

Evaluation of Acceptance and Commitment Therapy for Drug Refractory Epilepsy: A Randomized Controlled Trial in South Africa—A Pilot Study

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Summary: *Purpose:* Psychological interventions in the treatment of epilepsy have been developed and evaluated for many years but the amount of research has hardly made an impact on how epilepsy is treated. The purpose of this study was to develop and evaluate a psychological treatment program consisting of acceptance and commitment therapy (ACT) together with some behavioral seizure control technology shown to be successful in earlier research.

Methods: The method consisted of a randomized controlled trial group design with repeated measures ($n = 27$). All participants had an EEG verified epilepsy diagnosis with drug refractory seizures. Participants were randomized into one of two conditions, ACT or supportive therapy (ST). Therapeutic effects were measured by examining changes in quality of life (SWLS

and WHOQOL) and seizure index (frequency \times duration). Both treatment conditions consisted of only nine hours of professional therapy distributed in two individual and two group sessions during a four-week period.

Results: The results showed significant effects over all of the dependent variables for the ACT group as compared to the ST group at six- and twelve-month follow-ups.

Conclusions: The results from this study suggest that a short-term psychotherapy program combined with anticonvulsant drugs may help to prevent the long-term disability that occurs from drug refractory seizures. **Key Words:** Epilepsy—Acceptance and commitment therapy—Seizure control techniques—South Africa.

The conditioning mechanisms and subsequent psychological interventions used in the analysis and treatment of epilepsy have been evaluated and published for more than a half century. Behavioral treatment programs have shown to be promising in helping to reduce seizure frequency for individuals with drug refractory seizures, at a low cost (Goldstein, 1990; Yardi, 2000; Ramaratnam et al., 2004; Dahl and Lundgren, 2005; Wagner and Smith, 2005). Despite this substantial amount of research, psychological treatment for those individuals suffering from frequent seizures has generally not been made available. Twenty-five to forty percent of patients suffering from epilepsy are not fully controlled by anticonvulsant drugs (AED) and a significant percent also experience adverse effects secondary to this medication (Kwan and Brodie, 2000). AED treatment is also very expensive (Platt and Sperling, 2002) and therefore not available to the 45 million people with epilepsy (Scott et al., 2001) living in the

developing countries (Chrisholm, 2005). For most patients with epilepsy, recurrent seizures are only one of many contributors to the overall predicament. Persons with uncontrolled chronic seizures suffer a much higher risk for seizure-related head injuries, psychiatric disorders especially depression, shorter life expectancy, and generally poorer health outcome (Johnson et al., 2004; Tomson et al., 2004; Wallace and Farrell, 2004). Quality of life is generally ranked lower among those with chronic epilepsy as compared to most any other chronic illness (Cummins, 1997). The stigmatization of epilepsy along with the threat of seizure creates stressful emotions that themselves can exacerbate seizures. For those individuals who prefer an alternative or complement to drug therapy and for those who do not have access to modern anticonvulsant drugs, developing an effective psychological program is essential. The psychological treatment program described here was created, performed, and evaluated for institutionalized individuals with refractory seizures within the organization Epilepsy South Africa.

For behavioral researchers, it is self-evident that neuronal processes can be influenced by classic and operant conditioning (Rockstroh et al., 1984). According to a

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behavior medicine model, epilepsy is defined as a combination of a person's predisposition to seize together with internal and external factors, in a certain context. The complex increases or decreases the probability of seizure occurrence (Fenwick and Brown, 1989). Behavioral treatment of seizures includes teaching an awareness of the triggering factors, the process of the seizure behavior itself, and particular functions of seizures. Earlier work has shown that seizures can be prevented, and interrupted by the use of behavioral techniques (Dahl et al., 1992). Seizure control is important in the treatment of epilepsy and it is also important to target thoughts, feelings, and stigmatization related to epilepsy to decrease human suffering (Wolf, 1992). The stigmatization of having epilepsy can, especially in the developing countries be devastating to the possibilities of getting an education, obtaining a job, finding a partner, and making a family. A treatment model should therefore include not only seizure management techniques but also address the whole context of how having epilepsy influences important life dimensions.

Contextual behavior therapies like acceptance and commitment therapy (ACT) are becoming more and more important in empirical clinical psychology (Hayes et al., 2006). ACT is developed from the same theory of learning as cognitive behavior therapy (CBT) but linked to a new scientifically theory about language and cognitions called relational frame theory (RFT) (Hayes et al., 2001). ACT has been successfully evaluated for individuals suffering from chronic illnesses like pain and diabetes (Dahl et al., 2004; Gregg, 2004) and psychiatric disorders commonly associated with epilepsy like depression (Hayes, 2001). The goal of an ACT treatment is to create psychological flexibility and build a broader behavior repertoire in the service of the client's chosen values and life goals. The brief description of ACT is: accept, choose, and take action (Hayes et al., 1999). With regards to epilepsy, this implies accepting one's predisposition to seize along with the fears, thoughts, and memories associated with epilepsy and willingly choose actions in the service of one's vital valued life directions. A central concept in ACT is called experiential avoidance which in the case of epilepsy means that not only does the individual avoid the actual seizures but also fears, thoughts, feelings, and memories related to even the risk of seizures (Hayes and Strohals, 2005). Cull and Goldstein (1997) showed that persons with epilepsy tend to avoid activities generally, due to the thoughts and fears associated with an increased risk of seizure occurrence. The assimilation of behavior technology of seizure control into the ACT model may help to address the psychological complexity of having epilepsy. The aim of this pilot study is to evaluate the effects of combining an ACT treatment with seizure control techniques for persons suffering from epilepsy.

METHOD

Design

The design was a randomized controlled two-group study with repeated measures. Using a computerized randomization table participants were assigned into one of the two conditions; ACT or supportive therapy (ST) (Fisher and Yates, 1963). The design involved four sessions entailing one individual session and two group sessions followed by one individual session. The individual sessions were 1.5 hours each and the group sessions were 3 hours each. All participants were subsequently given individual boosters and followed up for an additional session at 6 and at 12 months. The booster sessions were conducted after the follow-up measures were taken. The total therapy time over the 12 months study was 11 hours.

Subjects

Twenty-seven adults ranging between the ages of 21 and 55 years, institutionalized or day workers in a center for epilepsy in South Africa participated in the study. All participants would be considered to be living under the minimum existence poverty level. Their only source of income was a minimal government disability grant. Those who lived outside the center in nearby townships were bussed into the center daily to work at the sheltered workshops and to receive food and antiepileptic medication. Inclusion criteria were: being able and willing to participate in the treatment program, having a minimum of four seizures during the past three months, and having a verified diagnosis of epilepsy using EEG. Participants were excluded if there were any signs of an ongoing progressive illness.

Tables 1 and 2 show an overview of the demographic data among the participants in the two conditions ACT and ST.

Procedure

The study was done during an initial five-week period followed by two one-week periods at 6 and 12 months inside a regional center for epilepsy in South Africa. Two clinical psychologists from Uppsala University in Sweden, (first and second authors) with ACT training and experience of behavioral treatment of epilepsy were responsible for the study in cooperation with Epilepsy South Africa and the Department of Neurology, University of Cape Town. Social workers and nurses at the center assisted with translations during sessions, assessing the seizure and medical charts as well as charting and evaluating the dependent variables. Assessments were taken at pre, post, 6 months and 1 year following the end of treatment. The psychologists were responsible for the content of both treatment conditions. To ensure the treatment integrity, the participating staff was given one-day workshop training in the treatment conditions. To avoid

TABLE 1. Demographic description of participants' gender, need for interpreter, living situation, age, seizure type, educational level, marital status, and use of AED in the two conditions, ACT and ST

	ACT (n = 14)	ST (n = 13)
Male	7	6
Female	7	7
Need for interpreter	4	5
Mean age group (yr)	38.85	42.5
Living situation		
Inside center	9	8
Outside center	5	5
Educational level		
Primary school	5	5
Secondary school	9	8
Marital status		
Married	7	6
Single	7	7
Seizure type		
Generalized tonic-clonic	10	9
Myoclonic jerks	1	
Partial complex seizures	2	1
Absences	4	7
Anticonvulsant drugs (AED):		
Phenytoin	8	6
Carbamazepine	8	7

unnecessary misunderstandings due to language and cultural differences both treatment protocols were adjusted to the context of an institution in South Africa after discussions with the center manager and staff. Using role-plays in the ACT treatment helped the participants to emotionally experience the exercises and seizure control techniques and in that way avoid language confusion. Parts of the sessions during the study and each of the follow-ups were recorded on video and audio.

All participants used the anticonvulsant therapy available to them. Prescriptions and dosages remained stable throughout the study. Anticonvulsants drugs were provided free of charge and in most cases prescriptions had been made at the time of diagnosis but with no or few neu-

TABLE 2. Description of participants with regard to side effects of AED and descriptions of seizure triggers in the two conditions ACT and ST

	ACT (n = 14)	ST (n = 13)
Side effects of AED		
Drowsiness	13	11
Memory loss	13	6
Concentration problems	11	10
Vomiting	3	2
Tired	12	10
Swollen gum	2	4
Weight gain	7	8
Seizure triggers		
Drowsiness	9	10
Tension	9	6
Worry	8	9
Flicker of light	4	4
Sudden changes in arousal level	10	8

rological follow-ups. The nursing staff kept seizure charts and distributed anticonvulsant drugs on a daily basis from the infirmary to the participants in this study.

Independent variable

The independent variable comprised of two treatment conditions: ACT (ACT plus behavioral techniques for seizure management) and ST. The treatment protocols were created for this study. The ACT protocol was developed using ACT (Hayes et al., 1999) and clinical handbook in treatment of epilepsy (Dahl, 1992). The ST condition was developed using the reflective listening protocol developed by Borkovec and Costello (1993).

Acceptance and commitment therapy

Participants in the ACT condition learned to improve valued living by building a broader behavior repertoire in valued life directions. They were exposed to techniques that helped them to built psychological flexibility around the chain of seizure behavior. Each session included the general principles of values, self as context, defusion, acceptance, contact with present moment, committed action, and empowerment (Hayes and Stroschal, 2005). The patterns of epileptic seizures were discussed as they occurred as obstacles to valued living. At the end of the second group session the therapists taught the participants individualized seizure management techniques. Each participant made records of seizure patterns in terms of antecedents (high risk situation, sensations) type of seizure response (topographical descriptions) and consequences (short- and long-term). Seizure control techniques often in the form of "counter-measures" (Dahl et al., 1992) were tailor made and practiced for each participant. The final individual session and the two follow-up sessions included applications of the ACT principles and seizure management techniques.

The aims of Sessions 1 and 2 are described below. The ACT protocol (Lundgren, 2004) can be downloaded at www.contextualpsychology.org and www.ACT-Forum.se.

Session 1: Individual session and the aims of the session were to:

1. Use the values compass to establish values as the context of therapy;
2. Examine discrepancies between how participants want to live and how they, in fact, are living their lives, currently;
3. Identify barriers and obstacles to participant's valued life;
4. Examine participant's reactions or ways of relating to described barriers and obstacles.
5. Examine the "function" of the participant's strategies in reducing or controlling these obstacles, which in ACT is called creative hopelessness.

Session 2: Group session (6–8 participants).

The aims of Session 2 were to present, practically demonstrate and provide the opportunity for the participants to experience the following components of ACT:

1. Self as context vs. self as content using mindfulness exercise “the observer self”;
2. Living a valued life vs. living a life in avoidance, exercise—discriminating your own values from rules of conduct;
3. Seeing thoughts as thoughts vs. seeing thoughts as true obstacles to a valued life. Exercise: “Kick your butts” showing the functions of sentences like: I want to have an intimate relationship but I have epilepsy leads to: no intimate relationship;
4. Acceptance of what cannot be changed (thoughts and feelings) and changing what can be changed. To illustrate this a dramatization of the “bus metaphor” was used. Participants attempt to drive the bus of life in a valued direction and all the thought obstacles, which come up are personified by bus passengers (members of the group), who argue and fight with the driver to bully him or her off course. The object is to relate to these obstacles in a manner of acceptance and at the same time keep on course.
5. Commitment of taking steps in valued directions: Exercise: Participants take turns in standing up at the end of session and stating:
 - a. a desired valued direction;
 - b. the identified “thought” obstacles;
 - c. how he or she typically handled the obstacles;
 - d. the experience of the workability of those coping strategies;
 - e. a committed action of a step in valued direction that will be taken today
6. In addition to the ACT components behavior technology of seizure control was presented in a simple ABC (antecedents, behavior, and consequences) chain of events. Participants recorded seizure chains and typical patterns of high and low risk for seizures were investigated. Participants practiced the simplest counter measure techniques to arrest an ongoing seizure.

Supportive therapy

The aim of the ST condition was to provide an equal amount of professional attention in a supportive environment. Using open questions the therapists focused on creating a climate where participants could reflect on their lives and their problems in a nonjudgmental, empathic and accepting environment. The content of the sessions were restricted to the following topics: What does having epilepsy mean to you? How do you experience seizures? How do you experience how others react to your epilepsy? The therapists were instructed to give no active advice.

Dependent variables

The dependent variables were seizure frequency, seizure index, WHOQOL-BREF, and SWLS. Daily kept medical charts at the center were used to measure the seizure frequency and duration. The seizure data were collected at an eight-month baseline and every month during one year, which gives a total of 20 months. The seizure data is presented as frequency and as a seizure index (index = frequency × duration).

The World Health Organization Quality Of Life (WHOQOL-BREF) has a reported Cronbach’s alpha at 0.81–0.90. The instrument consists of four domains of life quality, psychological health, physiological health, social relationships, and environmental health. The discriminant validity was satisfactory and the instrument did not show any ceiling or floor effects. (World Health Organization, 1996; Amir et al., 2000).

The satisfaction with life scale (SWLS) has shown strong internal reliability and moderate temporal stability, Diener 85 reported a Cronbach’s alpha of 0.87 for the scale and a test–retest stability coefficient of 0.82. According to previous research SWLS has shown to correlate with 10 other measurements of subjective wellbeing, $r \sim 0.50$ (Diener et al., 1985). The SWLS consists of five statements that the client could either agree or disagree with on a scale of 1–7, where 1 represents strongly disagree and 7 represents strongly agree with the statement.

Statistical analyses

The statistical analyses were done using Statistica 6.0 (Statistica, 2002). To analyze the interaction effect mixed ANOVA’S (two groups and four time periods) with repeated measure were done. Tukey post-hoc test was performed to detect the position of the changes and differences. Tukey post-hoc test is chosen to control for alpha because it is conservative and generally accepted. Cohen’s d effect sizes were calculated using Excel. The statistical analysis presented in the table is calculated using mean of periodical data from baseline, (eight months) postintervention, six months, and one year. One of the participants in the ST condition was excluded in the analysis of seizure frequency because of a value around five times bigger than the second largest value.

Ethical considerations

Written informed consent was obtained from each of the participant in the study. Participants were provided with written and verbal information that participation in the study was voluntary and could be terminated at any time and that all information gathered in the study was treated as confidential. Participants signed a separate informed consent form where they gave the therapists permission to video and audio record during the sessions to secure treatment integrity.

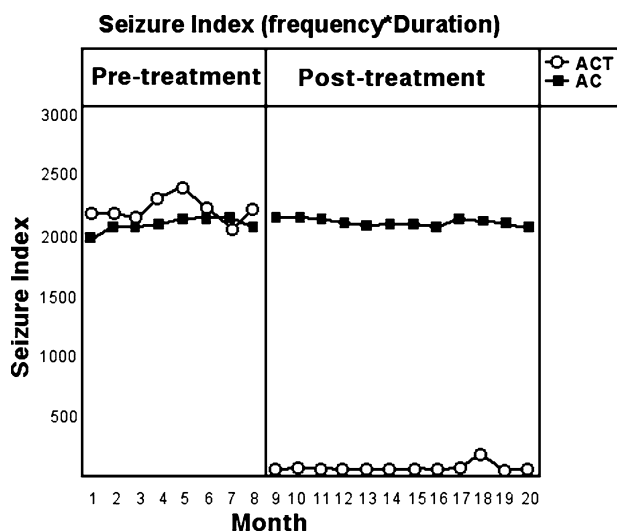


FIG. 1. Participants in the ACT group have reduced their seizure index significantly following the intervention as compared to the ST group. There are no significant changes in the ST group. Intervention takes place during the eighth and ninth month.

RESULTS

A comparison of effects of the two treatment conditions with respect to each of the dependent variables before and after treatment and at 6- and 12-month follow-ups is presented.

Seizures

Fig. 1 shows the eight months baseline and follow-up data for 12 months for “seizure index” per month measured by a continuous seizure diary filled out by staff nurses for both conditions. Index is counted by multiplication of frequency and duration of seizures.

The ANOVA shows a significant interaction effect between groups and time [$F(19,475) = 6.45, p < 0.001$]. Tukey post-hoc tests show a significant between group effects in favor of the ACT group at every posttreatment comparison between $p < 0.048$ and $p < 0.011$. No pretreatment differences were found.

Table 3 shows an overview of the result of seizure frequency and the seizure index. A continuous seizure diary filled out by staff nurses according to reports from the participant’s measures seizure frequency and number of seizing seconds. Seizure frequency and index data at pre, post, 6 months and 1 year follow-up is presented in Table 3.

Table 3 shows a significant interaction effect between groups and time for both variables frequency and index. The participants in the ACT group have a mean less than one seizure per month after the intervention and no significant changes in the ST group. Tukey post-hoc shows that the significant changes can be explained by the changes between pre and post ($p < 0.001$) in the ACT group. No significant pre differences are found in either variable.

Quality of life

Table 4 shows an overview of the result of the quality of life measures SWLS and WHOQOL-BREF.

Table 4 shows a significant difference between groups’ effect at every posttreatment measure point for SWLS. The difference between the ACT and the ST group increases over time and that is mainly because of higher ratings in the ACT group between post and 6-month follow-up. The WHOQOL-BREF shows a significant interaction effect between groups over time at 1-year and not at post or at the 6-month follow-up. No significant predifferences are found in either variable.

DISCUSSION

The results of the current study show that a short-term ACT therapy combined with seizure behavior management techniques have significant effects on seizure frequency, duration, and life quality as compared to supportive therapy. The present study contributes to previous psychological treatment of epilepsy research in at least two ways: (1) the experimental condition entails a combination of a new contextual behavior therapy ACT and seizure-control technology, which focuses on building a

TABLE 3. Description of the seizure frequency and seizing seconds as to mean, standard deviation, interaction effect, Cohen’s *d* and Tukey post-hoc test at pre, post, 6 months and 1 year

Dependent variable	Group	Pre M (Sd)	Post M (Sd)	6 mo M (Sd)	1 yr M (Sd)	Interaction effect Cohen’s <i>d</i>	Tukey
Seizure frequency	ACT	3.79 (1.73)	0.71 (0.91)	0.70 (0.89)	0.62 (0.86)	$F(3,72) = 26.79^*$	Post * 6 Mo* 1 yr *
	ST	5.84 (3.56)	6.00 (3.91)	5.86 (3.62)	5.80 (3.51)		
Seizure index	ACT	2,156 (2,499)	23 (35)	34 (70)	55 (110)	$F(3,75) = 9.28^*$	Post * 6 mo* 1 yr *
	ST	2,046 (3,543)	2,087 (3,539)	2,066 (3,544)	2,046 (3,555)		

* $p < 0.001$.

Ns, not significant.

TABLE 4. Description of the quality of life measures SWLS and WHOQOL-BREF as to mean, standard deviation, effect size Cohen's *d*, interaction effect, and Tukey post-hoc test at pre, post, 6 month and 1 year

Dependent variable	Group	Pre M (Sd)	Post M (Sd)	6 mo M (Sd)	1 yr M (Sd)	Interaction effect Cohen's <i>d</i>	Tukey
SWLS	ACT	16.29 (5.82)	23.28 (4.58)	27.07 (4.56)	27.07 (3.94)	F (3,75) = 18.497 ** Post 1.72 6 mo 2.29 1 yr 2.47	Post * 6 mo * 1 yr **
	ST	17.23 (5.99)	13.85 (5.98)	14.46 (6.28)	15.77 (5.17)		
WHOQOL-BREF	ACT	52.36 (9.62)	58.36 (9.66)	61.21 (8.13)	66.07 (6.04)	F (3,75) = 9.739 ** Post 0.37 6 mo 0.61 1 yr 1.78	Post Ns 6 mo ns 1 yr *
	ST	54.69 (6.50)	55.31 (6.59)	56.08 (8.58)	51.85 (9.51)		

***p* < 0.001.**p* < 0.05.

Ns, not significant.

broader behavior repertoire in valued directions; (2) the study was done in a developing country where western state of the art medicine were not available. The present study indicates that treatment of epilepsy can be noninvasive, low cost, and easy to conduct even when barriers like language and cultural differences are present.

The concept of acceptance of both actual seizures and fear of seizures appeared to have an inhibiting effect on seizure frequency and facilitate taking steps in valued directions. The seizure diaries show that seizures ceased for most participants following the first session, which contained values identification and acceptance procedures prior to learning the seizure management techniques. The effect of acceptance on seizure occurrence is commonly observed in the situation where the patient, hooked up to the EEG-video is "supposed" to show his or her seizure. Most commonly, even patients with very frequent seizures will not have a seizure in that situation. The seizure usually is forthcoming when the EEG is removed. A likely hypothesis is that the acceptance of and conscious desire to have a seizure to learn more about the seizure chain actually counteracts and inhibits the seizure occurrence.

The impact of working in groups with ACT probably facilitated social skills and social activities, which may in turn inhibit seizure activity. Greater seizure control is positively correlated with more effective social skills (Dahl, 1992). Social skills training were not specifically a part of the ACT condition but participants were encouraged to express feelings and values in the group, which led to an increased closeness, trust and feelings of belonging between the members. The group members continued to interact in positive, creative and productive ways outside the therapy session. The ACT program helped participants to develop their social skills and use them, which may have led to an increase in quality of life. Participants previously fused in a vicious circle of fears of seizures leading to social withdrawal and general avoidance changed to an acceptance of the seizure tendency and willingness to take the risk of having seizures and by doing that opened a positive circle of vitality, social interaction and natural positive stimulation.

The results in the study showed that most participants in the ACT condition became almost seizure free and obtained greater life quality. The context of this study was in an institution in South Africa where the negative stigmatization of epilepsy is detrimental. This is the first time ACT has been applied to epilepsy and this application needs to be replicated both by different researchers and in different contexts. Future psychological treatment studies should include a RCT design with a greater number of participants and containing four conditions; ACT, seizure control techniques, attention placebo and a waiting list. Such a study could help to dismantle therapeutic effects of the ACT and behavioral treatments. Furthermore, laboratory studies evaluating the therapeutic effect of specific techniques would add to the understanding of the facilitating and inhibiting effects influencing the seizure process.

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