

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

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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 needs¹
- Available antiseizure medications are associated with adverse events (AEs) that may result in discontinuation and reduced quality of life, and contribute to nonadherence²⁻⁴
- Although both patients and neurologists rank seizure control as the highest priority, patients place significantly more weight on AEs and tolerability compared with neurologists^{5,6}
- While seizure freedom remains the primary goal of epilepsy treatment,⁷ 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

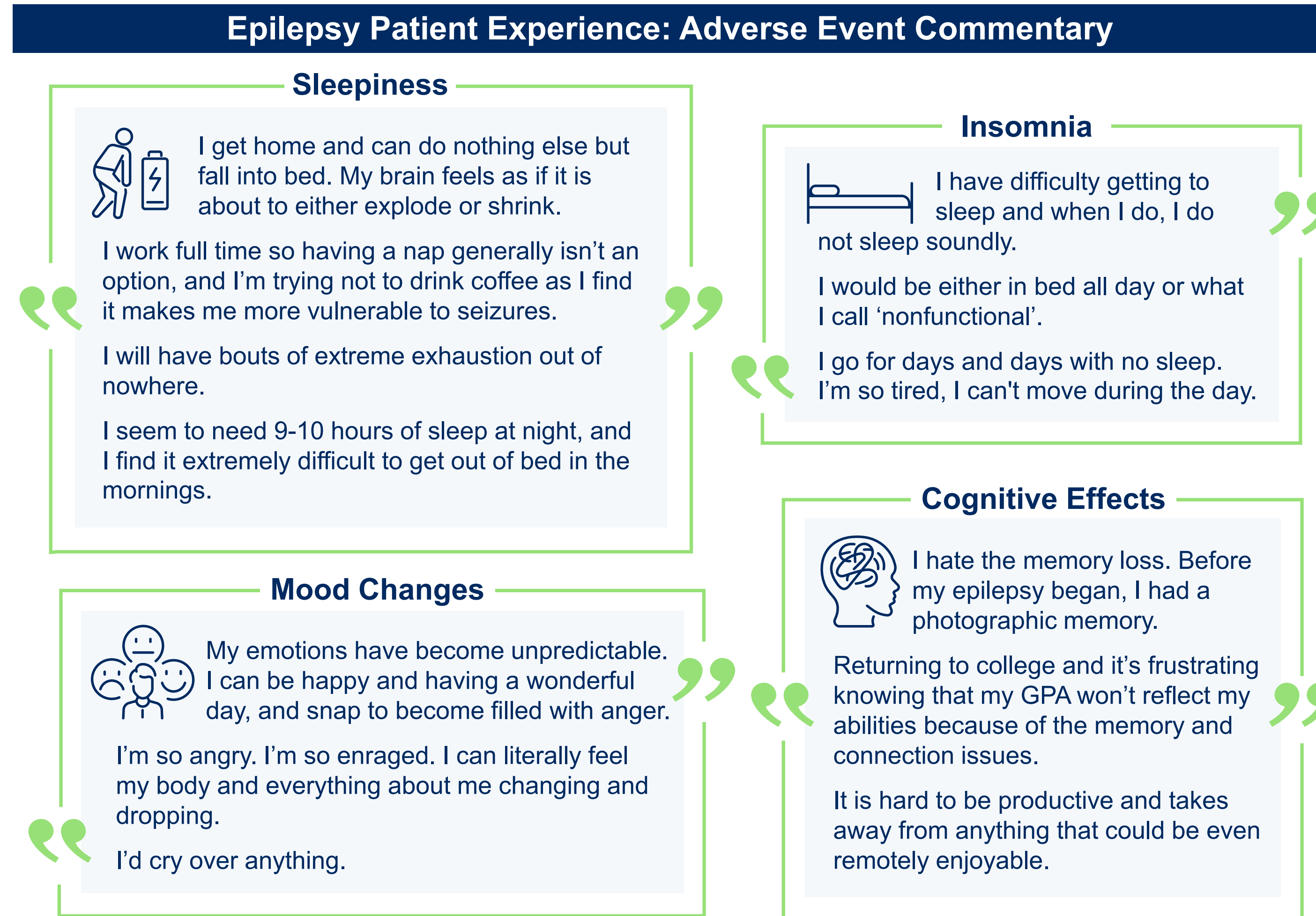
METHODS

- 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

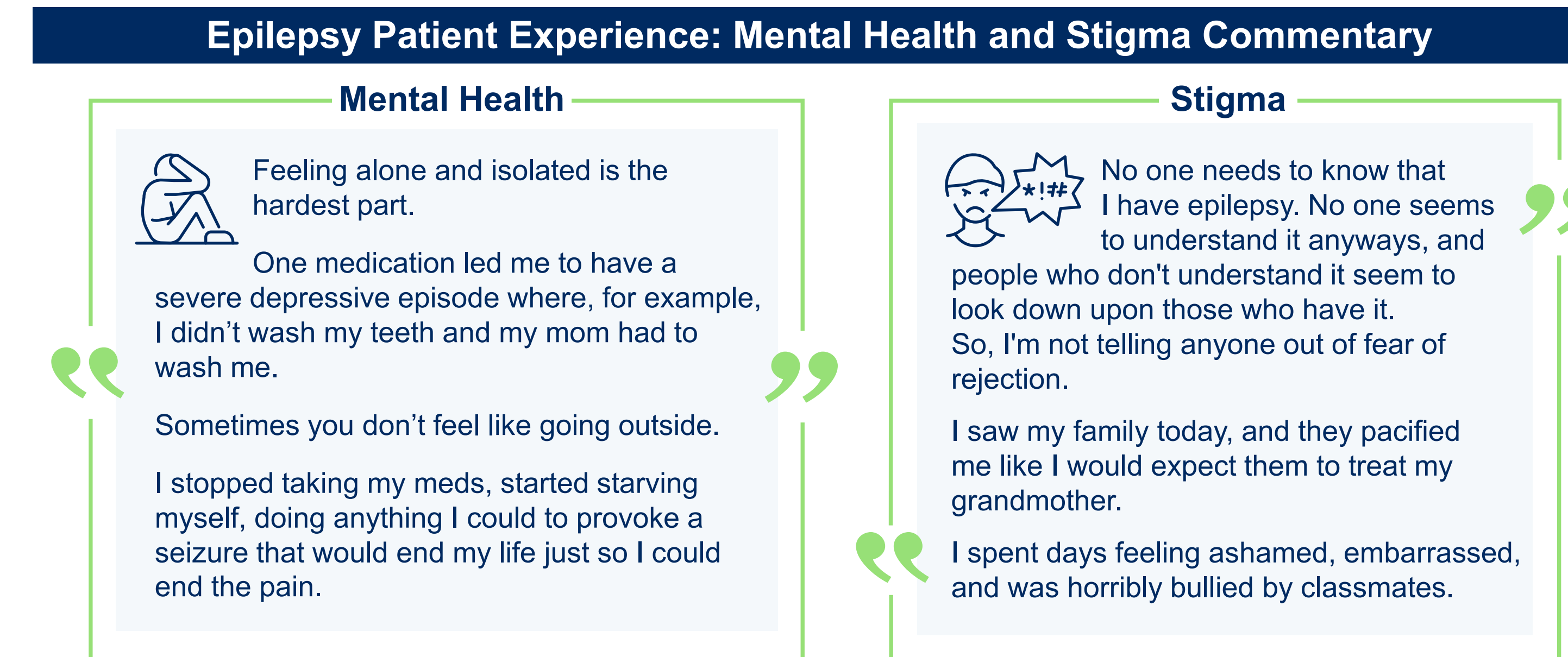
- We identified the 4 most frequently discussed AEs from antiseizure medications: sleepiness, insomnia, mood changes, and cognitive effects. Comments from patients captured the negative impact these AEs have on their quality of life (**Figure 1**)
- In addition to AEs, patients also reported a range 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

