Original article

Pre-surgery expectations and post-surgery life-changing validation process

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ABSTRACT – This study aimed to validate two instruments that evaluate pre-surgery expectations and post-surgery life changes of people with epilepsy. The expectations questionnaire comprises 18 yes/no questions and the life changes questionnaire 25 yes/no questions, which includes the 18 questions of the expectations questionnaire plus seven negative questions, considering that the surgery could have a negative effect on the patient quality of life. There were also questions asking the patients to state if they consider the surgery to be a success or a failure, and about the frequency of seizures and their intensity. Patients were interviewed in three different phases: pre-surgery, post-surgery 1 (six months after surgery) and post-surgery 2 (12 months after surgery). The internal consistency of the instruments showed a general Kuder-Richardson coefficient of 0.855 (pre-surgery), 0.833 (post-surgery 1), 0.756 (post-surgery 2), showing that both instruments have a satisfactory content validity and high internal consistency. In this context, the answers obtained in this study are important because they represent the development of a complete set of categorical instruments to evaluate pre-surgery epilepsy expectations and post-surgery life changes.

Key words: epilepsy, quality of life, surgery, social adjustment, expectations

Few studies have focused on what the patient is hoping to achieve beyond seizures relief before surgical treatment for epilepsy (Taylor *et al.* 1997) and no-one has focused on measures to evaluate the patient expectations before epilepsy surgery and the life changes that may or may not follow.

It is a universal given that the major goal of epilepsy surgery is the elimination of seizures (Taylor *et al.* 2001). However, the real measure of successful epilepsy surgery has to be the individual life changes following surgery. If those accidents and injuries, which seem to be caused by epilepsy, are somehow self-imposed, if embarrassment arises mainly from the perso-

nality of the patient, if the sense of stigmatization is a deeply held conviction, and if the major handicap is a mental disorder, removing epileptic seizures will not necessarily remove or ameliorate these conditions (Wilson *et al.* 2001, Taylor *et al.* 1997).

We believe that the motivation for patients to undergo epilepsy surgery must go beyond seizure control and should include aspects within the physical, psychological and social domains (Taylor *et al.* 2001). The physical domain includes areas such as cognitive dysfunction and use of anti-epileptic drugs (AEDs). The psychological domain involves sense of freedom, self-esteem, stigma, anxiety and

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depression. The social domain is about familial relationships, work/vocational functioning, driving, social adjustment and recreational activities.

Until now, the majority of the studies in this area used the "Epilepsy Surgery Inventory" – ESI-55 (Vickery 1993) to measure quality of life (QoL) in patients after epilepsy surgery. However, it is a generic instrument that evaluates the impact of epilepsy in aspects of general QoL, but does not include aspects such as social withdrawal, driving and expectations (Markand *et al.* 2000). The importance of knowing the patient's preoperative expectations is clear because these define the patient's ability to deal with planning and changing his/her life (Wilson *et al.* 1998).

Preoperative expectations of the benefits of surgery may influence its perceived success, and in turn, the perceptions of postoperative QoL (Flood *et al.* 1993). According to Taylor *et al.* (1997), if surgery does yield benefits beyond seizure relief; the scientific importance of such benefits is greatly reduced if they can not be predicted or measured. In addition, analyzing the patient's expectations only prior to surgery is not ideal. It is important to measure whether those expectations have been reached following surgery and, if the patient is satisfied after that, assuming that the positive life changes after surgery would make the patient more satisfied. Only by combining two measures (pre-surgery and post-surgery), would it be possible to evaluate the discrepancy between the expectations before surgery and the life changes afterwards.

The objective of this study was to present the validation of two measures that evaluate the pre-surgery patient expectations and the subsequent post-surgery life changes.

Methods and procedures

The process of creation of instruments to measure subjective concerns involves several methodological steps (Bunchaft and Cavas, 2002), such as the definition of the attribute, characterization and analysis of items (Bunchaft and Cavas 2002).

Definition of the attribute

The first step is to define the attribute to be measured. In our case, life expectations before epilepsy surgery and life changes after that. Both constructs were defined based upon the existing literature and the researchers' clinical experience.

Because of the absence of instruments to evaluate these concerns, the first versions of the instruments were exploratory, using open-ended questions to better understand the patient's reasons for undergoing surgical treatment ("What do you expect to change in your life after epilepsy surgery?"), and their perception of life changes after surgery ("Has your life changed after epilepsy surgery? How?").

Characterization of items

The items included in both questionnaires followed the answers obtained from this first interview with patients. The creation of items was based upon the following criteria:
- we carefully observed if all items expressed behaviours and attitudes rather than abstractions;
- the items should be simple and express a single idea;
- the items should also be clear, avoiding misinterpretations.

Item analysis

After creation of the items, a panel of three epilepsy specialists, not involved in the study, evaluated them. Then, the most appropriate items were chosen by consensus. The specialists judged the items according to their clearness and accordance with the attribute.

The preoperative questionnaire was first created with 20 items, and the life changes questionnaire with 27 items. The life changes questionnaire had seven additional items, created by the researchers, to measure negative aspects that could occur after epilepsy surgery. Then, we interviewed 45 patients who were waiting for surgery and 20 patients who had already undergone surgery.

Based on the results of these first questionnaires, we reviewed the items and the most common answers (50% were rejected), to produce the final questionnaires. Two questions were removed from both questionnaires because they were sparsely answered. Although being the most frequently chosen item, the expectation to be completely free of seizures was removed from the questionnaire because it was considered a "universal given" (Taylor *et al.* 2001); seizure relief is the way in which patients reach their expectations, and not the expectation itself. Seizure control was checked in the life changes questionnaire in a separate section. In this phase, 73 patients answered the expectations questionnaire (before surgery) and 63 the life changes questionnaire (after surgery). The patients interviewed at this phase were not the same ones who answered the first questionnaires.

Content and scoring

After analysis of the results obtained in the phases described above, the final version of both instruments were completed. The expectations questionnaire was completed with 18 yes/no questions *(see Appendix A).*

The final version of the life changes questionnaire had 25 yes/no questions concerning patient's life changes after surgery, which included the 18 questions found in the expectations questionnaire plus seven negative questions, bearing in mind that the surgery could have a negative effect on the patient's QoL (such as frequent headaches, depression and other cognitive, social and emotional problems). There were also questions where the patients should answer if they considered the surgery to be a success or a failure, and about seizure frequency (less or

more frequent) and intensity (less or more intense) *(see Appendix B)*.

The negative items included in the life changes questionnaire were inverted to positive answers so the final score could be calculated. The items from the questionnaires were summed and the score was linearly transformed onto a 0-100 scale, with higher scores in the expectations questionnaire indicating greater expectations, and higher scores in the life changes questionnaire indicating more positive life changes *(see scoring instructions on Appendix A and B)*.

Both questionnaires also included questions about the patient (age, marital status, school level, employment) and epilepsy data (seizures type, frequency, age at seizure-onset, epilepsy duration).

Content validity

Instrument validity is its capacity to measure what it was intended to measure (Kelsey *et al.* 1996). For this, the instrument must pass through a subjective and a more systematic evaluation, when it may be compared to a gold-standard. The absence of a gold-standard allows the use of clinical diagnosis or some other, previously defined criteria to be the gold-standard (Menezes and Nascimento 2000).

In order to overcome the lack of a gold-standard for internal correlation, we proposed a comparison of whether or not patients perceived the impact of epilepsy in their lives (Gold-standard 1), and whether or not they considered epilepsy to be a serious problem (Gold-standard 2). In this context, we aimed to evaluate whether those who said that epilepsy negatively influences their lives and consider epilepsy to be a serious problem, also have greater expectations of change and fewer positive life changes following surgery.

Sampling and questionnaire administration

All patients included in this study had refractory epilepsy and accepted surgery as treatment. Patients were told that, with surgery, there was a 70% chance that the number of seizures would decrease, and a 30% chance that it would have no effect. Personal expectations were not discussed with the medical team.

The patients were interviewed in three different phases: 1) 73 patients responded to the expectations questionnaire. 2) 41 patients from the waiting list (56%) underwent surgical treatment and responded to the life changes questionnaire six months after surgery. 3) 22 patients from this first follow-up (post-surgery 1) responded to the life changes questionnaire 12 months after surgery (post-surgery 2).

All patients were interviewed independently. The psychologist (PCBS) read the questions and the subjects wrote down the answers. The form was the same for all subjects.

All patients in this study were adults from the outpatient epilepsy clinic at the University Hospital of Campinas (UNICAMP). The study was approved by the Ethics Committee of UNICAMP (174/2004).

Analysis

Descriptive statistics were used for continuous variables, and frequency for categorical variables. The Kuder-Richardson coefficient (KR20) for reliability and internal consistency was used for validation and verification of internal consistency. This coefficient is used to verify the homogeneity or accuracy of instrument items. The accuracy should not be lower than 0.70 if the scale is widely used, although values above 0.60 indicate consistency (Pagano and Gauvreau 2004).

Categorical variables were compared using the Chi-Square or Fisher test. The McNemar test was used to compare "yes/no" answers before and after surgery. The Wilcoxon test was used to compare answers for the periods before and after epilepsy surgery. The Kruskall-Wallis test was used to compare categorical with numerical variables. The level of significance was set with $p < 0.05$.

Results

Descriptive analysis

The descriptive analysis of the subjects was divided into three different phases: pre-surgery, post-surgery 1 (six months after surgery) and post-surgery 2 (12 months after surgery). Although the frequency of seizures was significantly reduced after surgery (Wilcoxon test, $p > 0.05$), other variables such as school level, work and marital state did not change between periods *(table 1)*.

table 2 gives the descriptive results of the pre- and post-surgery questionnaires, as well as the gold-standard questions. Before surgery, epilepsy was considered to have a negative impact and to be a serious problem for most of the patients (84.9% and 76.7%, respectively). After six months, this number decreased considerably to 19.5% and 12.2% and after 12 months, only 9.1% (n = 2) of patients still considered their epilepsy as having a negative impact and to be a serious problem in their lives. Non-parametric analysis showed a difference among the three periods (Wilcoxon test, $p < 0.001$).

The mean (M) and standard deviation (SD) of the total scores obtained with the questionnaires were: pre-surgery expectations questionnaire (M = 38.52; SD = 22.7), post-surgery life changes questionnaire 1 (M = 50.51; SD = 19.49), post-surgery life changes questionnaire 2 (M = 58.18; SD = 17.45). There was a strong association between the periods pre-surgery and 12 months after surgery, indicating the necessity for longer follow-up for better life adjustments (Wilcoxon test, $p = 0.001$).

Table 1. Demographic and clinical characteristics of subjects before and after epilepsy surgery.

	Presurgery (n = 73)	Postsurgery 1 (n = 41)	Postsurgery 2 (n = 22)
Mean age	35.01	34.33	34.41
School level			
- Elementary school	50%	51.42%	51.42%
- High school	37.14%	34.28%	34.28%
- Started college	12.85%	14.28%	14.28%
Work			
- Yes	32.85%	25.71%	28.57%
- No	67.14%	74.28%	71.42%
Marital state			
- Married	30%	25.71%	34.28%
- Single	70%	74.28%	65.71%
Mean seizure frequency/month*	9.62	2.96	3.71
Mean epilepsy duration (years)	25.1	24.37	25.13

* $p < 0.05$.

Table 2. Pre- and postsurgery questions and gold-standard questions.

Questions	Presurgery		Postsurgery 1		Postsurgery 2	
	Yes n (%)	No n (%)	Yes n (%)	No n (%)	Yes n (%)	No n (%)
1. Drive	27 (37.0)	46 (63.0)	9 (22.0)	32 (78.0)	9 (40.9)	13 (59.1)
2. Work/Study	38 (52.1)	35 (47.9)	15 (36.6)	26 (63.4)	13 (59.1)	9 (40.9)
3. Children	9 (12.3)	64 (87.7)	18 (43.9)	23 (56.1)	13 (59.1)	9 (40.9)
4. Social life	33 (45.2)	40 (54.8)	12 (29.3)	29 (70.7)	8 (36.4)	14 (63.6)
5. Marry	8 (11.0)	65 (89.0)	15 (36.6)	26 (63.4)	8 (36.4)	14 (63.6)
6. Medication	38 (52.1)	35 (47.9)	8 (19.5)	33 (80.5)	4 (18.2)	18 (81.8)
7. Memory	29 (39.7)	44 (60.3)	10 (24.4)	31 (75.6)	9 (40.9)	13 (59.1)
8. Happiness	43 (58.9)	30 (41.1)	20 (48.8)	21 (51.2)	13 (59.1)	9 (40.9)
9. Worries	39 (53.4)	34 (46.6)	22 (53.7)	19 (46.3)	15 (68.2)	7 (31.8)
10. Family care	15 (20.5)	58 (79.5)	27 (65.9)	14 (34.1)	15 (68.2)	7 (31.8)
11. Leisure	31 (42.5)	42 (57.5)	24 (58.5)	17 (41.5)	13 (59.1)	9 (40.9)
12. Freedom	31 (42.5)	42 (57.5)	5 (12.2)	36 (87.8)	3 (13.6)	19 (86.4)
13. Sexual life	10 (13.7)	63 (86.3)	3 (7.3)	38 (92.7)	2 (9.1)	20 (90.9)
14. Self-confidence	23 (31.5)	50 (68.5)	6 (14.6)	35 (85.4)	4 (18.2)	18 (81.8)
15. General health	28 (38.4)	45 (61.6)	10 (24.4)	31 (75.6)	8 (36.4)	14 (63.6)
16. Calm	26 (35.6)	47 (64.4)	13 (31.7)	28 (68.3)	12 (54.5)	10 (45.5)
17. Normality	17 (23.3)	56 (76.7)	14 (34.1)	27 (65.9)	12 (54.5)	10 (45.5)
18. Family acceptance	8 (11.0)	65 (89.0)	7 (17.1)	34 (82.9)	9 (40.9)	13 (59.1)
19. Headaches			3 (7.3)	38 (92.7)	2 (9.1)	20 (90.9)
20. Depression			8 (19.5)	33 (80.5)	0 (0)	22 (100)
21. Worse memory			8 (19.5)	33 (80.5)	1 (4.5)	21 (95.5)
22. Nervousness			5 (12.2)	36 (87.8)	1 (4.5)	21 (95.5)
23. Loneliness			6 (14.6)	35 (85.4)	1 (4.5)	21 (95.5)
24. Revolt			8 (19.5)	33 (80.5)	1 (4.5)	21 (95.5)
25. Family problems			4 (9.8)	37 (90.2)	7 (31.8)	15 (68.2)
Gold-standard 1	62 (84.9)	11 (15.1)	8 (19.5)	33 (80.5)	2 (9.1)	20 (90.9)
Gold-standard 2	56 (76.7)	17 (23.3)	5 (12.2)	36 (87.8)	2 (9.1)	20 (90.9)

The negative items (19 to 25) are already inverted.

Descriptive statistics and scaling properties

The mean time for completion of the scale was 10 minutes. After completing the questionnaires, the subjects stated that they had not had any problems understanding the questions.

Reliability and validity evaluation

The internal consistency of the instruments showed a general Kuder-Richardson coefficient of 0.855 (pre-surgery), 0.833 (post-surgery 1) and 0.756 (post-surgery 2).

Comparative analysis

Regarding the gold-standard questions "Does epilepsy have a negative impact in your life?" (Gold-standard 1) and "Is epilepsy a serious problem in your life?" (Gold-standard 2), our results confirmed our hypothesis that both questions have a positive correlation to the patient's expectations before surgery. Non-parametric analysis showed an association of expectations and the gold-standard question 1 (Kruskall-Wallis test, $p = 0.003$) and the gold-standard question 2 (Kruskall-Wallis test, $p = 0.009$). Both questions are also linked before and after surgery (Fisher test, $p < 0.003$), which means that the impact of epilepsy is associated with seizure frequency.
After surgery, the gold-standard questions were not associated with a patient's positive life changes because the great majority of them did not perceive epilepsy as having an impact or to be a serious problem in their lives, as can be seen in *table 2*.

Seizure frequency and severity after epilepsy surgery

Table 3 gives the descriptive analysis of the frequency and severity of seizures after surgery. Almost all patients who

Table 3. Descriptive analysis of seizure frequency and severity after epilepsy surgery.

	Postsurgery 1 Yes n (%)	Postsurgery 2 Yes n (%)
How would you evaluate your epilepsy surgery?		
Success	39 (95.1)	21(95.4)
Failure	2 (4.9)	1 (4.6)
How has the frequency of seizures changed?		
Remission	30 (73.2)	20 (90.9)
Reduction in 75%	11 (26.8)	2 (9.1)
How has the intensity of seizures changed?		
Remission	30 (73.2)	20 (90.9)
Did not change	2 (4.9)	
Less severe	9 (22.0)	2 (9.1)
Has epilepsy surgery changed your life?	38 (92.7)	22 (100)

considered surgery to be successful had their lives changed and were completely free of seizures. Those, who did not reach seizure-freedom, experienced a reduction of at least 75% in seizure frequency.

Discussion

This study aimed to validate two instruments that evaluate the pre-surgery expectations and post-surgery life changes of people with epilepsy who undergo surgical treatment. Little has been written about the processes of recovery following life-changing medical interventions for chronic illness. This is the first, prospective, longitudinal study to focus on a patient's pre-surgery expectations of life, and post-surgery life changes.
The questions included in both instruments have a satisfactory content validity and high internal consistence. It complies with the main requirements of a validation process (Bunchaft and Cavas 2002), offering reliable measurements. The process of validation of our both instruments followed standards recommended for the preparation of instruments (Menezes and Nascimento 2000, Almeida *et al.* 1989; Morley and Snaith 1989), which involved two components: one conceptual and the other empirical. The conceptual component is the assessment by the researcher of whether the instrument actually measures what it should measure. It is a subjective evaluation, with statistical methods. The operational validation involves an analysis of statistical methods, usually by comparing with gold-standard criteria, if available.
Flood *et al.* (1993) observed that expectations act to alter the perceptions of signs and symptoms, rather than altering the disease and outcome *per se*. Expectations focus the patient's attention on improvement in health, so that when health improves, no matter how slightly, the change is perceived as proof of significant improvement. All patients can benefit from surgery, despite subsequent seizure control. What really matters are their expectations prior to that (Wheelock *et al.* 1998).
Unrealistic expectations can cause psychosocial difficulties after surgery, even when seizure control is achieved (Derry *et al.* 2000). This is an interesting contrast, and presumably an important factor may be how realistic are the expectations. Unrealistic expectations that cannot be achieved make the patients feel they did not improve at all. In our study, all patients reported that their life changed after surgery, independent of seizure control. Patients free of seizures and with seizure reduction of 75% were satisfied with the results of surgery.
This study highlights the importance of working with patient perceptions, beliefs and understandings about the surgery process, so it is possible to foresee the presence of psychosocial difficulties and consequently, prevent them before their occurrence (Salgado *et al.* 2004). To best help patients with their condition, we must be certain that we

know their aims for treatment, that the patient shares our treatment purpose and understands its limitations, and that they truly want the treatment, with all its implications, which include the challenges that will arise with being well (Taylor *et al.* 1997).

In this context, the answers obtained in this study are important because they represent the development of complete set of categorical instruments with which to evaluate pre-surgery epilepsy expectations and post-surgery life changes. This study supports the psychometric properties of both questionnaires and provides information regarding patient perceptions and expectations of surgery. In summary, both instruments are reliable and valid, and will generate further study of the pre-surgical expectations, post-surgical outcomes and overall satisfaction with epilepsy surgery. □

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Appendix A

This is a translated version from the original in Portuguese.

Epilepsy Surgery Expectations Questionnaire

Date: ___/___/ ___   Age: _____   ( ) Single ( ) Married

Working ( ) Not working ( )   School level: _____

Epilepsy duration: _____ Seizure frequency/month: _____

I. We would like to have your cooperation in answering the questions of this questionnaire. Read each of them and circle the ones that better describe your life expectations after epilepsy surgery, that means, the reasons that motivate you to undergo epilepsy surgery.

1. Drive
2. Work/Study
3. Have children
4. Improve my social life
5. Marry
6. Take less anti-epileptic medication
7. Improve my memory
8. Be happy
9. Be less worried
10. Take care of my house and family
11. Have fun
12. Fell free
13. Improve my sexual life
14. Be safe to hang out alone
15. Be healthy
16. Be less nervous
17. Fell ordinary
18. Be accepted by my family

SCORING INSTRUCTIONS:

Total score = $\frac{\text{Sum of answered items} \times 100}{18}$

Higher scores indicate more life expectations before epilepsy surgery.

Appendix B

This is a translated version from the original in Portuguese.

Life Changes After Epilepsy Surgery Questionnaire

Date: ___/___/ ___   Age: _____   ( ) Single ( ) Married

Working ( ) Not working ( )   School level: _____

Epilepsy duration: _____ Seizure frequency/month: _____

I. We would like to have your cooperation in answering the questions of this questionnaire. Read each of them and circle the ones that better describe your life changes after epilepsy surgery, which means, the aspects that changed in your life after you underwent epilepsy surgery.

1. I drive
2. I Work/Study
3. I am planning to have children
4. My social life is better
5. I am planning to marry
6. I am taking less anti-epileptic medication
7. My memory is better
8. I am happy
9. I am less worried
10. I take care of my house and family
11. I have fun
12. I fell free
13. My sexual life is better
14. I feel safe when I hang out alone
15. I am healthy
16. I am less nervous
17. I fell ordinary
18. I fell accepted by my family
19. I have more headaches now
20. I feel depressed
21. My memory is worse than before
22. I feel nervous
23. I fell lonely
24. I feel rebel with people and things
25. I have family problems that I did not have before

II. What is your opinion about epilepsy surgery? ( ) Success ( ) Failure

III. Your seizures: ( ) Never happened again
          ( ) Had a reduction of at least 75%
          ( ) Had a reduction of less than 75%
          ( ) Have the same frequency as before
          ( ) Are less severe
          ( ) Are more severe
          ( ) Have the same severity as befor

SCORING INSTRUCTIONS:

Total score = $\frac{(\text{Sum of positive answered items - sum of negative answered items}) \times 100}{18}$

Higher scores indicate more positive life changes after epilepsy surgery.