
Follow-up

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Presentation by Dr. S. Wiebe

SEIZURE CONTROL AS AN INDICATOR OF THERAPEUTIC USEFULNESS

Dr. A. Olivier: The neurologist and neurosurgeon must come to an agreement as to how much the patient has improved. To assess the patient's quality of life on a prospective basis seems to be a useful measure. It is important to involve the patient in the evaluation of the results. The goal is to stop the seizures altogether in order eventually to be able to taper and discontinue medication and to restore the self-confidence to the patient. In this way, the patient can experience a new life.

Dr. W. Blume: Measures of quality of life should be applied more than once preoperatively as well as several times postoperatively. There is a honeymoon period immediately after surgery.

Dr. N. Pillay: I think that it has been said before but the person who should be involved in assessing the seizures is the nurse or the nurse clinician. This person is quite accessible.

Dr. A. Lozano: Approximately 60% of the groups represented had such a nurse clinician.

Dr. F. Andermann: If you consider the mechanisms of epilepsy, to talk about cure is really not a term that we should use for many reasons. The number of postoperative events that people have are really difficult to assess: they may faint, they may develop classical migraine with and without aura, they may eventually develop ischemic attacks. All of us would agree that there is a bias.

Dr. R. Manchanda: It is very important to determine what it means to the patient. A number of patients may have a 90% reduction of seizures but if they lose the auras they may be disappointed because then they cannot predict the onset of the seizure. I also know that a patient may have more than 90% improvement but has a generalized seizure which he did not have before, and this is extremely devastating. So numbers in themselves are insufficient to assess the value of the surgical intervention.

Dr. G. Savard: A word of caution about outcome and quality of

life. We may protect the patient from further cognitive and psychiatric adverse events but the real quality of life is often his/her doing, not ours. It has to do with opportunity, with luck, with having family, a partner. These are all kinds of things that we cannot provide with surgery. Some patients, even if they are rendered seizure-free, will never be in a position to develop these skills that they could have developed at an earlier age or developmental stage.

Dr. J. Girvin: I do not think it is right to talk about cure. To me, a satisfactory result makes patients seizure-free for at least two years without medication. You have to go from day-to-day with the realization that at any point in the rest of your life, you could have a seizure.

Dr. S. Wiebe: I think seizure counting and validity of methods of seizure counting is one issue. We cannot go any further and make any further assumptions until we are sure that we are measuring the right thing and measuring it reliably. That should be separate from quality of life. I do not believe that cure is the appropriate word and we should probably be asking the person at stake what they feel the outcome has been. Who should be measuring? I feel it should be more than one person. If we have a more neutral seizure counter, then we should try to use it. What we are doing in the randomized clinical trial is using the next best thing that we can think of which is a seizure adjudicator system. An experienced epileptologist assesses each event; he/she determines whether it was a seizure or not. When there is a disagreement between the adjudicator and the treating neurologist, then we get together and study the issue further. Whenever we talk about quality of life, we are talking specifically about health-related quality of life, not about automobile related, house mortgage, family etc., we talk exclusively about the impact on health produced by the intervention.

Presentation by Dr. J. Maher and Dr. R. McLachlan

POSTOPERATIVE ANTIPILEPTIC DRUGS AND THEIR MANAGEMENT

Dr. M.A. Lee: If you stop antiepileptic drugs within the first 3-6 months you get your answer as to your success of the surgery.

Dr. A. Olivier: Dr. Rasmussen thought the drugs could be withdrawn a year and a half after surgery. Now we are down to nine months or a year and really we do not see much difference and I think we may accentuate that trend downward. We usually tell the patient that it will be a slow progressive decrease over several weeks and months, that there is no rush and usually this works very well.

Dr. N. Pillay: The patient with mesiotemporal sclerosis sometimes determines for us how fast they want to be off their medications. At six months they are applying for a driver's licence.

Dr. F. Andermann: The best way to deal with this is to make your arrangements before the surgery. Ideally, one could reduce the medications to a reasonable or average dose before the operation and this will prevent a disagreement between the various members of the team later. What you do depends essentially on what the patient and family want and they are really the major determinants. Give them the best informed opinion that you can and they will decide whether they want to continue the medication or not.

Dr. J. Girvin: Metabolism of antiepileptic drugs (AEDs) may be increased during the first weeks after surgery, irrespective of whether local or general anaesthesia was used. One thing we should not do, is reduce the drugs in the first month or two. I think anything after three months is open.

Dr. M. Jones: Personally I take patients off one dilantin pill per month. This is another pattern of practice.

Dr. J. Maher: There is a higher relapse rate if you take them off in a period less than six months. I think you will find this in the literature as well.

Presentation by Dr. S. Wiebe and Dr. P. Derry

MEASURING QUALITY OF LIFE AFTER EPILEPSY SURGERY

Dr. S. Wiebe: In reliability analysis, the fewer the number items in your tool, the more likely it will be unreliable. One item, unless it's extremely specific, is very likely to give you a lot of variable responses. A variable like "How is your quality of life today?", is going to give you a huge number of responses for the same patient, given by the same administrator, simply because it is so broad.

Dr. J. Maher: Before patients come in to me, I give them a couple of pages from Canadian Epilepsy Database and Registry (CEDaR) that has a list of questions on side effects and a little bit of quality of life and they mark up half-a-dozen ticks on side effects. So, I would suggest to the audience that it's handy to have a couple of pages from that CEDaR questionnaire on follow-up given out to the patients before the consultation.

Dr. R. Sahjapaul: In terms of the utilities, the time trade-off technique seems to make more sense to the clinician and it is probably easier to use than the Standard Gamble. Is it fair to ask them how many years of their life they would be willing to trade-off at the end to achieve a disease free state until then?

Dr. S. Wiebe: I don't think that time trade-off has been used in epilepsy and the question you ask is how many years of current health you'd be able to trade for years of perfect health.

Dr. J. Girvin: When you look at an intervention, is there anything you can get out of an inventory, or survey, or a patient's own list of expectations of an intervention that can aid in the correlation of the validity of the post hoc quality of life assessment?

Dr. P. Derry: The issue of expectations is obviously very critical. Some people have given a little bit of thought to try to measure expectations. We tried it once in a pilot study. It is a difficult thing to do. It's a worthwhile goal to work toward and I do think that trying to get a good standardized measure of preoperative expectations is going to correlate with psychological outcome at least.

Dr. S. Wiebe: I think that David Taylor tries to get at that by making a contractual agreement of outcome with the patients, although he uses it mostly for children. I think the idea is very attractive. The other alternative is to use instruments which are available for other conditions that actually have a segment which is patient-individual centred. There isn't one for epilepsy.

Dr. D. Lee: How do you score things like the ESI-55 and what exactly are you looking at with subsequent administration of the same questionnaire?

Dr. S. Wiebe: There are scoring manuals that come with every questionnaire. The ESI has its own scoring method and a manual. Now there are some, unfortunately, that don't have this. If you repeat it, then the direction of change or the magnitude of the change become important. How much is a meaningful change is what we are trying to decipher right now and there is a manuscript in preparation for that. We suspect that a change of 10-14% is a meaningful change in either the Quality 89 or ESI 55 and we've got fairly good data to show it.

Dr. D. MacDonald: Are any programs looking at funding problems if there is not demonstration of quality of life outcome data? In other words, will this data be important for a program's ability to maintain its funding?

Dr. S. Wiebe: I think so, but more and more government agencies and funding agencies are asking for evidence of improvement in quality of life to justify new interventions.

Dr. M. Jones-Gotman: Of the existing instruments, I am wondering which ones do you prefer?

Dr. S. Wiebe: If you really want to assess very globally and cover every aspect, then you need at least something like the Quality 89. If not, you probably need the batteries of Liverpool which include a generic instrument, the Nottingham Health Profile, and also some epilepsy specific instruments.

Dr. P. Derry: I think it would be either the ESI 55 or the Quality 89 which are almost identical and perhaps one or two other specific ones.

Dr. M. Jones-Gotman: How long does it take to administer these?

Dr. P. Derry: To administer a package consisting of the Quality 89, Seizure Severity Scales of Liverpool, the Liverpool 20-Item Scales, the General Health Questionnaire which is psychiatric, or detector of psychopathology, and Impact of Epilepsy, Adverse Drug Events and also Utility Measurement, which is Health Utility's Index – that's about 5-6 questionnaires. It takes approximately 40 minutes for the patient to complete these. Once the patients get to know the questionnaire, it probably takes no more than 15-20 minutes to answer a big questionnaire like the Quality 89. If you wanted to get a global, brief picture of the impact of epilepsy in a patient, I would probably choose the Impact of Epilepsy which is 10 items, brief and easy. The Liverpool Scales are very easy to score because you just add up the items. The Quality 89, ESI-55 are more laborious because you have to convert the scores.

Dr. S. Wiebe: If you hand-score, it can take 15 to 20 minutes. We have computer programs that do the arithmetic calculations in five minutes.

Dr. P. Derry: If you're going to be using quality of life instrument on a more or less routine basis, it really is worth entering a scoring system even on a spreadsheet program like Excel, or Lotus or whatever, and it'll automatically do it for you.

Presentation by Dr. P. Derry and Dr. S. Wiebe

PSYCHOLOGICAL ADJUSTMENT TO SUCCESS AND TO FAILURE FOLLOWING EPILEPSY SURGERY

Dr. M. Sadler: In quality of life issues, people who are in pretty good shape before surgery are likely to do better than people who are not so good. There is a certain futility there, I guess, because you would think the people who are badly off have got the most room to improve. But they don't.

Dr. P. Derry: Well, no, because they actually do. Some of them will improve and part of that is related to the seizure outcome. If they are made seizure-free, then certainly they are more likely to show improvement. Part of the issue though, is a measurement issue, which is that if you are already high in quality of life, you don't have much room to improve.

Dr. J. Girvin: Murray Falconer, in the last 5-10 years of his life kept saying to the world: "Don't leave the patients until they are 15, 20, 25, and 30 years old to be operated upon because if you do, even if you take away their seizures, they will have lost their ability to become socially integrated into the community again." Operate on them early so they can develop social skills as part of their early developmental life. I think we also agree with Murray Falconer in that, and probably earlier rather than later has become much more of a theme now in the last decade or decade and a half.

Dr. P. Derry: I would agree and the patients that I have seem to agree with that. If they have had 15 or 20 years of interacting and making decisions, based on having the seizures, and using that, as I said, as a reason to do or not to do things – then, once the seizures are gone, those same attitudes are there, and for some people it is very difficult adjustment to say "I don't have seizures as a reason for not doing things anymore". People around them have very clear expectations of them and prior to the surgery, those expectations were, in part based on their seizures. Now, a week later, the seizures are gone. The expectations of other people and employers have changed, yet they see themselves as the same.

Dr. S. Wiebe: I think that your data and Dr. McLachlan's data show that patients who are operated on earlier had larger improvement in quality of life.

Dr. R. McLachlan: Yes, there was a trend that way.

Dr. B. Woodhurst: I would wish to make a plea to recognize the organic basis for the psychosocial dysfunction that occurs and not to forget that these are brain damaged patients who have organic reasons for impairments in psychosocial function, and not fall into any trap of seeking primarily psychological explanations for this. There are developmental stages in child psychology that are all written out. There probably are developmental stages in adult life that we can recognize and these patients have many organic neurophysiological, neuroendocrine dysfunctions which will limit their re-adaptation to life.