

# A Qualitative Assessment of the Epilepsy Patient Experience Through Social Media and Web-Based Forums

Allie Herrera<sup>1,2</sup>; Alyssa Healy<sup>1,3</sup>; Christopher Jensen, PharmD<sup>1</sup>; Anne Neumann, RN, BSN<sup>1</sup>

<sup>1</sup>Biohaven Pharmaceuticals, New Haven, CT; <sup>2</sup>University of Arkansas, Fayetteville, AR; <sup>3</sup>Providence College, Providence, RI

## INTRODUCTION

- Epilepsy is a neurological disease with a risk of unprovoked seizures that can be considered both invisible and associated with stigma, making it challenging to fully understand patient perspectives and unmet needs<sup>1</sup>
- Available antiseizure medications are associated with adverse events (AEs) that may result in discontinuation and reduced quality of life, and contribute to nonadherence<sup>2-4</sup>
- Although both patients and neurologists rank seizure control as the highest priority, patients place significantly more weight on AEs and tolerability compared with neurologists<sup>5,6</sup>
- While seizure freedom remains the primary goal of epilepsy treatment,<sup>7</sup> we aimed to assess additional unmet needs of people with epilepsy by investigating the patient experience directly from social media influencers and online platforms where patients discuss epilepsy
- The platforms and influencers we investigated play a crucial role in providing an environment where the epilepsy community can express their voice
- The intent of this qualitative research was to identify potentially overlooked challenges that patients experience

## OBJECTIVES

- To identify perspectives on medication AEs, mental health issues, and stigma associated with epilepsy
- To understand how the community utilizes online platforms to discuss these challenges and how they foster an open environment for those living with epilepsy

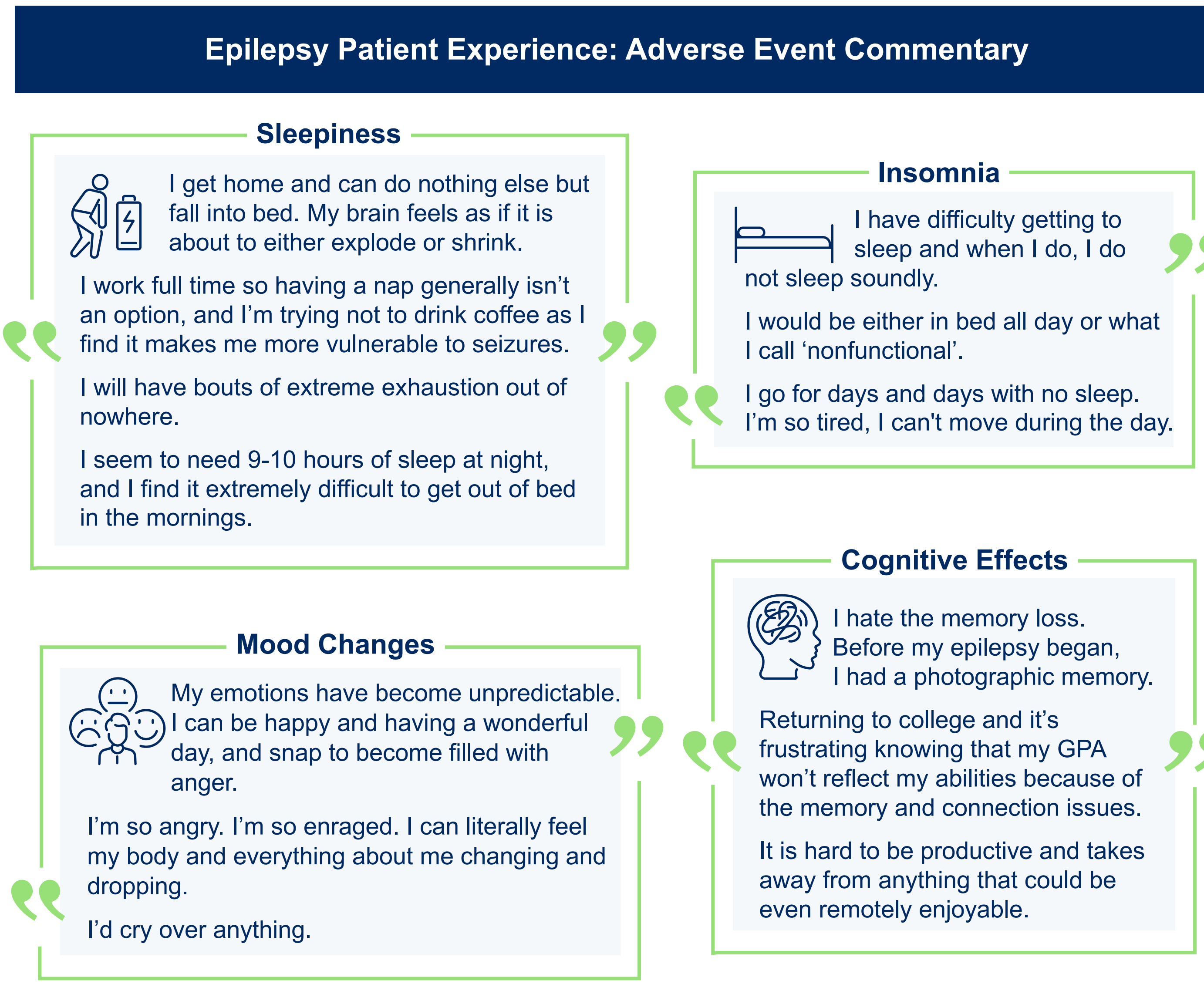
## METHODS

- This was a qualitative assessment of the epilepsy patient experience as observed through various web-based platforms conducted between June 15, 2024, and July 30, 2024
- Patient perspectives and unmet needs were identified across 3 areas: antiseizure medication AEs, mental health, and stigma
- Salient quotes and commentary from people living with epilepsy were passively captured from various media platforms, including YouTube, TikTok, Instagram, Reddit community forums, and Epilepsy Foundation community forums
- Individuals and influencers, who were most active within these forums based on reach, followers, and impressions, were identified; their posts, videos, and other media were analyzed for information related to medication AEs, mental health, and stigma

## RESULTS

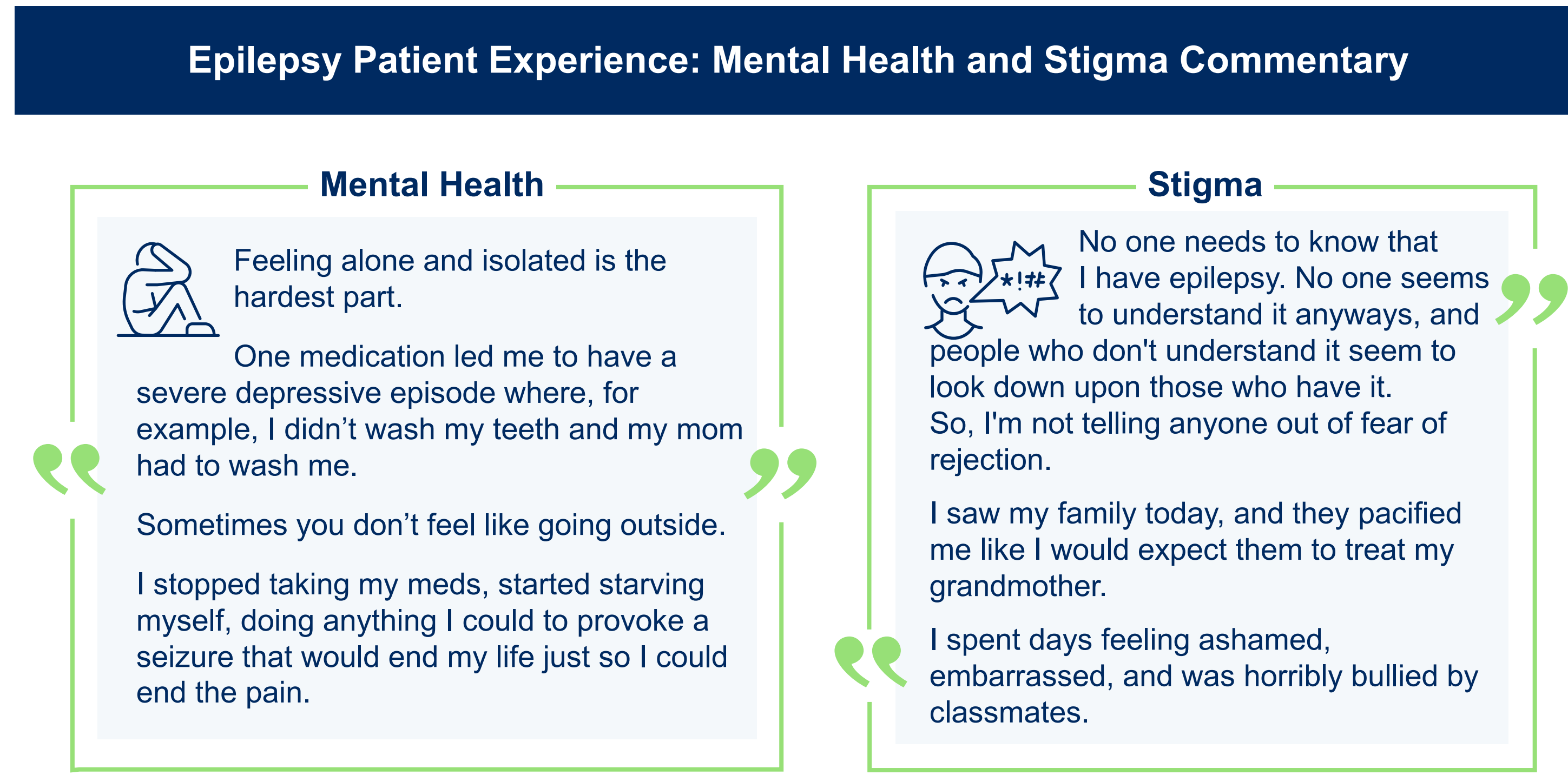
- We identified the 4 most frequently discussed AEs from antiseizure medications: sleepiness, insomnia, mood changes, and cognitive effects. Comments from patients captured the negative impact these AEs have on their quality of life (Figure 1)
- In addition to AEs, patients also reported a range of challenges with mental health, and the stigma associated with epilepsy pressured patients to remain silent about their struggles (Figure 2)

Figure 1. Perspectives and Unmet Needs Related to Antiseizure Medication Adverse Events



GPA, grade point average.

Figure 2. Perspectives and Unmet Needs Related to Mental Health and Stigma



## CONCLUSIONS

- This assessment of social media and online forums provided a unique understanding of the perspectives and unmet needs that people with epilepsy are vocalizing outside of a clinical setting
- Patients utilizing these forums shared their struggles with medication AEs, mental health, and stigma
- Across the various media platforms and influencers, it was clear that unmet needs persist beyond the goal of seizure freedom
- Through comment sections of videos and posts, it was also apparent that there is a community of patients who share similar experiences
- By providing a means for patients to share their voice, these influencers and platforms foster an environment where patients can feel empowered to advocate for their health and epilepsy education
- Further research is warranted on how these online forums may impact patient education, quality of life, and health outcomes

