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Brief Communication

Pins and PNES: Systematic content analysis of Pinterest for information on psychogenic nonepileptic seizures (PNES)☆

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ABSTRACT

Pinterest is a visual search based, the fourth largest social networking site in the U.S. with 81% of its users being women. Because of Pinterest's popularity and the high incidence of psychogenic nonepileptic seizures (PNES) among women, the aim of our current study was to perform a thorough content analysis of information available about PNES on Pinterest. The systematic search of Pinterest using various PNES related keywords revealed 57 unique pins. This was followed by content analysis by two independent reviewers. Most (87.7%) pins included in the final analysis reported at least one factor indicative of PNES. Most common were the consistent association of PNES with emotional triggers (61.4%), history of current or remote abuse (57.9%), and seizure's unresponsiveness to antiepileptic drugs (38.6%). Semiology of PNES was reported in 77.2% pins and two-thirds (66.6%) mentioned diagnostic procedures. Psychogenic nonepileptic seizure treatment and prognosis were reported in 68.4% and 56.1% pins, respectively. Around one-third of pins were from academic resources. More than 80% of pins targeted lay people with the primary aim of education and awareness and used a neutral or positive tone. To our knowledge, even though most pins have scientifically sound information, this widely popular web-based resource seems to be underutilized by academia, healthcare workers, and stakeholders for the dissemination of awareness about PNES.

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1. Introduction

Psychogenic nonepileptic seizures (PNES) are paroxysmal behavioral changes which clinically resemble epileptic seizures (ES) but lack the associated sudden, abnormal electrical activity in the brain. Recent estimates by International League Against Epilepsy (ILAE) PNES task force suggest its prevalence to be approximately 1/10 of that of epilepsy [1]. A higher preponderance of PNES among adult women is well established and they outnumber men in diagnosis by a ratio of 3:1 [2]. Several studies have estimated a significant delay in the diagnosis of PNES, ranging from 5 to 7 years [3,4]. It has also been noted that patients diagnosed as having PNES tend to disengage from medical services after the diagnosis is established [1]. The internet, including social media, is a popular and common means of communicating health information, and more than half of adult patient report searching the internet for health information [5,6]. Therefore, it can easily be construed that patients with PNES disengaged from medical service may turn to the internet for their health information needs.

A majority of patients with PNES socialize daily on the internet [7]. Previous research has looked into the online representation of PNES on platforms like Google®, Twitter®, YouTube®, and Instagram® [8]. However, Pinterest®, the fourth largest online social media platform as per the 2018 Pew Research Center analysis [9], has not been analyzed for the available PNES related information. This analysis is critical because 82% of Pinterest® users are women [10] and more than 40% of all women on the internet use it [9]. Pinterest is a visually oriented, social media platform. Users "pin" (i.e., post) pictures and save them to their "board" (i.e., typically a collection of related posts, organized by a theme, and tailored to specific interests). People can use hashtags or keywords to search pins and boards created by others, as well as save pins or entire boards. This community-style sharing of pins facilitates the creation and identification of subcultures, hobbies, and interests. Because of Pinterest's popularity and PNES's high incidence among women, the aim of our current study was to perform a systematic content analysis of information available about PNES on Pinterest.

2. Material and methods

We systematically mined Pinterest using various keywords including "psychogenic non(-)epileptic seizures", "PNES", "non(-)epileptic attack disorder", "NEAD", "psychogenic attack(s)", "non(-)epileptic attack(s)", "psychogenic non(-)epileptic attack(s)", "pseudo(-)seizure(s)", "non(-)epileptic seizure(s)", "non(-)epileptic event(s)", "stress seizure",

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"dissociative seizure", and "psychogenic seizure(s)". These search terms were informed by prior research revealing most commonly used terms to describe PNES on Google and in PubMed [8,11]. This search was performed from 07/10/18 to 07/18/18. Pins with unrelated or nonpertinent information about PNES or pins with not enough material for content analysis were discarded. Pins with information relevant to PNES were then arranged into various boards, titled based on the search term, in Pinterest. This was followed by the identification of duplicate pins, which were excluded from the final analysis. The pins included in the final analysis were independently reviewed by two reviewers (AD, TF) for the content of information about PNES. Pins were classified into ones containing static image or links to videos. Certain cases of disagreement were discussed thoroughly and were rectified by mutual agreement. The information available in pins was analyzed based on clinical information about PNES (factors indicative of PNES diagnosis, semiology of PNES, diagnostic methods, treatment, prognosis), the provider and origin of the pins, their tone (neutral/unclear, positive, negative), and purpose (clinical, educational, and advocacy) (Table 1). Categorical variables are described using absolute numbers and percentages.

Table 1
Content analysis of pins.

Variables analyzed	Number of pins (n = 57) (%)
1. Factors indicative of PNES	50 (87.7)
A) Anti-epileptic drug (AED) do not impact seizures	23 (40.4)
B) Events are consistently associated with specific emotional or environmental triggers	34 (59.6)
C) Presence of witness(es) (e.g., family members, hospital/clinic lobby, classroom) at the time of an event	3 (5.2)
D) History of (H/O) chronic pain, fibromyalgia, chronic fatigue syndrome	14 (24.6)
E) H/O comorbid psychiatric illness, personality disorder, or substance abuse	33 (57.9)
F) H/O remote or current abuse or trauma	18 (31.6)
G) Presence of repeatedly normal EEGs in presence of recurrent seizures	22 (38.6)
2. Semiology	44 (77.2)
A) Gradual onset	6 (10.5)
B) Rapid postictal reorientation	7 (12.3)
C) Undulating motor activity	36 (64.9)
D) Side to side head shaking	12 (21.1)
E) Closed eyelids during event	6 (10.5)
F) Event lasting >2 min	11 (19.3)
G) Resisted eyelid opening	9 (16)
H) Lack of cyanosis	1 (1.6)
I) Partial responsiveness during ictus	14 (25.6)
J) Pelvic thrusting	9 (15.8)
3. Diagnosis	38 (66.6)
A) Video electroencephalography (VEEG)	32 (56.1)
B) Psychiatric diagnostic evaluation with psychological assessment	21 (36.8)
4. Treatment	39 (68.4)
A) Psychological therapy (CBT)	34 (59.6)
B) Multidisciplinary care	27 (47.4)
5. Prognosis	32 (56.1)
6. Source	
A) Academic sources (lectures/scholarly articles)	21 (36.8)
B) Internet (videos, blogs, news etc.)	36 (63.2)
7. Purpose	
A) Clinical	11 (19)
B) Educational	48 (84.2)
C) Advocacy	4 (7)
8. Target	
A) Physician	10 (17.5)
B) Medical/nursing student	1 (1.8)
C) Lay people	50 (87.7)
9. Tone	
A) Neutral/unclear	18 (31.6)
B) Positive	28 (49.1)
C) Negative	11 (19.3)

3. Results

The systematic search returned a total of 3916 pins. After applying exclusion criteria, only 57 (1.5%) unique pins were included in the final analysis (Supplement Fig. 1). A total of 20 (35.1%) pins provided links to videos and rest were static images. Among the pins analyzed, 87.7% pins reported at least one factor indicative of PNES. Most common were the consistent association of PNES with emotional triggers (59.6%), history of current or remote abuse (57.9%), and seizure unresponsiveness to antiepileptic drugs (40.4%). Signs and symptoms of PNES were reported in 77.2% pins with undulating motor activity being the only semiological feature reported in more than 50% of pins. Side to side head shaking during PNES was reported in 12 (21.1%) pins and pelvic thrusting mentioned in 9 (15.8%) pins. Two-thirds (66.6%) of pins mentioned diagnostic procedures, including video electroencephalographic (EEG) monitoring in 56.1% of pins. Psychogenic nonepileptic seizure treatment and prognosis were reported in 68.4% and 56.1% pins, respectively.

Close to two-thirds (63.2%) of pins originated from internet sources while the rest were from academic lectures or scholarly articles etc. A large majority of pins (87.7%) were targeted towards lay people and the primary purpose of 94.2% of them was educational or to increase awareness about PNES. The tone of 80.6% pins was neutral or positive. A total of 6 (10.5%) pins were found to have some inaccurate information about PNES. A representative sample of PNES related pins is shown in Fig. 1. Detailed content analysis of the pins is shown in Table 1.

4. Discussion

The unique pins regarding PNES on Pinterest, which account for a very small percentage of all the pins pulled using our extensive search strategy, are overwhelmingly accurate and highly informative. Many emphasize the psychological underpinning of PNES and discuss the emotional triggers as associated factors. An overwhelming majority convey the information in a positive to neutral tone. The critical role of video-EEG monitoring in the diagnosis of PNES and subsequent role of cognitive behavioral therapy (CBT) in management of PNES [12] are also reported in more than 50% of the pins. This suggests that pertinent pins disseminate information grounded in scientific facts. This is similar to the analysis of status epilepticus related pins on Pinterest [13]. The primary purpose of the pins was educational and for spreading awareness about PNES. In comparison, advocacy for PNES was espoused by less than 10% of pins. Given the stigma associated with PNES faced by close to 90% of patients suffering PNES [14], the dearth of pins advocating for PNES represents an avenue that deserves more attention. Most of the pins originated from other internet-based resources like blogs, video etc. while academic sources contributed only one-third (36.8%) of the pins. In comparison, around 55% of pins related to status epilepticus could be traced back to academic sources [13]. This may be suggestive of lack of a motivated involvement of academic institutions on social media in the field of PNES.

Several studies analyzing the financial impact of PNES have found that early diagnosis and proper communication of the nature of the disease lead to significant reduction in healthcare utilization [15,16]. A critical part of effective communication is increasing the awareness about the condition. With the ubiquity of the internet in modern day life, there needs to be a concerted effort to engage patients online. Various online platforms like Twitter®, YouTube®, and Instagram® have already been shown to carry accurate information provided by professional sites [8]. The above referenced study by Myers et al. has also shown that internet content provided by patients serves to engage them in a 'peer to peer' expression of personal opinion about PNES [8]. The visually oriented, interactive format of Pinterest can be one such medium of information dissemination and patient engagement. Its use in medical and nursing education has already been described [17]. Being a dominant social media leader [9], with 4 out of 5 users being

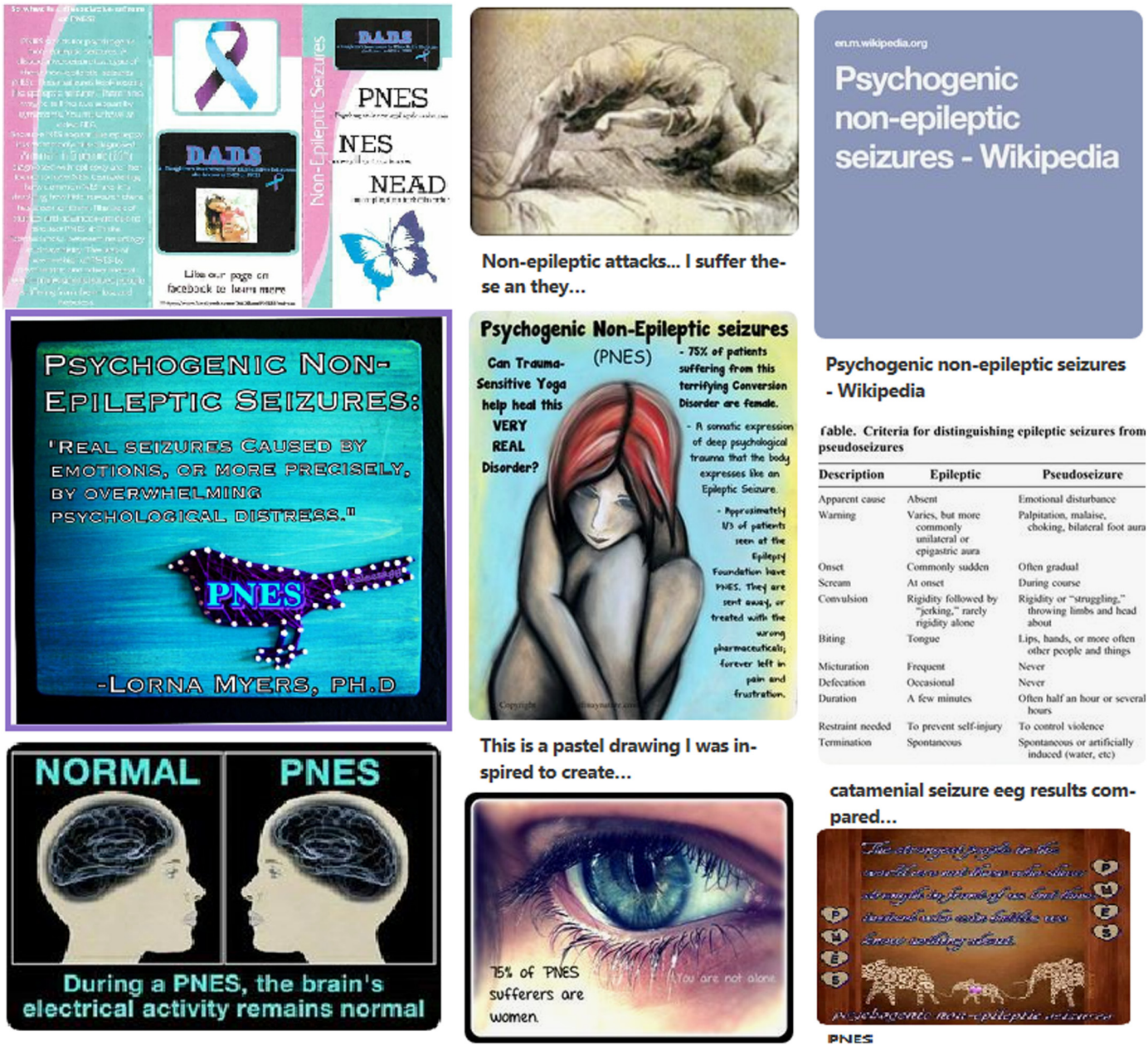

Fig. 1. Representative pins related to PNES on Pinterest. These pins were considered representative sample as they highlight various degrees of information generally available on Pinterest about PNES, from both patients and professionals.

women [10], Pinterest has the potential to reach out to a population that is at significantly high risk or already suffering from PNES.

A thorough systematic search of Pinterest to mine PNES related pins and the thorough content analysis are the major strength of our study. However, we did not investigate the measures of public engagement like comments or 're-pins' (sharing). Future studies of social media and PNES interplay should explore measures of such public interactions and engagement with online resources.

5. Conclusion

Psychogenic nonepileptic seizure-related information on Pinterest, although scant, is very informative. Pinterest represents a tremendous visually engaging online social resource. However, it is currently underutilized for information dissemination on PNES, especially by academia and advocacy groups. Future research should investigate the online engagement within social networks like Pinterest and its impact on patients with PNES.

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2019.01.020.

Conflicts of interest

Authors have no conflict of interest to disclose.

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