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The psychosocial effects of psychogenic non-epileptic seizures (PNES)

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What are Psychogenic Non-epileptic Seizures?

A recent research study conducted by Flinders University explores the experience of a disability which is both hidden and lacks physiological ‘evidence’; a condition which is not understood by health professionals, and results in individuals feeling confused and isolated. Psychogenic non-epileptic seizures (PNES) (also called pseudoseizures) are events resembling epileptic seizures, which are not associated with ictal electrical discharges in the brain but by psychological processes.

PNES may be triggered by anxiety, psychological tension and heightened defence against intense emotions. In some cases PNES may be a result of psychological trauma, previous psychiatric history, physical and sexual abuse or posttraumatic stress disorder (Fizman, Alves-Leon, Nunes, Dandrea, & Figueira, 2004).

Health professionals often overlook PNES due to the common misconception that they are “fake” (Benbadis, 2005) or are categorized as a “non-disease” (i.e. not epilepsy) (Bodde, et al., 2009). However, this is a very real condition, with considerable psychosocial implications. People diagnosed with PNES feel anger, shame, helplessness, and experience suicidal ideation (thinking about suicide with some intent but without actually making plans to commit suicide) (Thompson, Isaac, Rowse, Tooth, & Reuber, 2009). Stigma is often attached with this label, fuelled by poor understanding and little education and support following diagnosis (Benbadis, 2010).

One complicating factor is that an individual may experience both PNES and epileptic seizures. 15% of people with diagnosed PNES also have epilepsy

(Benbadis, 2010), and it is estimated that 10 to 50% of individuals with “intractable seizures” (seizures not adequately controlled by AEDs) have either lone PNES or a combination of epileptic seizures and PNES (LaFrance, et al., 2006). Co-morbidity can cause significant diagnostic and management issues, with health professionals often unable to accurately identify the cause of seizures, and thereby communicate and manage them appropriately. The current study aimed to further explore the psychosocial effects of PNES and their implications for the development of appropriate multidisciplinary support and management strategies.

Research Study

Four participants fulfilling selection criteria were recruited through the Epilepsy Association of SA and NT¹. Data was collected through medical records and documentation, interviews, and completion of the Washington Psychosocial Seizure inventory (WPSI) (Dodrill, et al., 1980) by participants with PNES, their significant others and Epilepsy Counsellors.

Semi-structured interviews were conducted with participants, their nominated significant other and Epilepsy Counsellor to gather information on the participant’s experience of PNES, including their:

- experience of seizures,
- diagnosis,
- living situation,
- social, recreational and vocational activities, and
- interventions and support received.

Interviews were recorded, transcribed and a thematic analysis conducted.

¹Ethical approval for this study was granted by Flinders University’s Social and Behavioural Research Ethics Committee.

Table 1. Participant Profiles (*pseudonyms have been used to maintain confidentiality)

Participant Information	Chelsea*	Jason*	Julia*	Eric*
Age	23	23	33	40
Diagnosis	PNES	PNES	PNES	PNES, Epilepsy
Age at diagnosis of PNES	22	21	32	39
Time from onset of seizures to diagnosis of PNES	11 months	5 years	3 years	11 months
Current seizures	-	-	-	PNES, Epilepsy
Medications	-	-	-	PHT, SV, DIA, LEV
Employment status	Employed	Unemployed	Employed	Unemployed
Relationship status	Relationship	Relationship	Married	Single
Transport	License	L Plates	License	No License

It should be noted that Chelsea, Julia and Jason were no longer experiencing PNES at the time of data collection, and were no longer taking anti-epileptic drugs (AED's). It was evident throughout interviews conducted with participants that the psychosocial implications of their PNES changed dramatically according to seizure frequency and the intake of AED's.

Psychosocial Effects of PNES

Impact of misdiagnosis

Chelsea, Jason and Julia were initially misdiagnosed with epilepsy, and took AED's until their diagnosis of PNES (mean of 2.64 years later). They felt medical professionals were continually increasing their medication doses, rather than seeking other management approaches.

Julia: "they were just upping my drugs and changing my drugs and giving me more drugs.. And at the end of the day, the medication was probably making me more sick than anything else."

Jason: "Like when I asked for help and that.. he was oh yea try these pills.. yea try these ones.. have these ones.. here have these different ones.. try both of them at once!.. didn't try anything but medication. Like they didn't class it as anything else (but epilepsy)."

There was a feeling of helplessness among participants; not being able to find answers and feeling out of control. This has been noted in previous studies in which participants felt overpowered by their PNES and remained passive and helpless (Thompson, et al., 2009).

Participants also experienced severe side effects which they believed were associated with the AED's, including depression, weight gain, aggression, drowsiness, effects on memory and concentration, and suicide attempts. Chelsea and Julia both attempted suicide more than once, and Jason has often spoken of it. According to Kaufman and Struck (2010), individuals with PNES have an increased risk for suicide/

suicide ideation compared with the general population. No studies have been identified which explore the rate and cause of suicide among this population and possible connections with AED intake.

Receiving a diagnosis of PNES

The diagnosis of PNES can be a double-edged sword, with participants experiencing enormous relief, but also anger and frustration relating to their misdiagnosis and associated side effects of AEDs. Julia and Eric reported a sense of abandonment from neurologists who gave them the diagnosis. Other studies report similar findings, where participants felt the shift from the diagnosis of epilepsy to PNES was accompanied by a transfer of responsibility from health professional to themselves (Karterud, Knizek, & Nakken, 2010).

Julia: "he (neurologist) just told me that it was in my head... and... that it is probably stress and I need to go talk to someone about it."

Eric: "they said that I had pseudoseizures and they can't do nothing for them."

None of the participants in this study felt they received adequate information regarding PNES following the diagnosis; receiving only limited verbal information and no written information. There has been little research on what information is conveyed to individuals with PNES and how this influences the way they perceive their diagnosis. However, the issue of communicating the diagnosis of PNES has attracted considerable interest (Harden, 2001; Shen, Bowman,

& Markand, 1990; Thompson, Osorio, & Hunter, 2005). Farias, Thieman, and Alsaadi (2003) found that, in most cases, a detailed explanation of the PNES diagnosis to the individual reduced the frequency of subsequent non-epileptic seizures. This was seen in the cases of Chelsea, Jason and Julia, who all stopped experiencing seizures since receiving a change of diagnosis from epilepsy to PNES.

Social experiences

The social lives of participants were severely impacted by their experience of PNES, due to high seizure frequency and negative side effects of AEDs. Julia withdrew from her social circle, Chelsea and Jason felt abandoned by friends, and Eric felt people avoided him because of his seizures. Chelsea and Julia also avoided social situations in fear of not knowing when they were going to have a seizure, and felt friends didn't want to go out with them because of this. This is in consensus with research conducted by Carton, Thompson and Duncan (2003), in which individuals with PNES reported social isolation and increased anxiety when engaging in everyday activities.

Participants from this study also reported difficulty describing their diagnosis of PNES to others, and often felt their explanation was received with scepticism. This may reflect both their limited understanding of this diagnosis and the lack of education in the wider community. The sense that the legitimacy of their seizures and their psychological wellbeing was being scrutinized made participants feel socially uncomfortable.

Julia's experience of PNES has severely impacted her ability to parent her 3 young children, aged 7, 11 and 13. When diagnosed with epilepsy and taking AEDs, Julia barely had the energy to provide adequate care for them. The impact of her PNES on her children was significant; they often witnessed her seizures and were required to call the ambulance on several occasions. She also struggled to provide for her family financially. She received no parenting support or psychological support for her children. The issue of parenting was not touched on by any of the literature concerning PNES, but this was highlighted as an area of major concern in the case of Julia.

Employment & education

All participants lost either paid employment or volunteer work due to their seizures. However, following cessation of seizures, Chelsea and Julia both regained employment. Jason and Eric both receive the disability support pension as their main source of income. Eric still experiences high seizure frequency and is not actively seeking employment. The literature similarly suggests that seizure cessation is a significant predictor of return to employment (Mayor, Howlett, Grünewald, & Reuber, 2010).

Jason also discontinued his chef apprenticeship due to his high frequency of seizures (when misdiagnosed with epilepsy) and Chelsea, who was looking to further her studies, did not do so until she had her seizures under control.

All participants were unable to drive during times when they were experiencing high seizure frequency, which also limited employment and social opportunities. This has had particular negative implications for Jason, who does not have easy access to public transport. He is currently studying for his driver's license so he can pursue further employment opportunities.

Conclusion

The following factors were considered influential in the management of PNES and improving quality of life of participants in this study:

- Receiving an accurate diagnosis of PNES and being withdrawn from AEDs
- Understanding the diagnosis of PNES and possible triggers
- Ability to access and/or accept psychological support
- Presence of family and friends who understand PNES and recognize it as a legitimate condition requiring treatment and support

According to this study, the most positive and influential factor was receiving an accurate diagnosis of PNES. Individuals with PNES need to be assured that their condition is legitimate, and need to feel understood. This is crucial not only for the management of seizures, but for the preservation of a positive self-perception.

The delay between seizure onset and PNES diagnosis needs to be minimized, followed by effective education and support to assist individuals and their families gain a greater understanding of PNES and manage their condition. Evidence suggests this increases confidence, social involvement and quality of life for this population.

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Epilepsy and the Workplace: A guide for workers and employers



This guide aims to provide an easy to read introduction to the legal issues relating to epilepsy and employment. It includes information for workers with epilepsy and employers on their rights and responsibilities in the workplace. It also explains the legal options available for people with epilepsy who feel they have been unfairly treated in employment matters.

The guide focuses on two main areas of the law workplace and anti-discrimination law. It then briefly discusses the emerging field of human rights law and the rights relevant to the workplace. In most of these areas the laws discussed apply throughout all of Australia. However, state and territory laws often operate concurrently and these may create additional legal rights and responsibilities. Also these different areas of law often overlap and interact with each other.

While this guide focuses on legal rights and remedies, this is not to suggest these are the only paths available to workers and employers dealing with epilepsy in the workplace. However, an understanding of legal rights and responsibilities encourages a more informed and fair workplace.

This guide has been prepared under the supervision of Jacinta Cummins and Cesira Costello of the Epilepsy Association of the ACT, an affiliate of Epilepsy Australia.



A copy of *Epilepsy and the Workplace: A guide for workers and employers* can be downloaded at www.epilepsyaustralia.net