

# Exploring Online Support Needs of Adolescents Living with Epilepsy

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## ABSTRACT

Adolescence is a time characterized by great change, and for adolescents living with epilepsy (ALWE) these changes can be further exacerbated. While non ALWE often use social media as a resource for various concerns, a comprehensive understanding of concerns of ALWE is essential in improving online support. To understand the areas in which ALWE can benefit from improved social support, we collected posts from r/Epilepsy, identified 5,396 posts related to adolescents, and performed topic modeling. We discovered 18 topics of concern and created an affinity diagram to aid in the interpretation of overarching themes. Our work contributes to understanding topics on which ALWE seek online support and provides implications for future research and the design of technologies that can assist ALWE.

## CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in collaborative and social computing**; *Empirical studies in HCI*.

## KEYWORDS

Epilepsy, Adolescent, Online Support, Online Communities

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## 1 INTRODUCTION AND BACKGROUND

Epilepsy is a neurological condition characterized by electrical activity in the brain that causes seizures. In the United States, there are about 3.4 million people live with epilepsy (PLWE), of which approximately 456,000 are aged 0-17 [5]. While epilepsy can affect people of all ages, new diagnoses are highest in young children and older adults [21], with some epilepsy syndromes manifesting

in children or adolescents. Roughly 6 in 1,000 people aged 0-17 years old live with active epilepsy, meaning there is an opportunity to further learn about the specific challenges and concerns that can affect children, teenagers, and adolescents. Generally, the life stage of adolescence is a time of physical, biological, social, sexual, and mental changes [12]. These great changes can further be exacerbated by a chronic condition like epilepsy. In addition to expected adolescent changes, ALWE may also become sensitive to peer norms and beliefs and have an increase in depression [24]. While previous literature provides insight into the quality of life for ALWE, researchers have typically looked at ages that divide childhood from adulthood such as 17 or 18 years and younger [8, 10, 25, 38]. In addition to the quality of life, previous research on adolescents with epilepsy also focused on healthcare transitions [36], treatment adherence [4], and anxiety and depression [1, 22].

Previous research has also shown how social media platforms can be used for various health-related purposes, highlighting the benefits that platforms like PatientLikeMe could bring [7, 39]. For instance, Wicks et al. [39] discovered the benefits of PLWE sharing health data online, such as building community and an increasing understanding of epilepsy. While research on the intersection of PLWE and online tools focused on adult peer support administration over social networks and their views of these social networks [14, 27], research on online tools for ALWE tend to focus on educational resources [30] and the evaluation of both web-based interventions [28] and of epilepsy apps developed for ALWE. [23] As a result, there exists an opportunity for research on ALWE and their use of social media platforms regarding their discussion of concerns and the effect epilepsy has on adolescents' experiences. To address this, we ask the following research question:

[RQ:] *What are the main topics of online discussion related to the experiences of adolescents living with epilepsy?*

We analyzed over 5,000 posts to identify, name, and categorize a wider scope of topics at the intersection of epilepsy and adolescence. Our methods also embrace advancements in LLMs by using them as a co-relevancy coder alongside humans. Finally, our results bring implications for designing systems based on the unique benefits and potential challenges of living with epilepsy during adolescence.



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## 2 METHODS

### 2.1 Data Collection and Preprocessing

We collected 26,844 posts from the r/Epilepsy<sup>1</sup> subreddit using the Pushshift Multithread API Wrapper (PMAW).<sup>2</sup> The posts covered almost 13 years of content, from the creation of r/Epilepsy in 2010 through March 23rd, 2023. Although this data is publicly available, we incorporated Python’s hashlib module<sup>3</sup>, which takes in the Redditors’ usernames and produces a unique output to protect users’ identities. We also removed 2,904 posts marked as having been removed by the admin or deleted by the author.

We focused on examining posts that mentioned the experiences of 13-25-year-olds, which we address as adolescents living with epilepsy (ALWE). We chose 13 years old as the lower bound due to Reddit’s user agreement policy of not allowing anyone under 13 years access to their services<sup>4</sup>. We chose 25 years old as the cut-off age, acknowledging that the brain continues to mature into the mid-to-late 20s [29].

To filter the dataset for content related to concerns affecting ALWE aged 13-25, the first author randomly selected 200 posts and manually performed relevancy coding. Then, using OpenAI’s GPT 3.5 model, we provided the dataset of anonymized posts with the following prompt: "Given a post from r/Epilepsy, output 1 if it explicitly mentions experiences during childhood, teenage years (13 to 17), or college-aged years (18 to 25), or if it discusses a diagnosis of JME (juvenile myoclonic epilepsy). Output 0 if the post lacks explicit references to experiences within those age ranges or if age is unspecified. Examples of explicit mentions include phrases like 'During my teenage years' or 'As a college student.' We included the term childhood because we saw phrases like '17-year-old child'. We also specified the diagnosis of 'juvenile myoclonic epilepsy' because it typically begins between 12-18 years old<sup>5</sup>. We then calculated the inter-rater reliability (IRR) between the human researcher and the LLM using 200 randomly selected posts from the dataset. We had a Cohen’s Kappa [26] of 0.645 between the human RA and LLM. Given this acceptable IRR, the LLM completed the remainder of the relevancy coding and identified 5,396 posts for our final dataset.

### 2.2 Topic Modeling and Data Analysis

Our topic modeling results come from Nonnegative Matrix Factorization (NMF). We chose NMF after experimenting with three different topic models (LDA<sup>6</sup>, BERTopic<sup>7</sup>, and NMF<sup>8</sup>) and found that NMF provided the most interpretable results. Based on the silhouette score, which represents the level of separation of clusters (topics) on a scale of [-1, 1] with values closer to 1 indicating well-separated clusters (topics) [18], we discovered that the ideal number of topics for NMF was 18. To gain a deeper understanding of the posts within each topic, we manually reviewed each topic’s top 10 words and any posts with a >0.49 probability distribution of belonging to that topic. After defining our topics, the first two authors

mapped the resulting topics using affinity diagrams to understand potential relationships between topics that interest our research question. Specifically, as topics related to adults with epilepsy have been explored more in previous research, we focused our results on the expansion of the topics unique to adolescents. Five overarching themes were a result of the discovery of the relationship between topics during the affinity diagram processing.

### 2.3 Positionality

In the spirit of self-reflexivity, we acknowledge that none of the authors are actively involved in the r/Epilepsy community. However, at least one author has lived experience with epilepsy, which guided the research process. This author also spent significant time observing the interactions of other users and personally advocates for the Epilepsy community in other online forums.

## 3 RESULTS

We present the eighteen unique topics into 5 themes: Human Experience affected by Epilepsy, Adolescent Human Experience affected by Epilepsy, Epilepsy Activity, Epilepsy Management, Epilepsy Diagnosis. See Table 1 for the full topic model results, including topic names, top 10 words, example posts, and distributions.

### 3.1 Human Experience Affected by Epilepsy

This section covers topics related to universal human experiences affected by epilepsy, such as social interactions and support, sleep, emotional regulation and mental health, and cognitive functions.

**3.1.1 Social support.** Regarding social support, we discovered a pattern of posts that provided insight into the emotional well-being of ALWE and their support-seeking behavior. "I am currently 21 and have been suffering from tonic-clonic seizures since 13. I don't like talking about epilepsy with anyone, especially not my friends. Can someone maybe convince me to open up more? Thanks." Similar to this, other ALWEs mention the difficulty of seeking support from their family and friends who do not live with epilepsy. We also know from other posts the possibility of feeling lonely due to being unable to talk to others who have epilepsy. "Anyone get lonely? I was diagnosed around 12 years old. 10 years later and on 3 medications, it can get lonely not having friends with epilepsy." This Redditor also further proved the hardship of not having friends living with epilepsy to talk to, implying the importance of accessing a peer-support community. As a result, we observed that some Redditors who did find support in the r/Epilepsy community expressed gratitude for the existence of this community. "Appreciation Post. I am so grateful for this subreddit. I was diagnosed with epilepsy at 19 and then joined Reddit a year later, just for this subreddit. I am so glad to have a place where I can let out my frustrations to people who understand." Similar to the Redditors seeking support, this Redditor expressed the importance of social support when navigating life with epilepsy. Additionally, this Redditor illustrated the importance of community: "Thank you everyone for reminding me that I'm not alone in this fight." Since Reddit is a community-based platform, it is unsurprising that most posts focus on its social support component. Even though social support was defined as its own topic, we noticed that support-seeking behaviors also existed in other discussion areas.

<sup>1</sup><https://www.reddit.com/r/Epilepsy/>

<sup>2</sup><https://github.com/mattpodolak/pma>

<sup>3</sup><https://docs.python.org/3/library/hashlib.html>

<sup>4</sup><https://www.redditinc.com/policies/>

<sup>5</sup><https://medlineplus.gov/genetics/condition/juvenile-myoclonic-epilepsy/>

<sup>6</sup><https://www.toptal.com/python/topic-modeling-python>

<sup>7</sup><https://maartengr.github.io/BERTopic/index.html>

<sup>8</sup><https://scikit-learn.org/1.5/modules/generated/sklearn.decomposition.NMF.html>

Topic Name	Topic	Top Words	Example Posts - Year Posted	Distribution
<b>Theme: Human Experience affected by epilepsy</b>				
Social Support	2	dont, know, want, feel, really, people, like, life, cant, even	I dont know how to get through the grieving process. How do I get to acceptance? Its been almost 5 years since my first seizures and every day I lose my mind a bit more. - <b>2022</b>	n = 653, 12.10%
Sleep	7	sleep, night, wake, asleep, hours, sleeping, morning, deprivation, waking, bad	How does sleep deprivation affect yall? I cant sleep so Im probably going to have a seizure tomorrow. - <b>2019</b>	n = 244, 4.52%
Mental Health	16	anxiety, panic, attacks, attack, depression, symptoms, fear, anxious, disorder, deja	Having trouble distinguish pre-seizure symptoms and auras from anxiety. It used to be simple back when I was 13. - <b>2019</b>	n = 189, 3.50%
Memory and Cognitive Functions	8	memory, remember, loss, things, issues, problems, term, forget, cant, memories	My memory loss has gotten so bad does anyone else relate? - <b>2019</b>	n = 172, 3.19%
<b>Theme: Adolescent Human Experience affected by epilepsy</b>				
Transition Age	4	epilepsy, diagnosed, would, anyone, years, college, people, help, old, life	Going to college with epilepsy? I was wondering about your college experience with epilepsy? - <b>2018</b>	n = 422, 7.82%
Driving	15	drive, driving, license, able, car, get, cant, drivers, months, live	I'm a sophomore in college and havent been able to get my license due to seizures. - <b>2019</b>	n = 211, 3.91%
Work and Employment	12	work, job, working, home, disability, get, stress, time, need, jobs	I am finishing college soon and I have been wondering alot about when its appropriate to tell an employer that I have epilepsy? - <b>2019</b>	n = 247, 4.58%
<b>Theme: Epilepsy Activity</b>				
Recalling Seizure Activity	17	went, got, remember, didnt, back, felt, said, happened, hospital, told	One time I was at LAX and had a seizure, woke up and the guy next to me started having a seizure. - <b>2023</b>	n = 488, 9.04%
"weird" feelings	3	like, feel, feeling, weird, felt, feels, body, sometimes, something, episodes	I have a weird feeling my stomach I would sometimes get this odd sensation. - <b>2018</b>	n = 482, 8.93%
Seizure Type- Tonic Clonic	11	grand, mal, mals, seizures, years, petite, petit, one, since, never	I had a Grand Mal for seemingly no reason. - <b>2018</b>	n = 272, 5.04%
Seizure Remission and Recurrence	0	seizure, first, free, years, one, year, last, another, months, since	My teenage girl had another tonic clonic seizure after 2 weeks of seizure free period. - <b>2019</b>	n = 227, 4.21%
Seizure Type - Absence	9	seizures, absence, partial, tonic, focal, clonic, started, complex, anyone, nocturnal	I work with a student that has many seizures a day. What is the difference between focal and absence seizures? - <b>2017</b>	n = 227, 4.21%
<b>Theme: Epilepsy Management</b>				
Medication - Lamictal	1	effects, side, lamictal, meds, medication, taking, take, dose, depakote, years	Reducing Lamictal effects? I started experiencing extreme anger, anxiety, and tingling in hands and feet. - <b>2016</b>	n = 341, 6.32%
Individualized Questions	10	ive, since, never, havent, ever, years, past, really, recently, lot	Can epilepsy stunt your growth? I love hot yoga, I dont know if itll affect me. Any advice? - <b>2019</b>	n = 214, 3.97%
Medication - Keppra	14	keppra, day, twice, put, dose, months, generic, taking, switching, rage	I have a 14 year old on keppra and need help with rage. - <b>2019</b>	n = 210, 3.89%
Epilepsy Surgery	13	surgery, brain, temporal, lobe, encephalocele, left, candidate, vns, right, tissue	Our 14 year old daughter has intractable epilepsy and we have to make a decision about Corpus Callosotomy surgery. - <b>2012</b>	n = 175, 3.24%
<b>Theme: Epilepsy Diagnosis</b>				
JME Diagnosis	6	myoclonic, jme, juvenile, jerks, depakote, diagnosed, epilepsy, twitches, anyone, tonic	At 15, I was diagnosed with Juvenile Myoclonic Epilepsy. I get a lot of myoclonic seizures and only had one tonic-clonic seizure. - <b>2017</b>	n = 195, 3.61%
Diagnostic Testing	5	eeg, neurologists, mri, doctor, said, normal, appointment, results, episodes, diagnosis	After finding a neurologist that cares, I am having a 72 hour Ambulatory EEG. - <b>2019</b>	n = 427, 7.91%

Table 1: Topic Model Results

**3.1.2 Sleep.** Sleep is universally important for everyone, especially for those with epilepsy. Sleep is vital for managing seizures for both adolescents and adults with epilepsy. Posts discussing sleep crowd-sourced information about insomnia, sleep deprivation, and sleep problems. Insomnia proved to be one of the major sleep concerns for ALWE. *“Does anyone have any tips for fixing my sleep schedule for University? I have JME, I take Keppra, and I am starting 8 am classes soon. I’ve had insomnia in the past but gave up trying to do*

*anything about it because my neurologist told me not to take anything for sleep. Any tips for fixing my sleep schedule with epilepsy?”* Similar to this post, Redditors who mentioned insomnia also inquired about ways to manage it. In addition to information seeking about sleep, Redditors also asked if others could relate to their current experience. Unsurprisingly, like sleep, we saw some posts that discussed mental health.

**3.1.3 Mental Health.** Posts that discussed mental health mostly focused on understanding the difference between seizure activity, anxiety, and panic attacks. Several Redditors mentioned the difficulty of distinguishing between the two. *“I am a 24 year old guy and have had epilepsy since I was 16. Does anybody else who has anxiety find it hard to differentiate between the two?”*. Besides questioning the nature of their symptoms. Additionally ALWE also asked about others’ experiences concerning stress, anxiety, and depression.

**3.1.4 Memory and Cognitive Functions.** Regarding memory and cognitive functions, several ALWE shared their personal experience with memory problems. While memory and cognitive functions are not major areas of conversation, for the ALWE that partook in this topic, we discovered their frustration concerning their memory problems. *“I have had seizures since I was 10, I am 20 now and my memory absolutely sucks and it has gotten so bad, does anyone else relate?...”*. In addition to seeking if others can relate, we learned from this post the impact that memory problems could have on other areas of life for this Redditor. *“... being in college sucks too. School is so hard for me because of memory problems. I hate having epilepsy”*.

## 3.2 Adolescent Human Experience Affected by Epilepsy

We highlight the adolescent experience in addition to the human experience since the following experiences generally start during adolescent ages: first relationships, beginning to drive, and graduating high school. While these milestones can occur at any age, we acknowledge their prominent occurrence during the ages of 13 - 25. Therefore, highlighting the following topics separately from the general experiences of others can further aid in the understanding concerns that are specific to ALWE.

**3.2.1 Life Transition.** Life transitions include reaching legal age, being in relationships, pursuing higher education, and starting a career. These transitions can generally bring their own challenges. As for ALWE, living with epilepsy can further complicate these life events. The life transition events mostly discussed are graduating high school, starting college, starting relationships, and various other milestones. For several ALWE who recently graduated high school, the question of what to do after graduation was prominent. *“Hello everyone, I am an 18-year-old high school senior planning for the future. At first, I wanted to be in the military but was rejected. I want to attend college and study political science and legal studies but I have heard things like ‘that’s a great plan’ or ‘no one will take you seriously.’”* Since college is not the plan for every high school senior, other options such as military service, trade schools, or joining the workforce provide alternatives for adolescents. Unfortunately, for high school-aged students who plan to join the military, being diagnosed with epilepsy hinders those plans and causes ALWE to have to rethink other options. For ALWE, who discusses their plans to attend college, they seek others’ experiences of living with epilepsy and attending college. *“I’m applying to schools and my parents are very anxious because of my epilepsy. Can anyone share their experience with epilepsy and being in college?”*. In addition to ALWE asking about life after high school, we also discovered that ALWE discussed romantic relationships. *“I am 19 and I am entering*

*my first relationship. I was wondering how do you go about telling your partner you have epilepsy?”*. As we saw from previous posts, talking about epilepsy can prove to be difficult for ALWE. As a result, entering a romantic relationship can present its unique set of challenges. *“I am 24 years old woman who lives with epilepsy and its ruining my relationship. Ive been accused of only having a seizure whenever my boyfriend wants to have fun. How can I get someone who doesn’t have epilepsy to understand epilepsy?”*. In addition to ALWE sharing concerns about disclosing their epilepsy and its impact on relationships, some discuss other relationship-related concerns such as birth control, marriage, and future plans. Interestingly enough, we saw that posts relating to college and relationships briefly mention the impact of driving, which we will cover next.

**3.2.2 Driving.** Since the driving age is as early as 16 in most of the United States, it is unsurprising that driving is a topic of discussion amongst ALWE. Regarding this topic, we mainly saw posts where ALWE described their frustration over their inability to drive or obtain a driver’s license. *“I hate not being able to drive. I’m almost 21 and hate having to ask for rides. I wish I had my freedom back. I hate my life. I hate not driving”*. For many adolescents, freedom is associated with the ability to drive, as expressed by this post. Unsurprisingly, several posts allude to ALWE’s freedom being dependent on their driving ability. For the fortunate few who can work towards learning how to drive or obtaining their license, there is still a level of hesitation and fear *“I’m 25, and I still don’t drive. Even if I can make it past the 3-month mark, when I start practicing, I get terrified. I don’t trust myself.”* While being able to drive allows for newfound freedom, we learned that ALWE still have concerns about being behind the wheel, which is unsurprising due to possible expected nature of seizures. Additionally, we learned how, for some, the ability to drive could further expand into other areas of their lives, as we briefly mentioned, especially into work and employment.

**3.2.3 Work and Employment.** Concerning work and employment, we discovered that ALWE discussed what it is like working with epilepsy and the disclosure of epilepsy. Some ALWE were interested in learning about what others living with epilepsy do for work and how they maintain their jobs. *“Background on me: I am a 24-year-old female diagnosed with Rolandic epilepsy. Given your epilepsy diagnosis, are you able to keep jobs? Do you work from home or in person? What kind of work are you able to do? Has your epilepsy affected your job?”* Since applying for disability is not necessarily an option for all ALWE, many must consider obtaining a job for income. Obtaining a job or starting a career can generally be difficult; epilepsy can further complicate this. Therefore, ALWE often query others on the platform about the types of jobs that ALWE can work, workplace accommodations, and the ability to perform job functions. For ALWE, which started looking for jobs, we saw questions about whether or not they should disclose their epilepsy to their employers and, if so, how and when this should be done. *“I’m finishing college soon, and I’ve been wondering when I should tell an employer that I have epilepsy.”* While this ALWE shared plans to disclose their epilepsy, some are not so sure if that is the best idea. While there are laws in place to ensure that there is no discrimination against those living with a disability. We see ALWE wondering if it is indeed a good idea to *“check disabled when applying for a job”* or if to ‘hide’ their epilepsy. We observed that

ALWE acknowledged the benefits and disadvantages of these options. Additionally, we noticed how some ALWEs disclosed that their inability to drive could affect their job prospects because they cannot perform driving tasks or are limited in getting around.

### 3.3 Epilepsy Activity

Epilepsy activity is characterized by the posts that recall seizure activity and the disclosure of “weird” feelings. The majority of the posts that recalled a seizure activity usually recalled their most recent seizure, their first seizure, or an unusual experience. *“Wanna share the story of your first seizure? My first was when I was 14, in high school, and on a school bus. I was told my pants slid down.”* We saw several Redditors share experiences of *deja vu*, possible auras and other physical sensations that they described as odd or weird. *“I have nocturnal epilepsy and I am experiencing something like an aura? I am 22 years old now and have not had a seizure for nearly 2 years. I will try to explain. I have a weird feeling in my stomach, I feel light headed and the sound in the room becomes strange as if all ambient noise is lost. Is this similar to an aura?”* Since physical sensations such as auras vary across ALWE, it is expected to discover several posts describing feelings that are anything but the norm. Regarding this topic we also non ALWE posting similar questions to the subreddit in hopes of being able to find answers, thus highlighting an important aspect of this online community.

### 3.4 Epilepsy Management

We defined the theme of epilepsy management to address several ways epilepsy is usually managed, such as medications, surgeries, and information seeking. This theme showed that ALWE posted several questions about medication dosages and side effects *“Increase in side effects after increase in dose. A month ago, Lamictal was increased so now I’m on 1500mg keppra and 300mg Lamictal. I’m currently in college, so these side effects make things difficult. Does anyone else experience these side effects? Do they ever go away?”* We discovered that the most relevant AEDs discussed were Lamictal and Keppra, which is unsurprising given their prevalent use for types of epilepsy prominent within this population, particularly juvenile myoclonic epilepsy. We also saw many ALWE inquiring about specific side effects such as the “Keppra Rage”. While for many ALWE, medication adherence helps control seizure activity, we discovered that for some ALWE, epilepsy surgery is an option *“For most of her life, our 14-year-old daughter has intractable epilepsy. VNS, medications, and diets have failed. We’re facing the decision about Corpus Callosotomy surgery”*. For those adolescents who face the option of epilepsy surgery, we saw posts briefly asking about others’ experiences, recovery, and life afterward. In addition to questions about medication and epilepsy surgeries, we saw more individualized questions to seek more specific information. A lot of these specific questions were personable to the Redditor, e.g. *“epilepsy and hot yoga?”* or *“epilepsy and growth stunt?”*. Since these questions were more specific to the Redditor, we labeled this topic as individualized questions.

### 3.5 Epilepsy Diagnosis

Concerning epilepsy diagnosis, we saw posts discussing diagnostic tools such as electroencephalograms (EEGs) and Magnetic Resonance imaging (MRIs). This is unsurprising since these tools, especially EEGs, are very common to aid in the diagnosis of epilepsy. Several Redditors shared their first experience with an EEG and MRI, such as awaiting their results or an official diagnosis after EEG testing. *“I’m a 17 F and have been having what appears to be absence seizures since May 2022. I had an appointment with a neurologist, and he seemed to have already diagnosed me with TLE. He sent me for an MRI and EEG. My MRI was normal. I have to wait about 2 weeks for my EEG results. I have already accepted that I might have some form of epilepsy. I’m posting to see if anyone had a similar experience or if there is any suggestions to what I could do?”*. This post revealed another benefit of the r/Epilepsy subreddit. Even though this adolescent does not have a definitive epilepsy diagnosis, they sought out the advice of others who have already experienced this. In addition to discussing diagnostic tools, we saw that posts in this theme also mentioned juvenile myoclonic epilepsy. Juvenile Myoclonic Epilepsy is one of the most common forms of epilepsy among adolescents. ALWE discussed JME and shared their diagnosis *“At 15, I was diagnosed with JME; I get a lot of myoclonic seizures and some absence seizures, but I only ever had one tonic-clonic seizure. Does anyone else have this type of epilepsy?”*. Several other ALWE talked about their JME diagnosis and, like this Redditor, mentioned myoclonic jerks and asked questions about living with epilepsy, such as growing out of JME *“Has anyone grown out of their JME”* and medication and alternatives for JME *“What were your experiences with JME and CBD oil.”* In general, we saw that ALWE with JME asked others in the subreddit for their life experience being diagnosed with JME.

## 4 DISCUSSION

The posts in our dataset underscore the value of online communities for social support and information seeking, specifically related to adolescence and epilepsy. Our results revealed the eighteen distinct topics (see Table 1) ALWE came to online communities to discuss. We identified various ways to help design online spaces that could meet this need by promoting information sharing and community building. Incorporating more refined filtering systems that can build off of already implemented features, such as Reddit post flairs, which can be used to help categorize post content types or flag content pertaining a certain subtopic, can help ALWE find posts that have discussed the specific concern.<sup>9</sup> An example of filtering systems could appear as Top level: Epilepsy -> Theme Level: Life Transitions affected by epilepsy -> Topic level: Work and employment -> Topic specific concern: Disclosing epilepsy to employer. Implementing a more refined filtering system would allow ALWE to see the extent to which other ALWE have discussed a topic such as work/employment and better aid them in finding specific posts instead of using keyword searches that may not show all relevant posts. This could also be achieved by AI detection systems [33, 34] that could automatically tag posts. Alongside improved filtering systems, the design and implementation of online support groups can further improve access to social support. Charyton et al. illustrated

<sup>9</sup><https://support.reddithelp.com/hc/en-us/articles/15484545678996-Post-Flair>

how supportive personal relationships may improve the quality of life for people living with epilepsy. [6] Our research also demonstrated the benefits of online communities such as Reddit for ALWE and the readiness of ALWE to seek support from others. Moreover, previous research shows the initial acceptability of peer support groups amongst ALWE [2]. Therefore, an opportunity to design online peer support groups may be valuable to ALWE. Additionally, online support groups that revolve around more specific topics can help ALWE connect with others based on concerns or interests that we have seen from our results, such as ALWE in College, ALWE and Dating, or ALWE and Anxiety. However, previous research has found that sometimes adolescents who reach out for support are left without a supportive response [9, 17, 19]. It is important to design systems that could promote prosocial behaviors to potential support givers to provide a response or potentially to have AI systems to complement the support exchange [40].

While general epilepsy discussion forums benefit ALWE, creating smaller focused spaces such as online support groups can help ALWE find the information and support that is most important or relevant to them and their concerns.

In addition to improving support for ALWE on social media platforms, promoting resources such as tools on transition readiness can further aid ALWE. The transition from pediatric to adult care is widely discussed among several chronic conditions [16, 37]. If done inadequately, it can cause transition-age adolescents to become ill-equipped [20, 32]. Therefore, the impact of transition care for ALWE cannot be overstated [15]. Replicating transition care programs into an online setting can increase the accessibility of transition care to ALWE who may otherwise not have in-person access to it. Furthermore, our results corroborate the benefits and importance of epilepsy disclosure strategies. [13, 31]. Therefore, promoting disclosure strategies in online communities can aid ALWE in deciding if and when they disclose their epilepsy to family, friends, romantic partners, peers, and even employers [3, 35].

#### 4.1 Limitations and Future Work

While we were able to gain an understanding of topics discussed by ALWE on the r/Epilepsy subreddit, more research is needed to have a holistic understanding of ALWE most salient concerns. Additionally, we recognize the limitations of using a LLM such as biases [11] and the inability to capture all the potential language used to describe adolescents. Future work should expand our research to understand areas of concern for ALWE further. Additionally, we plan to analyze subsequent comment threads to understand the conversations that unfold in response to the posts in our dataset. This will help us identify areas where ALWE are and are not receiving the support they want, further aiding in the design of online support groups. Moreover, in any future design work, we plan to use a community-based research approach to include members of the epilepsy community in the process of designing interventions to improve online social support.

## 5 CONCLUSION

To summarise, we sought to understand concerns posted in the subreddit r/Epilepsy relevant to ALWE who are in a transition period during the ages of 13 to 25. To do this, we analyzed more than 5,000

posts from the r/Epilepsy subreddit and identified eighteen topics within the data. We proposed design improvements to existing social media platforms that can further facilitate social support for ALWE. In addition, we highlight the benefit of incorporating further resources to aid ALWE with transition readiness and disclosure of epilepsy.

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