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## **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.

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REFERENCES

- Alajouanine T. (1963). Dostoevsky's epilepsy. *Brain*, 86, 209–218
- Åsheim Hansen, B., & Brodtkorb, E. (2003). Partial epilepsy with “ecstatic” seizures. *Epilepsy & Behavior*, 4(6), 667-673.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Publications.
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.
- Brett, C., Heriot-Maitland, C., McGuire, P., & Peters, E. (2014). Predictors of distress associated with psychotic-like anomalous experiences in clinical and non-clinical populations. *British Journal of Clinical Psychology*, 53(2), 213-227.
- Britton, W.B., & Bootzin, R.R. (2002). Temporal lobe paroxysmal EEG activity in near-death experiencers: Results of a single overnight sleep study. *The Parapsychological Association 45<sup>th</sup> Annual Convention: Proceedings of Presented Papers*. 45-61
- Dolgoff-Kaspar, R., Ettinger, A. B., Golub, S. A., Perrine, K., Harden, C., & Croll, S. D. (2011). Numinous-like auras and spirituality in persons with partial seizures. *Epilepsia*, 52(3), 640-644.
- Devinsky, O. (2003). Religious experiences and epilepsy. *Epilepsy & Behavior*, 4(1), 76-77.
- Devinsky, O., & Lai, G. (2008). Spirituality and religion in epilepsy. *Epilepsy & Behavior*, 12(4), 636-643.
- Fadiman, A. (2012). The spirit catches you and you fall down: A Hmong child, her American doctors, and the collision of two cultures. Farrar Straus & Giroux.
- Fenwick, P. (1996). The neurophysiology of religious experiences in Bhugra, D. (1997). *Psychiatry and religion: Context, consensus and controversies*. Psychology Press. London: Routledge.
- Fenwick, P. & Fenwick, E. (1996). *Living with epilepsy. A guide to taking control*. London: Bloomsbury Publishing Plc.
- Garcia-Romeu, A., & Tart, C. T. (2013). Altered states of consciousness and transpersonal psychology. *The Wiley-Blackwell Handbook of Transpersonal Psychology*. Chichester: Wiley-Blackwell, 121-140.
- Honnekeri, B., Rane, S., Vast, R., & Khadilkar, S. V. (2018). Between the Person and the Pill: Factors Affecting Medication Adherence in Epilepsy Patients. *Journal of The Association of Physicians of India*, 66, 24.
- Jackson, J. H., & Colman, W. S. (1898). Case of epilepsy with tasting movements and “dreamy state”—very small patch of softening in the left uncinate gyrus. *Brain*, 21(4), 580-590.
- James, W., & Nock, A. D. (2006). *The varieties of religious experience: A study in human nature*. Fountain Books, Collins.
- Kaminker, J., & Lukoff, D. (2013). Transpersonal Perspectives on Mental Health and Mental Illness, 419. In Friedman, H.L., & Hartelius, G., (Eds). (2013). *The Wiley-Blackwell Handbook of Transpersonal Psychology*, John Wiley & Sons.
- Kasper, B. S., Kasper, E. M., Pauli, E., & Stefan, H. (2010). Phenomenology of hallucinations, illusions, and delusions as part of seizure semiology. *Epilepsy & Behavior*, 18(1), 13-23.
- Landtblom, A. M. (2006). The “sensed presence”: an epileptic aura with religious overtones. *Epilepsy & Behavior*, 9(1), 186-188.
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative research in psychology*, 3(2), 102-120.
- Lukoff, D., Lu, F., & Turner, R. (1992). Toward a more culturally sensitive DSM-IV: Psychoreligious and psychospiritual problems. *The Journal of nervous and mental disease*, 180(11), 673-682.
- Neppe, V. M. (1981a). Symptomatology of temporal lobe epilepsy. *S Afr Med J*, 60(23), 902-7.
- Neppe, V. M. (1981b). Non-epileptic symptoms of temporal lobe dysfunction. *South African medical journal Suid-Afrikaanse tydskrif vir geneeskunde*, 60(26), 989-991.
- Neppe, V. M. (1983). Temporal lobe symptomatology in subjective paranormal experiments. *Journal of the American Society for Psychical Research*. Vol 77(1), Jan 1983, 1-29.
- Neppe, V. M. (2011). Models of the out-of-body experience: a new multi-etiological phenomenological approach. *NeuroQuantology*, 9(1).
- Palmer, J., & Marcusson-Clavertz, D. (Eds.). (2015). *Parapsychology: A handbook for the 21st century*. McFarland.
- Palmer, J., & Neppe, V. M. (2003). A controlled analysis of subjective paranormal experiences in temporal lobe dysfunction in a neuropsychiatric population. *The Journal of Parapsychology*, 67(1), 75-97.
- Penfield, W., & Jasper, H. (1954). *Epilepsy and the functional anatomy of the human brain*. Churchill, London.

- Persinger, M. A. (1983). Religious and mystical experiences as artifacts of temporal lobe function: a general hypothesis. *Perceptual and motor skills*, 57(3\_suppl), 1255-1262.
- Persinger, M. A. (1984). Propensity to report paranormal experiences is correlated with temporal lobe signs. *Perceptual and Motor Skills*, 59(2), 583-586.
- Persinger, M. A. (2001). "The neuropsychiatry of paranormal experiences. *The Journal of neuropsychiatry and clinical neurosciences* 13 (4): 515–24.
- Persinger, M. A., & Makarec, K. (1993). Complex partial epileptic signs as a continuum from normals to epileptics: normative data and clinical populations. *Journal of Clinical Psychology*, 49(1), 33-45.
- Picard, F., & Craig, A. D. (2009). Ecstatic epileptic seizures: a potential window on the neural basis for human self-awareness. *Epilepsy & Behavior*, 16(3), 539-546.
- Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal*, 20(1), 7-14.
- Ramachandran, V. S., & Blaklee, S. (1999). God and the Limbic System. *Phantoms in the Brain: Probing the Mysteries of the Human Mind*. New York: William Morrow.
- Reynolds, E. H., & Kinnier Wilson, J. V. (2008). Psychoses of epilepsy in Babylon: the oldest account of the disorder. *Epilepsia*, 49(9), 1488-1490.
- Schachter, S. C. (1993). *Brainstorms--epilepsy in our words: personal accounts of living with seizures* (Vol. 1). Raven Pr.
- Smith, J. A. (2011a) Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5, 9-27.
- Smith, J. A. (2011b) 'We could be diving for pearls': the value of the gem in experiential qualitative psychology. *Qualitative Methods in Psychology Bulletin*, 12, 6-15
- Smith, J. & Eatough, V. (2012). Interpretative Phenomenological Analysis in Breakwell, G.M., Smith, J.A. & Wright, D.B.(Eds.). (2012) *Research Methods in Psychology* (4th ed.). London, UK: Sage
- Smith J.A., Flowers P, Larkin M. (2009). *Interpretative phenomenological analysis: theory, method and research*. London: Sage.
- Smith, J. A., Harré, R., & Van Langenhove, L. (Eds.). (1995). *Rethinking methods in psychology*. London, UK, Sage Publications.
- Smith J.A., Osbourn M. (2003) Interpretative phenomenology analysis. In Smith J. A. (Ed.). *Qualitative Psychology: A Practical Guide to Methods*. Sage, London.
- Smith J.A., Osborn M. (2007). Pain as an assault on the self: an interpretative phenomenological analysis. *Psychological Health*; 22, 517–534.
- Smith, J. A., & Rhodes, J. E. (2015). Being depleted and being shaken: An interpretative phenomenological analysis of the experiential features of a first episode of depression. *Psychology and Psychotherapy: Theory, Research and Practice*, 88(2), 197-209.
- Stefan, H., Ben-Menachem, E., Chauvel, P., & Guerrini, R. (Eds.). (2012). *Case Studies in Epilepsy: Common and Uncommon Presentations*. Cambridge University Press.
- Stol, M. (1993). *Epilepsy in Babylonia*. Brill.
- Temkin, O. (1994). *The falling sickness: a history of epilepsy from the Greeks to the beginnings of modern neurology*. JHU Press.
- Trimble, M., & Freeman, A. (2006). An investigation of religiosity and the Gastaut–Geschwind syndrome in patients with temporal lobe epilepsy. *Epilepsy & Behavior*, 9(3), 407-414.
- Trimble, M., Kanner, A., & Schmitz, B. (2010). Postictal psychosis. *Epilepsy & Behavior*, 19(2), 159-161.
- Waxman, S. G., & Geschwind, N. (1975). The interictal behavior syndrome of temporal lobe epilepsy. *Archives of General Psychiatry*, 32(12), 1580-1586.
- Kinnier-Wilson, J. V. (1965). An introduction to Babylonian psychiatry, 289-98. In Guterbock, H., & Jacobsen, T. (Eds.). (1965). *Studies in Honor of Benno Landsberger*.
- White, R. A. (1997). Anomalous human experiences and the experiential paradigm. In Tart, C. (Ed.) *Body, mind, spirit: Exploring the parapsychology of spirituality*, 83-100. Hampton Roads Publishing Company, Inc.
- Williams, D. (1956). The structure of emotions reflected in epileptic experiences. *Brain*, 79(1), 29-67.
- Wooffitt, R., (1992). Telling tales of the unexpected: The organization of factual discourse. Rowman & Littlefield.