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"Seizures have become a means of somehow learning things about myself" — A qualitative study of the development of self-efficacy and mastery during a psychotherapeutic intervention for people with epilepsy

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ABSTRACT

Background: Psychological interventions may enhance health-related quality of life in people with epilepsy. The concepts of self-efficacy and mastery may be particularly relevant in the context of epilepsy. To date, the investigation of psychological interventions has not included a qualitative analysis of the effects of such interventions on the interrelation between mastery and general and epilepsy-specific self-efficacy. This qualitative study aimed to explore the relationship between the lived experiences of these concepts in people with epilepsy who participated in a resource-oriented and mindfulness-based psychotherapeutic intervention delivered on a one-to-one basis in an outpatient setting.

Methods: Semi-structured pre- and postintervention interviews were conducted with people with epilepsy who participated in a six-month resource-oriented and mindfulness-based intervention. The formulation of intervention goals was based on the preintervention interviews. The intervention involved regular one-to-one interactions with the therapist, journal-keeping, and mindfulness-based relaxation. Qualitative content analysis of pre- and posttherapy interviews was conducted to characterize changes in subjective experiences.

Results: Nine people with epilepsy aged 18–59 years participated in 9 to 22 (median 13) sessions. The following six main themes emerged: (A) Encouragement of individual solutions, (B) Awareness of the link of personal traits with seizure-related worries, (C) How to develop self-efficacy, (D) Shaping everyday life in a way that is good for oneself (general self-efficacy), (E) Coping with seizures (seizure-related self-efficacy), (F) Epilepsy as a means of increasing self-knowledge and control over one's life (sense of mastery). The patients' development of self-efficacy was motivated by their personal initial goals and facilitated by the encouragement to find individual solutions and an increased awareness of the link of personal traits with seizure-related worries. A sense of mastery only emerged through the development of general self-efficacy and as a result of the active self-examination prompted by the challenge of living with epilepsy.

Conclusion: The qualitative differences observed before and after a psychotherapeutic intervention for individuals with epilepsy increase our understanding of the complex process of psychotherapy-associated change involving self-efficacy and mastery and highlight the contribution that qualitative research approaches can make.

1. Introduction

1.1. Background

Health-related quality of life (HRQoL) is lower in people with epilepsy than in those with other chronic diseases [1], and most psychiatric disorders are at least twice as common in people with epilepsy as in the general population [2]. Factors beyond seizure control and the side effects of medical epilepsy treatments may decrease HRQoL in people with epilepsy [3]. The most relevant factors include loneliness, stigma, and illness perceptions, such as fear of unpredictable seizures and their potential social and/or life-threatening complications [4–9]. These multifaceted factors are rarely systematically and sustainably addressed in the usual care of people with epilepsy, despite their strong contribution to patients' HRQoL. However, there is great scientific and

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clinical interest in the effective integration of psychological treatments into comprehensive epilepsy care to optimize treatment outcomes and psychosocial functioning of people with epilepsy [10].

A number of different psychotherapeutic approaches have been studied in individuals with epilepsy [10,11]. Several of these psychotherapeutic treatment studies have specifically looked at the effects of increases in self-efficacy and mastery on HRQoL and psychiatric comorbidity. These concepts may be particularly relevant in the context of epilepsy since the repeated sense of loss of personal control is a central problem that needs to be addressed. Self-efficacy has been defined as "the conviction that one can successfully execute the behavior required to achieve [desired] outcomes." [12]. Applied to epilepsy, this general conviction may relate to seizure-related situations or epilepsy-specific tasks (epilepsy-specific self-efficacy, seizure-related self-efficacy). Mastery on the other hand is an even broader concept that has been described previously as "the degree to which individuals feel they have control over their own lives despite a medical condition" such as epilepsy [13,14].

1.2. Self-efficacy, mastery, and HRQoL in the context of epilepsy

Several previous studies have highlighted the importance of addressing self-efficacy and mastery in psychotherapeutic treatments for people with epilepsy [15–17]; for instance, the results of one study indicated that the correlation between disease severity and HRQoL in people with epilepsy is mediated by mastery [14]. However, in this study the construct of mastery also incorporated self-efficacy. The interaction between these two concepts could therefore not be elucidated. Another study has found HRQoL to be more strongly correlated with general than epilepsy-specific self-efficacy measures but failed to investigate the influence of mastery [16]. Furthermore, a specific aspect of seizure-related self-efficacy (aura interruption) has been reported to correlate positively with an internal health locus of control (a concept that is closely related to the idea of mastery). However, there was no significant association between this aspect of seizure-related self-efficacy and clinical outcomes such as psychiatric comorbidity [18]. Overall, the specific interrelationship between the three concepts of mastery and general and epilepsy-specific self-efficacy (and how they can be supported by psychotherapeutic treatments for people with epilepsy) has not yet been established. Qualitative research methods have previously been identified as the most appropriate means to develop hypotheses about the interaction of such subjective concepts and to clarify how patients with epilepsy experience the support by psychotherapeutic treatments [19].

1.3. Qualitative studies of psychological interventions in people with epilepsy

Randomized controlled trials in people with epilepsy have demonstrated that psychological interventions can lead to an increase of HRQoL and a decrease of psychiatric comorbidities such as depression and anxiety disorders [11]. Some of these studies have also reported significant therapy-associated improvements on an epilepsy-specific self-efficacy scale [20,21].

While the mediating mechanisms of psychological interventions have been investigated qualitatively in patients with psychiatric conditions [22–24], only a very few studies have pursued this sort of research approach in people with epilepsy [25,26]. None of these studies used qualitative preintervention data to inform the analysis of postintervention data. Furthermore, no trials investigating epilepsy-specific one-on-one psychological interventions have included any in-depth qualitative evaluations. Two case reports from this study cohort have been published previously to illustrate how pre- and postintervention qualitative data can be used to characterize therapy-associated developments of general and epilepsy-specific self-efficacy [27]. This qualitative study is the first to explore the interrelationship between the lived experiences of the concepts of general and epilepsy-specific self-efficacy and mastery in people with epilepsy who participated in a resource-oriented and mindfulness-based psychotherapeutic intervention delivered on a one-to-one basis in the outpatient setting.

2. Methods

2.1. Design

This was a longitudinal uncontrolled intervention study intended to characterize the changes in the subjective experiences of participants in a six-month resource-oriented and mindfulness-based psychotherapeutic intervention by obtaining qualitative pre- and postintervention data and analyzing this material with a particular focus on the development of general self-efficacy, epilepsy-specific self-efficacy, and mastery and the interrelationship of the subjective experiences of these three concepts.

2.2. Ethical aspects

Ethical approval was obtained from the ethics board of the University Witten/Herdecke (UWH, 85/2014). All patients gave written informed consent to participate in the intervention, pre- and postintervention interviews and for pseudonymized data captured to be included in publications.

2.3. Recruitment and enrollment

This article is based on the integration of our patient-centered approach to the routine outpatient epilepsy care in the neurology department of a community hospital in Germany (Gemeinschaftskrankenhaus Herdecke, GKH). The GKH provides medical care for the local population with an emphasis on anthroposophical treatments [28,29].

We aimed to recruit ten patients (20 interviews) to capture a manageable amount of qualitative data and identify key themes while reflecting the heterogeneity of the patient population. This sample-size was predetermined at the outset. It was beyond the scope of this project to enroll additional patients until thematic saturation had been reached (i.e., no additional new themes were discovered by analyzing the contributions from further recruits) [30]. German-speaking adults (≥18 and ≤65 years) with a diagnosis of epilepsy according to the criteria of the International League against Epilepsy (ILAE) and the motivation to participate in a psychological intervention to work on personal epilepsy-related challenges were included. Exclusion criteria included a diagnosis of additional psychogenic nonepileptic seizures, epilepsy surgery within six months prior to the intervention, and severe psychiatric comorbidity that would have warranted hospitalization instead of an outpatient psychotherapeutic approach (e.g., suicidality). Previous brain surgery was not considered an exclusion criterion as long as the immediate postoperative recovery period was over, and the patient was at least six months postsurgery [10,11].

A purposive sampling strategy was applied by instructing the epileptologist (MK) working in the hospital's outpatient epilepsy clinic and three community-based practitioners (one anthroposophical neurologist, one neurologist trained in psychotherapy, and one psychologist with specific interest in epileptology) to offer participation to patients with epilepsy and particular issues for which they thought psychotherapy might be beneficial.

Due to service limitations, patients entered this study during two distinct recruitment periods (only a limited number of patients could be taken on because of the therapist's (RM) variable other clinical commitments as a resident in neurology. This means that patients were recruited intermittently, when psychotherapy could be offered). All five patients who were treated in the first cohort (09/2014–03/2015) were recruited at the beginning of 2014, and all four patients who were treated in the second cohort (04/2015–11/2015) were