EPILEPSY CURRENTS

Current Literature
in Clinical Science

Perceptions in PNES: A Bidirectional Problem

Epilepsy Currents
2019, Vol. 19(1) 31-32
© The Author(s) 2019
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1535759718823798
journals.sagepub.com/home/epi
SAGE

Health Care Practitioners' Perceptions of Psychogenic Nonepileptic Seizures: A Systematic Review of Qualitative and Quantitative Studies

Rawlings GH, Reuber M. *Epilepsia*. 2018;59(6):1109-1123. doi:10.1111/epi.14189. Epub 2018 May 11.

A recent systematic synthesis of qualitative research demonstrated that patients with psychogenic nonepileptic seizures (PNES) often experience unsatisfactory encounters with health-care practitioners (HCPs). It is important to understand such interactions from the perspective of those responsible for delivering care. This systematic review aimed to examine the attitudes and perceptions of HCPs toward PNES. A systematic search of 3 databases (Web of Science, PubMed, and CINAHL) was conducted in November 2017. Studies from around the world published after 1997 using qualitative or quantitative methodologies were reviewed. An interpretative stance was taken to analyze the data utilizing a grounded theory approach. The quality of studies included was assessed using the Mixed Methods Appraisal Tool. Overall, 30 separate studies capturing the views of at least 3900 professionals were included. Five concepts emerged from the analysis: (1) HCPs' responses demonstrated uncertainty about many aspects of PNES, including diagnosis and treatment; (2) HCPs understood PNES in dualistic terms, perceiving the condition as largely associated with psychological factors; (3) patients with PNES were considered challenging and frustrating; (4) HCPs held mixed or contested views about who is responsible for treating patients with PNES; and (5) PNES was viewed as less severe or disabling than epilepsy and associated with a greater degree of volition. Although some HCPs have an excellent understanding of PNES, the views of many give rise to concern. The number of qualitative studies that directly ask HCPs about their perceptions of PNES is limited. Moreover, some professional groups (ie, mental health specialists) are underrepresented in current research. This study reveals a demand for additional training. However, effort is needed also to change the attitudes of some practitioners toward PNES.

Commentary

One of the most important contributors to patient outcomes is the doctor–patient relationship, which is particularly pertinent for patients with somatic symptom and related disorders.[1] Psychogenic nonepileptic seizures (PNES) are the commonest form of functional neurologic disorder, a type of somatic symptom disorder quite prevalent in neurology outpatient visits.[2] The development of a therapeutic health-care provider (HCP)–patient alliance (which emphasizes patient and HCP working together toward a common, mutually agreed goal) is based on trust, communication, and mutual respect, and is likely the key reason for adherence to treatment and maintenance of the connection between patients and their clinical providers.[3,4] When this relationship is not established, or breaks down, there is often dissatisfaction on the part of both patients and HCPs, an increase in medical utilization, an increased risk of medico-legal issues and a decline in positive outcomes for patients.[5] Outcomes for PNES are generally poor and are often blamed on patients rejecting psychiatric care, disagreeing with the diagnosis, or invested in the conscious or unconscious motivation to remain out of work. When queried about the reason for not following up with recommended treatments, patients may mention that their interactions with the providers were poor and they felt they were not listened to or not believed.[6]

There is interesting work emerging from the study of qualitative communication patterns between patients and HCPs showing distinct patterns between PNES and epilepsy.[7,8] In addition, conversations between HCPs and patients with PNES can involve language that inadvertently distances or even alienates patients, with words revealing HCP beliefs or biases[9] such as telling patients they don't have "real seizures," "everything is normal," or that "nothing is wrong" despite the patient feeling physically quite unwell and unable to function. Studies also show that physicians use ambiguous words within their notes that imply a less than certain diagnosis which can lead patients to search for more opinions.[10] Treatments are emerging for PNES, but recent data reveal lack of adherence to treatment as a major problem in PNES.[11] Given the importance of the clinician–patient relationship, investigations targeting HCP attitudes may help to mitigate treatment adherence obstacles and lead to improved outcomes.

Rawlings and Reuber[12] performed a systematic review using a mixed methods design to try to understand the perceptions and attitudes of HCPs when approaching PNES patients. They selected 30 studies including approximately 3900 professionals, uncovering 5 main themes from their qualitative methods: (1) uncertainty with diagnosis and treatment, (2) understanding the disorder as a mind versus body or "dualistic" problem, (3) PNES patients are challenging/frustrating/difficult, (4) there are mixed/contested views on which HCP should follow these patients, and (5) PNES are less disabling/more volitional than epileptic seizures. There were limitations to this study in that those HCPs who were included/sampled were more likely subspecialists from wealthier countries and less likely to be mental health specialists. However, these themes have clear face validity and may provide insight into reasons for the poor outcomes.

There are several unanswered questions that arise from this research. Are HCPs' negative attitudes part of the reason for the poor outcomes? Is there a reliable and effective way to change physician and patient attitudes and improve communication with patients? What is the best way to help make HCPs more comfortable (and skillful) with difficult conversations? Clinician-related factors making management of PNES patients challenging have been outlined before.[13] A therapeutic alliance is based on a bidirectional transaction: if both parties mistrust each other, and there is no alliance established, and thus there is no possible beneficial outcome.

Beliefs and attitudes are difficult to change, but research into effective methods may lead to new and fruitful ways to improve outcomes. It is clear that specific training to improve the care of PNES patients is warranted and must begin with the true desire to heal and understand how to develop mutual trust between patients and their HCPs. Patients with PNES must be guided to treatment, rather than being told they do not need a neurologist or, even worse, insinuating that they "don't have a real illness." When such a positive shift begins to happen, clinicians will be less worried about dismissing these challenging patients and more about engaging them in treatments proven to work for this disorder. The assumption that nothing is wrong with the brain in PNES is beginning to be proven incorrect through functional imaging studies: PNES is a true brain disorder. Changing HCP attitudes and approach to PNES patients will likely be accomplished only through education, training, practice, and assessment; it will also likely entail convincing neurologists and other HCPs that there are brain mechanisms responsible for affective processing and development of functional neurological symptoms whether or not there is a convincing abnormality on brain magnetic resonance imaging. The role of HCP perceptions in PNES outcomes should be investigated and the therapeutic nature of clinician–patient relationship targeted for potential treatments. While clinicians are not wholly responsible for poor outcomes in PNES, any contribution from negative HCP interactions should be eliminated.

By Barbara Dworetzky

References

1. Jackson JL, Kroenke K. The effect of unmet expectations among adults presenting with physical symptoms. *Ann Intern Med*. 2001; 134(9 Pt 2):889-897.
2. Stone J, Carson A, Duncan R, et al. Symptoms 'unexplained by organic disease' in 1144 new neurology out-patients: how often does the diagnosis change at follow-up. *Brain*. 2009;132(Pt 10): 2878-2888.
3. Salazar-Fraile J, Sempere-Verdu E, Perez-Hoyos S, Tabares-Seisdedos R, Gomez-Beneyto M. Five interpersonal factors are predictive of the response to treatment of major depression with antidepressants in primary care. *Front Psychiatry*. 2018;9:416.
4. McCabe R, Healey PGT. Miscommunication in doctor-patient communication. *Top Cog Sci*. 2018:10(2);409-424.
5. Bertakis KD, Azari R. Patient-centered care is associated with decreased health care utilization. *J Am Board Fam Med*. 2011; 24(3):229-239.
6. Martiros M, Myers L. *In Our Own Words: Stories of Those Living With, Learning From and Overcoming The Challenges of Psychogenic Non-Epileptic Seizures (PNES)*. Scotts Valley, CA: CreateSpace Independent Publishing Platform; 2015.
7. Rawlings GH, Brown I, Reuber M. Narrative analysis of written accounts about living with epileptic or psychogenic nonepileptic seizures. *Seizure*. 2018;62:59-65.
8. Plug L, Sharrack M, Reuber M. Seizure metaphors differ in patients' accounts of epileptic and psychogenic non-epileptic seizures. *Epilepsia*. 2009;50(5):994-1000.
9. Dworetzky BA. What are we communicating when we present the diagnosis of psychogenic nonepileptic seizures. *Epilepsy Curr*. 2015;15(6):353-357.
10. Altalib HH, Elzamamy K, Pugh MJ, et al. Communicating diagnostic certainty in psychogenic nonepileptic seizures—a national study of provider documentation. *Epilepsy and Behav*. 2016;64(Pt A):4-8.
11. Tolchin B, Dworetzky BA, Baslet G. Long-term adherence with psychiatric treatment among patients with psychogenic nonepileptic seizures. *Epilepsia*. 2018;59(1):e18-e22.
12. Rawlings GH, Reuber M. Health care practitioners' perceptions of psychogenic nonepileptic seizures: a systematic review of qualitative and quantitative studies. *Epilepsia*. 2018;59(6): 1109-1123.
13. Baslet G, Seshadri A, Bermeo-Ovalle A, Willment K, Myers L. Psychogenic nonepileptic seizures: an updated primer. *Psychosomatics*. 2016;57(1):1-17.