Understanding suicidality among teenagers and adults suffering epilepsy using a big data, machine learning analysis of digital conversations.

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Introduction

- Epilepsy is the fourth most common neurologic disorder and depression is noted in 30 – 50% of people with epilepsy (PWE).
- In a review of several meta-analysis, suicide accounted for 32% of the deaths of patients with epilepsy.
- Prior research has reported estimated annual rate for suicide among adults with epilepsy 22% higher than in the general population.
- One of the major drivers for suicidal thoughts in people with epilepsy is the high incidence of depression in this population.
- Social media has become one of the most common medium of interpersonal communication.
- Digital conversations among PWE may provide a window to understand the fears and concerns about the disease and their mental state.

Objectives

- To mine spontaneous conversations about suicide from the voice of teens and adults with epilepsy in the USA, in order to understand key topics, mindsets, sentiments and the main drivers for the suicidal thoughts.
- To identify how teens mindset differ from adult mindset when talking about suicide and epilepsy.
- To get insight about the implications of having epilepsy in teens.

Methods

- The population of interest were self-identified teenager and adult users online who endorsed suffering from epilepsy.
- CulturIntel used their advanced software platform to mine and structure qualitative digital conversations on epilepsy and suicide.
- The search was limited to a 12-month period (September 26, 2017 through September 25, 2018).
- The search was limited to US based IP addresses.
- The data mining and collection occurred across various relevant sites (topical sites, blogs, social network & message boards).
- To avoid duplicity, a single user with multiple posts/comments within a conversation was counted once.

Results

- A total of 222,000 digital conversations about epilepsy were posted online during the study period.
- Of all the discussions, a total of 41,000 were posted online by teenagers and 181,000 by adults.

Figure 1: Origins of posts on suicide and epilepsy among teenagers.

- Further analysis showed that, 3200 (8%) of posts among teens were related to suicide compared to 5800 (3%) among adults
- Content analysis showed that 30% of posts by teenagers discussed social consequences of seizures compared to 21% posts by adults.
- Another 29 % of posts by teenagers were looking for emotional support to deal with the impact of the illness compared to 19% adults.
- In contrast to above findings, concerns about physical impairments from seizure were expressed in 29% posts by adults compared to 21% teenagers.

Figure 2. Mindset analysis: teenagers and adults

Drivers (n)		Teens (%)	Adults (%)	Quotes from Teenagers
Negative drivers (barriers) N=2100	Feeling alone	32	23	"I'm 16 and...I was wondering if anyone else feels kinda alone with epilepsy and like when you tell someone they'll just freak out...."
	Low spirit	28	17	"My math teacher called me up in front of the class and said, 'If you feel like 'something' is going to happen, just leave the room.' there was a huge amount of twittering and giggling!"
	Social embarrassment	25	31	"I am having a really hard time lately... I'm very depressed (suicidal even), and not finding much joy in life."
	Sense of loss	15	29	"I'm just super annoyed with my epilepsy. It's been limiting what I can do...I can't do anything. Not only have I been having more seizures, but I also have panic and anxiety attacks."
Positive drivers N=96	Encouragement via connection	50	38	"I haven't been treated any differently around my friends because of my epilepsy but I have GREAT friends. "
	Empowerment over the epilepsy	41	23	"Forget the shame u may feel figure out what it is u wanna do in life make it happen it's all still possible."
Neutral drivers N=960	Adaptation to epilepsy	9	39	"Asking myself 'Why me' I'm on my 3rd year of gran mal epilepsy disorder doing much better..."
	Emotional connection	45	29	"I was diagnosed with epilepsy about 6 months ago and I have been having some trouble processing everything. Does anyone have any suggestions to help? "
	Support	37	22	"Hey everyone! ...I was wondering if anyone would like me to start a snapchat so we could chat on there?"
	Information and resources	18	49	"Hey everyone... I got epilepsy when I was two 1/2... I am trying to look for a support group and meet new people in my area with epilepsy... Does anyone know any places? I am going to try this one too."

Table 1: Sentiment analysis of conversation 'drivers

Conclusions

- We present one of the first big data analysis of online conversations among epilepsy patients expressing suicidality.
- The internet seems to provide a much-needed outlet for PWE whose disease can cause isolation and insecurity regarding connecting with others in direct social situations.
- We found important differences in the concerns and the shared sentiments among teenagers and adults regarding coping with the disease.
- This knowledge could be used during the counselling of PWE regarding depression and suicide prevention.