

# Preliminary findings from an IPA study into spirituality in epilepsy

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# Epilepsy & spirituality

- Ecstatic, numinous, cosmic, seizures
- Connection known since the Neo-Babylonians (626-539BC)
- Medical model – pathologises this & explains experiences as:
  - Symptoms
  - Hallucinations
  - Delusions
  - Temporal Lobe Personality Disorder
  - Psychosis



The Conversion of St. Paul (1767),  
Nicolas-Bernard Lepicie

# My research

Focus is on the lived experience:

Study 1: Qualitative -  
Autoethnography

Study 2 : Qualitative – IPA

Study 3 : Quantitative survey



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

# Method

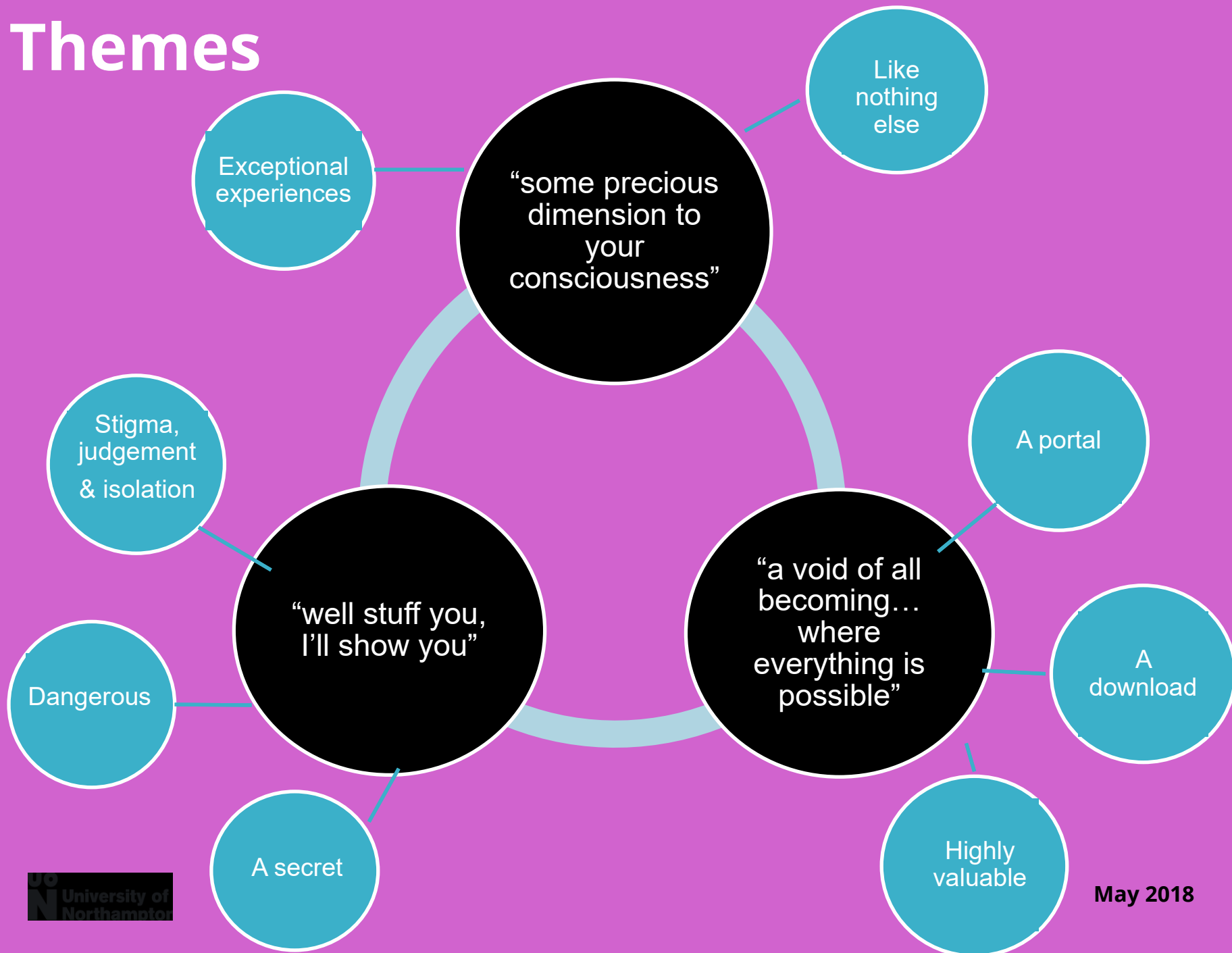
- **Face to face interview – 2 hours, 15 minutes**
- **Semi-structured interview schedule developed using funneling**
  - **Can you tell me about what it's like for you to have epilepsy?**
    - **When were you first diagnosed? What was it like for you?**
  - **Questions about spirituality**
    - **What does spirituality mean to you?**
    - **Can you describe (if any) your spiritual practices?**
    - **What (if any) connection does this have to any religious beliefs?**
    - **Which other areas of your life does it connect with – can you explain this to me?**
  - **Questions about spiritual experiences in epilepsy**
    - **Can you describe your spiritual experiences in epilepsy?**
    - **What (if anything) else are they like in your life?**
    - **How long have you had them?**
    - **How many / how frequently / when do you have them?**
    - **What do they feel like?**
    - **How are they spiritual – what is their nature?**
    - **What influence do they have in your life?**
    - **What effect (if any) do you think the medication has on your spiritual experiences in epilepsy?**
  - **Questions about others' responses**
    - **Have you ever told anyone else about your spiritual experiences in epilepsy?**
    - **What has their response been?**
    - **How about medical professionals / their responses?**
- **Questions sent in advance**

# Participant details

- Deborah (pseudonym)
- Age 51
- Epilepsy (type unknown)
- Since age 5
- Takes 2 anticonvulsants:
  - Tegretol (carbamazepine)
  - Chlonazepam (benzodiazepine)
- Epilepsy 80 – 100% controlled by medication

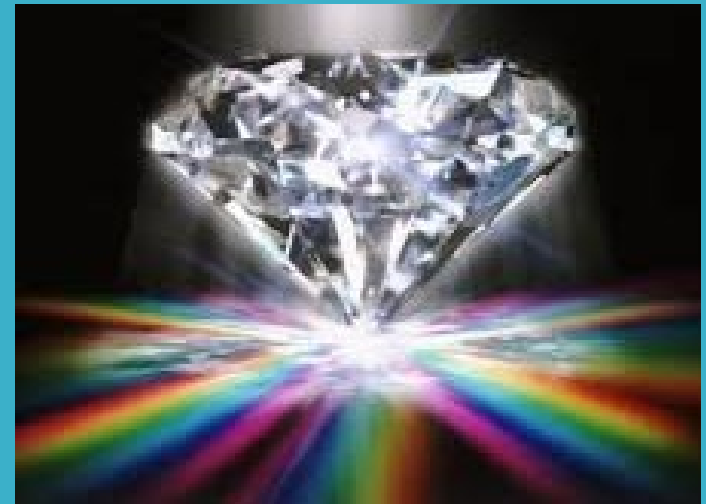


# Themes



# “some extra dimension to your consciousness”

- A precious by-product
- “psychic knowing & things like this...and that was all kind of developing at the same time as the epilepsy”
- An important feature of self-identity
- Something that started at the same time as epilepsy, enmeshed
- Intertwined holistically with all other parts of her life (work, personal, hobbies)



## Exceptional experiences

“It felt like a mystical experience, like some sort of multi-dimensional separation from... my physical body... a sort of astral version of me... part of me was having a vision ” (Deborah, page 23, lines 1072-3)

I've been aware of other people in the room, you know, shadow people, or strange lights, things like that... (Deborah, page 23, lines 1186-9)



# “a void of all becoming... where everything is possible”

- Deborah trusts this unique knowledge over other types
- “you've opened a portal” – spatial
- The download is the knowledge itself that is transferred during the experience
- Has developed advanced skill in using it; can use at will for problem solving
- Wants her knowledge in this area to be taken seriously & validated



## A download

“I’ve had that explained to me in these states of epileptic sort of reverie... it’s like it comes to me like a sort of download, there’s no other word for it”

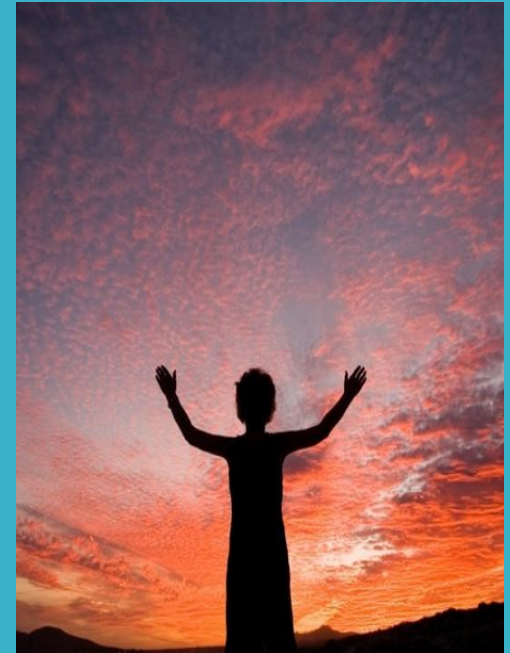
(Deborah, page 32, lines 1486-9)

“You step into this other dimension...you’re dragged out of yourself into this other reality, for a split second...But the download that you can get in a split second...of being outside of your physical self...is ...who knows”

(Deborah, page 8, lines 352-62)

# “well stuff you, I’ll show you”

- Beyond illness into sense of wellbeing
- “some sort of mental illness”
- Social rejection & isolation
- There is much loss in her experience of societal responses to her condition
- She feels her experience is much judged & misunderstood
- She does not make herself vulnerable or disclose her experiences
- An ambivalent relationship - she takes great pride in its gifts, but sometimes she resents what it does to her



## A secret

“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, page , lines 846-50)

“They would think I had some sort of mental illness”

(Deborah, page 18, line 840)

# Next stage

- 7 further interviews to transcribe and analyse
- Iterative process:
  - ✓ Analyse participants individually
  - ✓ Analyse participants as a group
  - ✓ Develop emergent themes
  - ✓ Discussion





thank

you

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