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Understanding the experience of non-epileptic seizures in young people: A multi-perspectival qualitative analysis.

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MA Children and Young People's Mental Health.

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Declaration

- This dissertation does not include work accepted for any other degree or professional qualification

Signed……………………Alison Upstill…………………………… (Candidate)
Date…………………… 20th March 2025……………………………

- This dissertation has been completed and research carried out by me and is my work alone. However, other works have been referenced and can be found in the appended reference list.

Signed……………………Alison Upstill……………………………(Candidate)
Date………………………20th March 2025…………………………

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1.1 Research summary

Non-epileptic seizures, also known as psychogenic non-epileptic seizures (PNES) or functional seizures, can look like epilepsy or affect changes in behaviour, although there is no change in brainwave activity when a video-electroencephalogram (V-EEG) is carried out (Myers et al., 2022).This means that non-epileptic seizures are a physical response to psychological internal or external stress and are not epilepsy.

Half of the people who go to accident and emergency with a severe seizure are later diagnosed with non-epileptic seizures (NHS, 2017) and the most affected are females in late adolescence or early adulthood (Reuber & Brown, 2017). Non-epileptic seizures have a negative impact on many aspects of the person’s life including education, employment and relationships. A lot of stigma is attached to the disorder, diagnosis can take years and the social consequences far-reaching. Explanations and treatment are inconsistent due to healthcare professionals’ lack of knowledge of the disorder (Jennum, Ibsen & Kjellberg, 2019; Peacock et al., 2023).

There is limited research on non-epileptic seizures, and little is available on the experiences of young people between the age of 18-25 years from a multiple-perspective viewpoint and none in Wales, UK at all.

1.2 Applied research

A qualitative multi-perspective approach examined the experiences of non-epileptic seizures in young people, the perceptions of their parents, and the knowledge and understanding of professionals who work with them. Online semi-structured interviews took place, and transcriptions were analysed using thematic analysis.

A systematic literature review was carried out to investigate previous literature about non-epileptic seizures.

In conclusion, the experiences of young people and their parent/carers in this study echoed previous literature. The knowledge and understanding of the disorder by professionals working with young people in the health and well-being sector was limited and therefore support systems could not be adequately given.

1.3 Key findings

Themes developed from the interviews identified that young people and their families had inconsistent or no explanations of non-epileptic seizures. They educated themselves and then explained the disorder to educational staff and other health professionals.

All aspects of young peoples and their families' lives were negatively impacted by non-epileptic seizures including changes in work, isolation, inability to drive and additional mental health disorders including anxiety and depression.

Young people developed better understanding of themselves, and the family was their main support system. National Health Service care after diagnosis was inadequate leaving families to pay privately for therapy. Therapists had limited knowledge of the disorder. Young people’s teachers and lecturers were all accommodating and made adaptations to educational access although they had no knowledge of the disorder.

The professionals in this study all worked in the health and well-being sector. Four of the five professionals had little or no knowledge of non-epileptic seizures. There was little knowledge of first aid procedures for epilepsy and none for non-epileptic seizures, relying on the client to tell them what they needed. One professional could explain what non-epileptic seizures were but not the cause.

Further research is needed on non-epileptic seizures in Wales, UK. Psychoeducation is reported to be of value in the reduction of seizures after diagnosis and support groups improve well-being for young people.

Professionals working with young people in the health and well-being sector require training to improve knowledge and understanding of the disorder and therefore positive outcomes for young people.

Chapter two: Systematic Literature Review.

The experiences of Non-epileptic seizures in young people and professionals' interactions and understanding of these patients: A systematic literature review

2.1 Abstract

Aim: Exploring the experiences of those with non-epileptic seizures (NES) is essential in understanding the disorder to inform treatment and support systems. Therefore, the aim of this study was to review previous literature relating to patients' lived experiences of NES and healthcare professionals' understanding of the disorder.

Methods: Fifteen papers were identified for inclusion following searches in ProQuest Central, ScienceDirect, Elsevier, Sage Complete, Wiley Online and Directory of Open Access Journals. Search terms included non-epileptic seizures, functional seizures, psychogenic seizures and adolescent, young people (YP), parent and professional and qualitative.

Results: Due to the paucity of qualitative papers on the experiences of YP with NES and the knowledge and understanding of professionals, a broader search was required to include adults and children, parents, medical and healthcare professionals. Papers included five qualitative studies on the experiences of non-epileptic seizures in YP and adults plus parents' perspectives, two qualitative studies on school nurses and psychiatrists' experiences of YP with NES, six papers, the views of professionals with regards terminology, diagnosis and experience and two studies relating to the links between autism spectrum disorder and NES. Three superordinate themes emerged: Management and attitudes in education, knowledge and understanding of NES in health services and finally, terminology, ‘what should we call it?’

Conclusion: NES is a complex multifaceted disorder which impacts the patient’s life. Knowledge and understanding of the disorder is limited across the health sector and there is no multi-perspective research on the experiences of NES in young people, warranting further exploration of this area in order to inform future pathways to diagnosis, treatment and care.

2.2 Introduction

Psychogenic non-epileptic seizures (PNES), functional seizures (FS), non-epileptic seizures (NES), dissociative seizures (DS) and non-epileptic attack disorder (NEAD) are all one of many names given to a disorder, which in the *Diagnostic and Statistical Manual of Mental Health Disorders 5th Edition* (DSM-5) comes under conversion disorder (functional neurological symptom disorder) with attacks or seizures (F44.5) (American Psychiatric Association, 2013). This literature review shall use the term non-epileptic seizures (NES) purely to denote the non-organic nature of the disorder in relation to epilepsy and other brain disorders which have biological rather than psychological origins (Peacock et al., 2023).

NES are complex heterogenous events which may appear to look like epileptic seizures and can include changes to behaviour and awareness (Sawchuk, Buchhalter, & Senft, 2020; Anzellotti et al., 2020). However, on medical examination, these seizures do not occur with any abnormal electrical brain activity and diagnosis for the exclusion of epilepsy is confirmed after many typical electroencephalographs (EEG's) (Morgan & Buchhalter, 2015a) and normal video-electroencephalograph (v-EEG) (Deli et al., 2021).

Figures indicate 1 in 6 children and young people (YP) suffer with a diagnosable mental health disorder including NES, with a noticeable increase post Covid-19 pandemic (Welsh Government, 2024). Prevalence rates of NES have previously been noted at 2-33 per 100,000 (Benbadis et al, 2004). However, indications in epilepsy clinics perceive these rates to be higher with NES being diagnosed in 1 in 5 patients (Angus-Leppan, 2008). Additionally, half of patients arriving in emergency care with suspected serious epilepsy are later diagnosed as having NES (NHS, 2017). More recently, a study in Norway examined prevalence rates of NES between 2010-2019 and found it disturbingly high amongst 15–19-year-olds at 59.5/100,000 (Villagrán et al., 2021), however, no reliable data exists for YP, as too their outcomes (Appleton, 2022). Due to the difficulty in distinction between NES and epilepsy, many patients are misdiagnosed and receive subsequent iatrogenic treatments prior to a lengthy pathway to NES diagnosis (Anzellotit et al., 2021).

2.2.1 Aims

Therefore, the aim of this review is to;

Examine the literature relating to the experiences of those with NES.

Examine professionals’ interactions and understanding of these complex patients.

This review was informed by the ENTREQ Framework (Tong et al., 2012), as the aim is also to inform current practice.

2.3. Methodology

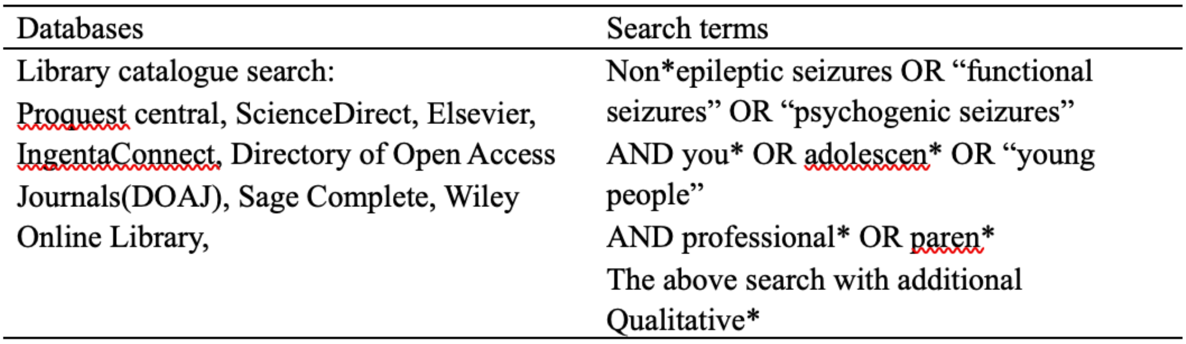
2.3.1 Literature search

The search process was carried out though The University of Wales Trinity Saint David (UWTSD) library catalogue. Databases included: Proquest Central, ScienceDirect, Elsevier, IngentaConnect, Directory of Open Access journals (DOAJ), Sage Complete and Wiley Online Library. Search terms included: non*epileptic seizures OR “functional seizures” OR “psychogenic seizures” AND any field containing: you* OR adolescen* OR “young people” AND any field containing: professional* OR paren*. An additional search was also carried out with the added “qualitative*” search term. The asterisk boolean code was added in the search terms to generate more results, such as parent or parents (see Table 2.1).

The purpose was to examine the qualitative literature relating to people’s lived experiences of having NES, additionally, the understanding by healthcare professionals such as nurses, psychiatrists, consultants and educational staff. Qualitative research enables a deeper understanding of a phenomenon through participant interaction by interviews, focus groups or questionnaires (Aspers and Corte, 2019). The objective was to examine whether patients’ lived experience of having non-epileptic seizures is indicative to a single pathway of diagnosis and care and whether those working with these people have the knowledge and understanding of the disorder in order to provide positive ongoing support.

Table 2.1

List of databases and search terms/keywords. Search was carried out July-August 2024.



Databases	Search terms
Library catalogue search: Proquest central, ScienceDirect, Elsevier, IngentaConnect, Directory of Open Access Journals(DOAJ), Sage Complete, Wiley Online Library,	Non*epileptic seizures OR “functional seizures” OR “psychogenic seizures” AND you* OR adolescen* OR “young people” AND professional* OR paren* The above search with additional Qualitative*

2.3.2 Inclusion and Exclusion (see Table 2.2)

Searches were refined to include only peer reviewed articles and terminologies, for example, Conversion Disorder and PNES. Potential studies were also searched manually in article reference lists. A time scale of 10 years between 2014 and 2024 was included to capture the most recent lived experience of people with NES, perceptions of parents and professionals' knowledge and understanding of non-epileptic seizures in a contemporary world. In total 15 articles were identified for analysis (n = 15) (see Table 2.4). Of these were: qualitative studies on the experiences of YP, their parents and adults (n = 5), qualitative research on school nurses and psychiatrists experience of nonepileptic seizures (n = 2), views of professionals with regards to terminology, diagnosis and experience of working with children and YP with non-epileptic seizures (n = 6) and articles specific to autistic YP with an additional diagnosis of non-epileptic seizures (n = 2). Due to the limited research data on the experiences of YP with non-epileptic seizures, four articles included YP and three were the experiences of adults (see Table 2). The term 'young people' includes a variant of ages from paper to paper. For the purpose of this review due to the lack of research available, young people means anyone between the age of 0 – 25 years.

Table 2.2

A List of Inclusion and exclusion criteria.

Inclusion	Exclusion
Articles involving young peoples lived experience of having non-epileptic seizures.	Patient experiences of a sole diagnosis of epilepsy.
Parents perspectives of caring for a child with non-epileptic seizures.	Learning problems and non-epileptic seizures.
Professionals experience of diagnosing, use of terminologies and caring for young people in the community.	
Timescale between 2014 -2024	
Including other terminologies for the same disorder: Conversion disorder, dissociative seizures, non-epileptic attack disorder, functional neurological disorder.	
In the English Language.	

2.4 Results

Table 2.3

A diagram showing the results of the literature search. Fifteen studies were included in this review.

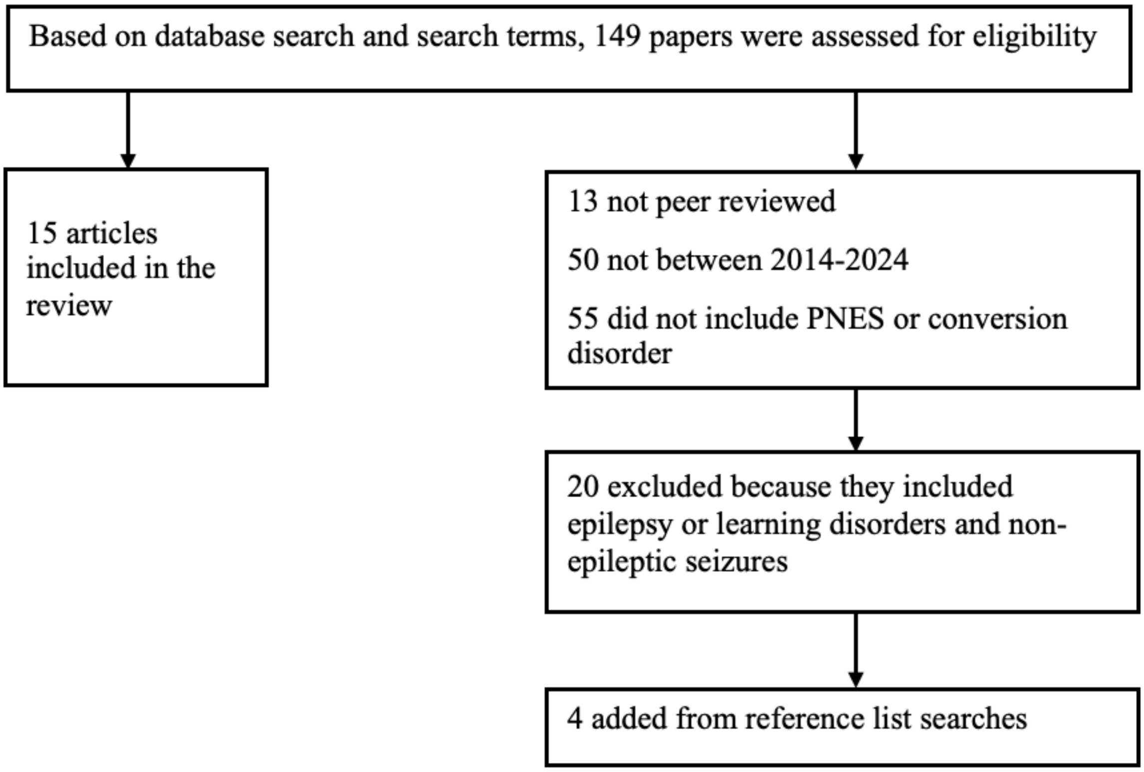


Table 2.4. List of the included papers (n=15)

Reference and country	Design and focus	Method, sample and setting (if relevant)	Key findings/ themes	Quality and comments
Cole et al.(2014). United States of America.	Analytical review of the ethical dilemmas facing clinicians when diagnosing paediatric and adolescent psychogenic nonepileptic seizures (PNES).	An ethical analysis of the challenges faced in four areas: 1. Conducting and communicating a diagnosis of PNES. 2. Advising patients about full transparency and disclosure to other members of their community and peers. 3. Responding to requests for continued antiepileptic drugs. 4. Managing challenges arising from school policy and procedure.	Even skilled clinicians struggle with ethical dilemmas faced when diagnosing PNES. Ethical values which should be accountable include trust, transparency, professionalism, confidentiality, Justice and the autonomy of all stake holders. Multi-disciplinary collaboration. Stigma and lack of resources mean that the needs of patients are not met.	This review is a brief overview of some of the ethical dilemmas faced by clinicians when communicating with young people and their parents. However, it does highlight the necessity of a timely diagnosis for the successful recovery of the young person and the early introduction of mental health specialists. It highlights the difficulty parents have in accepting that their child has mental health difficulty.

Doss. (2022) United States of America.	A retrospective chart review of individual and family psychiatric characteristics in youth with PNES using semi-structured clinical interviews.	62 youth aged 5-18 with a v-EEG diagnosis of PNES all of whom had been admitted to the paediatric epilepsy unit at the Children's Hospitals and Clinics of Minnesota between 2008-2019. Data collected included: prior psychological history, length, frequency and severity of PNES, family psychological history and medical history.	Parental awareness of their child's other related psychiatric symptoms was poor. Youths' difficulties with alexithymia could contribute to this. Seven families also reported a first-degree family member with conversion disorder. A significant number of first-degree family members also reported experiencing a psychiatric disorder historically such as anxiety and or depression. Functional nonepileptic attack(FNEA) was the most preferred term followed by dissociative and functional seizures.	A relatively small paper for a larger sample. Little in-depth description of methodology, however, interesting introduction to alexithymia and a parent having a mental health disorder.

Flewelling et al. (2020a). United States of America.	A study of children and young people with a diagnosis of PNES, a third of whom had a co-morbid diagnosis of epilepsy, measuring whether there are improvements or not in seizure frequency, school attendance, health related quality of life (HRQoL) and Emergency Department usage after psychoeducational interventions explaining their condition, development of response plans and behavioural management of seizures amongst others.	19 consecutive patient referrals from the Integrative Epilepsy Clinic (IEC) at the Children's Hospital Colorado between May 2015-August 2017, all of whom had a diagnosis of PNES after video-electroencephalography (v-EEG). Subjective and objective measures pre and post intervention included: Medical service utilisation from databases.	Re-measuring 6 months post intervention noted a decrease in seizures, significant decrease in frequency of visits to the ED and decrease in school absence. However, no significant difference in reporting of somatic complaints anxiety, social difficulties or depression and HRQoL although parent proxy-reporting of specifically depressive symptoms based on their perception had decreased.	A small sample size, however, positive to note that education, understanding and knowledge by both clinicians, patients and their families improves outcomes for children and young people with PNES. A larger study is required.

Flewelling et al. (2020b). United states of America.	Quantitative study of HRQoL in youth (8-18 years) with PNES and their parents'.	37 consecutive referrals to the Children's Hospital Colorado Integrated Epilepsy Clinic. All participants had a diagnosis of PNES by v-EEG. Measures included medical and demographic details, the Child Behaviour Checklist, the MASC-2, the CDI-2 and the PedsQL.	Parent proxy-reports of anxiety and depression are related to parent proxy-reports of HRQoL. Greater symptoms of PNES correlated to poorer functioning.	Similar research to Flewelling et al. (2020) using the same measures. A different sample. A positive consecutive method of measuring HRQoL. Also, noteworthy that parents perspectives of their child's mental health and concerns can often be different to the child's.

Jennum, Ibsen and Kjellberg. (2019). Denmark.	Quantitative evaluation of costs of patient care for those with PNES from 2011-2016 compared to controls for the same period. Focus to evaluate the direct and indirect costs of those with PNES.	The Danish National Patient Registry (NPR) allows access to patient traces of inpatient and outpatient care whilst all health sector costs for an individual are available from central databases.	PNES is associated with higher health, social and home care use costs and lower levels of income and employment than those with a diagnosis of epilepsy. Early intervention would reduce health related costs.	A valued study which could inform policy and understanding of PNES therefore improving the lives and possible recovery of those with the disorder.

Jordan et al. (2019). United Kingdom.	A qualitative study using thematic analysis to analyse semi structured interviews exploring psychiatrist’s perspectives of working with patients with dissociative seizures(DS) in the UK healthcare system as part of the CODES trial.	Participants were involved with the ‘cognitive behavioural therapy vs standardised medical care for adults with dissociative non-epileptic seizures’ (CODES). Of 29 selected, ten were then selected purposively to represent a geographical demographic across England.	Themes evolved included psychiatrists accounts of working with other healthcare professionals including GP’s, highlighting that they were not equipped or knowledgeable enough to deal with patients with DS often panicking and in the first instance prescribing antiepileptic drugs.	A small-scale study. Positive implications for professional training across healthcare services in DS.

Loewenberger et al. (2020). United Kingdom.	An online survey investigating the preferred terminology for functional seizures.	108 healthy participants were recruited by circular emails sent to university students from a range of disciplines. 87 provided data. Participants were aged between 18-25. Less than a third had heard of the disorder before. 8% either had the disorder or knew someone that did. eight different diagnostic terms for functional seizures were ranked in preference order (1 - most preferred, 8 – least preferred).	The least preferred were those with a derogative psychological connotation: pseudo seizure, psychogenic seizure and hysteria.	The results from this study suggest that the term FNEA or functional seizure should be used across the healthcare sector. However, this study does not include a large cohort of those with lived experience suggesting a further study including their views.

McWilliams et al.(2016). United Kingdom.	Qualitative research analysed using thematic analysis. Focus group and telephone interview design. A study of patient and family experiences of nonepileptic seizures.	All young people had received a diagnosis of conversion disorder and were under the Psychological Medicine Team (PMT) at Great Ormond Street Hospital (GOSH). Ten young people (0-19 years) with nonepileptic seizures and 29 family members were invited to attend semi structured focus groups or telephone interviews to discuss four main topic themes.	Question topics derived from literature and the research teams clinical experience. Prompts were added for further exploration. 1. Contact with health services. 2. Receiving the diagnosis. 3. Effects on education. 4. Coping mechanisms for events.	Qualitative research allows young people to have a voice. Key issues which arose were: isolation, stigma, disruption in family life and education. Understanding their disorder was important in aiding recovery. Teachers have insufficient knowledge of NES making it appear less of a diagnosis than epilepsy.

McWilliams et al. (2019). United Kingdom	Descriptive statistics used to describe key features of samples. A case series capturing the rates of Autism Spectrum Disorder (ASD) in 59 children and young people referred to GOSH specialist paediatric mental health services with non-epileptic seizures between 2012-2016.	Analysis of database where all children referred between the period had a diagnosis of NES and under the age of 18 (n = 59). Statistical testing used to compare ASD with non-ASD and presentation to the team of ASD with NES.	Of the 59 samples with NES, 10 (16.9%) had a diagnosis of ASD. 5/10 (50%) at the time did not, however, subsequently were diagnosed with ASD with appropriate diagnosing tools.	An informative study which highlights the increase in ASD diagnosis and that clinicians should be aware of comorbid ASD when diagnosing NES. NES possibly occurring after the psychological stress of living with undiagnosed or inadequately managed ASD.

Miyawaki et al. (2016). Japan.	A case study of a child with PNES and undiagnosed ASD.	A child with childhood epilepsy is admitted to the Pediatric Medical Center of Osaka City University Hospital with new and variable seizures after a period of distress in school due to isolation, bullying and communication difficulties. Compared with EEG, v-EEG confirmed there were no brain electrical charges. A diagnostic procedure was started for Autism and a diagnosis confirmed.	Treatment related to Autistic hypersensitivity such as ear defenders for sound and psychoeducation for PNES and the seizures decreased and eventually stopped.	There is little or no research into the comorbidity of ASD with PNES. A scaled research study is required to investigate this occurrence. There is little collaboration of clinician's expertise in either field.

Peacock et al. (2023). United Kingdom.	A small exploratory study exploring medicalisation and the search for legitimacy in people diagnosed with Non epileptic attack disorder (NEAD). The Free Association Narrative Interview (FANI) methodology was used with topics raised from literature.	5 participants were recruited from a single NHS centre. All had a diagnosis of NEAD confirmed by v-EEG, MRI to eradicate epilepsy or brain injury and EEG. Face to face interviews were carried out either in the hospital setting or in the participants' home.	Topic guides were used, and the FANI approach aimed to allow the narrative to be led by the participant. Narrative approaches enable the story to be viewed as something greater than what is seen, such as the social and political context. In this instance there is no organic medical reason for NEAD and therefore no place in society. A medical diagnosis allows legitimacy.	An informative paper, however small, on the legitimacy for a 'real' diagnosis. NEAD often occurs with other somatic symptoms and patients often feel 'othered', that there is no legitimate reason for their diagnosis. It can be difficult to believe that a psychological difficulty produces a physiological response.

Pretorius. (2016). South Africa.	Qualitative research analysed using thematic analysis. Carried out using semi structured interviews lasting approximately 60 minutes. This examined the subjective experiences of patients during the prolonged and complicated process of diagnosis for PNES, specifically barriers and facilitators.	An explorative qualitative design. Ten participants over the age of 18 all formally diagnosed with PNES through two hospitals, one private and one public, both with VEEG access.	Three main themes emerged with regard to barriers: inexpert healthcare providers, limited medical insurance and loss of independence. Facilitator emerging themes included: social support, comprehensive medical support and healthcare providers.	A small study sample. However, the author aims to raise awareness in South Africa as there is little expertise on PNES, Additionally to educate healthcare professionals and family and friends of those with PNES.

Rawlings et al. (2017). United Kingdom.	Cross-sectional qualitative research analysing the written accounts of living with PNES. Using thematic analysis of four pieces of writing covering 1) their thoughts and feelings about their condition. 2) a letter to their condition. 3) a letter to their younger self and 4) about a personal value.	19 participants over the age of 18 were recruited through membership led organisations for people with PNES and from an outpatient neurology clinic at Hallamshire Hospital Sheffield. Participants were asked to complete four booklets with the four topics and given a timescale of 20 minutes per topic.	Six main themes and 26 subthemes emerged. Main themes were: Living with PNES, emotions, seizure symptoms, treatment and outcomes, causation and development and lack of understanding. Examples of subthemes include: Isolation, loss, stigma, depression, fear, trauma, triggers and going into seizure.	A sample size of 19 participants all wrote about shared experiences covering topics already discussed in previous literature from people with PNES, including how debilitating it can be across their whole life.

Terry and Trott. (2019). United States of America.	A small-scale qualitative study using semi-structured interviews. Content analysis was used to analyse the data regarding school nurses experience caring for students with psychogenic nonepileptic events (PNEE).	School nurses (53-61 years) were recruited by email through Ohio Association of School Nurses. Nurses were included if they were currently working in schools, and they had experience with at least one student with PNEE. Ten nurses suited the inclusion criteria and were interviewed with open ended questions over the phone. Prompted as required.	Prior to their first experience with a student with PNEE, only one nurse had heard of the disorder before. Four themes identified: Lack of awareness, Inadequate information, feelings of doubt and insecurity, time consuming and additional barriers and facilitators.	An informative study understanding the challenges faced by school nurses including limited resources and training in PNEE. Nurses developed positive relations with students once they had an understanding. A major focus needs to be on the psychoeducation of school staff.

Tanner et al. (2022). United States of America.	Qualitative study using semi structured interviews analysed using content analysis in order to have a deeper understanding of the complexities of adolescents attending school with PNES.	Purposive sampling identified adolescents (12-19 years) with PNES. Informational flyers were distributed to adolescent caregivers via three gatekeeper groups: School nurses, mental healthcare providers and PNES social media groups.	Thematically derived themes analysed from the interviews bought up topics of bullying, 'faking it' by healthcare and school staff, feeling left out and school management. Comorbid stressors such as anxiety or depression also influenced their experience at school with PNES.	A qualitative study, listening to the voices of young people, who wish to be more in control of their own management of PNES in school. Not having a specific policy pathway to follow born out of a lack of understanding of the disorder also confounded difficulties at school.

2.4.1 Overview

All 15 articles met the criteria for this literature review. However, due to limited data on the experiences of YP with NES this review required a broader search in its investigation, hence the inclusion of parental perspectives and the knowledge and understanding of those professionals working with patients with NES including consultants, neurologists, primary healthcare professionals and educational staff.

Four studies utilised thematic analysis (Pretorius, 2016; McWilliams et al., 2016; Rawlings et al., 2017; Jordan et al., 2019) and two content analysis (Terry & Trott, 2019; Tanner et al., 2022). One study (Peacock et al., 2023) used the Free Association Narrative Interview approach with five women who had a diagnosis of NEAD. One study (Flewelling et al., 2020a) was an observational study on parent-proxy reporting and self-report measures of psychological functioning and Health Related Quality of Life (HRQoL) in 19 youths (9-17 years) pre and post-psychoeducational sessions for YP with PNES and their families, with recommendations for accommodations and response plans in their educational settings.

Two articles discussed the recent interest in Autism Spectrum Disorder (ASD) and the co-occurrence of PNES and NES in YP (Myawaki et al., 2016; McWilliams et al., 2019) whilst one author (Flewelling et al., 2020b), with a particular interest in HRQoL in YP with Psychogenic Non-epileptic Seizures, investigated the correlates of HRQoL with parent-proxy and self-reported symptoms of anxiety and depression in relation to seizure frequency, somatic complaints and social difficulties. Doss (2022) discussed the individual and family mental health characteristics of YP with PNES and whether this plays a part in the onset of their seizures. In relation to societal challenges for those with NES, one study examines the ethical dilemmas for clinicians when diagnosing and treating pediatrics and adolescents with PNES (Cole et al., 2014) while Jennum, Ibsen & Kjellberg (2019) investigate the welfare consequences in people diagnosed with NES both from an employability and benefits aspect.

Throughout this overview there is a noticeable difference in terminologies for NES; for example, Loewenburger et al. (2020) investigates the preferred terminology for FS in 87 healthy adults. This has been included in this literature review due to the historical confusion and medical difficulty in arriving at a single terminology for diagnosis.

Three key themes emerged. The first theme, ‘Management and Attitudes in Education’ was found across several papers (Cole et al., 2014; Flewelling et al., 2020a; McWilliams et al., 2019; McWilliams et al., 2016; Peacock et al., 2023; Tanner et al., 2022; Terry & Trott., 2019). Discussions involved YP’s experiences with NES with both negative and limited positive attitudes from school staff and inconsistent response plans for seizures due to lack of knowledge. The second theme, ‘Knowledge and Understanding of NES in health services’, was found in ten of the 15 papers (Cole et al., 2014; Jemmum, Ibsen & Kjellberg, 2019; Jordan et al., 2019; Loewenberger et al., 2020; ; McWilliams et al., 2016; Peacock et al., 2023; Pretorius, 2016; Rawlings et al., 2017; Tanner et al., 2022; Terry & Trott., 2019).

The third theme, Terminology, ‘what should we call ‘it?’ occurs across seven of the 15 papers (Cole et al., 2014; Jemmum, Ibsen & Kjellberg, 2019; Loewenberger et al., 2020;

McWilliams et al., 2019; McWilliams et al., 2016; Peacock et al., 2023; Tanner et al., 2022). where specific reference is made to the many differing terminologies for the same disorder and the contentious nature of the diagnostic process and treatment pathway.

Within themes one and two, four subthemes arose: Theme one, management and attitudes in education, included the subthemes: Inconsistent response plans and negative attitudes from school staff. Theme two, knowledge and understanding of NES in healthcare, included the subthemes: primary and secondary care (see Table 2.5).

Table 2.5 A summary of themes and subthemes to be discussed.

Themes/subthemes	Comments	Authors.
Main theme 1. Management and attitudes in education. Subtheme 1. Inconsistent response plans. Subtheme 2. Negative attitudes from staff.	Being in education causes a great deal of distress for young people with NES. Management and attitudes in education are discussed in seven of the papers. Highlighted are topics such as stigma, bullying, incorrect response plans, accusations of faking it, treated as if they have epilepsy and lack of collaboration between health and education.	(Tanner et al., 2022) (Flewelling et al., 2020a) (McWilliams et al., 2019) (McWilliams et al., 2016) (Cole et al., 2014) (Terry and Trott., 2019) (Miyawaki et al., 2016)
Main theme 2. Knowledge and understanding of non-epileptic seizures in the health sector. Subtheme 1. Primary health. Subtheme 2. Secondary health.	Ten of the fifteen papers highlight knowledge and understanding of NES as a consistent gap in health services both at primary and secondary levels. Not only are there inconsistencies in this area but a lack of a guiding pathway of treatment.	(Peacock et al., 2023) (Tanner et al., 2022) (Rawlings et al., 2017) (Pretorius, 2016) (McWilliams et al., 2016) (Cole et al., 2014) (Terry and Trott, 2019) (Jordan et al., 2019) (Jemmum, Ibsen and Kjellberg. 2019) (Loewenberger et al., 2020)

Main theme 3. Terminology, “What should we call it?”	Reference to the differing terminologies for the diagnosis of non-epileptic seizures is discussed specifically across seven of the fifteen papers, highlighting the confusion in both health and academia. However, all fifteen papers use a variety of terminologies in their titles.	(Peacock et al., 2023) (Tanner et al., 2022) (McWilliams et al., 2019) (McWilliams et al., 2016) (Cole et al., 2014) (Loewenberger et al., 2020) (Jemmum, Ibsen and K Kjellberg. 2019)

2.4.2 Management and attitudes in education.

Young people with NES often underachieve and their attendance is low. They have difficulties with relationships and losing friendships and are on the receiving end of negative attitudes from teachers (Dunne et al., 2019) all of which can exacerbate pre-existing anxiety and depression disorders (Fredwall et al., 2021). A recent retrospective study of 52 inpatient YP receiving treatment for PNES between 2012-2020 reported that 49(94%) had found education difficult due to their seizures and ten (19%) had left school altogether. 36 (69%) had received adapted education and the conclusion was that HRQoL for YP with NES is determined by personally adapted treatments and accommodations at the earliest opportunity (Karterud et al., 2024).

Across the literature, YP stated consistently that they had difficulties within their educational settings. Participants in the study by McWilliams et al (2016) reported being separated from their peers in class and not allowed to attend trips, often being sent home from school post seizure through the school's lack of understanding about their condition. Some schools decided that the YP could not attend school and alternative arrangements were made for home educating. YP were accused of fabricating their seizures by pupils and staff and McWilliams et al (2016) summarised that YP with NES often felt stigmatised by the inappropriate handling of their seizures by schools, that they called an ambulance when told not to, had no policy in place and there was little or no collaboration with health.

Additionally, YP describe school-related stress originating from within the environment, such as the pressure of missing school deadlines and hearing inappropriate talk about them from students and staff (Cole et al., 2014; Tanner et al., 2022).When discussing management by schools, YP stated that response plans for their seizures were often ‘guessed’, teacher-led, and fear driven. Furthermore, management was led by liability measures resulting in inappropriate medical intervention from ambulance calls and hospitalisations. However, outcomes for YP with NES improve when management plans for seizures are developed (Flewelling et al., 2020a) and there is collaboration between paediatrics and educational settings (McWilliams, Reilly & Heymen, 2017).

Difficulties for families when choice-making between disclosure and non-disclosure to education are reported in Cole et al. (2014). The legitimacy of a diagnosis of epilepsy has long been accepted within education, therefore families of YP feel it is easier to disclose an incorrect diagnosis of epilepsy with less stigma attached, than that of a mental health disorder. However, the difficulties for YP with NES are compounded when response plans for epilepsy are followed resulting in invasive and inappropriate medical care such as anti-epileptic drugs (AED’s) which can cause iatrogenic harm (Campbell et al., 2019). A review of literature (Morgan & Buchhalter, 2015b) found that although the semiology for NES is similar to that of epilepsy, once identification and a diagnosis of NES has been made, it is important that collaboration between school administrators, teachers and well-being staff is promoted and a plan for future NES events developed. This decreases unnecessary hospital visits, diagnostic tests and medication intervention. Additionally, educating other students in the YP's friendship group or class, can eliminate fear and stigmatisation.

As part of the management team and at the forefront of health services in education, are school nurses. They may be the first to identify students with difficulties in physical, emotional, psychosocial and mental health areas. Additionally, an increase in mental health disorders in YP post Covid-19 Pandemic has led to recognising the need for investment in mental health services in all educational settings (Worsley, Pennington & Corcoran, 2022). However, nurses may have a broader knowledge base rather than specific understanding of complex individual presentations (Skundberg-Kletthagen & Moen, 2017). A small-scale study of ten school nurses from the review literature (Terry & Trott, 2019) examined school nurses experiences of caring for students with PNES. Lack of awareness was raised as a theme. Only one nurse had heard of the disorder before caring for a child in their own setting, and there was an additional lack of understanding of the diagnosis from the school staff. Nurses had feelings of doubt and insecurity as to how to respond to seizures, with little collaboration and information from healthcare professionals. Nurses were unsure of what they were doing and conducted their own research into NES in their own time, although medical information on the internet was limited too. Furthermore, nurses developed their own response plans to YP seizures, with little help from psychiatrists or mental health staff. They also reported that caring for a YP having a NES was time-consuming and difficult to deal with when staff and students felt the YP was 'faking it'. Nurses also felt torn when they could not attend to other students in medical need. However, they did feel a sense of pride and leadership when they were more confident and able to train and educate staff on NES and response plans.

A study of 284 public health nurses working in schools in Norway (Moen & Skunfberg-Kletthagen, 2017) found that 25% of their time was spent with students with emotional and psychological needs, however, there were fewer referrals to specialist mental health services by those nurses with a post-graduate qualification in mental health compared to those with a single nursing degree. Nurses with a mental health qualification were more able and confidant to provide support and interventions to improve YP mental health outcomes. Furthermore, a review in the United States (Tanner et al., 2019) on school-based mental health interventions and the implications for students with PNES found that, although the school nurses' role was recognised by *The American Epilepsy Soci*ety (2018) as the first responder to NES events and in training staff, their role in the continued application of interventions for YP with NES in education was limited. Additionally, their role in the continuing care of YP with NES has not been recognised by authors in paediatric literature (Doss & Myers, 2023), although interventions such as parental education, cognitive behaviour therapy (CBT) and clear and concise information regarding the diagnosis have been found to reduce NES events in YP (Rawat et al., 2015).

Two studies in the review literature discuss possible links between ASD and NES (McWilliams et al., 2019; Myawaki et al., 2016). Rates of Autism diagnosis in Wales have risen from 0.2% in 2003/2004 to 1% by 2012/2013 (Holtem et al., 2016) and *The National Autistic Society* states that there are now 1 in 100 people in Wales on the autistic spectrum (Sakhuja, 2024). Additionally, a comorbid diagnosis of epilepsy occurs in 6-37% of those with ASD with an additional likelihood of NES occurring in 22% of those with epilepsy (Freedman et al., 2022). McWilliams et al. (2019) suggest that medical professionals working with YP with ASD should be aware of NES, and a consideration of ASD should not be dismissed in those YP with NES. They also state that the psychological stress of living with undiagnosed ASD and lack of accommodations in education could precipitate the onset of NES. The case report of a 10-year-old girl in Myawaki et al. (2016) with undiagnosed ASD and NES concluded that her NES ceased post-diagnosis, with psychoeducational understanding and educational accommodations put in place.

2.4.3 Knowledge and understanding of non-epileptic seizures in the health sector.

Across the literature, in both primary and secondary sectors, knowledge and understanding of NES by medical professionals was inconsistent. Three studies (Rawlings et al., 2017; Tanner et al., 2022: Terry & Trott, 2019) report participants' experience of inadequate understanding of their disorder by primary healthcare professionals, including, nurses, school nurses, paramedics and GP's. Fourteen of the 19 participants in Rawlings et al. (2017) highlight lack of understanding, support and awareness from healthcare professionals and paramedics, with those in emergency departments being the worst. Participants were often accused of 'faking it' and felt failed by doctors. A scoping review (Reilly et al., 2023) of literature confirms that awareness and understanding of the disorder by professionals in health is deficient; however, health professionals did report a need for a single pathway of assessment, diagnosis and treatment.

Adolescents participating in one study (Tanner et al., 2022) describe doctors talking in front of them in hospital disclaiming their seizures as fake so they could be discharged, while another school nurse accused them of putting on seizures in front of certain people. A study of 135 participants with NES who had experienced medical interactions which were stigmatising (Robson & Lian, 2017) reported many negative responses from medical practitioners. One participant had water thrown over them mid-seizure by one doctor, whilst another was punched and pinched by a nurse trying to get her seizure to stop. In conclusion, Roberts and Lian (2017) reported that the treatment and care of people with NES required an urgent update with lack of knowledge and understanding from medical professionals as an overriding causation of patients' stigma and medical trauma. Terry and Trott (2019) conclude from their qualitative study on school nurses experience of NES that nurses have an increasing number of challenges to face in schools, with mental health conditions taking up much of their time. However, more awareness and education needs to be provided to nurses in their preliminary training with concise and clear guidance from healthcare providers when facilitating a student with NES (Huff et al., 2024).

A scoping review (Welsh Government, 2019) found that school nurses' skill and expertise was variable in different areas of Wales. Several nurses interviewed for the review also reported that they did not have the specialism to deal with mental health disorders of children and YP, although essential for their care.

Several articles in the literature (Cole et al., 2014; Jemmum, Ibsen & Kjellberg, 2019; Jordan et al., 2019; Loewenberger et al., 2020; Peacock et al., 2023) report patient and clinical staff experiences of confusion and lack of clarity in pathways for the diagnosis and treatment of those with NES. A study of ten psychiatrists (Jordan et al., 2019) found they too experience inconsistencies with the treatment and aftercare of those with NES from all healthcare providers. They felt that GPs should have better understanding and healthcare providers were unskilled to deal with patients with DS. Psychiatrists felt there were gaps within the NHS where even Neurologists were continuing to prescribe AEDs for NES when families could not understand a non-organic diagnosis. Cole et al (2014) report there are many ethical considerations surrounding the diagnosing of a patient with NES. However, many Neurologists often lean towards a diagnosis of epilepsy first with prescribed AED’s and then apply the process of elimination resulting in a diagnosis of NES. Wichaidit, Østergaard & Rask (2014) found inconsistencies with coding of diagnosis for NES including ‘syncope and collapse’ and ‘unspecified convulsions’, causing confusion amongst families and patients and a lack of clarity for direction in diagnosis for doctors. Additionally, McWilliams, Reilly and Heyman (2017) study of 66 psychiatrists confirmed a self-reported lack of coordinated services and standardised care access for patients with NES further disengaging doctors from these patients.

An increase in mental health disorders in YP has led to a greater proportion attending accident and emergency departments when in crisis (Cozzi & Barbi, 2018). Additionally, it is more common that children and YP present with physiological somatic symptoms for psychological difficulties. (Chun, Mace & Katz, 2016). A recent study (Morabito et al., 2021) found the over medicalisation of children and YP used in a search for answers for somatic symptoms including hospital admissions and unnecessary medical procedures. This is further discussed in Peacock et al. (2023), using narrative interviews with five patients with NEAD, the conclusion being that the only legitimate pathway was through an organic or medical diagnosis. Psychological and stress-based explanations for NES, as well as not providing legitimacy, can give rise to personal and perceived stigma of mental health disorders attached to social position and identity (Billings, 2020). Furthermore, Jennum, Ibsen and

Kjellberg (2019) discuss the direct and indirect welfare consequences of living with PNES in a comparative study of 1057 people of all ages in Denmark matched with a control of 2113. Results showed that people with PNES had lower income levels than controls whilst social care costs and hospitalisations were higher. Additionally, compared to those with epilepsy, the healthcare costs for patients with PNES were considerably higher, €25,523 compared to €11,223 for those with epilepsy. In conclusion a diagnosis of PNES is associated with lower levels of employment and higher health and social related costs (Teagarden et al., 2020).

A non-organic diagnosis for a presenting physical disorder can be difficult to convey for clinicians and for some parents and patients hard to accept (Malas et al., 2017). Furthermore, as discussed in Loewenberger et al (2020), a process of the elimination of a diagnosis of epilepsy can sometimes be viewed by patients and families as derogatory when a communication of a ‘non’ disorder is relayed. However, having families and YP engaged with clinicians after a diagnosis with a psychological causation promotes recovery (Wiggins et al., 2022). When parents fully accept a diagnosis, the YPs chances of recovery are 17 times higher than those whose parents do not (Gao et al., 2018).

Finally, two studies (Pretorius, 2016; McWilliams et al., 2016) echo the same conclusion. To inform a standardised and streamlined pathway to diagnosis and treatment, further understanding is required from the lived experience of those with NES. Additionally, many healthcare providers in all medical settings have limited expertise of the disorder, therefore an introduction to NES as a standard module in nursing and healthcare training could be a positive addition. Furthermore, additional studies on the characteristics and triggers of NES in YP could prevent further NES events and the way in which a diagnosis of NES is communicated as well as the subsequent treatment of the disorder can affect the frequency of seizures and aid complete recovery (Gurcan et al., 2022).

2.4.4 Terminology, “what should we call it?”

The terminology of functional phenomena or NES, prior to a scientific distinction, has been described as ‘hysteria’ (Bruno, Machado & Auxéméry, 2021). After the development of scientific work in magnetics in the 1870s by Jean-Marie Charcot (1825-1893) a distinction between epilepsy and NES was made, that being the presence of differing electrical brain activity of those with epilepsy when experiencing a seizure (Beghi et al., 2015). Currently, the DSM-5 (APA, 2013) places NES or PNES under the terms of Conversion and Functional Disorders; on-the-other-hand, *The Classification of Mental and Behavioural Disorders Clinical Descriptions and Diagnostic Guidelines ICD-10* (World Health Organisation, 1992) categorises dissociative convulsions (pseudo seizures) under the term of Dissociative (conversion) disorders (F44). The confusion over a valid terminology for NES still exists and is noted by The Epilepsy Society in its guidance for NES describing the differing terminology’s healthcare professionals use such as DS, NEAD and PS (Epilepsy Society, 2023).

Seven of the literature review papers (Cole et al., 2014; Jennum, Ibsen & Kjellberg, 2019; Loewenberg et al., 2020; McWilliams et a;., 2016; McWilliams et al., 2019; Peacock et al., 2023; Tanner et al., 2022) denote difficulty in deciding which name to call the disorder. Cole et al. (2014) draw attention to differing terminology which can impact the outcome of a patient’s treatment, whilst McWilliams et al. (2019) state the ‘many alternative names and varying semiology’s’. However, Peacock et al. (2023) comment that their preferred terminology of NEAD was the most widely used term in the UK at the time of their study, despite the unresolved medical and social framing of the disorder. Additionally, Tanner et al. (2022), whilst choosing to use the term 'psychogenic' in their paper, also mention terminologies of functional or dissociative seizures. The term psychogenic can, in itself, cause offence to those diagnosed, as it implies that the patient is 'psycho' or symptoms are 'all in their head'. This denotes a medical disengagement between the psychological cause and the physical symptoms even more difficult to comprehend as YP with NES can feel that they do not have a mental health difficulty, but a medical disorder (Koslowska et al., 2017).

As many as 15 different diagnostic names exist for NES and the translation of the disorder can have a profound effect on its acceptance by the recipient, especially if they have previously been misdiagnosed with epilepsy (McWilliams et al., 2016; Reilly, McWilliams & Heyman, 2014). Furthermore, whilst Jennum, Ibsen and Kjellberg (2019) state that presentations of functional neurological symptoms and conversion disorder are common in emergency rooms, they still use the term PNES in their paper, implying a 'psych' disorder rather than NES, a 'non' disorder. A study of neurologists in Italy (Tinazzi et al., 2021) examined the preference for terminology when explaining a diagnosis to patients. 1057 responses were recorded, the two most frequent being 'Functional Neurological Disorder' (*n*=374) and 'Somatization Disorder'(*n*= 68) followed by 'Non-Organic Disorder' (*n*=134). The preferred causation was described to patients as a "disorder due to the abnormal functioning of the nervous system" (*n*=284), with several choosing 'Psychogenic Disorder' (n=104) and ‘Absent Neurological Disorder’ or ‘Stress’. A previous study carried out by Stone et al. (2003) of ‘offensive’ terminology for, what was then known as ‘pseudo seizures’, concluded that the most offensive term was, ‘symptoms all in the mind’, ‘hysteria’ or ‘pseudo seizures’ and the most accepted, epilepsy. More recently a study by Loewenberger et al. (2020), examined the opinions of 87 healthy individuals on the terminology for NES. They concluded the three most accepted terms to be ‘Functional Neurological Attack Disorder,’ ‘Dissociative seizures’ and ‘Functional seizures’ with the three most offensive still being ‘Pseudo Seizures’, ‘Conversion Disorder’ and ‘Hysteria’.

The decision for one singular terminology for NES is a worldwide controversy, as different nations draw on different medical specialities for guidance. However, patients’ wellbeing is not only defined by their illness but from the label they are given (Asadi-Pooya, et al., 2020). Further research, including all specialities and stakeholders, is needed to improve pathways to diagnosis and treatment and a better understanding of the disorder.

2.5 Summary

The aim of this study was to critically review the literature relating to the experiences of those diagnosed with Non-Epileptic Seizures and the interactions of medical professionals with these patients. Fifteen articles were explored. Of these, five included the lived experience of adults, children and YP and their parents, two articles researched the experiences of school nurses and psychiatrists when working with patients with NES and other health professionals, six examined the views of professionals with regard to diagnosis, terminology and working with children and YP with NES, and two examined the links between Autism and NES.

Findings from the literature suggest that those with NES have reduced HRQoL (Woodward et al., 2023) and often experience lengthy periods of time to diagnosis. They can be accused of ‘making it up’, whilst also having difficulty either attending education or fulltime work. Compounding people’s perceptions of their disorder are healthcare professionals’ attitudes, lack of knowledge and confusion over terminology, along with differing pathways to diagnosis and lack of support thereafter.

Although, the disorder can present at any point in a person’s life, there is a stronger female prevalence of NES and generally, events appear to initially occur in early adulthood (Asadi-Pooya & Sperling, 2015). The Welsh Government define a YP as being aged between 16-25 years old (WG, 2023); however, there is a paucity of research in both studying YPs lived experience with NES (Doss, 2022; Karterud, Risør & Haarvet, 2015; Smith, 2014; Valani and

Gledhill, 2021) and the perspectives of those caring for them, as well as professionals working within this age range. There is also, little research in England and Scotland within this field and currently, none in Wales (J. Stone, personal communication, July 24, 2024; H. Cook, personal communication, August 12, 2024), therefore warranting further exploration in order to inform practice and more positive outcomes for YP with NES.

2.6 Limitations

There are some limitations to this review. To capture a contemporary perspective on peoples and professionals experience of NES, the time scale explored was 2014-2024, however, there was limited data in both qualitative research and exploring the understanding of healthcare professionals, especially in the UK. A wider timescale may have been useful in producing more studies. Additionally, the criteria surrounding the age range was difficult to define as various studies used different ages for children, adolescents, YP and young adults, rendering the author to use the age 0-25 for review paper criteria. The Welsh Government define a YP to be anyone between the age of 16-25 years, enabling a specific age group to be justifiable for future research in Wales. Finally, due to the paucity of research for this age group it is difficult to draw firm conclusions on both the experiences of YP and the understanding of healthcare professionals.

Chapter three:

Research Report.

Understanding the experience of Non-Epileptic Seizures in young people: A multi-perspectival qualitative analysis.

This manuscript has been written for the submission to the Elsevier *Journal of Epilepsy and Behaviour* following the journal's instructions to authors.

3.1 Abstract

Purpose: To use a qualitative multi-perspectival approach to better understand the experience of non-epileptic seizures (NES) in young people (YP).

Objective: To understand the experiences of young people (18-25 years) diagnosed with non-epileptic seizures (or other terminology), the perceptions of their parent/carers (P/Cs) and the knowledge and understanding of NES from professionals working with YP in the health and well-being sector. Topics explored included diagnostic process, how NES was explained, treatment and support, accommodations, impact and knowledge and understanding.

Method: Thirteen participants took part in online semi-structured interviews. Data was analysed using thematic analysis.

Results: Four YP diagnosed with NES, Four P/Cs and five professionals took part. Three superordinate themes developed: explanations of NES, the impact of NES and "who's going to help us?”. YP discussed not having an adequate explanation of NES from health professionals and having to research the disorder themselves. P/Cs talked about how their lives had changed and the accommodations they had to make. Professionals discussed their lack of knowledge on the disorder and felt it was too specialised for them to know about.

Conclusions: Throughout their illness, YP had consistently poor experiences with healthcare professionals, with little understanding or explanation from medical professionals. However, most had positive experiences of accommodations in education although staff had no knowledge of the disorder. P/Cs had little support and researched NES themselves. All YP and P/Cs reported close familial bonds. Professionals working with YP had little or no knowledge of NES, were unaware of first aid protocols and could not provide a ‘safe space’. The research suggests a need for a psychoeducational approach to the diagnosis of NES incorporating explanations, causation and self-management, including for education and health and well-being professionals.

3.2 Introduction

Non-epileptic seizures (NES) or psychogenic non-epileptic seizures (PNES) are physical events which involve changes in behaviour, cognition, awareness and often appear like epileptic seizures, however, there is no equative change in electrophysiological brain activity (McWilliams et al., 2016). There are many differing terminologies for the disorder including dissociative seizures (WHO, 1993) and conversion disorder (APA, 2013; Asadi-Pooya., et al). This paper uses the term NES to emphasise the non-organic nature of seizures which lie in psychological origins rather than biological (Peacock et al., 2023). The 'gold star' pathway to diagnosis for NES is video-electroencephalogram (V-EEG) (Kanemoto et al., 2017).

Due to the challenges in differentiating between epilepsy and NES, the latter can often be misdiagnosed as epilepsy (Toffa, Poirier & Nguyen, 2020). Almost 50% of severe cases presenting with epilepsy to emergency care result in a later diagnosis of NES (NHS, 2017). This can lead to a lengthy diagnosis process' of up to 7 years and mismanagement of the disorder due to iatrogenic anti-seizure medication being used instead of cognitive behaviour therapy (CBT) or psychoeducation. These therapies have been found to be the most positive treatment of NES along with psychotropic medications (Kerr et al., 2017).

NES can affect people of all ages, however, a study in Norway found prevalence rates to be higher amongst 15–19-year-olds at 59.5/100,000 (Villigrán, et al., 2021). The age group most likely to have NES being between 15-24-years-old, and those most affected female (75-85%) (Hansen et al., 2020).

Being a multi-faceted biopsychosocial disorder, there is no one causative element (Perez & La France Jr, 2016). However, the impact on a person's day-to-day life is multifarious, effecting education, employment, familial and social relationships plus healthcare interactions. Additionally, having further consequences for physical and mental health (Karterud, et al., 2024; Sarudiansky et al., 2017; Walsh et al., 2024).

Previous studies have examined the experiences and outcomes of children and adolescents (Doss, 2022; Flewelling et al., 2020a and b; McWilliams et al., 2016) with NES, as well as adults. (Peacock, et al., 2023; Pretorius, 2016), along with the perspectives from medical professionals (Cole et al., 2014; Jordan et al., 2019). However, there is little research in the UK and none in Wales incorporating a multi-perspective approach on the experiences of YP between 18-25 years old, the perceptions of their P/Cs and the knowledge and understanding of professionals who work with them.

Therefore, the aim of this research study is to examine possible disparity between the experiences of YP with NES, the perceptions of their P/Cs whilst navigating the health and education systems, and whether professionals who work with YP have knowledge and understanding of the disorder.

3.3 Methodology

3.3.1 Design

The research carried out was a qualitative study utilising thematic analysis of 13 interviews exploring the experiences of YP with NES, the perspectives of their P/Cs and the knowledge and understanding of professionals working with this group. Research ethics were approved by The University of Wales Trinity Saint David (see Appendix A).

3.3.2 Setting

Interviews were carried out via Microsoft Teams for recording and transcription purposes. YP participated from their own home with a parent/carer nearby. If they felt unwell or distressed they were advised they could take a break or reconvene on a different day. Professionals undertook their interviews from their workplace.

3.3.3 Sample

Purposive sampling was used because it provides meaningful and unique information (Etikan, Musa & Alkassim, 2016). It was carried out between September and October 2024 and included four YP, all female, between 18-25 years of age, with variably termed diagnoses of NES, four parents, siblings or carers of those YP and five professionals working with YP in the health and well-being sector. Of the five professionals, three were from a medically trained background. Two were trained as Mental Health Nurses with thirty and 4-years' experience respectively and were now a university Well-being Advisor and Specialist Autism

Practitioner. The third, was a Specialist Psychiatrist with eleven years' experience. One professional had worked as a counsellor in a university setting for 25 years and the last was an On-line Counsellor for YP for twelve years.

3.3.4 Recruitment

YP and their parent/carers were initially recruited via social media and followed up with an 'invitation to participate letter'(see Appendix B) and consent form (see Appendix C). Professionals were contacted via their place of work and all participants were given pseudonyms to protect their identities.

3.3.5 Data collection

Semi-structured interviews included a differing range of questions for each participant group (see Appendix D). Questions were decided from previous interview schedules relating to literature on the experiences of children and YP with NES (McWilliams et al., 2016), their families, and the understanding of professionals on the disorder (Terry and Trott, 2019).

Demographic information collected relating to YP included: whether the YP had ongoing NES, treatment, time delay to diagnosis, and length, frequency and presentation of their seizures. For carers: who they cared for, their work and their YP's diagnosis. Professionals were asked for their job role, duration and previous roles (see Table 3.1).

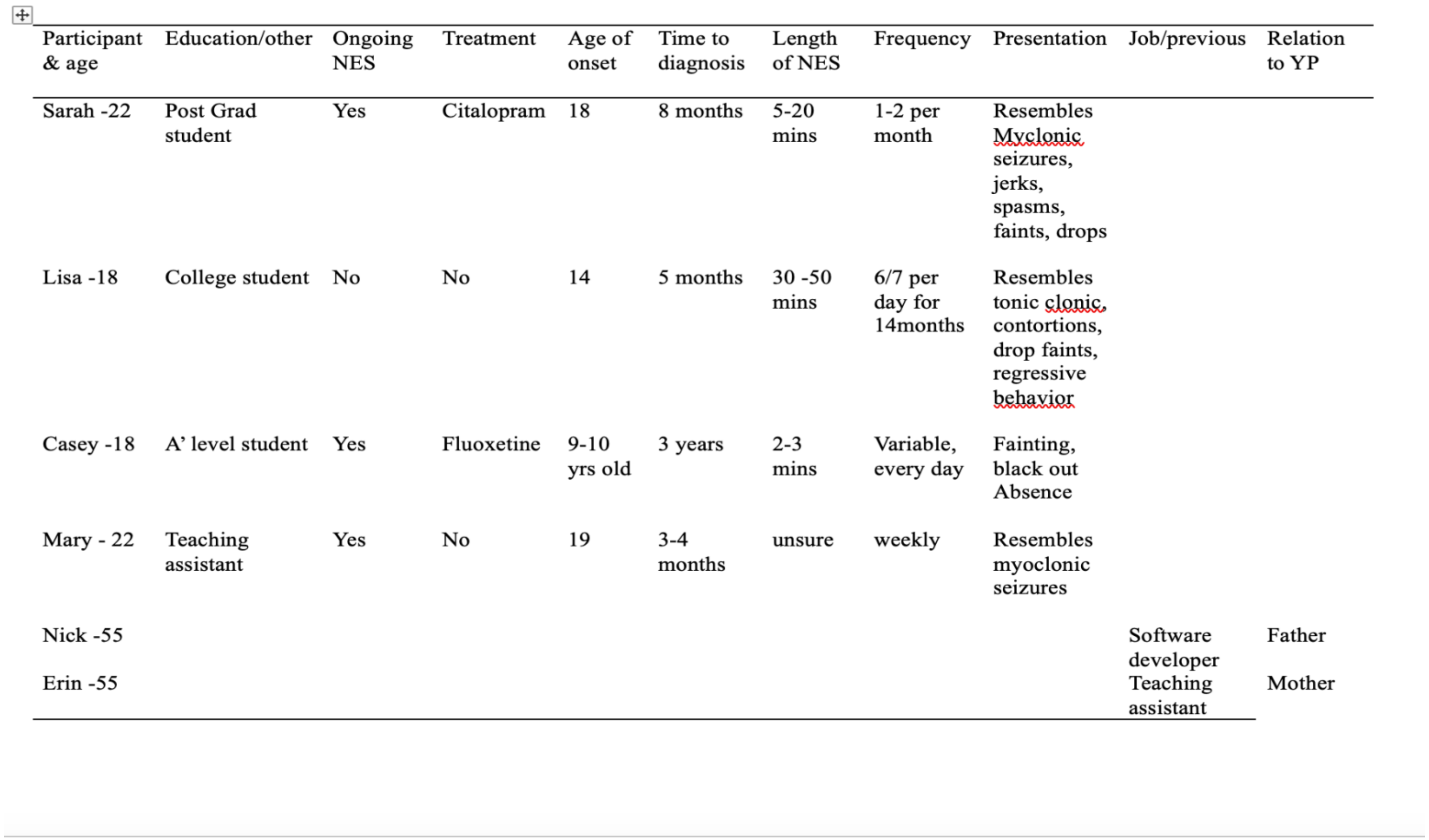
3.3.6. Data Analysis

Braun and Clarke's (2006) six-stage process of thematic analysis offers a systematic way of generating patterns of codes and themes in a pliable and academically sound way enabling flexibility with the questioning, data collection, sample size and creation of meaning generation.

Interview recordings were transcribed and hardcopies printed. Recordings were then deleted. For the first stage, familiarisation, the scripts were read several times for a deeper level of understanding and notes were taken by pen on any presenting evocation (see Appendix E). The second stage, generating initial codes, highlighter pens were used to systematically read through each line of each interview to highlight codes or areas of interest (see Appendix F). A list of 113 variable codes were generated for stage three (see Appendix G) and a pattern of themes started to immerge for stages four (see Appendix H) and five (see Appendix I), generating and reviewing themes. The finalised themes were transposed to a thematic analysis results table (see Table 3.2) ready to be discussed in the written-up research report at stage six.

Table 3.1

Participant characteristics



Participant & age	Education/other	Ongoing NES	Treatment	Age of onset	Time to diagnosis	Length of NES	Frequency	Presentation	Job/previous	Relation to YP
Sarah -22	Post Grad student	Yes	Citalopram	18	8 months	5-20 mins	1-2 per month	Resembles Myclonic seizures, jerks, spasms, faints, drops		
Lisa -18	College student	No	No	14	5 months	30 -50 mins	6/7 per day for 14months	Resembles tonic clonic, contortions, drop faints, regressive behavior		
Casey -18	A' level student	Yes	Fluoxetine	9-10 yrs old	3 years	2-3 mins	Variable, every day	Fainting, black out Absence		
Mary - 22	Teaching assistant	Yes	No	19	3-4 months	unsure	weekly	Resembles myoclonic seizures		
Nick -55									Software developer	Father
Erin -55									Teaching assistant	Mother

Eric - 19		Student & farmer	Brother
Simon - 30		Not reported	Boyfriend
Nadine - 62	Uni well-being advisor -10 yrs	Mental health staff nurse- 30 yrs	
Olive - 37	Specialist Autism practitioner - 1 yr	Community mental health nurse- 4 yrs, early intervention for psychosis-6 months.	
Henry - 44	Online Integrative Counsellor - 12 years	LA Teaching, Youth work anti-bullying, EOTAS, Young Offenders	
Taalish -	Specialist Psychiatrist/On call adult mental health – 11 years		

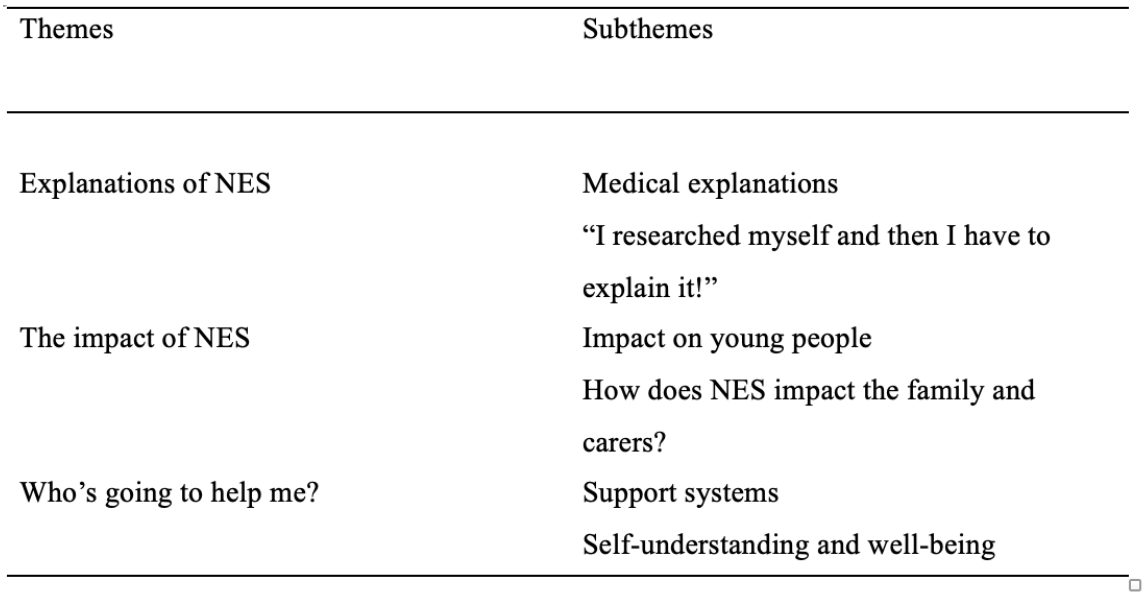
3.4 Results.

3.4.1 Overview of themes.

Three distinct themes and six sub-themes emerged: explanations of NES, the impact of NES and “who’s going to help me?” (See Table 3.2). There were consistent negative experiences from the YP and their families and self-reported lack of knowledge or understanding of NES from professionals. However, YP felt closer to their families because of the experience of NES and reported positive experiences of accommodations from educational settings. Professionals reported that they knew little about the disorder and that attention had been drawn to their lack of first aid and seizure policy knowledge.

Table 3.2

Themes and subthemes



Themes	Subthemes
Explanations of NES	Medical explanations
	“I researched myself and then I have to explain it!”
The impact of NES	Impact on young people
	How does NES impact the family and carers?
Who’s going to help me?	Support systems
	Self-understanding and well-being

3.4.2 Theme 1. Explanations of NES.

A strong theme across all 13 participants was, ‘Explanations of the disorder’. All four YP felt that they had not had an explanation of the disorder and had relied on self-education from online sources or from parents who had researched for themselves. In the following quote Sarah explains.

> *“Well to be honest I don’t think a medical professional actually ever explained it to me. It was me and my family that did the research… experienced Counsellors that don’t even know what the definition of Dissociative seizures is then meaning I’m actually having to explain that to them” (Sarah, p2, 34-37).*

One YP was given her diagnosis by her mother when she was nine years old as she was too young to comprehend at the time. Information leaflets had been given to two pairs of YP and their P/C without verbal explanation.

Only one professional, the Specialist Psychiatrist, could explain NES whilst the others had little or no knowledge of the disorder. Nadine, a university well-being advisor states.

“I’ve got to say, I’ve got to be truthful, I don’t know much about it really”(Nadine, p3, 106-107).

3.4.3. Sub-theme 1. Medical explanations.

Explanations of NES to YP and their families from medical professionals were inconsistent across the participants. YP often felt confused after consultation. Some had no memory of an explanation from anyone.

"I was told little or no information about the seizures and left in the dark" (Mary, p1, 22-24)

P/Cs also had inconsistent experiences of explanations from medical professionals. On occasions a diagnosis took months and for one YP this was after a misdiagnosis and treatment for epilepsy.

> *"We were under the assumption that they were Epileptic seizures round about 2020 and possibly caused by photosensitivity…there wasn't a lot of information which was quite a big barrier for us to kind of understand"*(Nick, p1, 16-18, 24-27).

However, one parent had a more positive experience, although again, after a lengthy process of investigation for narcolepsy.

> *"She just came over and she went 'right', she said. 'I know exactly what this is' she said. 'This is something called Non-epileptic Attack Disorder"*(Erin, p4, 127-129).

Explanations of NES for two participants were given by other family members, or they were unsure where their understanding had come from, relying on secondary information.

> *"When she* <YP> *came back she explained it to me along with giving me a booklet which helped explain the situation and how I can help"* (Simon, p2, 36-37).
>
> *"I don't really know exactly where my understanding of it today has come from, I can't remember exact conversations of being explained it"* (Eric, p2, 62-63).

The professionals had 93 years' experience between them working in the mental health sector. However, only one could explain NES, although not why it happened.

> *"So, psychogenic mean that it does not have an organic base. If you do EEG which you do with Epilepsy, there are some changes which are not visible for this young person, yeah, so why we use the term psychogenic"*(Taalish, p2, 66-68).

Four professionals had limited or no knowledge of NES, although there had been YP using their service with the disorder and one had personal experience of a sibling with a misdiagnosis of epilepsy, later diagnosed as NES.

> *" I don't think it was explained enough what the alternative was"* (Olive, p3, 103-104).
>
> "*I had a client recently that was suffering with, suffering with [sic] that when she first came to me … it's not my area, specifically in terms of that, I know my limitations"* (Henry, p2, 52-57).

3.4.4 Sub-theme 2. "I researched myself and then I have to explain it!".

Without an explanation from medical professionals YP, parents and carers educated themselves online to understand the disorder.

> *"I came home and then looked it up and that's how I got information on it and my Mum looked into it a lot as well"*(Lisa, p2, 39-40)".
>
> *"Having researched it, I know now that a lot of people that are first diagnosed with epilepsy have got this not epilepsy"*(Erin, p5, 145-146).

Finding on-line explanations for NES has enabled YP to explain to others what they have and what they need. YP want to reassure those around them that they are fine, and others do not need to panic when they have a seizure.

> *"I quite happily say, 'this is what I have and this is what I need'…It's important to be open because I would never want a seizure to happen and someone else feel stressed or worried"*(Sarah, p6, 193-197).
>
> *"I mainly say, I have this thing, it's called Non-epileptic Attack Disorder or NEAD and I'm completely fine when it happens…when I was explaining it, I had to explain it to Teachers so I'd say so like I can still hear things you know"* (Casey, p7, 244-248).
>
> *" when you describe non-epileptic seizures, people just hear the seizure bit and just assume it's Epilepsy or something similar to that"*(Nick, p4 138-144).

3.4.5 Theme 2. The Impact of NES

For all YP in this study having NES had an impact on their lives physically, emotionally and socially, as well as on their family members. Seizures ranging from syncope, or tonic clonic resemblance, altered states of consciousness or regressive changes in behaviour which lasted minutes or hours many times a day, left YP feeling exhausted, isolated and unable to function both physically and cognitively. However, three of the YP endeavoured to continue their education whilst managing this complex disorder. One YP was unable to return to education and left at 14 years old. Another had two years intermittently in and out of education, whilst two were attending university.

Whilst YP attended educational settings, well-being and medical professionals still felt the disorder was too rare and specialised, even though they had all had contact with a YP with the disorder at some point.

> *"Probably I think more training or more, [Sic] should be provided for us. I think that is because I have seen not many, but I've seen a few…I think that would be helpful for people who work in mental health"* (Taalish, p5, 174-178).

3.4.6 Sub-theme 1. Impact on the young person.

The impact of NES on two YP was significant enough for them to stop going to school. One lost all contact with their friends and was isolated from society for nearly 3 years.

> *"I got sent home so much that the school were essentially like, 'we can't deal with this, we can't deal with you passing out all the time, so we're going to get you on this home school thing"*(Casey, p3, 70-80).
>
> *"I lost contact with all my friends and all my social skills have pretty much gone…because I was so isolated and unable to do anything for so long it has kind of delayed things in my life quite a bit"*(Lisa, p5, 157-160).

NES not only impacts YP when they are having seizures, but once the seizures have stopped, other somatic symptoms affect the YP's life.

> *"Even though I don't have seizures anymore… I get fatigued very easily and sometimes my brain can completely shut down. I get muscular tics and spasms. I had surgery on my stomach when I was young so now I tend to get stomach tics, as well as facial ones"* (Lisa, p5, 148-152).

YP felt their lives were different to their peers, some of whom did not believe their seizures were real.

> *"And I still think to this day that they <friends> don't fully understand it, I have explained, but sentences are used such as like 'oh not proper seizures' or 'not real seizures' it's like those words can be quite demoralising as to the disorder I do have"* (Sarah, p4, 140-143).

Learning to drive was not an option for three of the YP who still had seizures. YP with NES have to think before going out, in case of triggering environments.

> *"My life has been hugely affected by NES. I am unable to drive…Most of the time I am stuck at home. I often miss out on plans because I'm unable to get there or if I've had seizures or unable to attend…It affects my mental health, I feel anxious a lot and I'm often worried about having seizures"*(Mary, p2, 70-73).

Being Autistic and experiencing overwhelm and sensory overload was also acknowledged as being impactful for onset of NES.

> *"This is probably being attached to the Autism and stuff, but I definitely think I have to be more aware when it comes to working to not overdo it"* (Sarah, p4, 129-132).

> *"Being in crowded corridors is one of my triggers… my Mum and I recently learnt that people with Autism are more likely to have this thing and my friends been telling me for years I've got Autism"*(Casey, p3, 96, p11, 397-399).

Professionals noted that they had experience of the impact of NES on YP within their settings, however, were not aware of how to respond. Nadine commented,

> *"I think we had one person, well, yeah, she was having one of those…she ended up staying on the couches…I mean it's above the ground . I mean, easily she could fall off"* (Nadine, p3, 104-105; p 4, 136-138).

Responding to a question relating to knowledge of first aid treatment for NES, Olive responded, *"none, no idea"* (p4, 124).

3.4.7 Sub-theme 2. How does NES impact the family and carers?

Family members said that NES had directly impacted their family life. Two mothers had not been able to work whilst caring for their YP.

> *"As far as work is concerned, I didn't work whilst all this was going on, I couldn't so I didn't…then I just started part time at a local school…my husband he's now, he's working nights so he can help go and get her if he needs to"*(Erin, p8, 252-262).
>
> *"My Mum had to quit her job to care for me and I'd say now my Mum has quite a lot of stress going on"*(Lisa, p7, 221-222).

One sibling discussed whether he had missed out on occasions with his friends or not been able to have friends over.

> *"If my mates were out doing something or asked if I wanted to go, the immediate answer is no, I need to check first. I need to make sure I'm able to because having someone at home with my sister was the important thing."*(Eric, p5, 161-164).

Participants raised topics of difficult relationships within the family, feelings of frustration, guilt and disagreements about management or understanding NES.

> *"There are sometimes where my Dad is, that he, I don't know if he knows how to express his emotions or he well, so sometimes I'll be passing out all day and then he'll come and pick me up and he'll kind of like shout at me about it"*(Casey, p5, 175-177).
>
> *"It's been hard, really hard. You know it has caused disagreements. The way I deal with it and the way my husband deals with it. He wants to solve it and I know that it probably won't be solved"*(Erin, p8, 267-270).

3.4.8 Theme 3. Who's going to help me?

YP and their families had mixed experiences of support. However, teachers and lecturers, although not understanding NES, had listened and made accommodations for access to education. All YP noted that family gave the most positive support, although there were incidences of disparity. Lack of external support systems were reported by all YP, parents and carers. Treatment for NES was inconsistent due to lack of referrals to mental health services, misdiagnosis, and lack of understanding from therapeutic professionals. Those who were referred and offered CBT stated that they did not find it helpful.

> *"Whilst I did it [CBT] my seizures didn't improve. My mentality didn't really improve…They didn't focus on the bits that gave me PTSD or brought me to where I am, so I personally don't think CBT, or how CAMHS did CBT helped me"* (Lisa, p10, 289-293).

However, two YP were taking anti-anxiety medications which they felt reduced their seizure frequency and three paid privately for psychotherapy. Throughout their experience, YP reported areas of personal growth and noted that doing things that made them happy lessened seizure frequency and promoted well-being. One YP stated that having a seizure made her feel better.

> *"I am now more able to control seizures even though I don't know how…Sometimes having a seizure feels like a release valve from just coping"*(Mary, p3, 75-78).

Support could not be given to YP by four of the professionals due to lack of understanding of the disorder and discussions that it was too specialist.

> *" We did discuss…what was best for her, and she identified that she'd like to talk to somebody who, you know, is more raised in that, you know…so that she can have that support with someone who is more specialised in that"*(Henry, p4, 141-146).
>
> *"If I'm honest, I wouldn't really be working with <a YP> that affected*" (Angela, p4, 120).

3.4.9. Sub-theme 1. Support systems.

Family was reported by all the YP to be their main support system.

"All in all, it bought us very close, we're a very tight knit family"(Lisa, p7, 222-223).

However, one YP reported frustration from a parent, and another felt their family could never really understand.

> *"My family will listen and be empathetic, but they don't fully understand what I'm talking about"* (Mary, p2, 36-37).
>
> *"They have been very supportive of me, It's the main annoyance from Dad comes from when he has to pick me up from school…'oh why did you do, you know, why are you donking <seizures> so much?'…I'm just like this is why and then he's like Ok and then we just don't talk anymore"* (Casey, p6, 199-201).

Educational settings were reported to be accommodating and supportive for all YP whether they were able to be in the setting or not.

> "*They were very good at being like, 'what adjustments can we make to make the classroom more better for you…in a different room, better lighting, where there's less classmates"*(Sarah, p6, 209-212).

YP were intermittently able to attend and although one was not, they were offered Education Other than at School (EOTAS) however, they were too unwell to participate. Additionally, one YP still experienced stigmatisation and hostility from staff members.

> *"When I'm passed out I can still slightly hear and I heard them <Teachers> talking about it…I just felt really guilty"*(Casey, p4, 118, 124).

3.4.10. Sub-theme 2. Self-understanding and well-being.

Throughout the process of acceptance of NES and for one YP, recovery, YP reported that doing things that made them happy lessened the possibility of seizures. Self-analysis and understanding the root cause enabled YP to take control of their lives.

> *"Through counselling, I learned to self-analyse why certain things that gave me anxiety or PTSD and then I also learnt to communicate it…If I like notice something about how my brain works or how my body reacts cause, I tend to have very physical reactions to anxiety"* (Lisa, p10, 297-298, 319-320).

For some of the YP there was an air of submission that they had NES.

> *"I had to accept that all this is probably going to be in my life for quite a while now…just to re-find what I enjoy, going out and going to places you feel grounded and that make you happy…gives you good emotions as opposed to…focusing on bad emotions definitely helps more as well"* (Sarah, p3, 95, p8 259, 268-270).

Although professionals had no knowledge of NES, they all advocated listening to their client and having a person-centred approach to well-being.

> *"Because that's the most important thing is you know what's gonna make her feel safe while she's here you know?*" (Nadine, p4, 126-127).
>
> *"It would be a priority to think about what the student would need from me, the student would be able to tell me, this is what I would need"*(Angela, p7, 229-230).

3.5. Discussion

This is one of the first multi-perspectival qualitative studies to explore the experiences of YP with NES, and the first on this topic in Wales UK. Although a small sample of three different groups, it was possible to find common themes which correlate with previous literature (Cole et al., 2014; Dunne et al, 2019; Hinton & Kirk, 2018).

Thwarted by experiences of lengthy diagnostic times, misdiagnosis and lack of explanations, the YP and P/Cs in this study showed resilience adjusting to the far-reaching impact of NES and the reliance on '*self*' as a tool for meaning making (Pretorius & Sparrow, 2015).

The YP in this study attend educational settings when they are able, are not in receipt of NES specialised treatment and pay for private therapy when public health professionals have limited understanding of the disorder. Chew, Carpenter & Haase (2018) found through positive, collaborative, familial bonds, YP develop resilience to cope with their adverse experiences. The families in this study reported similar experiences of positive, supportive family relations.

The YP and carers emitted feelings of "*confusion*" "*bewilderment*" and then resignation that there is no support, nobody understands, and they just 'get on with it'. This is reiterated in the developed themes; "Explanations of NES", The impact of NES and "Who is going to help us?". Across the trajectory of their illness, interactions with healthcare professionals gave little reassurance to YP and their families of a positive prognosis due to their limited understanding of the disorder, lack of treatment options and support systems. One YP had experienced seizures for nine years and another for four, the latter was initially misdiagnosed with epilepsy and had visited several therapists who had no knowledge of NES.

However, research has shown that YP with a chronic illness attempt to normalise their lives if possible in the context of education and develop strategies to cope (Ferguson & Walker, 2014). Additionally, YP with a chronic illness such as NES take an increasing role in the self-management of their disorder whilst also negotiating integration into their day-to-day lives with their tutors and peers who may not always understand (Flick & Röhnsch, 2024; Lerch & Thrane, 2019). The YP in this study took control of their own education of the disorder, coping strategies and management of NES by researching, explaining to others, understanding themselves and what they can cope with, such as work limits, missing out on events and having to rest.

The professionals reported having limited or no understanding of NES, believing it to be too rare or specialised a condition for them to know about irrespective that all professionals had had contact, or heard of students, clients or family with the disorder. Previous literature has reported that people with NES often experience poorer quality of healthcare and gaps in understanding and knowledge (Annandale, Vilyte & Pretorius, 2022). For example, a systematic synthesis of 21 qualitative studies of patients experiences of NES (Rawlins & Reuber, 2016), found that negative experiences of healthcare professionals' knowledge and understanding were common and expected by patients and this reiterates the experiences in this study.

Although at risk of elevated negative outcomes (De Aveirio et al., 2024), the legitimacy of an organic diagnosis of epilepsy promotes better social and professional understanding (Peacock et al., 2023), however, an NES diagnosis leads to experiences of stigma and exclusion because of limited research, training and therefore understanding (Karakis et al., 2020; Rawlings, Brown & Reuber 2017). All the YP and their P/Cs had experience' of stigma and exclusion due to the lack of understanding and knowledge of others, for example one parent reported the assumption that their YP had epilepsy when they mentioned seizures and another YP was told by friends' that their seizures were "*not real seizures*".

None of the YP and P/Cs in this study experienced explanations of NES which left them fully understanding the disorder and its causation, however, clarification of a diagnosis and clear explanations conveyed in a way which is meaningful for the recipient affect the way in which a diagnosis of NES is accepted (Karterud, Risør & Haavet, 2015), and can affect future engagement with healthcare professionals (Smith, 2014). The use of psychoeducation when delivering a diagnosis empowers the patient, their families and carers through education about their disorder and enables them to make informed decisions about pathways to recovery (Oliveira & Dias, 2023).

When psychoeducation is used to explain and promote the self-management of NES, seizures may diminish or cease altogether (Mayor et al., 2013). Additionally, previous studies (Cope et al., 2017; Gurcan et al., 2022) suggest that psychoeducation at the earliest opportunity promotes understanding, confidence when explaining the disorder to others, better management and outcomes and less emergency service use.

3.6 Limitations

Some limitations existed within this study. This was a small sample size, 13 in total, within that were sub-sample groups. YP included four females and therefore as NES is a heterogeneous disorder there were limited representation of symptoms or differentiation in experience, due to size and gender. Additionally, the study took place in a small area of Wales and experiences could differ between health boards. Finally, due to the limited knowledge and understanding of the small sample of professionals it was problematic to compare and contrast experiences between the groups.

3.7 Conclusion and implications

This study on NES is the first in Wales, UK. Four YP were interviewed about their experiences of NES, four P/Cs their perceptions, and five health and well-being professionals their knowledge and understanding of the disorder. Three key themes emerged: Explanations of NES, the impact of NES and “who’s going to help me?”.

YP had consistently poor experiences with healthcare professionals throughout the course of their illness due to limited explanations, treatment and knowledge of the disorder. YP and their families sought their own education about NES, and found they had to explain it to others, including teachers, lecturers, counsellors and peers. This was reiterated from the limited knowledge and understanding from the health and well-being professionals despite them having contact with clients with NES. However, this study highlighted to professionals the limitations of their knowledge and lack of a ‘safe space’ for care.

Although NES impacted YPs’ mental health, feelings of isolation and ‘being different’ to their peers, YP developed positive levels of self-understanding and developed strategies to cope with everyday life. Additionally, although their primary support network was their family, apart from one YP who had a supportive friendship group throughout, there was no external opportunity or psychoeducational support for YP with NES and their families to improve YPs’ outcomes.

This relatively common yet poorly understood disorder, often misdiagnosed as epilepsy (Huff, Lui. & Murr, 2024) warrants further investigation in order to provide education to those working with YP with NES in the health and well-being sectors. Additionally, the provision of psychoeducational support systems for YP and their families would improve outcomes and aid recovery.

Chapter four:

Reflective Chapter.

This chapter is a reflective piece about the process of my master's dissertation research using Gibb's Reflective Model (1988) as a framework. It follows the whole process and draws upon my experiences and emotions as the researcher. This was an applied research study and therefore involved recruiting and interviewing members of the public who met the criteria for my chosen topic. Initially, my title was:

'The experiences of young people (YP) with Non-epileptic seizures (NES), the perceptions of their parents and the knowledge and understanding of professionals who work with them'. However, this felt like a longwinded title and so after discussions with my supervisor, I decided on the title,

'Understanding the experience of Non-epileptic seizures in young people: A multi-perspectival qualitative analysis.'

I have not come across a multi-perspectival approach in any papers throughout my literature search, or previous study, so I was pleased that I could research from a different angle. Additionally, after communications with two medical experts in the field of neurology and functional disorders in the UK, I discovered there is no research on NES in Wales and this reiterated to me that I had chosen the right topic.

I had decided previously that I was going to use a qualitative approach to research in order to gain deep and meaningful insight into the experiences of YP with NES and their family's perspective, whilst also examining what the level of understanding was from medical and well-being professionals. After recruiting participants through social media and approaching relevant professionals via their workplace, I used semi-structured interviews to collate data and thematic analysis to analyse. For some participants discussing their own personal mental health difficulties and those of their family, semi-structured interviews allowed an element of flexibility to give truly authentic results (Clarke and Braun, 2017).

Drawing attention to Gibbs' section on feelings I will now describe how I felt throughout the process. Initially, I felt that one of the most difficult decisions for me was, what am I going to call the seizures from both an academic and socially acceptable viewpoint? A lot of the research I had already read used variable terminologies for the disorder, as had people I had met, leaving me to feel confused as to which terminology to use. Terminologies read included but were not limited to: Non-Epileptic Attack Disorder, Psychogenic Nonepileptic seizures and Dissociative seizures. I decided on Non-epileptic seizures purely so that the reader could note that the seizures, 'were not epileptic'. They had a psychological origin and not an organic basis.

I was excited about starting the process. Due to personal experiences, I already had some knowledge and was enthusiastic in furthering my learning via the University library. My own experience had shown me that there are young people trying to cope in society with this disorder with little or no support and so it was very important that I did not allow any bias to affect my ability to research. After ethical approval had been met, I was keen to get started. I felt that I was very well prepared as I am an organised person and spent September and

October of 2024, making connections with YP, their family members and professionals via social media and workplaces. One thing that I found difficult, and frustrating was that I could not give professionals a true explanation of the topic for their interviews as I did not want them to Google NES if they did not know what it was. I had to explain that I was researching around mental health disorders, and all would become clear in the interview. I felt really conflicted by this as I did not want to appear deceptive. I discussed this with my supervisor and a previous research lecturer, and they reassured me that I was not being deceptive as I wanted a true baseline account of their knowledge and understanding of NES.

I was pleased that YP were keen to share their experiences. I had the impression that they wanted someone to talk to who understood what non-epileptic seizures were. I was also relieved that I did not have to chase people to participate, and it did not take too long for consent forms to come back. I ended up with 13 participants, which was adequate purposive sampling for a qualitative study (Vasileiou et al., 2018).

There were a couple of occasions when I felt anxious, and this took me by surprise. I knew already that I have difficulties with computer processes and sequencing as I have Dyscalculia and so, having not done online interviews before, which involved recording and then transcribing on Microsoft Teams, this made my heart race, and I could feel panic rising. I practiced a few times prior to my first interview so that I felt more confident. However, the first time I had to do an interview I felt anxious. I decided to use calming techniques and read up about massaging either side of your ears as I had read this calms the Vagus Nerve. I closed my eyes, did the box breathing method too and thankfully this worked for me, and I was able to continue with the interviews, prepping myself in this way each time.

Interviewing YP with a chronic illness and their families could be classed as highly emotive, especially because of my own family experience of NES. For some interviewers it may be very difficult to remain focused, objective and yet still express empathy. I felt that I was able to do this well and this is, in part, due to my therapeutic work as a Play Specialist Support Worker with toddlers with complex and additional needs and their families. This requires a certain amount of objectivity in order to achieve positive outcomes for the child. This does not mean that I do not care or am not emotionally moved by the experiences I witness; it means that I am able to listen, make a connection, whilst remaining objective and focused on the aims for both the child I am working with, and the YP I am interviewing. However, at times it made me feel sad to hear of the impact of NES on the lives of YP and their families. Additionally, the negative way in which young people were spoken to sometimes, due to the lack understanding of the disorder and that it was still affecting the YP many years after onset. The isolation they felt, the loss of time learning and developing at one of the most important times of their lives was equally unsettling, as too was hearing about related family disagreements and frustration.

It was also very interesting listening to the young people talk about their seizures and how different the presentations were for each person. The more I read about the disorder, the more I understood about somatic symptoms and a person’s physiological response to psychological trauma. I felt in awe of the young people as they tried to navigate their way through their lives with little support.

Alternatively, interviewing the professionals was enlightening yet disturbing to me. Between them the five professionals had many years' experiences of working in the mental health sector both medically and in the health and well-being of YP. The limited knowledge of professionals on, not only NES, but seizures, care of, point of contact for first aid and their settings policies for processes of care was eye-opening. In comparison to my own line of work in the early years sector, where it is mandatory to have a Safeguarding and First Aid qualification, as well as continuing professional development in Prevent, Encompass and Adverse Childhood Experiences (ACE's), I felt quite perturbed that this level of attention to detail is not carried out within all educational and health settings where vulnerable children and young people are educated or cared for.

Once I had completed the interviews, I spent most of December transcribing the scripts. My preferred method was to have hard copies of scripts, a pencil and highlighters so that I could make notes in the margins. Following Braun and Clarkes (2006) thematic analysis stages, I read and re-read to familiarise myself with the scripts. Over this period, I often found myself waking up at nighttime with thoughts I needed to jot down, or I would make notes on my phone. I started to realise that I had taken on a really big job interviewing three groups and soon there were a lot of topics developing. In order to develop themes after the scripts had been coded, I drew mind-maps to help me visualise. Initially I ended up with seven themes!

These were all relevant and all with supporting literature; however, some of these topics such as treatments, and Autism and NES warranted having their own paper and research, especially in Wales. I had to make a decision about how I could balance the data I had from the YP and their families with the equating or contradictory data I had from the professionals. I was eventually able to condense themes to three which reflected the main areas discussed by my sample group whilst also incorporating some of the other topics developed.

When evaluating and analysing my research, in line with Gibbs third and fourth sections, I feel that I was able to remain consistent in my time management throughout the whole research process. My passion motivated me. Themes raised were compatible with previous literature for children, adolescents and adults with NES (Jordan et al., 2019; McWilliams et al., 2016). However, one theme stood out for me which differed. The YP I interviewed had all had good educational support systems, even though NES was not understood. Support systems were bespoke, and person centred. This had not been the case in the literature I had read previously (Flewelling et al., 2020a; Tanner et al., 2022) and I wondered if this may be due, in part, to the recent Additional Learning Needs and Educational Tribunal (Wales) Act 2018. It could be possible that educational staff in Wales have robust systems and pathways of support but not the medical or additional needs knowledge.

I am pleased that I remained determined in being specific with my age group of 18-25 years as this age group had not been studied. Also, I am glad that I was able to compare professionals' knowledge and understanding of NES with YP's experiences. When I think about what worked well, I believe I was able to make a good connection with YP and their families when they were being interviewed. I felt attuned to their needs and this in turn enabled them to open-up to me fully, giving good in-depth data.

On reflection, the main area I would do differently would be to consider my questions for interview. I feel that the broad range of my questions for YP and their families invited too much scope for answers and therefore themes, there was so much I could have discussed, and it was difficult to limit this and be concise. The amount of information was actually quite overwhelming, and I could have focused on a more specific line of questioning. However, because it was qualitative semi-structured interviews and therefore flexible, I understand that one can never predict where the participants' answers will go and how much they will want to talk.

In conclusion, for stage five of this reflection, I have been proud of myself in undertaking the topic of NES for my applied research dissertation and been consistently determined to learn and understand as much about the topic as I can. As discussed earlier, I feel that I did go into this research with a possible preconceived idea from the research I had read of how YP were going to talk about school, college and university support. This has taught me that one should never approach research with a preconceived idea, the researcher must always be non-biased.

Finally, for future students doing an applied research dissertation I would recommend deep thinking about a topic you passionately want to research at the earliest opportunity as this drives your motivation and wish to read and learn. It also enables you to stay within your time constraints and not procrastinate.

Throughout the process of my dissertation, I have been acutely aware that the people that I have been working with in my study, especially the young people and their families, are really lacking in access to support and opportunities for knowledge and understanding of non-epileptic seizures. I have come to understand myself, that I personally have an opportunity, if not a duty, to use the knowledge I have gained in order to better the lives of those affected and to educate those who do not understand, especially those with access to helping and supporting young people. With this in mind, I have wavered between either doing a PhD to promote further research on this topic in Wales, or to work directly with young people with mental health disorders and non-epileptic seizures to aid their recovery and improve their outcomes. Additionally, I am thinking I would like to promote and provide education and training to professionals who work with young people in the health and well-being sector.

Moving forward, I shall be using the research skills and knowledge learnt to train to be a psychotherapist specialising in adverse experiences, trauma and Non-epileptic seizures whilst promoting awareness and understanding of the disorder. I have already had conversations with a leading Doctor in psychogenic seizures and prolonged exposure therapy in New York, America who runs successful programmes on this disorder and invites clinicians from Europe and the UK to shadow her work in this field.

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