



This is a repository copy of *A prospective service evaluation of acceptance and commitment therapy for patients with refractory epilepsy.*

White Rose Research Online URL for this paper:  
<http://eprints.whiterose.ac.uk/90646/>

Version: Accepted Version

---

**Article:**

Dewhurst, E., Novakova, B. and Reuber, M. (2015) A prospective service evaluation of acceptance and commitment therapy for patients with refractory epilepsy. *Epilepsy and Behavior*, 46. 234 - 241. ISSN 1525-5050

<https://doi.org/10.1016/j.yebeh.2015.01.010>

---

**Reuse**

Unless indicated otherwise, fulltext items are protected by copyright with all rights reserved. The copyright exception in section 29 of the Copyright, Designs and Patents Act 1988 allows the making of a single copy solely for the purpose of non-commercial research or private study within the limits of fair dealing. The publisher or other rights-holder may allow further reproduction and re-use of this version - refer to the White Rose Research Online record for this item. Where records identify the publisher as the copyright holder, users can verify any specific terms of use on the publisher's website.

**Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing [eprints@whiterose.ac.uk](mailto:eprints@whiterose.ac.uk) including the URL of the record and the reason for the withdrawal request.



[eprints@whiterose.ac.uk](mailto:eprints@whiterose.ac.uk)  
<https://eprints.whiterose.ac.uk/>

**A prospective service evaluation of Acceptance and Commitment Therapy for patients with refractory epilepsy**

Edel Dewhurst <sup>a</sup>, Barbora Novakova <sup>b,\*</sup>, Markus Reuber <sup>a,b</sup>

<sup>a</sup> *Department of Neurology, Royal Hallamshire Hospital, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, S10 2JF, UK*

<sup>b</sup> *Academic Neurology Unit, University of Sheffield, Royal Hallamshire Hospital, Glossop Road, Sheffield, S10 2JF, UK*

Email addresses: edel.dewhurst@sth.nhs.uk (E. Dewhurst), [bnovakova1@sheffield.ac.uk](mailto:bnovakova1@sheffield.ac.uk) (B. Novakova), [markus.reuber@sth.nhs.uk](mailto:markus.reuber@sth.nhs.uk) (M. Reuber)

\* Corresponding author. Address: Academic Neurology Unit, University of Sheffield, Royal Hallamshire Hospital, Glossop Road, Sheffield, S10 2JF, UK. Email: [bnovakova1@sheffield.ac.uk](mailto:bnovakova1@sheffield.ac.uk). Tel.: 44 (0) 1142713006.

## **Abstract**

*Objective:* The aim of this service evaluation was to explore the effectiveness of a psychotherapeutic treatment for patients with epilepsy based on the Acceptance and Commitment Therapy (ACT) approach and to assess whether this treatment is likely to be cost-effective.

*Method:* We conducted an uncontrolled prospective study of consecutive patients with refractory epilepsy referred for outpatient psychological treatment to a single psychotherapist because of emotional difficulties related to their seizure disorder. Participants were referred by consultant neurologists, neuropsychologists or epilepsy nurses and completed a set of validated self-report questionnaires (Short Form -12 Version 2, Generalised Anxiety Disorder - 7, Neurological Disorders Depression Inventory for Epilepsy, Work and Social Adjustment Scale, and Rosenberg Self-Esteem Scale) at referral, the end of therapy and six months post therapy. Patients received a maximum of 20 sessions of one-to-one psychological treatment supported by a workbook. Cost-effectiveness was estimated based on the calculation of quality-adjusted life year (QALY) gains associated with the intervention.

*Results:* Sixty patients completed the pre- and post-psychotherapy questionnaires, 41 also provided six-month follow-up data. Patients received six to 20 sessions of psychotherapy (mean = 11.5, S.D. = 9.6). Psychotherapy was associated with significant medium to large positive effects on depression, anxiety, quality of life, self-esteem, work and social adjustment ( $P_s < .001$ ), which were sustained six months after therapy. The mean cost of the psychotherapy was £445.6 and, assuming that benefits were maintained for at least six months after the end of therapy, the cost per QALY was estimated to be £11,140 (€14,119, \$18,016; the cost per QALY would be half this amount if the benefits lasted one year).

*Conclusion:* The findings of this pilot study indicate that the described psychotherapeutic intervention may be a cost-effective treatment for patients with epilepsy. The results suggest that randomised controlled trial of the psychotherapy programme is justified.

**Keywords:** Psychotherapy; Refractory epilepsy; Depression; Anxiety; Quality of Life; Self-esteem

## **1. Introduction**

Epilepsy is defined by recurrent epileptic seizures. However, seizures are not the only source of disability in patients with this disorder. Epilepsy is associated with an increased risk of cognitive deficits (especially memory problems), and rates of mood and anxiety disorders which are two or three times higher than in the general population [1]. The initial diagnosis of epilepsy can cause adjustment disorders, refractory epilepsy can challenge coping resources, and epilepsy can give rise to specific anxieties about seizures, which may cause significant restrictions of patients' independence and social functioning [2-4]. Having epilepsy is associated with perceived stigma, especially in the presence of comorbid mood disorders and low self-esteem [5, 6]. This means that there are many aspects of living with epilepsy, which could be considered targets for psychological treatment. However, access to psychological treatments, specifically designed to address the concerns of people with epilepsy, appears to be the exception rather than the rule, although in the United Kingdom (UK) national epilepsy treatment guidelines state that psychological treatment should be available to all patients with complex or refractory epilepsy [7]. Many of the psychological treatments which have been developed for patients with epilepsy have focussed on the attainment of seizure control [8], a therapeutic target perhaps better achieved by other means.

To date it has been relatively easy for healthcare purchasers to ignore references to the provision of psychological treatments in epilepsy treatment guidelines because there is insufficient evidence for the effectiveness of such interventions [9, 10]. A Cochrane review concluded that many studies were of poor methodological quality and yielded contradictory results. More specifically, the review found no evidence that relaxation therapy, cognitive behaviour therapy, electroencephalographic (EEG) or galvanic skin response biofeedback used alone or in combination had an impact on seizures or quality of life. They acknowledged that educational interventions showed greater promise in terms of reducing anxiety, improving medication compliance and social competency, but stated that further well-designed trials are needed [11].

Our prospective service evaluation explores the effectiveness of a treatment for patients with epilepsy based on the Acceptance and Commitment Therapy (ACT) approach. The general aim of ACT is to increase psychological flexibility (i.e. our ability to engage in valued behaviours while experiencing difficult thoughts, emotions, or sensations). The approach incorporates mindfulness and behaviour change processes. The treatment was supported by a patient workbook and offered to a large consecutive series of patients by a single psychotherapist. The intervention focused especially on anxiety, depression, lack of acceptance of the epilepsy diagnosis, emotional difficulties, e.g. guilt and shame, interpersonal and memory problems. Apart from providing information

required for group size calculations of a future randomised study, this service evaluation was intended to explore how effective this particular intervention may be if it is offered to patients treated routinely in a clinical epilepsy service in which neurologists, neuropsychologists and epilepsy specialist nurses are able to refer patients without restriction.

## **2. Material and methods**

### ***2.1 Subjects and recruitment***

Patients with emotional problems relating to their refractory epilepsy were identified and referred by Neurology Consultants, Neuropsychologists and Epilepsy Nurses working at the Sheffield Teaching Hospitals NHS Foundation Trust in Sheffield, UK. The therapy was delivered in a hospital outpatient setting. Patients were sent self-report questionnaires (see below) as a way of opting in to therapy. The same questionnaire was sent out by a member of staff not involved in the delivery of the treatment immediately after therapy ended and again after 6 months post therapy.

### ***2.2 Therapeutic intervention***

#### ***2.2.1 Structure of the intervention***

Treatment consisted of an initial one and a half hour assessment followed by 6-20 follow-up appointments. Sessions were arranged on a weekly or fortnightly basis. Therapy was offered on a one-to-one basis. However, if the patient wished for a family member or friend to accompany them to their initial appointment or occasional subsequent appointments this was welcomed. Therapy was delivered by a Cognitive Behavioural Psychotherapist with training in ACT. An exemplary case formulation is provided as supplementary web-content.

#### ***2.2.2 Assessment session***

The assessment was aimed at identifying what the patient perceived as the main problems relating to their diagnosis of epilepsy. This was placed within the ACT formulation. The ACT formulation focuses on how the patient's past and current life context function to maintain their on-going struggle with life. The 'Hexaflex' (see Figure 1) is a very useful six-component diagram, which aids assessment and formulation in ACT. The six processes included in the diagram are conceptualised as promoting the patient's psychological flexibility. By focusing on these processes the therapist is alert to the patient's experiential avoidance (feelings, thoughts memories or sensations which the patient is unwilling to endure); cognitive fusion (thoughts and language which the patient buys into to the point where their actions are controlled by their perception of who they are and who they 'should' be); and loss of life direction (loosing sight of what the patient wants his or her life to really stand for

in the present, excessive concerns about the past and the future). The patient's agreement with the emerging formulation was always sought, and this formulation shaped the subsequent intervention. The assessment session also included the provision of psycho-education about the ACT model [12]. This and an open, accepting, listening approach to the patient were intended to build rapport at this early stage of the treatment process and to assess the patient's motivation for further treatment. Once the patient understood the ACT model the session began to outline the treatment goals. Treatment goals were characterised more clearly in the follow-up sessions. Table 1 provides an overview of the six components and typical problems addressed by ACT.

\_\_\_\_\_Insert Figure 1 here\_\_\_\_\_

### *2.2.3 Workbook*

During the first or second follow-up session, patients were given a copy of the workbook "Understanding Epilepsy – A Psychotherapeutic Approach" to reinforce concepts and strategies learned in the therapy and provide self-help resources and worksheets for exercises [13]. The workbook is a 124-page illustrated brochure, which offers patients with epilepsy information about their condition and some of the commonest problems addressed by psychological treatment: anxiety, depression and concerns about memory failures. The self-help materials include, amongst others, a weekly activity schedule, thought record, valued directions worksheet, willingness and action plan worksheet, goal-setting worksheet, problem solving worksheet, building a compassionate image exercise, compassionate letter writing exercise, seizure, sleep, and eating diary, materials for the practice of cue controlled breathing, progressive muscle relaxation, mindful awareness, mindfulness in daily life, loving-kindness meditation, visualisation techniques, body scan exercise, grounding techniques, strategies for dealing with emotions, and more.

### *2.2.4 Subsequent sessions*

In the follow-up sessions, the patient's treatment goals were initially clarified further. The values component in ACT steers the patient towards a reflection on what they really want for their lives. It was considered important to spend time exploring the patient's most important values prior to goal-setting using ACT worksheets such as Valued Directions or Life Compass [13].

Since all six components of ACT are interconnected, explicit reference was made to them whenever they were touched upon in therapy. Patients were given homework at the end of each session (eg. values-led exposure to enhance commitment to action along with Mindfulness exercises to promote acceptance and self-compassion). Homework was reviewed at the beginning of the subsequent session and discussed with the patient with particular reference to their therapy goals and their proclaimed values. If anything got in the way of the patient being able to commit to their goals, this was discussed and worked on.

In addition the overall aim of ACT was re-emphasised in every session. Mindfulness practice was taught as a way of helping the patient to open up to all emotions, memories and thoughts. Patients were taught to practice being more fully present to ordinary daily experiences without judgement. They were encouraged to practice meditation and self-compassion exercises, e.g. compassionate letter-writing, Compassionate Image (creating a compassionate/caring/nurturing image in the mind, characterised by the qualities of wisdom, strength, warmth and non-judgement), Safe Place (spending a few moments during the day thinking of and visualising a safe place to feel calmer and more relaxed), instructions for all of which were included in the workbook. If the therapist noticed that the patient was fusing with language (getting overwhelmed by unhelpful thoughts or words), attention was drawn to the impact this was likely to be having on the patient. Metaphors, both verbal and visual were used throughout therapy. Metaphors are an important resource in ACT and are used to help reinforce relevant components of the treatment and to develop and normalise the patient's understanding of their difficulties. Every session ended with the formulation of a plan for the following week.

---

Insert Table 1 here

---

#### *2.2.5 End of therapy*

Patients were made aware that they could attend up to a maximum of 20 sessions. Therapy process was reviewed at intervals of four weeks. Therapy endings were always mutually agreed.

An illustrative treatment report of a typical case is offered as web content (*insert details of link to supplementary web content here*).

### **2.3 Outcome measures**

#### *2.3.1 Short Form – 12 Health Survey Version 2 (SF-12v2)*

SF-12v2 is a 12-item self-report measure of health-related quality of life, adapted from the original SF-36 questionnaire [14]. It assesses eight dimensions of HRQoL over a 4-week recall period, including physical functioning (2 items), role limitation-physical (2 items), bodily pain (1 item), general health (1 item), vitality (1 item), social functioning (1 item), role limitation-emotional (2 items), and mental health (2 items). These can be further summarised into a Physical Component Summary Scale (PCS) and Mental Health Component Summary Scale (MCS). The SF-12v2 is has been found a valid and a reliable substitute for the SF-36 [15, 16].

Individual items on the SF-12v2 were re-coded and combined into the eight subscales. Raw data have been transformed into final 0-100 scores and combined into the component summary sales.

Higher scores represent better quality of life. The component summary scales were assessed for internal consistency reliability using Cronbach's alpha (PCS  $\alpha = 0.81$ ; MCS  $\alpha = 0.71$ ). Subjects with missing data on any of the subscales were excluded from the analyses.

The raw SF-12 data can be transformed into a six-dimensional classification of health state, the SF-6D, which allows using the SF-12 in economic evaluations of health-related interventions. The SF-6D health index is a number ranging from 1 ("health") to 0 ("death") that can be used to calculate quality-adjusted life year (QALY) gains associated with an intervention.

### *2.3.2 Generalised Anxiety Disorder (GAD-7) Scale*

The GAD-7 is a 7-item self-report anxiety questionnaire, assessing anxiety symptoms experienced over the course of the past two weeks [17]. The reliability and validity of the GAD-7 have been tested and supported by a number of studies in both the general population and patients with psychopathology [18] [19, 20]. The GAD-7 has been validated by significant positive correlations with a number of anxiety measures, including the Hamilton Anxiety Scale, Beck Anxiety Inventory and the anxiety sub-scale of Symptom Checklist-90 [17, 21] and it has previously been used as a screening tool in epilepsy [22].

The seven items of the GAD-7 were combined to produce a total score (higher score reflects higher anxiety levels). The internal consistency reliability of the total score in our sample was acceptable ( $\alpha = .78$ ). Where one item was missing, a median replacement method was employed. Subjects with more than one item missing were not included in the analyses.

### *2.3.3 Neurological Disorders Depression Inventory for Epilepsy (NDDI-E)*

The NDDI-E is a 6-item inventory developed to detect depression in patients with epilepsy. The six items represent common symptoms of depression experienced in the past two weeks that can be differentiated from adverse effects of anti-epileptic drugs [23]. Higher scores on the NDDI-E indicate greater impairment. The inventory was found to have good internal consistency and test-retest reliability [23, 24]. A score of more than 15 on the NDDI-E was found to have 90% specificity, 81% sensitivity and a predictive value of 0.62 for a diagnosis of major depression [23] and NDDI-E was also found to have significant positive correlation with another screening tool for depression, the Patient Health Questionnaire [24].

Responses to the six items on the NDDI-E were summed into a total score and assessed for internal consistency reliability ( $\alpha = 0.78$ ). Missing data on one item were replaced by the median of the completed items. Subjects with more than one item missing were excluded from the analyses.

### *2.3.4 Work and Social Adjustment Scale (WSAS)*



The WSAS is a 5-item measure of impaired functioning attributable to a particular problem or disease [25]. The scale assesses impairment in five areas of work and social activities, including work, home management, social leisure activities, private leisure activities, and family and relationships, with higher values indicating greater impairment. The WSAS has been established as a valid, reliable and sensitive measure in a number of different disorders, including depression, anxiety, OCD, phobic disorders, or insomnia and it has proven a sensitive measure in a number of studies of patients with psychogenic non-epileptic seizures [25-29].

The five item scores were combined into a total score, which was found to have acceptable internal consistency reliability ( $\alpha = 0.79$ ). Missing values on one item were replaced by median scores of the completed items. Cases with more than one item missing were excluded from the analyses.

#### *2.3.5 Rosenberg Self-Esteem Scale (RSES)*

The RSES is a 10-item measure of self-esteem measuring both positive and negative feelings about the self [30]. The scale is uni-dimensional and produces a single total score, with higher values representing higher self-esteem. The RSES is a well-established scale that has been used and validated by a number of studies [31-33].

Responses to the RSES were combined into a total score and assessed for internal consistency reliability ( $\alpha = 0.87$ ). Median replacement was used in cases with one missing item on the RSES. Cases with more than one item missing were excluded from the analyses.

#### *2.3.6 Demographic questionnaire*

A simple demographic questionnaire was developed for the study to collect information about gender, marital status, employment status, education level, seizure duration and frequency.

#### *2.3.7 Seizure frequency*

Seizure frequency expressed as the number of seizures per one month was self-reported by patients in the demographic questionnaire. Patients who reported zero seizures in the past month were classed as 'seizure free'.

### **2.4 Cost-effectiveness**

The estimation of cost-effectiveness of the therapy was based on the calculation of quality-adjusted life year (QALY) gains associated with the therapy and the cost of the therapy. QALYs were calculated using the SF-6D health index derived from the original SF-12v2 data [34]. The number of QALYs gained by the therapy was obtained by subtracting the mean post-therapy (T1) from the mean baseline (T0) SF-6D index and multiplying the resulting score by the number of years for which the improvement was expected to last.

The direct therapy costs were estimated for one hour of treatment. This figure was obtained by following a procedure described in a similar study [35]: The midpoint of the gross annual salary for Band 7 salary scale (£36,193) plus 25% for employment on-cost provisions is £45,241 (€57,123; \$72,984). This figure was divided by 52 (weeks) and 37.5 (hours), and time for keeping notes, supervision, and other related activities was added to the time spent with patients face to face at a ratio of 0.67:1. The resulting cost was £38.75 (€49; \$63) per one hour of therapy. This was multiplied by the mean number of therapy sessions attended by the patients of the study. The resulting cost of the therapy was then divided by the number of QALYs gained to get an indication of the cost-effectiveness of the therapy (cost/QALY).

### **2.5 Statistical analyses**

Data were analysed using SPSS (version 21; SPSS Inc., Chicago, IL, U.S.A.). Distribution of scores was assessed for normality using the Shapiro-Wilk test. As scores on the WSAS, GAD-7, RSES, and most of the SF-12 sub-scales were non-normally distributed ( $p < .001$ ), non-parametric tests were used throughout. Data at baseline (T0) and after therapy (T1), as well as after therapy (T1) and at follow-up (T2) were compared using paired-samples Wilcoxon Signed-Ranks Test. Bonferroni correction was applied to the T0/T1 and T1/T2 comparisons. As there were 15 comparisons in each analysis, Bonferroni adjusted p-values of  $<0.003$  were considered statistically significant ( $0.05/15$ ). Effect sizes ( $r$ ) were calculated based on the formula for Wilcoxon Signed-Ranks Test [36]. According to the Cohen's criteria, an effect size of 0.1 was considered 'small', 0.3 represented a 'medium' effect size and 0.5 was considered 'large' [37].

### **2.6 Regulatory approval**

The data, which form the basis of this report, were collected as part of the routine evaluation of our psychotherapy service required by the funders of the service. The service evaluation was approved by the Clinical Effectiveness Unit of Sheffield Teaching Hospitals NHS Foundation Trust and conducted in full compliance with the Governance Regulations of this organisation.

## **3. Results**

### **3.1 Subjects**

A total of 159 patients completed the initial set of questionnaires. Of these, 60 patients completed both the baseline (T0) and post-therapy (T1) questionnaires and were included in the analyses. A further 41 patients returned the follow-up (T2) questionnaires. Three of these patients did not

return the post-therapy (T1) questionnaires and the T1 versus T2 comparisons were therefore performed using data from the 38 patients who had returned data at both time points.

### **3.2 Demographic and clinical characteristics**

Of the 60 patients who completed T0 and T1 questionnaires, 76.7% were female (N = 46). The median age of the group was 40 years (age range 19 – 75). At the time of the therapeutic treatment, 57.1% of the patients were ‘economically inactive’ (unemployed or retired), while 42.9% of the patients were ‘economically active’ (employed full-time or part-time or in full-time education). More information about the demographic characteristics of the group is detailed in Table 2.

\_\_\_\_\_Insert Table 2 here\_\_\_\_\_

The patients’ clinical characteristics are summarised in Table 3. The mean number of therapy appointments attended was 11.5 (S.D. = 9.6).

\_\_\_\_\_Insert Table 3 here\_\_\_\_\_

### **3.3 Comparisons of baseline (T0) versus post-therapy (T1)**

Psychotherapy was associated with significant improvements on most of the outcome measures at T1 (Table 4).

A significant improvement was found on most of the eight dimensions of the SF-12. Only the improvements on the physical functioning sub-scale and the physical health summary scale of the SF-12 were not significant.

Therapy was associated with significant improvement of work and social functioning (WSAS score), as well as a decrease in anxiety and depression (as measured by the GAD-7 and NDDI-E).

We also observed a significant improvement in the patients’ self-esteem, reflected by a significant increase on the RSES.

There was a change in the median seizure frequency, which approached significance ( $p = .006$ ).

Effect size calculations revealed that the effect sizes of the changes from T0 to T1 that reached significance ranged from medium to large (see Table 4).

\_\_\_\_\_Insert Table 4 here\_\_\_\_\_

Improvement was further explored for the psychological outcome measures that showed significant change, namely the SF-12, WSAS, GAD-7, NDDI-E, and RSES. Overall, 73.3% of the patients improved by at least 1 S.D. on at least one of the five measures, 53.3% improved on two or more measures,

and 35.0% improved on three or more measures. Deterioration by at least 1 S.D. on one or more of the measures was found in 21.7% of the patients (see Table 5 for more information).

\_\_\_\_\_Insert Table 5 here\_\_\_\_\_

As there was a large variability in the seizure frequency data. Table 6 shows the percentage improvement in seizure frequency.

\_\_\_\_\_Insert Table 6 here\_\_\_\_\_

### ***3.4 Comparisons post-therapy (T1) versus follow-up (T2)***

There was no significant change in any of the outcome measures between T1 and T2, suggesting that the immediate benefits of the psychotherapeutic intervention were sustained for at least six months after treatment (see Table 4 for further details).

### ***3.5 Cost-effectiveness***

The mean baseline (T0) SF-6D index was 0.57 and the mean SF-6D index after therapy (T1) was 0.65 (difference = 0.08). As the cost of one hour of therapy was estimated to be £38.75 and the mean number of therapy sessions attended was 11.5, the cost of the therapy was approximately £445.6 (€563; \$718). Given the 0.08 QALY gain and assuming that the benefits of the therapy would last for six months, the resulting cost/QALY associated with the therapy was £11,140 (€14,119; \$18,016). If the benefits persisted for one year, the cost would be reduced to £5,570/QALY (€7,039; \$8,979).

## **4. Discussion**

Epilepsy is a complex condition. It is associated with a wide range of comorbidities, and psychosocial complications, which may be more disabling and detrimental to the patients' quality of life than the seizures itself. A number of studies have highlighted the psychosocial impacts of epilepsy and emphasised the need for treatments addressing the full spectrum of problems associated with the disorder, rather than focus purely on seizure reduction [3, 4, 38, 39]. However, there is a lack of accessible and cost-effective psychological and behavioural interventions that are supported by high quality empirical evidence. This is likely to be one of the reasons why this treatment need therefore remains largely unmet [9, 11].

The aim of the current service evaluation was to explore the effectiveness of a psychotherapy programme based on the ACT approach and to provide information about effect sizes that could inform the design of future RCTs. The results of the evaluation show that the therapy had significant

medium to large effects on depression, anxiety, quality of life, work and social adjustment, and self-esteem, which were sustained several months after therapy. Given the adjustments for multiple comparisons that were made on the significance levels, the results of this evaluation provide a conservative estimate of the effects of the intervention.

The observed improvements of depression and anxiety are particularly encouraging, as depression and anxiety are common comorbidities with a complex, bi-directional relationship with epilepsy which often complicate the management of the disorder [39, 40]. Appropriate treatment of comorbid mood disorders has been suggested to have potentially important benefits for both seizure management and improved quality of life [39].

Significant improvement was found in most aspects of quality of life (measured by the SF-12) following the therapy, as well as on the Work and Social Adjustment scale. This finding is concordant with existing evidence from a small number of controlled studies of cognitive behavioural therapy and ACT for epilepsy. Martinovic et al. reported both significant reduction of depressive symptoms and improved quality of life in adolescent patients receiving a CBT intervention, compared to a control group [41], a CBT intervention was also effective in improving quality of life in a small RCT from Hong Kong [42], and two small-scale RCTs by Lundgren et al. showed significant improvements in quality of life following a short-term ACT treatment [43, 44].

Whilst scores on all the mental health related sub-scales of the SF-12 were significantly better after therapy, no change was found on the physical health component summary scale and the physical functioning sub-scale. This may suggest that our therapeutic approach, which was primarily focused on emotional, interpersonal and cognitive difficulties, was indeed more effective in improving the emotional and social aspects of HRQoL rather than physical functioning. Having said that, all the other physical sub-scales of the SF-12 including general health, bodily pain and role limitations due to physical health did show significant improvement after treatment. It is possible that the particular issues captured by the physical functioning sub-scale, which include physical activities such as 'pushing a vacuum', playing golf or climbing up the stairs may not be compromised in patients with epilepsy or may not be amenable to change by psychotherapy alone. This interpretation would be supported by other studies that failed to find any effects of psychotherapy on the physical functioning sub-scale of the SF-36 [35].

In addition to the positive effects on depression, anxiety and overall quality of life, which were the focus of the psychotherapy, we also found a significant improvement in self-esteem. Self-esteem is

often low in patients with epilepsy and could play an important role in the psychosocial adjustment to epilepsy, especially in relation to the perceived stigma associated with the disorder [6].

The change in median seizure frequency following therapy only approached significance. Closer examination of the changes in seizure frequency showed that although 37.2% of patients reported a more than 50% reduction in seizure frequency, there were more patients (39.5%) who experienced a smaller than 50% improvement or no change at all. This finding is in contrast with the findings of the studies by Lundgren et al. [43, 44] who reported a significant decrease in seizure frequency as a result of ACT psychotherapeutic treatment. However, the overall evidence for effectiveness of psychological interventions for reducing seizures is mixed [11], and it is important to emphasise that the focus of the therapeutic approach used in our study was on the psychosocial issues associated with epilepsy rather than reduction of seizure frequency per se.

The estimated cost-effectiveness of the therapy suggests that our psychotherapy programme is relatively inexpensive and far below the National Institute for Health and Clinical Excellence cost-effectiveness threshold of £25,000 - £35,000 [45].

#### **4.1 Limitations**

The Cochrane review of psychological treatments for epilepsy mentioned above stated that more “high quality evidence” conforming to the biomedical model is required. “High quality evidence” usually means double-blind randomised controlled trials (RCTs). Whilst therapists in psychotherapy cannot be blinded, and there are significant study design challenges relating to the control condition of psychological RCTs, studies in many areas have demonstrated that psychotherapy RCTs are feasible [46-48]. This means that there is no reason why psychological treatments for patients with epilepsy could not be conducted in this way. Having said that, there are issues with the generalisation of the results of psychotherapy RCTs, which may not apply in the same way to RCTs of simpler interventions, for instance the use of a new drug. Patients undergoing psychological treatment have to make a considerable investment in time, hope and energy to complete a course of treatment. Taking part in a psychotherapy RCT is likely to be particularly difficult and likely to require a high level of motivation on the part of the patient. This means that the patients taking part in psychotherapy RCTs may be quite different from those seen in routine clinical practice and referred for psychological treatment. The lack of a randomisation procedure or exclusion criteria in the current service evaluation means that the results may be more readily generalisable to patients routinely seen in neurological practice. Nevertheless, the uncontrolled, exploratory design of the study is an obvious limitation of our evaluation and makes it difficult to determine with certainty

that the psychotherapy was the sole cause of the observed improvements in the psychological measures.

All of the psychological treatment in this service evaluation was delivered by a single therapist. Whilst this and the fact that the therapeutic approach was supported by a manual means that the treatment offered was relatively homogeneous, and the treatment effect sizes seen in our service evaluation were similar to the those in other studies using a similar therapeutic approach [49], the fact that only one therapist was involved here means that it is impossible, at this stage, to separate between therapist and treatment effects.

In addition, there are limitations related to the reliance on self-report measures, which are subjective and prone to a range of biases, such as the social desirability bias or a tendency to respond in a way that may be viewed favourably by the researcher or the therapist.

## **5. Conclusions**

Bearing in mind these limitations, this service evaluation suggests that the described psychotherapy programme, based on the ACT approach, has medium to large positive effects on depression and anxiety, quality of life, adjustment and self-esteem. These positive effects were observed immediately after treatment and sustained for at least six months beyond the end of therapy. Benefits were associated with relatively low costs. These results are promising and suggest that a randomised controlled trial of the psychotherapy programme is justified.

## **6. Acknowledgements**

The production of the workbook used in this study was supported by a grant from Epilepsy Action.

## **7. Conflict of Interest Statement**

ED was the therapist who delivered the therapy described in this study. MR was involved in securing funding and developing the epilepsy psychotherapy service. The authors have no other conflicts of interest to declare.

## **8. References**

- [1] Tellez-Zenteno, J.F., Patten, S.B., Jette, N., Williams, J. and Wiebe, S. Psychiatric comorbidity in epilepsy: A population-based analysis. *Epilepsia* 2007; **48**:2336-2344.
- [2] Fisher, R.S., Vickrey, B.G., Gibson, P., Hermann, B., Penovich, P., Scherer, A. and Walker, S. The impact of epilepsy from the patient's perspective I. Descriptions and subjective perceptions. *Epilepsy Res* 2000; **41**:39-51.
- [3] Lu, B. and Elliott, J.O. Beyond seizures and medications: Normal activity limitations, social support, and mental health in epilepsy. *Epilepsia* 2012; **53**:e25-e28.
- [4] Baker, G.A., Jacoby, A., Buck, D., Stalgis, C. and Monnet, D. Quality of life of people with epilepsy: A European study. *Epilepsia* 1997; **38**:353-362.
- [5] Baker, G.A., Brooks, J., Buck, D. and Jacoby, A. The stigma of epilepsy: A European perspective. *Epilepsia* 2000; **41**:98-104.
- [6] Jacoby, A. Epilepsy and stigma: An update and critical review. *Current Neurology and Neuroscience Reports* 2008; **8**:339-344.
- [7] NICE The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care. In: National Institute for Health and Clinical Excellence clinical guideline 137, 2012.
- [8] Goldstein, L.H. Effectiveness of psychological interventions for people with poorly controlled epilepsy. *Journal of Neurology Neurosurgery and Psychiatry* 1997; **63**:137-142.
- [9] Mittan, R.J. Psychosocial treatment programs in epilepsy: A review. *Epilepsy & Behavior* 2009; **16**:371-380.
- [10] Tang, V., Michaelis, R. and Kwan, P. Psychobehavioral therapy for epilepsy. *Epilepsy & Behavior* 2014; **32**:147-155.
- [11] Ramaratnam, S., Baker, G.A. and Goldstein, L.H. Psychological treatments for epilepsy. *Cochrane Database of Systematic Reviews* 2008; 37.
- [12] Hayes, S.C. and Strosahl, K.D. *A Practical Guide to Acceptance and Commitment Therapy* Springer Science & Business Media, Inc., 2010.
- [13] Dewhurst, E. and Reuber, M. *Understanding Epilepsy – A Psychotherapeutic Approach*, Unpublished Brochure.
- [14] Ware, J.E., Kosinski, M. and Keller, S.D. *A 12-Item Short-Form Health Survey: Construction of scales and preliminary tests of reliability and validity*. *Medical Care* 1996; **34**:220 - 233.
- [15] Lam, E.T.P., Lam, C.L.K., Fong, D.Y.T. and Huang, W.W. Is the SF-12 version 2 Health Survey a valid and equivalent substitute for the SF-36 version 2 Health Survey for the Chinese? *Journal of Evaluation in Clinical Practice* 2013; **19**:200-208.
- [16] Cheak-Zamora, N.C., Wyrwich, K.W. and McBride, T.D. Reliability and validity of the SF-12v2 in the medical expenditure panel survey. *Quality of Life Research* 2009; **18**:727-735.
- [17] Spitzer, R.L., Kroenke, K., Williams, J.B.W. and Lowe, B. A brief measure for assessing generalized anxiety disorder - The GAD-7. *Archives of Internal Medicine* 2006; **166**:1092-1097.
- [18] Lowe, B., Decker, O., Muller, S., Brahler, E., Schellberg, D., Herzog, W. and Herzberg, P.Y. Validation and standardization of the generalized anxiety disorder screener (GAD-7) in the general population. *Medical Care* 2008; **46**:266-274.
- [19] Dear, B.F., Titov, N., Sunderland, M., McMillan, D., Anderson, T., Lorian, C. and Robinson, E. Psychometric Comparison of the Generalized Anxiety Disorder Scale-7 and the Penn State Worry Questionnaire for Measuring Response during Treatment of Generalised Anxiety Disorder. *Cognitive Behaviour Therapy* 2011; **40**:216-227.

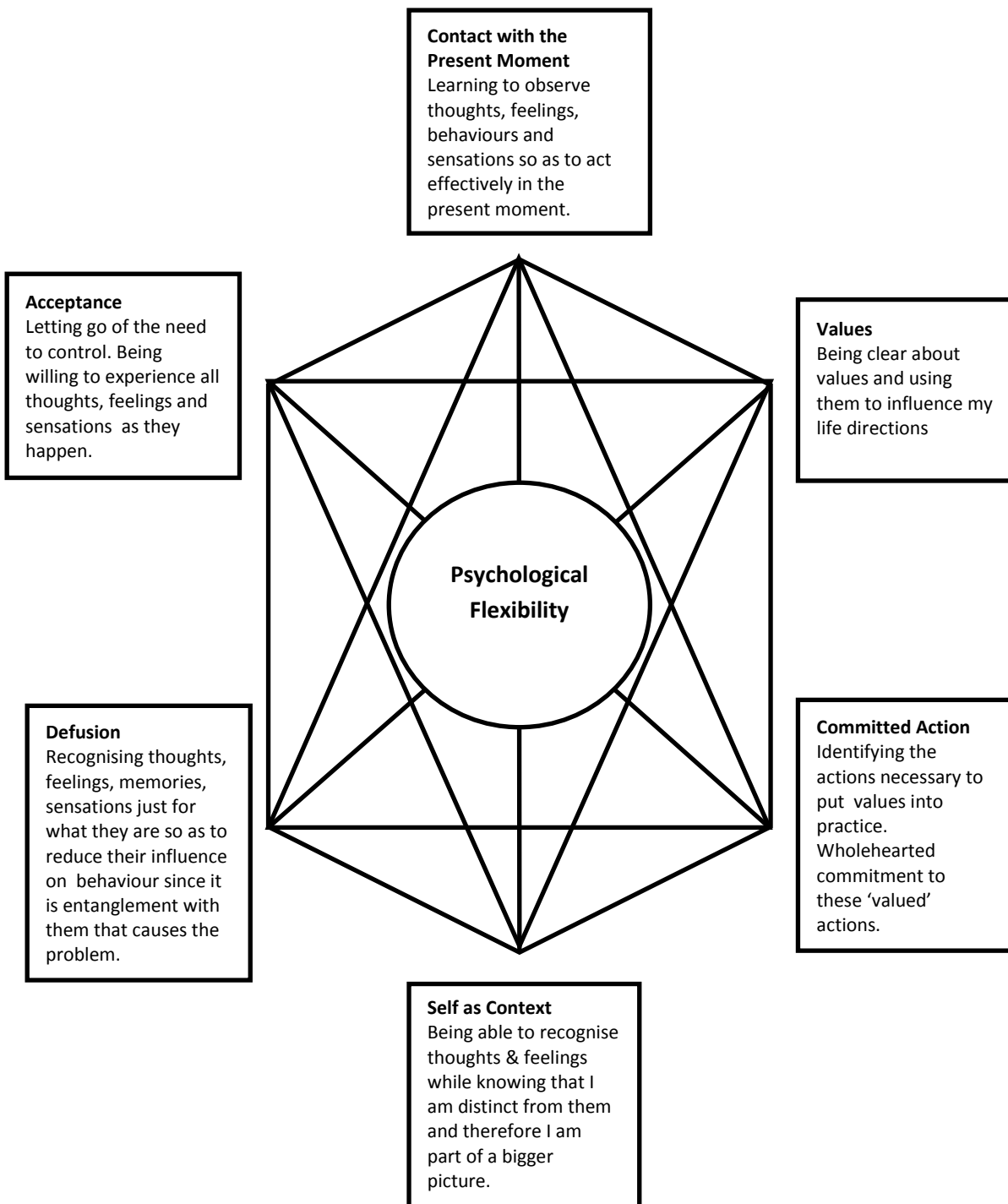


- [20] Delgadillo, J., Payne, S., Gilbody, S., Godfrey, C., Gore, S., Jessop, D. and Dale, V. Brief case finding tools for anxiety disorders: Validation of GAD-7 and GAD-2 in addictions treatment. *Drug and Alcohol Dependence* 2012; **125**:37-42.
- [21] Ruiz, M.A., Zamorano, E., Garcia-Campayo, J., Pardo, A., Freire, O. and Rejas, J. Validity of the GAD-7 scale as an outcome measure of disability in patients with generalized anxiety disorders in primary care. *Journal of Affective Disorders* 2011; **128**:277-286.
- [22] Rakesh, S.P., Ramesh, R., Rachel, P., Chanda, R., Satish, N. and Mohan, V.R. Quality of life among people with epilepsy: A cross-sectional study from rural southern India. *The National medical journal of India* 2012; **25**:261-264.
- [23] Gilliam, F.G., Barry, J.J., Hermann, B.P., Meador, K.J., Vahle, V. and Kanner, A.M. Rapid detection of major depression in epilepsy: a multicentre study. *Lancet Neurology* 2006; **5**:399-405.
- [24] Margrove, K., Mensah, S., Thapar, A. and Kerr, M. Depression screening for patients with epilepsy in a primary care setting using the Patient Health Questionnaire-2 and the Neurological Disorders Depression Inventory for Epilepsy. *Epilepsy & Behavior* 2011; **21**:387-390.
- [25] Mundt, J.C., Marks, I.M., Shear, M.K. and Greist, J.H. The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *British Journal of Psychiatry* 2002; **180**:461-464.
- [26] Mataix-Cols, D., Cowley, A.J., Hankins, M., Schneider, A., Bachofen, M., Kenwright, M., Gega, L., Cameron, R. and Marks, I.M. Reliability and validity of the Work and Social Adjustment Scale in phobic disorders. *Comprehensive Psychiatry* 2005; **46**:223-228.
- [27] Jansson-Frojmark, M. The Work and Social Adjustment Scale as a Measure of Dysfunction in Chronic Insomnia: Reliability and Validity. *Behavioural and Cognitive Psychotherapy* 2014; **42**:186-198.
- [28] Goldstein, L.H., Chalder, T., Chigwedere, C., Khondoker, M.R., Moriarty, J., Toone, B.K. and Mellers, J.D.C. Cognitive-behavioral therapy for psychogenic nonepileptic seizures A pilot RCT. *Neurology* 2010; **74**:1986-1994.
- [29] Chen, D.K., Maheshwari, A., Franks, R., Trolley, G.C., Robinson, J.S. and Hrachovy, R.A. Brief group psychoeducation for psychogenic nonepileptic seizures: A neurologist-initiated program in an epilepsy center. *Epilepsia* 2014; **55**:156-166.
- [30] Rosenberg, M. *Society and the adolescent self-image*, Princeton University Press, Princeton, NJ, 1965.
- [31] Schmitt, D.P. and Allik, J. Simultaneous administration of the Rosenberg Self-Esteem Scale in 53 nations: Exploring the universal and culture-specific features of global self-esteem. *Journal of Personality and Social Psychology* 2005; **89**:623-642.
- [32] Hagborg, W.J. THE ROSENBERG SELF-ESTEEM SCALE AND HARTER SELF-PERCEPTION PROFILE FOR ADOLESCENTS - A CONCURRENT VALIDITY STUDY. *Psychology in the Schools* 1993; **30**:132-136.
- [33] Shevlin, M.E., Bunting, B.P. and Lewis, C.A. CONFIRMATORY FACTOR-ANALYSIS OF THE ROSENBERG SELF-ESTEEM SCALE. *Psychological Reports* 1995; **76**:707-710.
- [34] Brazier, J.E. and Roberts, J. The estimation of a preference-based measure of health from the SF-12. *Medical Care* 2004; **42**:851-859.
- [35] Reuber, M., Burness, C., Howlett, S., Brazier, J. and Grunewald, R. Tailored psychotherapy for patients with functional neurological symptoms: A pilot study. *Journal of Psychosomatic Research* 2007; **63**:625-632.
- [36] Field, A. *Discovering Statistics Using SPSS*, Third ed., SAGE Publications Ltd, London, 2009.
- [37] Cohen, J. A POWER PRIMER. *Psychological Bulletin* 1992; **112**:155-159.
- [38] Hermann, B. and Jacoby, A. The psychosocial impact of epilepsy in adults. *Epilepsy & Behavior* 2009; **15**:S11-S16.
- [39] Kerr, M.P., Mensah, S., Besag, F., de Toffol, B., Ettinger, A., Kanemoto, K., Kanner, A., Kemp, S., Krishnamoorthy, E., LaFrance, W.C., Mula, M., Schmitz, B., van Elst, L.T., Trollor, J. and Wilson, S.J. International consensus clinical practice statements for the treatment of neuropsychiatric conditions associated with epilepsy. *Epilepsia* 2011; **52**:2133-2138.

- [40] Kanner, A.M. Psychiatric issues in epilepsy: The complex relation of mood, anxiety disorders, and epilepsy. *Epilepsy Behav* 2009; **15**:83-87.
- [41] Martinovic, Z., Simonovic, P. and Djokic, R. Preventing depression in adolescents with epilepsy. *Epilepsy & Behavior* 2006; **9**:619-624.
- [42] Au, A., Chan, F.F., Li, K., Leung, P., Li, P. and Chan, J. Cognitive-behavioral group treatment program for adults with epilepsy in Hong Kong. *Epilepsy & Behavior* 2003; **4**:441-446.
- [43] Lundgren, T., Dahl, J.A., Melin, L. and Kies, B. Evaluation of acceptance and commitment therapy for drug refractory epilepsy: A randomized controlled trial in South Africa - A pilot study. *Epilepsia* 2006; **47**:2173-2179.
- [44] Lundgren, T., Dahl, J., Yardi, N. and Melin, L. Acceptance and Commitment Therapy and yoga for drug-refractory epilepsy: A randomized controlled trial. *Epilepsy Behav* 2008; **13**:102-108.
- [45] Rawlins, M.D. and Culyer, A.J. National Institute for Clinical Excellence and its value judgments. *British Medical Journal* 2004; **329**:224-227.
- [46] Ekers, D., Richards, D. and Gilbody, S. A meta-analysis of randomized trials of behavioural treatment of depression. *Psychological Medicine* 2008; **38**:611-623.
- [47] Beltman, M.W., Voshaar, R.C.O. and Speckens, A.E. Cognitive-behavioural therapy for depression in people with a somatic disease: meta-analysis of randomised controlled trials. *British Journal of Psychiatry* 2010; **197**:11-19.
- [48] Smit, Y., Huibers, M.J.H., Ioannidis, J.P.A., van Dyck, R., van Tilburg, W. and Arntz, A. The effectiveness of long-term psychoanalytic psychotherapy-A meta-analysis of randomized controlled trials. *Clinical Psychology Review* 2012; **32**:81-92.
- [49] Ost, L.G. Efficacy of the third wave of behavioral therapies: A systematic review and meta-analysis. *Behaviour Research and Therapy* 2008; **46**:296-321.

## 9. Figures

Figure 1: 'Hexaflex' – schematic representation of the six main components of ACT.



## **10. Tables**

*Table 1. The six components of ACT*

| <b>Six components of ACT</b>                        | <b>Typical core problems</b>       |
|---|------------------------------------|
| Contact with the present moment                     | Absorbed in the past or the future |
| Acceptance and willingness as an alternative agenda | Experiential avoidance             |
| Self as context                                     | Self as content                    |
| Cognitive defusion                                  | Cognitive fusion                   |
| Commitment & behaviour change processes             | Inaction or ineffective action     |
| Values-guided action                                | Disconnection from values          |

Table 2. Demographic Information

| Variable                    | N  | Mean (S.D.)/Percent |
|-----------------------------|----|---------------------|
| Full-time Education (years) | 51 | 12.77 (4.45)        |
| Employment Status Total     | 56 |                     |
| Full-time                   | 14 | 25.0%               |
| Part-time                   | 8  | 14.3%               |
| Unemployed                  | 21 | 37.5%               |
| Student                     | 2  | 3.6%                |
| Retired                     | 11 | 19.6%               |
| Marital Status Total        | 58 |                     |
| Single                      | 18 | 31.0%               |
| Married                     | 28 | 48.3%               |
| Live with partner           | 4  | 6.9%                |
| Divorced/Separated          | 8  | 13.8%               |
| Widowed                     | 0  | 0%                  |

Note. S.D. = standard deviation.

Table 3. Clinical variables

| Variable                                       | N  | Mean (SD)/Median (IQR)/Percent |
|--|----|--------------------------------|
| Epilepsy duration (years)                      | 56 | 14.9 (14.8)                    |
| Median seizure frequency (seizures/month)      | 42 | 2.00 (3.40)                    |
| Type of epileptic seizures                     |    |                                |
| <i>Primary generalised seizures</i>            |    |                                |
| Tonic-clonic seizures                          | 9  | 15.0%                          |
| Absence seizures                               | 3  | 5.0%                           |
| Myoclonic seizures                             | 5  | 8.3%                           |
| <i>Partial</i>                                 |    |                                |
| Simple or complex partial seizures             | 20 | 33.3%                          |
| Partial seizures with secondary generalisation | 10 | 16.7%                          |
| <i>Unknown</i>                                 | 17 | 28.3%                          |

Note. S.D. = standard deviation.

*Table 4. Comparison of median scores of the main outcome measures at baseline (T0), post-therapy (T1), and at follow-up (T2)*

| Outcome Measure             | Score at T0<br>M (IQR) | Score at T1<br>M (IQR)<br>(N=60) | Score at T2<br>M (IQR)<br>(N=38) | P for T0/ T1<br>comparison | Effect<br>size (r) | P for T1/T2<br>comparison |
|-----------------------------|------------------------|----------------------------------|----------------------------------|----------------------------|--------------------|---------------------------|
| <b>SF-12</b>                |                        |                                  |                                  |                            |                    |                           |
| Mental Health Summary       | 25.89 (17.49)          | 38.39 (18.11)                    | 34.06 (19.71)                    | <.001                      | .46                | n.s.                      |
| Physical Health Summary     | 43.33 (16.60)          | 48.32 (16.29)                    | 45.93 (19.71)                    | n.s.                       | .19                | n.s.                      |
| Physical Functioning        | 47.88 (17.18)          | 47.88 (25.77)                    | 47.88 (23.62)                    | n.s.                       | .06                | n.s.                      |
| Role Limitation – Physical  | 34.14 (14.97)          | 38.75 (18.42)                    | 38.75 (23.03)                    | .001                       | .31                | n.s.                      |
| Bodily Pain                 | 47.25 (30.57)          | 47.25 (20.38)                    | 47.25 (30.57)                    | .002                       | .29                | n.s.                      |
| General Health              | 29.65 (15.09)          | 44.74 (15.09)                    | 29.65 (15.09)                    | .001                       | .29                | n.s.                      |
| Vitality                    | 37.69 (20.13)          | 47.75 (10.06)                    | 37.69 (10.06)                    | <.001                      | .33                | n.s.                      |
| Social Functioning          | 26.27 (10.10)          | 36.37 (30.30)                    | 36.37 (30.30)                    | <.001                      | .35                | n.s.                      |
| Role Limitation - Emotional | 22.53 (16.77)          | 33.71 (22.37)                    | 33.71 (22.37)                    | .001                       | .32                | n.s.                      |
| Mental Health               | 27.97 (9.14)           | 40.16 (12.19)                    | 40.16 (12.19)                    | <.001                      | .49                | n.s.                      |
| WSAS                        | 22.50 (12.00)          | 12.75 (12.63)                    | 15.00 (19.00)                    | <.001                      | .50                | n.s.                      |
| GAD-7                       | 15.00 (6.25)           | 7.00 (12.25)                     | 9.00 (9.25)                      | <.001                      | .47                | n.s.                      |
| NDDI-E                      | 19.00 (4.25)           | 15.50 (7.00)                     | 15.00 (4.00)                     | <.001                      | .42                | n.s.                      |
| RSES                        | 12.00 (8.00)           | 15.00 (9.00)                     | 14.00 (6.00)                     | <.001                      | .35                | n.s.                      |
| Seizure Frequency           | 2.00 (3.40)            | 1.00 (3.16)                      | 2.00 (2.50)                      | n.s.                       | .30                | n.s.                      |

Note. M = median; IQR = interquartile range; n.s. = non-significant difference.

*Table 5. Improvement and deterioration on the outcome measures that showed significant change from baseline (T0) to post-therapy (T1)*

| Outcome Measure          | N (100%) | N Improved by $\geq 1$ S.D. (%) | N Deteriorated by $\geq 1$ S.D. (%) |
|--------------------------|----------|---------------------------------|-------------------------------------|
| SF-12 MHS (S.D. = 11.14) | 47       | 21 (44.7%)                      | 2 (4.3%)                            |
| WSAS (S.D. = 8.77)       | 52       | 25 (48.1%)                      | 2 (3.9%)                            |
| GAD-7 (S.D. = 4.49)      | 54       | 31 (57.4%)                      | 6 (11.1%)                           |
| NDDI-E (S.D. = 3.19)     | 54       | 26 (48.2%)                      | 3 (5.6%)                            |
| RSES (S.D. = 5.94)       | 51       | 19 (37.3%)                      | 4 (7.8%)                            |

Note. S.D. = standard deviation from the mean.



*Table 6. Improvement and deterioration of seizure frequency from T0 to T1.*

| Change  | N  | %     |
|---|----|-------|
| Total   | 43 | 100%  |
| 100% Improvement (seizure-free)                                   | 4  | 9.3%  |
| >50% Improvement  | 16 | 37.2% |
| No change ( $\leq 50\%$ improvement to $\leq 50\%$ deterioration) | 17 | 39.5% |
| >50% Deterioration  | 1  | 2.3%  |
| >100% Deterioration   | 5  | 11.6% |