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A prospective service evaluation of acceptance and commitment therapy for patients with refractory epilepsy

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ABSTRACT

Objective: The aims of this service evaluation were 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, completed a set of validated self-report questionnaires (Short Form — 12 version 2, Generalized Anxiety Disorder — 7, Neurological Disorders Depression Inventory for Epilepsy, Work and Social Adjustment Scale, and Rosenberg Self-Esteem Scale), and reported their seizure frequency at referral, the end of therapy, and six months posttherapy. 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 prepsychotherapy and postpsychotherapy questionnaires, among whom 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, and work and social adjustment ($ps < .001$), 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 a randomized controlled trial of the psychotherapy program is justified.

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]. These psychosocial complications may be more disabling and detrimental to the patients' quality of life than the seizure itself [7]. This means that there are many aspects of living with epilepsy, which could be considered targets for psychological treatment. Indeed, a number of studies have emphasized the need for treatments addressing the full spectrum of problems associated with the disorder rather than an exclusive focus on seizure reduction [3,4,7–9]. However, access to psychological treatments, specifically designed to address the concerns of people with epilepsy, appears to be the exception rather than the rule [10], 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 [11].

To date, it has been relatively easy for health-care purchasers to ignore references to the provision of psychological treatments in epilepsy treatment guidelines because there is only limited evidence for the effectiveness of such interventions [10,12]. Most existing interventions target improvement of psychological well-being and seizure control.

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Although many individual studies reported improvements in both of these areas, there is a lack of methodologically robust evidence [12]. A Cochrane review of psychological interventions for epilepsy concluded that many studies were of poor quality and yielded contradictory results. More specifically, the review found no evidence that relaxation therapy, cognitive–behavioral therapy (CBT), and 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 and improving medication compliance and social competency but stated that further well-designed trials are needed [13].

Two more recent reviews of psychobehavioral therapy for epilepsy have reported somewhat more positive results [12,14]. A number of the reviewed randomized controlled trials have shown beneficial effects of cognitive–behavioral therapies (CBTs), mindfulness-based approaches, and multimodal educational interventions on the psychological well-being of patients with epilepsy, including significant reductions of depression and anxiety, adjustment, social functioning and quality of life, as well as improvements in knowledge about and adjustment to the disorder [15–21]. Certain behavioral and CBT-based interventions also showed reduction of seizures [22–25], but others failed to show any improvements [26], and the evidence for effects of psychological interventions on seizure control remains inconsistent [12]. Both reviews highlighted the need for more trials of higher methodological quality [12,14].

Our prospective service evaluation aimed to contribute to the existing evidence base by exploring the effectiveness of a treatment for patients with epilepsy based on the acceptance and commitment therapy (ACT). Acceptance and commitment therapy is one of the 'third-generation' cognitive–behavioral therapies together with dialectical behavioral therapy, mindfulness-based cognitive therapy, or functional analytic psychotherapy [27]. The general aim of ACT is to increase psychological flexibility (i.e., the ability to engage in valued behaviors while experiencing difficult thoughts, emotions, or sensations) [28]. The approach incorporates mindfulness and behavior change processes. There is supporting evidence for the effectiveness of ACT for psychiatric disorders including anxiety [29] and depression [30,31]. The ACT approach has also been successfully used in the management of chronic health problems such as diabetes [32], chronic pain [33,34], or obesity [35,36]. There is also promising evidence for the effectiveness of ACT in epilepsy. Two small-scale RCTs by Lundgren et al. conducted in India and South Africa showed significant improvements in quality of life as well as reduction of seizures in patients with drug-resistant epilepsy following a short-term ACT treatment [20,21].

The treatment evaluated in this study 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, and interpersonal and memory problems. Apart from providing information required for group size calculations of a future randomized 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. The primary research aims were to assess the effects of the intervention on measures of health-related quality of life, social adjustment, self-esteem, depression, and anxiety as well as to evaluate the cost-effectiveness of the therapy program. In addition, the effects of the intervention on seizure frequency were explored as a secondary outcome.

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 Section 2.3 for the outcome measures) as a way of opting in to therapy. The same questionnaires were sent out by a staff member not involved in the delivery of the treatment immediately after therapy ended and again 6 months after the end of therapy.

A total of 159 patients completed the initial set of questionnaires. Of these, 60 patients completed both the baseline (T0) and posttherapy (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 posttherapy (T1) questionnaires, so T1 versus T2 comparisons were, therefore, performed in only 38 patients who had returned data at both time points. For demographic characteristics of the sample, see Table 1.

2.2. Therapeutic intervention

2.2.1. Structure of the intervention

Treatment consisted of an initial 1.5 h of 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 the initial appointment or occasional subsequent appointments, this was welcomed. Therapy was delivered by a cognitive–behavioral 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 functions to maintain their ongoing struggle with life. The 'Hexaflex' (see Fig. 1) is a very useful six-component diagram, which aids assessment and formulation in ACT. The six processes included in the diagram are conceptualized 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 the point where their actions are controlled by their perception of who they are and who they 'should' be); and loss of life direction (losing sight of what the patient wants his or her life to really stand for in the present and 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 psychoeducation about the ACT model [37,38]. This and an open, accepting, and listening approach to the patient were intended to build rapport at this early

Table 1
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.