which is characterized by strong family ties that tend to be over protective and it promotes more reliance on family rather than independence from it. This study was unique because it compared children who underwent epilepsy surgery with matched patients who did not undergo surgery. Most of the literature is based on data gathered on patients before surgery and for varying lengths of time after surgery.

Cross sectional and longitudinal investigations from surgical centers in US (such as Johns Hopkins, UCLA etc) and centers in Canada, have also documented stable or improved psychological adjustment and parental satisfaction with outcomes following focal resections or hemispherectomy. However all these studies have recognizable limitations
and results are variable, sometimes inconsistent. A Mayo clinic study (2008)\textsuperscript{3} concluded that siblings of children with intractable epilepsy are functioning well.

\textbf{How does it affect me?}

More than ever before, the current times are one of “knowledge workers” and “knowledge care givers”. Yet, we realize that the available studies provide mere glimpses of insight to understand the pre surgical and post surgical issues related to QOL. Impact of epilepsy on the lives of siblings is much more severe than predicted. Psychological assistance to the patient and family is often overlooked and rarely offered even when problems are identified. Resources allocated to address these issues are very limited and non-existent under most circumstances. Demystification of beliefs due to psychotherapy and support groups has a positive influence in the family and ensures effective care during the lifetime of an epileptic patient. This effort can sustain effectively with better understanding of the ramifications of uncontrolled seizures as well as with a clear picture on changes in quality of life after surgical intervention.

6-13

Reference List


