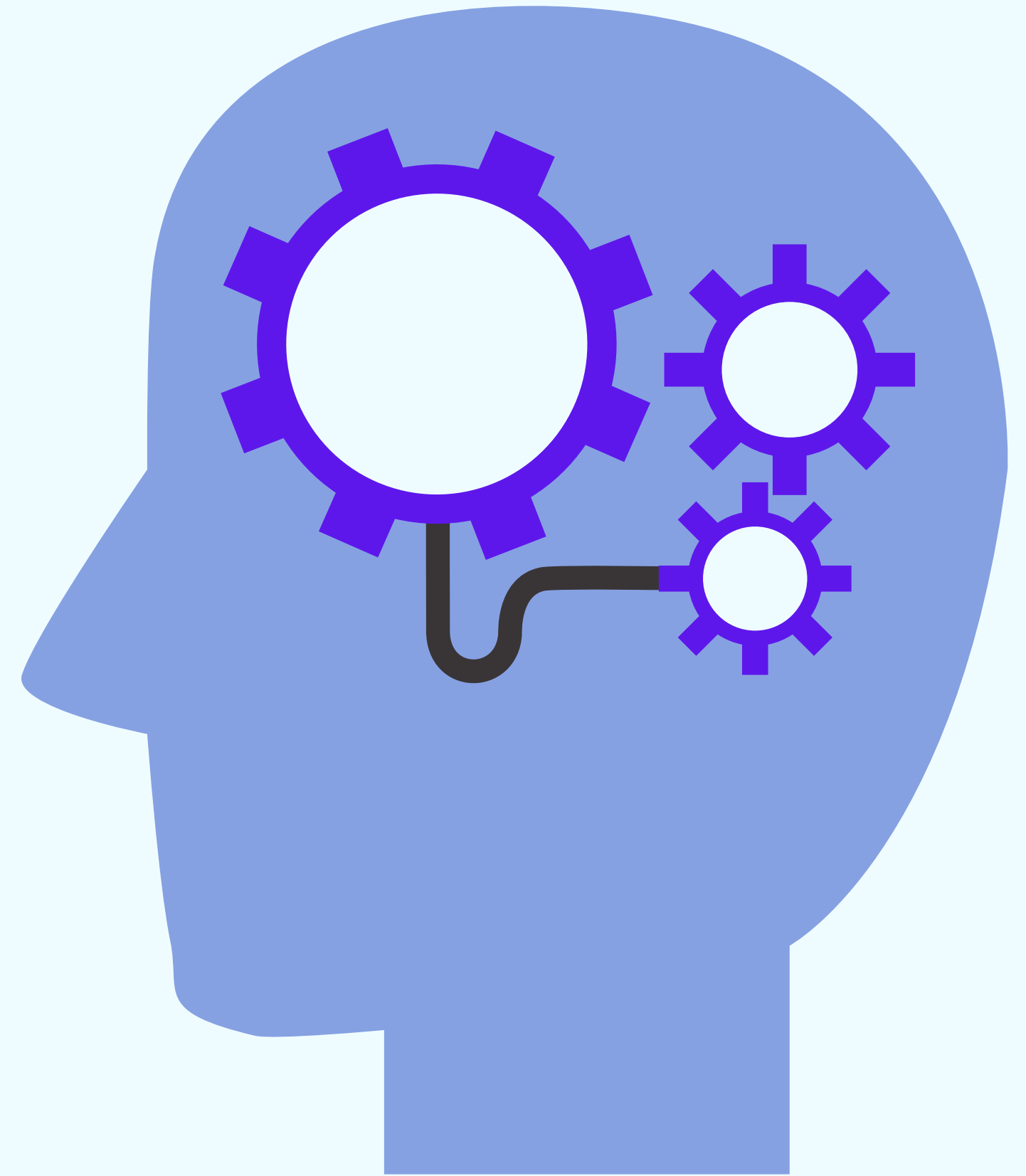


"I always think of my mind, my brain being like that - like it's out to get me"

A Qualitative Exploration into the Experience of People Living with Epilepsy and Mental Illness

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Epilepsy is a neurological disorder characterised by recurrent seizures and their psychosocial impact.



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graph TD; A["Epilepsy is a neurological disorder characterised by recurrent seizures and their psychosocial impact."] --> B["Epileptic seizures are caused by abnormal electrical activity in the brain"]; A --> C["Epilepsy has a major impact on quality of life"];
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Epileptic seizures are caused by abnormal electrical activity in the brain

Epilepsy has a major impact on quality of life

1 in 100 people live with epilepsy, making it one of the most common neurological disorders globally.

(ILEA., 2014)

Epilepsy and Mental Illness

- **1 in 3 people with epilepsy will be diagnosed with a mental illness** during their lifetime (likely an underestimate) (Lu et al. 2021)
- Presence of the comorbidity is the **strongest predictor of poor quality of life** in people with epilepsy (Alsaadi et al., 2017)
- Research has found the comorbidity is associated with **worse treatment outcomes** (Michaelis et al., 2018), **negatively affects disease course** (Josephson et al. 2017), and **negatively affects mortality** (Kanner., 2016).

The epilepsy mental illness comorbidity is significant in prevalence and impact.



- Limited understanding of how these impacts manifest for individuals (day-to-day and over lifetime) and of the psycho-social impact of the comorbidity
- No qualitative research exploring the experience of people with the comorbidity -> absence of lived experience!

Research Question 1: **How do people living with epilepsy and mental illness understand the relationship between the two?**

Research Question 2: **What is the day - to - day experience of living with epilepsy and mental illness?**

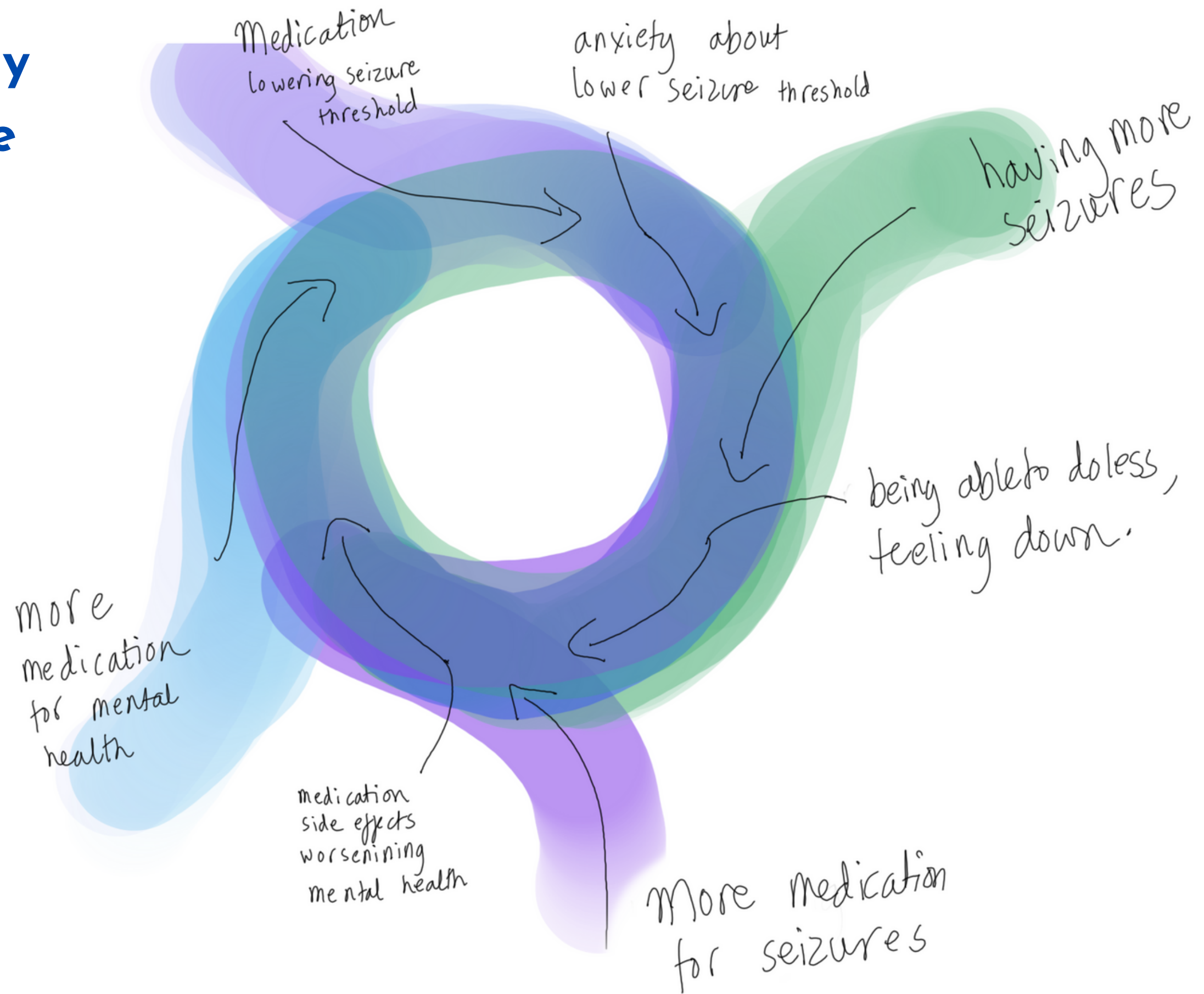


- 3 semi - structured interviews with people living with epilepsy and mental illness
- Transcripts analysed using Interpretative Phenomenological Analysis (IPA)
- 5 themes developed

How do people living with epilepsy and mental illness understand the relationship between the two?

Theme 1. An Endless Cycle

“It feels like you're stuck in the loop a lot of the time because the more you have a seizure then the more anxious and depressed you get and then you're more likely to have a seizure (*laughs*). It's just, it feels very self-destructive at times. I think I always think of my mind, my brain being like that - like its out to get me I guess (*laughs*).” (C 153 - 155)

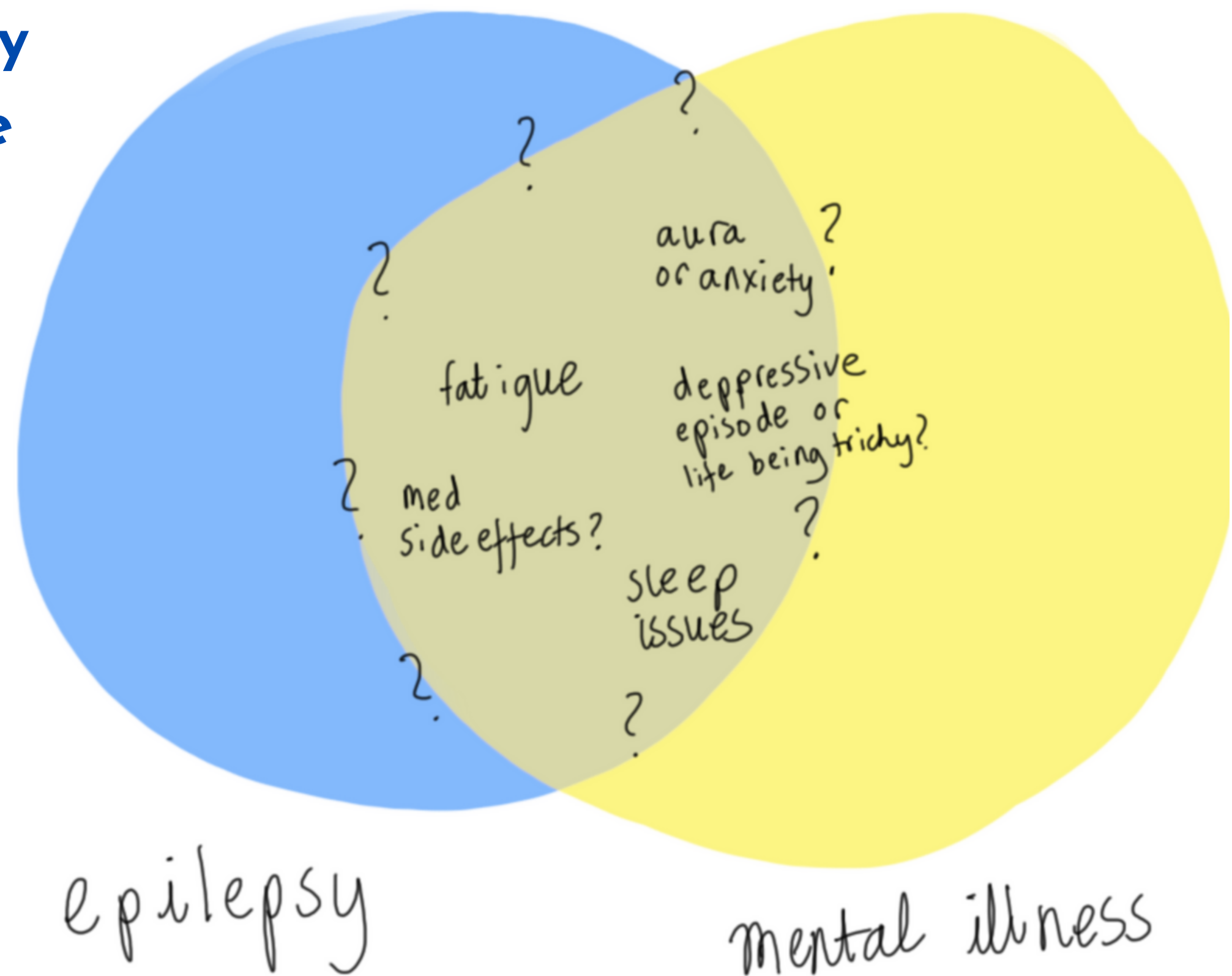


How do people living with epilepsy and mental illness understand the relationship between the two?

Theme 2. A Blurred Relationship

“With bipolar, like how do you, how do you know when you're going into a depressive part of that cycle versus when if you're struggling because your seizures are unmanaged in life just sucks sometimes, you know?”

(A 206 - 209)



What is the day - to - day experience of living with epilepsy and mental illness?

Theme 3. Stigma

3a. Social Exclusion and Isolation

“Seeing those things (seizures) and not knowing how to handle them kind of makes people not want to be here as frequently, especially while they're so unmanaged” (A 110-113)

3b. Stigma negatively impacting healthcare

“So, I actually didn't find out until this past October that I've been having seizures my whole life because everybody just blew everything off to mental health problems, especially with bipolar having such like this stigma of craziness and unpredictability around it, they're like, “well, that's that's what it is that that has to be it.” (A 9-13)



What is the day - to - day experience of living with epilepsy and mental illness?

Theme 4. Feeling out of control

4a. Health conditions in control

“I was getting more and more depressed to the point where I was and like self-harming and having suicidal thoughts um because I just seeing everyone around me doing things I couldn't or like going on with their daily lives where I felt like I was stuck um there was just times where I thought like I'm never gonna get to where everyone else is so what's, what's the point?” (C 146-150)



4b. Lack of Agency in Healthcare

“I would go to doctors and say these things and they'd say 'no, that's your mental health.that's anxiety that just they present the same way'.” (A 150 - 152)

What is the day - to - day experience of living with epilepsy and mental illness?

Theme 5. High Mental Load

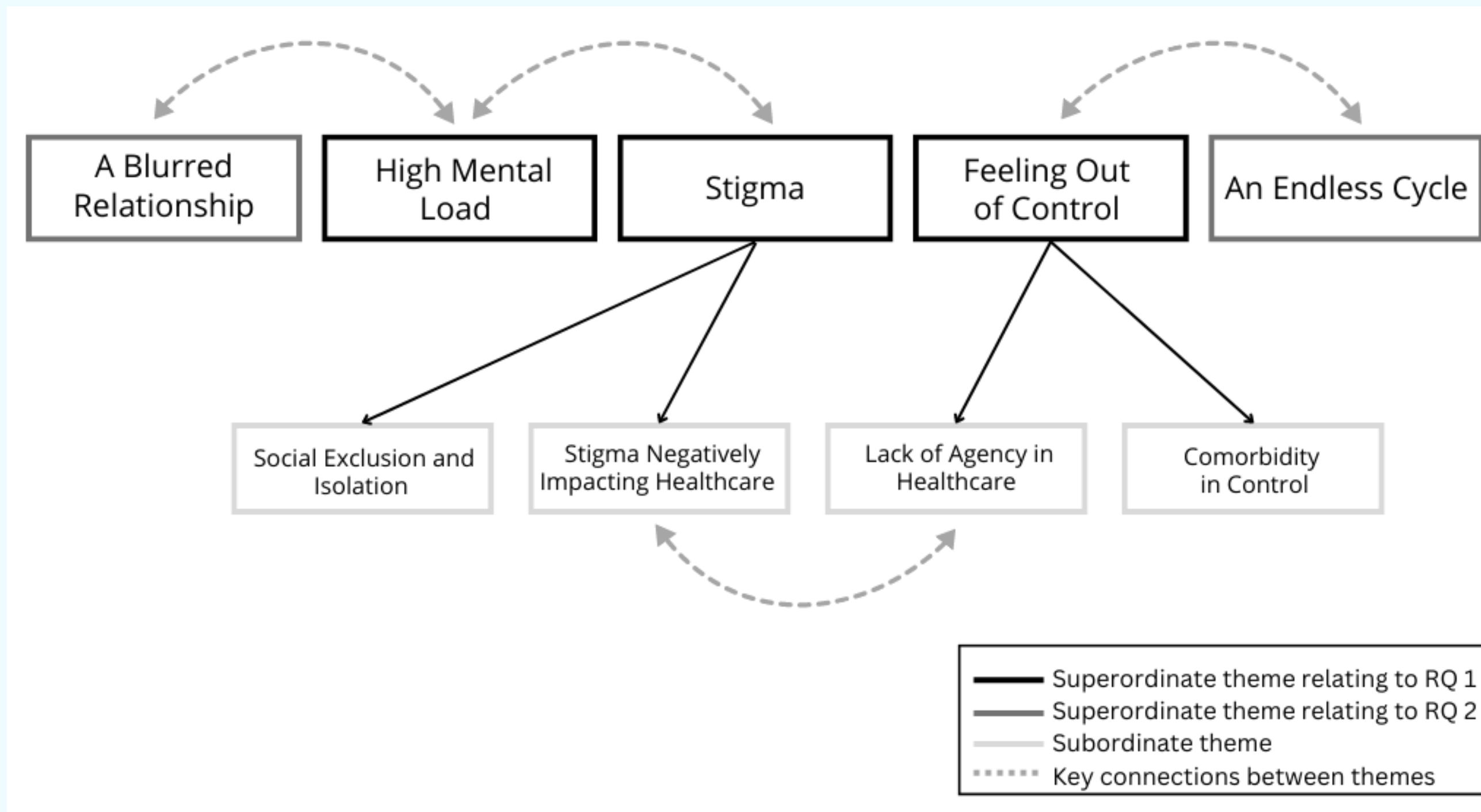
“So it's definitely very anxiety inducing because even when I'm not having seizures, it's still at the back of my head like am I going to? and I have to think okay, have I got like information on me for if I do have a seizure um and so I can't go a day without thinking about it, even if I'm having a good day, it's still constantly affecting me.”

(C 58 - 61)

“I need to calm down ASAP otherwise I might trigger an anxiety attack or seizure”

“What if I had a seizure right now?”

“Was that an aura? Should I tell the person I am with?”



Overall, people with epilepsy and mental illness experience the comorbidity as highly interconnected and overlapping, and to impact thier day - to - day life negatively and significantly.

Looking Forward

- Current research asked very broad questions -> more research investigating specific aspects of the experience
- Current research included people with all epilepsy and mental illness -> future research which builds on this, and which narrows and widens inclusion criteria
- Epilepsy and Mental illness are not experienced as two separate conditions -> more holistic and joined up healthcare and support needed to reflect this
- The impact on people's life is significant and negative and the comorbidity is associated with distinct challenges -> need for tailored support for people with epilepsy and mental illness

To conclude

- The epilepsy mental illness comorbidity is **significant** in prevalence and impact
- People with epilepsy and mental illness conceptualise the relationship between the conditions to be **highly interconnected and overlapping**
- Has a **significant negative impact** on a day to day basis - high mental burden, a feeling of being out of control, and associated with harmful stigma
- There is a need for **better healthcare and support** for people with epilepsy and mental illness
- This has just scratched the surface - **more research is needed!**

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