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What information about sudden unexpected death in epilepsy (SUDEP) is available on YouTube?

Appaji Rayi [a,*], Samip J. Borad [b,c], Suzanne E. Kemper [d], Konark Malhotra [b,c]

[a] The Ohio State University Wexner Medical Center, Columbus, OH, USA
[b] Charleston Area Medical Center, Charleston, WV, USA
[c] West Virginia University/Charleston Division, Charleston, WV, USA
[d] Department of Internal Medicine, West Virginia University/Charleston Division, Charleston, WV, USA

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ABSTRACT

Objective: We sought to assess and analyze the information available about sudden unexpected death in epilepsy (SUDEP) and the general perception of this condition by the public on YouTube.
Methods: We evaluated all consecutive videos containing references to 'sudden unexpected death in epilepsy' and 'SUDEP' on YouTube. Data were extracted after applying the inclusion and exclusion criteria. Various characteristics of the videos including the type of content, uploading source, likes, dislikes, and comments received were classified and analyzed.
Results: A total of 113 videos were included, with the majority uploaded by individual users (51.3%) followed by activist groups (40.7%). The primary content from individual users created videos were tribute to family members who died because of SUDEP (43.1%) and personal narration (36.2%), whereas educational/scientific information (55%) and advertisements (45%) to raise SUDEP awareness comprised the videos from professional societies and activist groups. More than three-fourths of the comments to the videos were in response to individual user uploaded videos, and mainly comprised of positive statement conveying empathy or describing personal encounters.
Conclusion: Substantial information is available regarding SUDEP on YouTube; however, the viewer engagement remains limited. Individual user-created videos about SUDEP are the most popular and viewer engaging. Incorporating personal/anecdotal experiences in addition to scientific information in the video content might further improve the viewer engagement.

1. Introduction

With the combined advancement in medical field and global availability of the internet, the users tend to engage and procure more detailed information regarding health-related queries [1]. YouTube (www.youtube.com) is a popular, free video sharing website and is a platform for easy dissemination of video content by masses. Interestingly, it has been used as a mode to spread awareness on health-related topics and followed closely as a medium to learn advancements in the health and medical sector [2–4]. Professional organizations, awareness groups, news channels, along with individual users often utilize YouTube to disseminate health-related videos. Various previous studies have analyzed YouTube to assess for different health-related issues including myocardial infarction, stroke, epilepsy, immunization, and rheumatoid arthritis [5–9]. Common reasons cited for conducting a YouTube analysis study were to investigate the accuracy of information available and gauge public awareness/opinion about the pertinent medical condition or procedure.

Sudden unexpected death in epilepsy (SUDEP) refers to sudden, witnessed or unwitnessed, nontraumatic or nontoxicological cause of death in patients with epilepsy, with or without the evidence of a seizure after excluding status epilepticus [10]. According to the recent American Academy of Neurology practice guidelines, the incidence of SUDEP is 1 in 1000 adult population and 1 in 4500 children with epilepsy [11]. Sudden unexpected death in epilepsy ranks next to stroke in the total years of potential life lost compared with other selected neurological conditions [12,13]. It presents a significant public health burden, and warrants global awareness to educate and potentially prevent this fatal condition. Various professional societies and activist organizations are devoted to improve the awareness for SUDEP. A survey investigating the awareness and perspectives on SUDEP among adult patients with epilepsy reported that the majority wished knowing more about SUDEP at the time of diagnosis [14]. To our knowledge, there is no study evaluating the availability of information and public

* Corresponding author at: The Ohio State University Wexner Medical Center, Department of Neurology, 395 W. 12th Ave, 7th Floor, Columbus, OH 43210, USA.
E-mail address: appaji.rayi@osumc.edu (A. Rayi).

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perception about SUDEP on YouTube that is a web-based platform to disseminate the appropriate information and increase awareness. Thus, our main objectives were to assess the nature of information available about SUDEP on YouTube. We also sought to learn about the general perception to this condition, specifically by analyzing the comments and reactions posted to the videos by the public.

2. Methods

A search was performed on YouTube (www.youtube.com) using the terms "sudden unexpected death in epilepsy" and "SUDEP". The inclusion criteria included videos in English language, content or description of the video relevant to SUDEP, and view counts of more than 100. The initial search was conducted on two different computers separately on January 9, 2018, and the results were verified to be similar before proceeding to further analyses. We excluded the duplicated videos and those not meeting our inclusion criteria. The duplicate videos were the videos that were precisely similar in duration and content but with different upload dates and responses. Among the duplicates, the earliest uploaded video was included in our analyses. The characteristics of viewer engagement (i.e., comments, view counts, likes, dislikes) to these videos were combined for final analyses, since the responses were toward the actual content. Videos in parts were considered as one video, and the parts, which did not have any information pertinent to SUDEP, were excluded. We extracted the following information from individual videos: date of video upload, number of views, number of likes and dislikes, video duration, total number of comments, and the source of the video. The sources of the video were classified into three categories: a) individual user defined as any single individual or person; b) professional societies including academic institutions, organization, or society of professionals with interest in epilepsy and engaged in the professional and public interest of the condition (such as, American Epilepsy Society, International League Against Epilepsy); c) activist groups defined as the organizations involving individuals of various backgrounds with a mission to provide support, awareness, and services, and improve the life of people with epilepsy (such as SUDEP aware, Epilepsy Foundation). The videos were then classified independently by two authors (AR, SB) based on the video content into five categories of type of video content (Table 1). The comments received for every video were then reviewed together by the two authors (AR, SB). Every comment was coded into the single most appropriate category (Table 2). In case of conflict in choosing a category, a consensus was reached after reviewing with the third author (KM).

2.1. Statistics

We used descriptive statistics including medians (min, max) for continuous variables, whereas proportions and frequencies for categorical variables. Comparisons between the source groups were performed using two-sample *t*-test for continuous and chi-square test/Fisher's exact test for categorical variables. We further assessed the level of agreement between the two raters using Kruskal–Wallis test. A p-value ≤ 0.05 was considered to be statistically significant. All the data analysis was performed using SAS Version 9.3 (SAS Institute, Cary NC).

Table 1
Categories of the type of video content.

Type of content	Definition/meaning
1. Tribute	Video uploaded in memory of a person or people who passed away because of SUDEP
2. Awareness event	Video showing pictures or video of community events raising SUDEP awareness
3. Educational/Scientific	Video showing a health professional providing information about SUDEP
4. Advertisement	Advertisement raising SUDEP awareness
5. Personal	Video describing the story about a relative or somebody whom they knew with SUDEP, seeking or providing information about SUDEP in general, or describing doing things to raise SUDEP awareness

Table 2
Categories of comments received for the videos.

Type of comment	Definition/Meaning
1. Providing type	Providing information about SUDEP
2. Seeking information	Seeking information about SUDEP
3. Personal	Personal information about their own history of seizures or about a close relative or somebody they knew with SUDEP or seizures.
4. Positive	Positive comment like thanks or conveying empathy
5. Negative	Negative or derogatory comment
6. Wishing	Comment suggesting about wish knowing about SUDEP earlier
7. Physician's not informing	Comment conveying that the physicians did not mention or did not know about SUDEP being present or even possible
8. Nonspecific	Other (does not fit into the above category)

3. Results

Our initial search identified a total of 6310 videos. Of those, 6197 videos were excluded because of either of the following reasons: with less than 100 view counts, a duplicate video, in non-English language, or video in parts. The remaining 113 videos were included in the final analysis (Fig. 1). A moderate to substantial level of agreement was observed among the two raters on the type of content, giving a weighted kappa statistic for interrater agreement of 0.68 (95% confidence interval [CI]: 0.56–0.79) [15].

The majority of the videos were uploaded by individual users (51.3%), followed by activist groups (40.7%), and professional societies (9%). The median duration of the videos uploaded by professional societies was 605 s (min–max: 68–3434 s), and was significantly longer compared with those of the other groups ($p = 0.002$) (see Table 3). Interestingly, the videos uploaded by professional societies were more recent as compared with those uploaded by individuals ($p < 0.001$). No difference was observed between the groups regarding the number of views, likes, or dislikes.

The content of the videos uploaded by individual users primarily consisted of tribute to patients who encountered SUDEP (43.1%) and personal narration (36.2%). The video content by professional societies and activist groups mainly consisted of educational/scientific information (55%) and advertisements (45%) to raise SUDEP awareness.

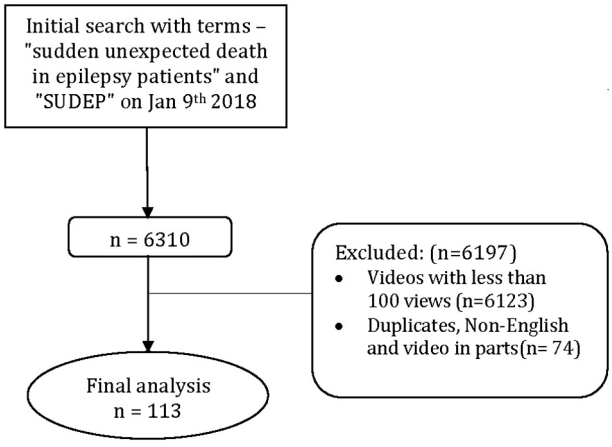

Fig. 1. Flowchart illustrating the search criteria and the number of videos included in the final analysis.

Table 3
General video characteristics.

Variable	Individual user	Professional society[a]	Activist group[b]	p-Value
1. Number of videos	58(51.3%)	9(8.0%)	46(40.7%)	
2. Duration in sec	292(22–2004)	605(68–3434)	250(30–4777)	0.002
3. Views	530 (109–30,284)	323(135–850)	538(104–13,770)	0.35
4. Comments	1(0–86)	0(0–2)	0(0–28)	0.008
5. Days since upload	1580 (433–4024)	361(242–1412)	831 (39–3353)	<0.0001
6. Type of content				
a. Tribute	25(43%)	0	2(4%)	<0.0001
b. Awareness-related event	5(9%)	0	1(2%)	0.26
c. Educational/Scientific	0.0	5(56%)	26(57%)	<0.0001
d. Advertisement	7(12%)	4(44%)	13(28%)	0.03
e. Personal	21(36%)	0	4(9%)	0.0009
7. Likes	4 (0–218)	4 (1–8)	3 (0–59)	0.06
8. Dislikes	0(0–16)	0	0(0–7)	0.39

Data are presented as median (min–max) and percentage.
[a] Videos uploaded by an academic institutions and professional societies.
[b] Videos uploaded by any group or charity working toward SUDEP and Epilepsy awareness.

Overall, 298 comments were received among all the videos. The comments received for the individual user and activist group videos were 232 (77.85%) and 62 (20.80%) respectively. The distribution of categories based on type of comment is illustrated in Fig. 2. Most of the video comments involved positive statement conveying empathy (34.22%) or describing a personal encounter (32.55%).

4. Discussion

Our study shows that substantial information exists on YouTube about SUDEP, but the viewer engagement to the videos appears to be limited. The content of the videos primarily consisted of personal experience or conveying tribute to patients who encountered SUDEP, which suggests a great level of engagement from individuals who either personally have seizures or are relatives of persons who have epilepsy or were deceased from SUDEP. These videos are more empathetic relative to providing technical or educational information about SUDEP, which is understandable. The educational/informational videos are the group of videos, which provided the most accurate information/content about SUDEP.

Our findings are in line with previous studies evaluating epilepsy videos in YouTube. Wong et al. evaluated the video content on the presentation of seizures and epilepsy on YouTube [16]. Their commonly observed video contents were personal or anecdotal experiences (44%) followed by educational/informative content (38%). In addition to their report, we have observed that individual users uploaded over 50% of all the videos on SUDEP. The individual users commonly provided personal experience or tribute type of content. These were the videos, which received the highest number of comments (77.85%) indicating the highest viewer responses. The comments were mainly empathetic and personal encounters or anecdotal. A higher number of empathetic comments to these videos suggest a positive understanding and awareness about the condition. This is encouraging to the video uploaders, especially for individuals who are seeking support or empathy from the viewers who have shared a similar experience. It remains challenging to know clear intentions and expectations of the individual uploaders. However, a higher viewer engagement is probably encouraging for those who advocate educating and disseminating information about the tragic effects of SUDEP due to their previous experiences. There were few videos that provoked negative comments during the video content (7%), which probably were either due to lack of knowledge about epilepsy and SUDEP or due to poor content provided by the video uploaders. The activist group generated videos encompassed all types of videos content compared with those of the rest of the sources; individual generated videos lacked educational/scientific content, whereas professional society generated videos lacked personal, tribute, or SUDEP awareness-event related content. Videos uploaded by scientific societies and activist groups consisted mainly of advertisements and educational/scientific videos, which were technically informative about SUDEP, however lacking the viewer engagement as evidenced by the minimal corresponding viewer comments. In addition, the videos uploaded by the professional societies are more recent compared with the individual user videos. This could in part be contributing to a lower viewer engagement as noted in our analysis. The time to capture comments/engagement might have been insufficient.

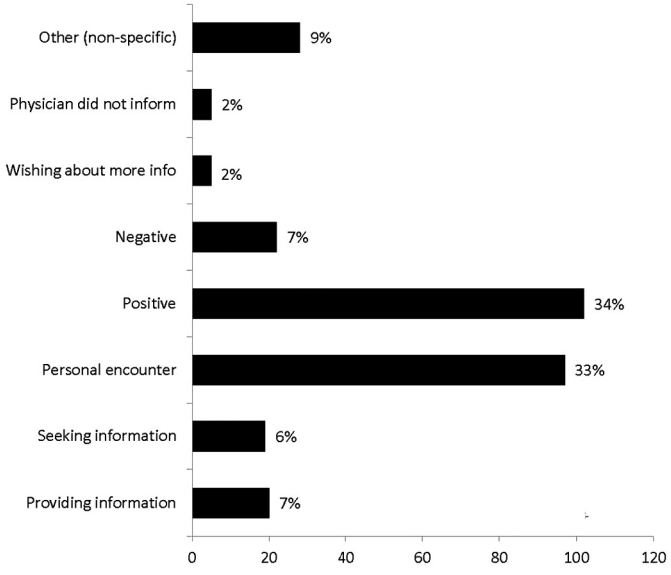

Fig. 2. Distribution based on the type of comments.

There are a few limitations in our study, which need to be acknowledged. Many videos have been excluded based on inclusion and exclusion criteria, which might have limited a significant number of videos. The videos that are not viewed at least 100 times are also usually the ones, which are not popular among the viewers and least commented. The view counts and the comments on YouTube are dynamic and ever changing. There are multiple videos uploaded on YouTube on a daily basis, which makes similar studies and analyses difficult to be repeated. Additionally, different terminology could have been used by video uploaders including “sudden *unexplained* death in epilepsy” instead of “sudden *unexpected* death in epilepsy” that could have potentially resulted in capturing those videos in our analysis. The majority of the comments received from viewer engagement are clustered to a subset of videos, mostly uploaded by the individual users. Thus, acknowledging the relative lack of comments to rest of the videos needs further consideration.

5. Conclusion

Our study underscores the utility of YouTube in raising awareness of SUDEP. It is a cost-effective method that can be tapped further to reach a larger community of people around the globe. Sudden unexpected death in epilepsy demands extensive attention and awareness in the society. The professional societies and activist groups may have to consider utilizing YouTube to enhance and appraise the SUDEP awareness programs. Uploading videos consisting of scientific information in addition to personal/anecdotal experiences might improve overall viewer engagement and SUDEP awareness.

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Disclosures of conflicts of interest

The authors have no conflicts of Interest.

Ethical publication statement

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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