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Louise N. Spiers, Chris A. Roe, & Melinda Spencer
University of Northampton
Northampton, UK

BEYOND ILLNESS: AN IPA STUDY OF ANOMALOUS EXPERIENCES IN TEMPORAL LOBE EPILEPSY

ABSTRACT

The attribution of anomalous experiences in Temporal Lobe Epilepsy (TLE) is discussed extensively in neuropsychiatric contexts; the DSM V lists such experiences as delusional or hallucinatory events, symptomatic of ictal (epilepsy related) psychosis. Discussion of case studies of anomalous experiences in epilepsy offers limited qualitative information about the phenomenology of the experience, as they are primarily concerned with differential diagnosis and appropriate medical interventions.

This study forms the second part of a mixed methods PhD, exploring lived experiences and meaning making of spirituality in epilepsy. The first study, an autoethnography, included an exploration of the phenomenology of non-shared reality and altered states of consciousness. Themes included stigma, shame, relationality and illness. A conclusion of the autoethnography was that this compartmentalization of spiritual experiences in epilepsy does not help in understanding them or the meaning that they have for those who experience them.

In this present study, the aim of recording and formally comparing the phenomenology of anomalous experiences in epilepsy is addressed using Interpretative Phenomenological Analysis (IPA). The focus is on the phenomenological elements of spirituality in TLE from the perspective of the meaning that they have for experiencers. Nine individuals participated in the study and were interviewed at various locations in the UK. In order to identify a homogenous sample, participants self-selected according to the following question: 'Do you have epilepsy and related experiences that for you are spiritual?' Interested potential participants were provided with an information sheet outlining the background and aims of the project, ethical and data management considerations and that participation would involve an interview lasting approximately one hour. Data was gathered by means of face-to-face interviews that were audio recorded and subsequently transcribed. Analysis was undertaken following IPA guidelines, which involved listening to the audio recording multiple times, reading and re-reading the transcripts and developing codes in an iterative manner. An idiographic approach was employed by considering each participant individually and developing emergent themes and subthemes one by one. Five idiographic analyses have been completed thus far – hence the presentation is of a work in progress.

Preliminary findings are that individuals with TLE highly value the abilities that their condition provides, but do not share the anomalous nature of their experiences with medical professionals or the wider public, for fear of stigma and being pathologized. Most participants stated that they would rather keep their epilepsy and the perceived gifts these spiritual experiences afford, than lose their epilepsy and the spiritual experiences that come from it. This would suggest that the participants do not view their condition as an affliction, but rather a naturally occurring doorway to altered states of consciousness that some non-epileptic individuals go to great lengths to experience. Participant interviews suggest a conflict between how the medical model and professionals diagnose and respond to the anomalous experiences and the participant's subjective experience and understanding of the meaning of them.

Idiographic interpretation of experiences in this IPA study suggest that participants' lives have been profoundly changed as a result of their spiritual experiences. The value and status of these preliminary findings are at variance with the neuropsychiatric literature, which regards such experiences as problematic seizure-related events that require medication and need to be stopped. The medical model assumes and acts as if individuals will not want to encounter these anomalous experiences, and if they do not, then this is also deemed to be a contributory factor of epilepsy-related psychosis. However, the likeness of the spiritual experiences described by individuals such as those in this IPA study to altered states of consciousness and anomalous experiences of individuals without epilepsy suggests that, in fact, not all spiritual experiences in individuals with epilepsy are undesirable symptoms of the condition and have great meaning for those who experience them.

[louiseking2@northampton.ac.uk]

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