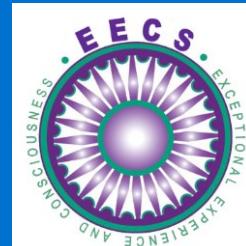


# 'THEY'D THINK YOU WERE A BIT LOOPY': AN IPA STUDY OF SPIRITUAL EXPERIENCES IN TEMPORAL LOBE EPILEPSY



LOUISE SPIERS



A collage of three circular images set against a red and white background. The top-left circle shows a stone building with a blue sky. The bottom-left circle shows a golden stupa-like structure. The right circle shows a view of the Dome of the Rock in Jerusalem.

 WORLD PSYCHIATRIC ASSOCIATION

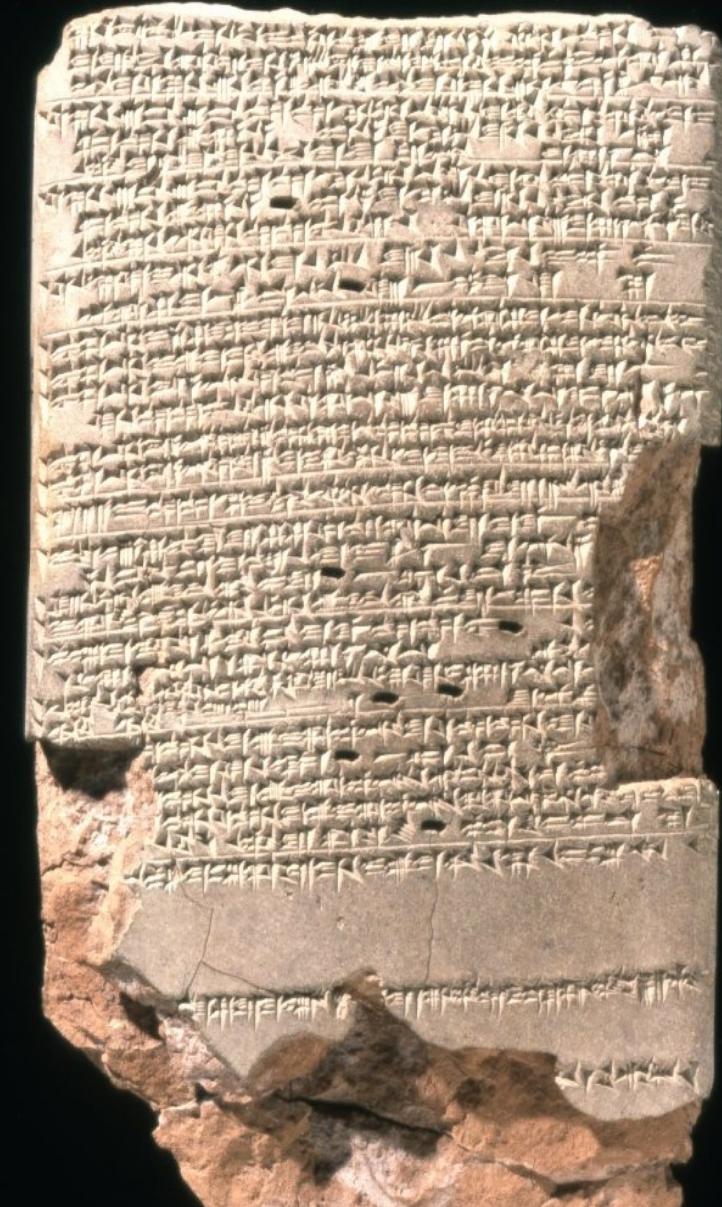
International Congress in Spirituality and Psychiatry  
4<sup>th</sup> Global Meeting in Spirituality and Mental Health

Organized by the WPA Section on Religion, Spirituality and Psychiatry  
WPA Co-sponsored Congress

December 1-4, 2019 Jerusalem, Israel

# Epilepsy & spirituality

- Connection known since the Neo-Babylonians (626-539BC)
- TLE: Ecstatic, numinous, cosmic seizures, 'dreamy states'
- Medical model – symptomatic:
  - Hallucinations
  - Delusions
  - Psychosis
  - Temporal Lobe Personality Disorder – 'Geschwind Syndrome'
- Fear of judgement – kept a secret, stigma



Tablet XXVI on Epilepsy, The Babylonian 'Diagnostic Series'. BM47753, obverse, British Museum

# Interpretative Phenomenological Analysis (IPA)

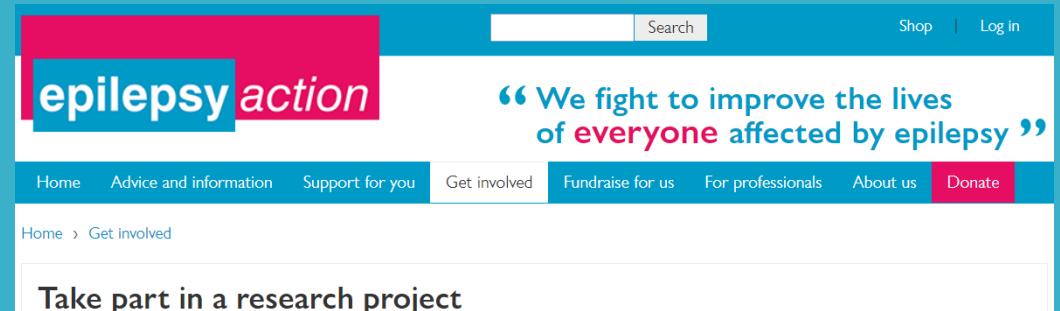
- Qualitative methodology focused on lived experience
- Key features: Phenomenology, Idiographic, Hermeneutic
- Often used in health contexts & areas of taboo
- Engaged with meaning-making



# Data collection

'Do you have experiences from epilepsy that for you are spiritual?'

- Epilepsy Action Research webpage
- Individuals with published accounts
- Word of mouth
- Face-to-face, semi-structured interviews
- 10 questions with prompts for more detail  
*'If you could lose your epilepsy and all of its effects, but this would mean that you would not have your spiritual experiences, would you want to?'*



# Participants

- 5 females, 4 males
- Aged 24 - 51

Pseudonym	Gender	Age at interview	Age at onset	Medication
Deborah	F	51	5	Y
Nicholas	M	45	6	Y
Nelle	F	24	16	N
Erin	F	35	24	Y
Mary	F	30	25	Y
John	M	47	18	Y
Joe	M	27	16/17	N
Holmes	M	28	20's	N
Gwen	F	32	27	Y

# Superordinate themes

Theme 1: "one leg here & one leg somewhere else"

Theme 2: "spontaneous spiritual mystical states"

Theme 3: "they don't have a category for it"

Theme 4: " a higher level of being"



Huaxtec statue of Tlazolteotl, Goddess of epilepsy, Mexico, 900-1521 CE (Am+.7001, British Museum).

# Theme 1

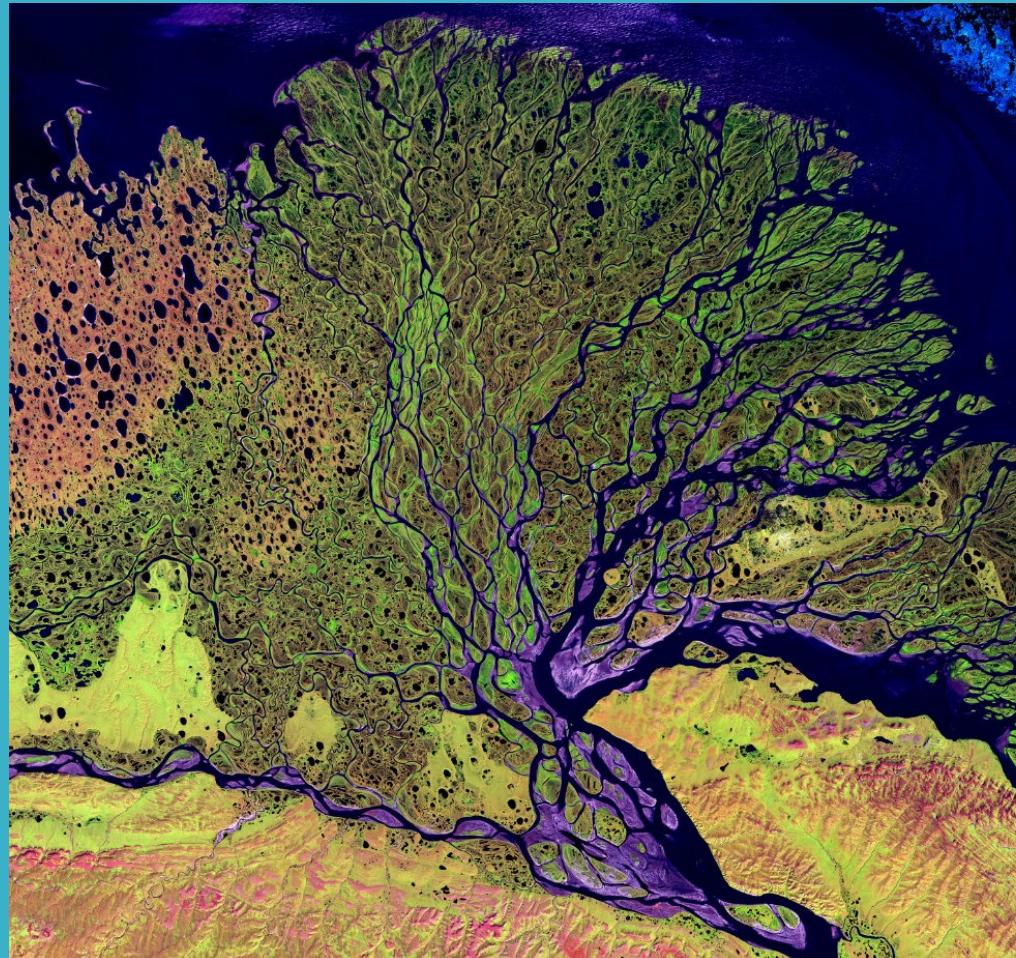
## “one leg here & one leg somewhere else”



“it's like going & having a chat with God... it was a sense of leaving the body. The body was quite fine, it was a trance state, & just going, literally going up to heaven...there was a me up there & my body was still wherever it was...so the connection was still there...it was amazing, actually” (Nicholas)

# Theme 2

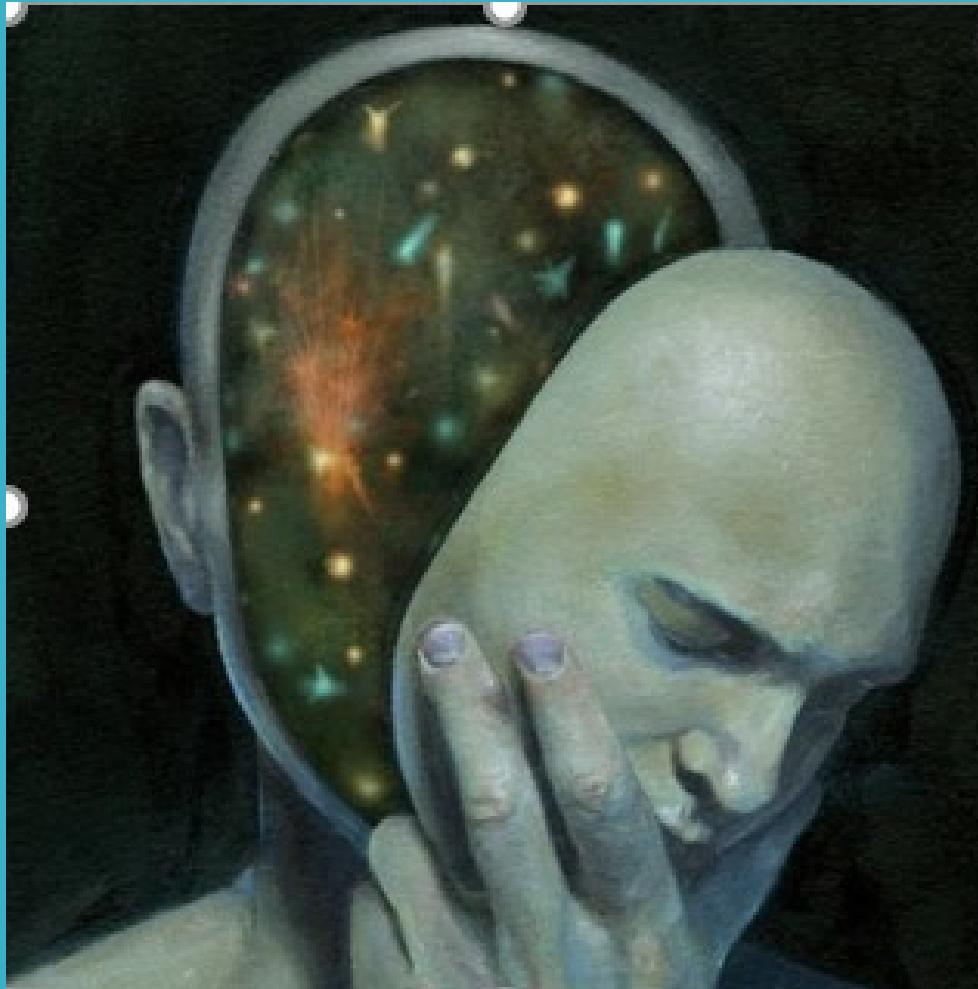
## “spontaneous spiritual mystical states”

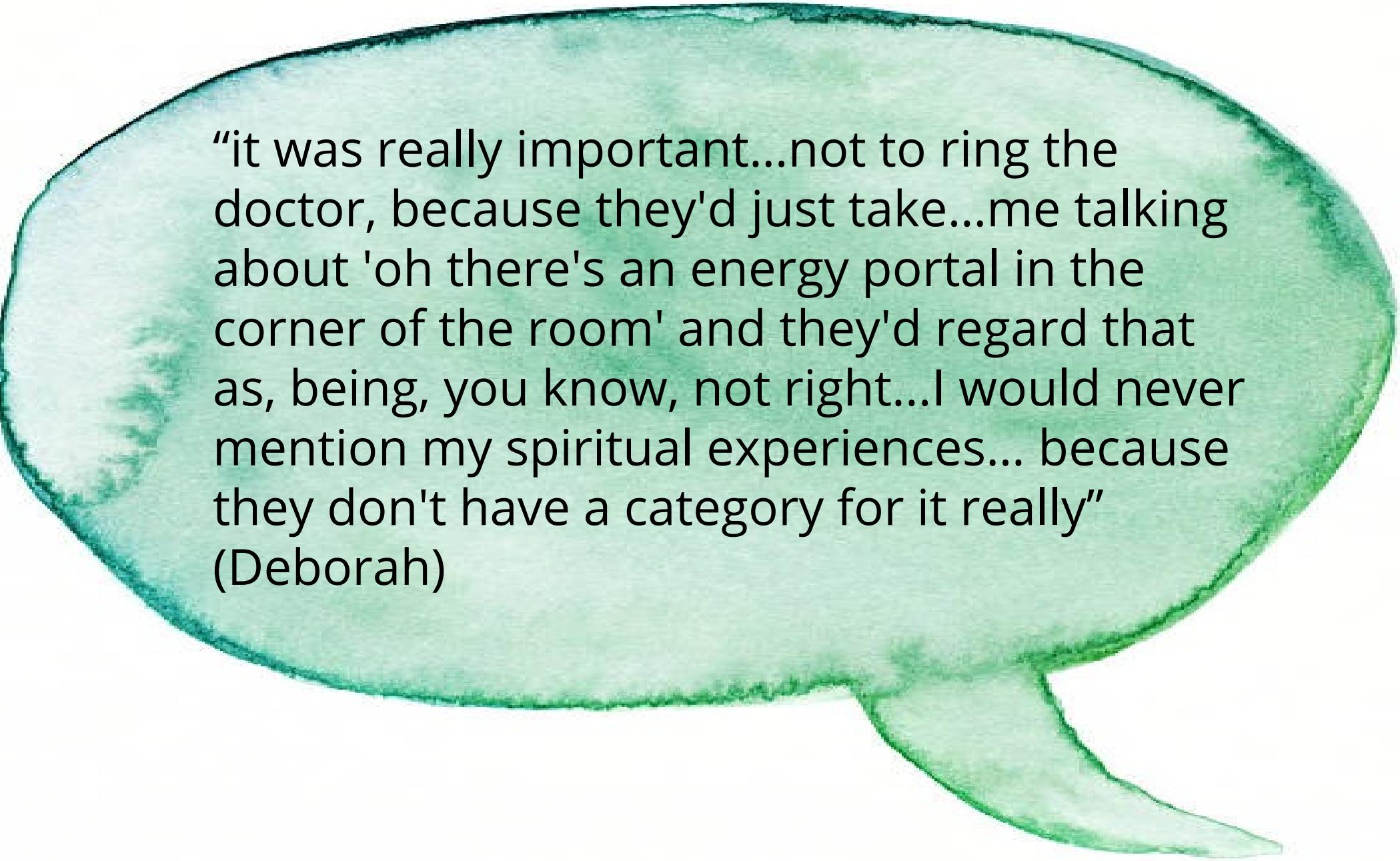


“spontaneous spiritual mystical states where that breaks down, where the brain's grip on the structure of reality breaks down and these things come through...feeling as though I wasn't really connected to my body any more, it was just almost like a point of consciousness” (Joe)

# Theme 3

## “they don't have a category for it”





“it was really important...not to ring the doctor, because they'd just take...me talking about 'oh there's an energy portal in the corner of the room' and they'd regard that as, being, you know, not right...I would never mention my spiritual experiences... because they don't have a category for it really”

(Deborah)

# Theme 4

## “ a higher level of being”



“that kind of niggling thing in the back of my mind – if they take that cyst away, are they taking what allows my brain to connect away, as well? Are they taking that spiritual connection away?” there’s no way that I would have chosen to do what I do, no way, if I’d have felt that I had another, you know, an option. Now I love it...& I totally embrace it, fully embrace it...I have this ability & actually it helps people.” (Erin)

# Summary

- These spiritual experiences share much with spiritual experiences of non-epileptic populations, supporting notion that lability of temporal lobes allows access that others need an altered state of consciousness to reach
- Participants do not want to have this medicated away
- Some experiences in TLE are not symptomatic or psychotic but spiritual
- A need for medical professionals to be open to listening to the phenomenology (as per WPA statement on spirituality & religion)
- The meaning that they have in patient's lives is an important part of their well-being and quality of life

**TEACHING  
LEARNING**

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