Quality of Life and the Caregiving Experience in Functional Neurological Disorder.

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Thesis Portfolio Abstract

Background: Functional Neurological Disorder (FND) is a condition characterised by neurological symptoms which are understood in relation to alterations in brain network functioning (Bennett et al., 2021; Hallett et al., 2022). FND is associated with significant impacts on the lives of affected individuals, and emerging evidence suggests that carers may also experience substantial psychological, social, and relational impacts.

Aims: This thesis aimed to contribute to the emerging literature by exploring the quality of life (QoL) and lived experience of carers of individuals with FND.

Methods: A systematic review was conducted to narratively synthesise the existing literature relating to the QoL of caregivers of individuals with FND. In addition, a qualitative study using inductive reflexive thematic analysis (RTA) explored the lived experiences of carers of young people experiencing non-epileptic seizures (NES) as a presentation of FND.

Results: The systematic review identified 11 papers and demonstrated that caregiving in the context of FND is associated with reduced QoL, particularly within psychological and social domains. Findings also highlighted the influence of wider relational and healthcare systems on caregiving experiences. The qualitative study generated four themes and associated subthemes, conceptualising caregiving as an ongoing process characterised by uncertainty, adaptation, and interaction with wider systems.

Conclusions: This thesis portfolio illustrates that caregiving in the context of FND extends beyond the practical demands of caregiving. Carers are often directly affected by uncertainty, advocacy demands, system navigation, and wider relational impacts, underscoring the importance of systemic and psychologically informed approaches to support.

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Chapter One: Thesis Portfolio Introduction

Introduction to Functional Neurological Disorder

Functional Neurological Disorder (FND) is a condition characterised by neurological symptoms associated with alterations in the functioning of brain networks, rather than structural neurological pathology (Bennett et al., 2021; Hallett et al., 2022). FND can present with a broad range of symptoms affecting motor, sensory, cognitive, and perceptual functioning, including limb weakness, movement disorders, sensory disturbance, speech difficulties, and seizure-like episodes (Finkelstein et al., 2025). Symptom severity and progression varies, ranging from mild and intermittent difficulties to severe, persistent, and life-changing impairment (Mavroudis et al., 2024).

FND is increasingly recognised as a common presentation within neurological services. FND symptoms, in conjunction with other functional and psychological symptoms, were identified by Stone et al. (2010) as the second most common category of presentation in neurology clinics after headache. A recent systematic review estimated an incidence of approximately 10-22 cases per 100,000 people annually, with prevalence estimates ranging from 80-140 per 100,000 in the general population (Finkelstein et al., 2025). In the United Kingdom, approximately 8,000 new diagnoses are made each year, with an estimated 50,000-100,000 individuals living with the condition (Bennett et al., 2021; Mavroudis et al., 2024). FND occurs across the lifespan, including within paediatric and older adult populations (Chouksey & Pandey, 2019; Yong et al., 2023).

Historical Development and Terminology

Historically, FND presentations have been understood according to societal and medical understandings of the time. In Ancient Mesopotamia, Ancient Greece, and throughout the Middle Ages, functional symptoms were frequently interpreted through supernatural or spiritual frameworks, with treatment approaches reflecting these beliefs (Raynor & Baslet,

2021). The term “hysteria” later became prominent, referring to symptoms attributed to dysfunction of the female reproductive system (Raynor & Baslet, 2021). During the nineteenth century, physicians and neurologists such as Charcot moved away from explanations centred on reproductive dysfunction, instead conceptualising symptoms as a disorder of the nervous system, while Freud later understood symptoms as manifestations of unconscious psychological conflict through processes of “conversion” (Raynor & Baslet, 2021; Velazquez-Rodriquez & Fehily, 2023). These early conceptualisations contributed to longstanding uncertainty regarding the nature of functional symptoms and the position of such presentations within medicine (Kanaan, 2022).

The diagnostic frameworks and terminology relating to FND have changed considerably over time. Earlier editions of the International Classification of Diseases (ICD) and the Diagnostic and Statistical Manual of Mental Disorders (DSM) classified symptoms under terms such as “somatoform disorder” and “conversion disorder” (Velazquez-Rodriquez & Fehily, 2023). Diagnostic approaches required the exclusion of neurological explanations or feigning, and the inclusion of a psychiatric explanation such as trauma, but challenges arose since feigning could be difficult to exclude and research did not consistently demonstrate relevant trauma history among individuals (Kanaan, 2022; Keynejad et al., 2019; Ludwig et al., 2018). Although trauma, adversity, and stress are recognised as important and relevant experiences for some individuals with FND (Ludwig et al., 2018; Paredes-Echeverri et al., 2022; Pun et al., 2020), contemporary understandings acknowledge that these experiences are not universal nor necessary for diagnosis. Reflecting this shift, the DSM-5 (American Psychiatric Association, 2013) removed the requirement for identifiable psychological stressors.

The terminology used to refer to FND remains varied and, at times, contested. While the DSM-5 (American Psychiatric Association, 2013) uses the term “Functional Neurological Symptom Disorder” (FNSD), “Functional Neurological Disorder” is more commonly used within

clinical and research settings (Kanaan, 2022). Other terms historically associated with FND, including “psychogenic”, “conversion”, and “dissociative”, continue to be used variably within the literature (Bratanov et al., 2023). Terminology is clinically significant, as the language used to describe symptoms may contribute to uncertainty among clinicians and patients regarding the conceptualisation of the disorder (Ding & Kanaan, 2017; McLoughlin et al., 2024), and may be perceived as offensive where it implies symptoms are imagined or fabricated (Stone et al., 2002).

Terminology relating to seizure presentations, for example, varies and includes terms such as psychogenic non-epileptic seizures (PNES), non-epileptic attack disorder (NEAD), dissociative seizures, pseudoseizures, and functional seizures. Terms such as “pseudoseizures” and “conversion disorder” can be considered offensive, implying a person is faking or malingering in some way, and can contribute to stigma (Loewenberger et al., 2020; Walsh et al., 2024), whereas terms referring to “functional” or “non-epileptic” seizures have generally been found to be more acceptable (Ding & Kanaan, 2017; Loewenberger et al., 2020). Given the focus of the current thesis on caregiving experiences, the term “non-epileptic seizures” (NES) is used throughout, as literature has suggested this terminology is generally considered acceptable by caregivers (McWilliams et al., 2016; Morgan et al., 2013).

Contemporary Understanding and Treatment Approaches

Contemporary understandings of FND increasingly adopt biopsychosocial perspectives, conceptualising symptoms as arising through complex interactions between biological, psychological, and social processes (Joos et al., 2023; Kola & LaFaver, 2022). There has also been increasing recognition of potential neurobiological mechanisms involved in FND, including altered neural network functioning, neurotransmitter systems, and neuroplasticity (Kozlowska & Scher, 2024; Mavroudis et al., 2024). Contemporary models therefore move away from dualistic understandings of mind and body, instead recognising interactions between neurological,

psychological, and social processes in symptom development and maintenance (Bennett et al., 2021).

Recent diagnostic approaches emphasise the identification of positive clinical signs, such as Hoover's sign in functional limb weakness, positioning FND as a 'rule-in' diagnosis rather than a diagnosis of exclusion (Bennett et al., 2021; Stone, 2025). However, diagnostic uncertainty and inconsistency can still occur, with challenges in assessment and differential diagnosis discussed within the literature (Bennett et al., 2021; Filho & Mutarelli, 2022; Kirkwood & Mark, 2022). Misdiagnosis may occur particularly in atypical presentations, or where symptoms overlap with neurological conditions such as epilepsy and Parkinson's disease (Baglioni et al., 2024; Carle-Toulemonde et al., 2023). Individuals with FND frequently report lengthy diagnostic journeys and experiences of misdiagnosis (McLoughlin et al., 2025; Pritomanova et al., 2026), reflecting the complexity of FND within healthcare systems.

Given the heterogeneity of FND, multidisciplinary management is often considered beneficial, incorporating neurological and psychological perspectives alongside physiotherapy, occupational therapy, and speech and language therapy where appropriate (Aybek & Perez, 2022; Bennett et al., 2021; Keatley & Molton, 2022). Psychological intervention is commonly a key component of treatment, with evidence suggesting positive effects (Gutkin et al., 2021). For example, treatment of non-epileptic seizures may include psychoeducation and formulation within a biopsychosocial framework, with therapeutic approaches including Cognitive Behavioural Therapy (CBT), Acceptance and Commitment Therapy (ACT), and psychodynamic approaches (LaFaver et al., 2021).

Although FND is increasingly recognised as a legitimate and disabling condition, stigma and misunderstanding can still occur within healthcare systems. The involvement of psychological formulations and interventions may sometimes be interpreted as implying that symptoms are fabricated or that the individual is somehow at fault (Fairclough et al., 2014;

Staton et al., 2024). Individuals may also question the diagnosis where they do not identify with psychological explanations for their symptoms (Fairclough et al., 2014), reflecting a persistence of dualistic understandings of physical and psychological health. Individuals with FND frequently report dismissal, invalidation, and delegitimisation within healthcare contexts (Foley et al., 2024; Walsh et al., 2024). A scoping review identified stigmatising attitudes among healthcare professionals, including perceptions that symptoms are "fake" or that individuals with FND are "difficult" or "time wasters" (Annandale et al., 2022).

The Impact of FND Beyond the Individual

FND is associated with substantial functional impairment and reduced quality of life (QoL). Individuals with FND have been shown to have a reduced QoL (Gelauff et al., 2018; Jones et al., 2016). Studies have demonstrated levels of disability and reduced functioning comparable to those observed in other chronic neurological conditions, including Parkinson's disease and epilepsy (Anderson et al., 2007; Karakis et al., 2014), alongside elevated levels of psychological distress and psychiatric comorbidity (Patron et al., 2022; Tinazzi et al., 2020).

Symptoms are often experienced as fluctuating and unpredictable, contributing to uncertainty and distress (Dosanjh et al., 2021; Walsh et al., 2024). The impact of FND frequently extends beyond symptoms alone, affecting educational, occupational, social, and relational functioning; individuals have reported disruption to daily life, social participation, identity, and relationships (Dosanjh et al., 2021; McWilliams et al., 2016; Szasz et al., 2025; Walsh et al., 2024). Additionally, FND is associated with high levels of healthcare utilisation, including repeated medical investigations, lengthy diagnostic journeys, and emergency presentations (O'Mahony et al., 2024; Watson et al., 2023).

Given the substantial functional and psychosocial effects of FND, its impact may extend beyond the individual. Family members and friends may become involved in emotional support, practical care, symptom management, and navigating healthcare systems. In paediatric

contexts, for example, caregivers may play a central role in day-to-day management and treatment engagement. Evidence suggests that caregivers experience burden and reduced quality of life themselves (Burn et al., 2025; Karakis et al., 2020a). Caregiver experiences may also have wider relational and clinical relevance. Within adult FND, caregiver burden has been demonstrated to relate reciprocally to patient psychosocial wellbeing (Karakis et al., 2020a). In paediatric FND, family unwillingness to accept the diagnosis has been associated with poorer outcomes (Maitra et al., 2025). Understanding caregiver experiences may therefore be important in recognising the impact of caregiving itself, as well as in supporting wider family adjustment and engagement with care. Despite this, research relating to the experiences and wellbeing of caregivers of individuals with FND remains comparatively limited.

The terms “carer” and “caregiver” are both used within the literature to describe individuals who provide unpaid support to another person due to illness or disability. Within this thesis, “caregiver” is primarily used when discussing the systematic review in order to remain consistent with the terminology used in broader international literature. “Carer” is used within the empirical paper, reflecting the terminology commonly used within UK healthcare contexts. The terms are used interchangeably throughout the thesis to refer to informal unpaid support provided by family members or others close to the individual with FND.

Thesis Overview

This thesis aims to contribute to current understanding of caregiving experiences within the context of FND. Chapter Two presents a systematic review synthesising existing literature relating to the QoL of caregivers of individuals with FND. Chapter Three provides a brief bridging chapter linking the systematic review to the empirical study presented in Chapter Four, a qualitative study exploring the experiences of caregivers of young people with NES. Finally, Chapter Five critically reflects on the thesis as a whole; considering the strengths and limitations of the work, implications for clinical practice, and directions for future research.

Chapter Two: Systematic Review

Quality of Life in Caregivers of Individuals with Functional Neurological Disorder: A Systematic Review

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Abstract

Purpose

Functional Neurological Disorder (FND) is associated with substantial disability and psychological distress, yet the impact of caregiving on informal caregivers' quality of life (QoL) remains underexplored. This review aimed to synthesise evidence examining caregiver QoL in FND, conceptualising caregiver burden and psychological distress as mechanisms shaping QoL rather than discrete outcomes.

Methods

Five databases (CINAHL Ultimate, MEDLINE Ultimate, PsycINFO, PubMed Central, Scopus) were searched for studies published between January 2013 and November 2025. Eligible studies included informal caregivers of individuals with FND and reported caregiver QoL, wellbeing, psychological impact, or burden. Methodological quality was appraised using the Quality Appraisal of Diverse Studies (QuADS) tool. Findings were synthesised narratively, conceptualising caregiver QoL as the overarching outcome shaped by interrelated psychological and contextual mechanisms.

Results

Eleven studies were included (six quantitative, five qualitative). Quantitative evidence indicated mild to moderate caregiver burden and elevated anxiety and depression, with psychological aspects of QoL more affected than physical domains. Qualitative findings described reduced QoL through emotional labour, vigilance, advocacy demands, stigma, and disruption to social, occupational, and family life as key contributors to reduced QoL.

Conclusions

Caregiving for individuals with FND is associated with meaningful impairments in caregiver QoL, particularly in mental and social domains. Caregiver-inclusive clinical approaches and further high-quality research are needed.

Plain English Summary

People with Functional Neurological Disorder (FND) often experience significant difficulties that can affect many areas of life, yet less attention has been given to the experiences of family members and other informal caregivers who provide support. Understanding the impact of caregiving is important because caregivers play a central role in supporting individuals with FND, and they might experience reduced wellbeing and quality of life themselves.

This review explored how caring for someone with FND affects caregivers' quality of life, as well as how factors like psychological distress, caregiving burden, stigma, and interactions with services might contribute to these experiences.

Eleven studies were included in the review. Findings suggested that caregivers often experience anxiety, depression, and emotional difficulties, as well as disruption to family, social, and working life. Many caregivers described feeling vigilant, unsupported, and responsible for navigating healthcare systems and advocating for their relative.

The findings suggest that caregiving for someone with FND can have significant impacts on caregivers' mental and social wellbeing. Better recognition of caregiver experiences and more caregiver-inclusive approaches in healthcare services might help improve support for both caregivers and individuals with FND.

Introduction

Functional Neurological Disorder (FND) is a condition characterised by genuine neurological symptoms without structural abnormalities which is understood to sit at the interface of neurology and psychiatry [1]. FND can present with a wide range of symptoms affecting voluntary motor, somatosensory, and perceptual systems, including seizure-like episodes, motor disturbances (e.g., limb weakness, tics, gait abnormalities), and sensory, speech, or cognitive symptoms [2, 3].

FND occurs across the lifespan, with cases reported from early childhood to late adulthood in the literature [4, 5]. Epidemiological estimates suggest an incidence of 10-22 per 100,000 people and a prevalence of 80-140 per 100,000 in the general population [2], while targeted paediatric studies estimate an incidence rate of between 1.3-18.3 per 100,000 children [6-8].

FND is associated with substantial functional impairment, reduced quality of life (QoL), and high levels of psychological distress. Individuals with functional motor symptoms have been shown to have similar levels of disability and physical health-related QoL as those with Parkinson's disease, alongside poorer mental health-related QoL and higher levels of psychological distress [9]. High rates of psychiatric comorbidity further evidence the psychosocial impact of FND on individuals [10].

Caregiving and QoL

QoL is conceptualised as a subjective, multidimensional construct encompassing individuals' perceptions of their physical health, psychological state, social relationships, and wider environmental context [11]. In caregiving research, QoL can therefore be understood not simply as an endpoint, but as a dynamic outcome shaped by ongoing psychological, relational, and contextual demands. Within this framework, experiences such as caregiver burden, emotional distress, and role strain can be conceptualised as mechanisms through which caregiver QoL is influenced, rather than as outcomes distinct from QoL.

Empirical and theoretical work within caregiving research supports this integrative conceptualisation. Howson and McKay [12] describe caregiver stress and burden as intertwined within QoL, and position psychological distress and identity disruption as central components influencing QoL. From a theoretical perspective, stress-process models of caregiving support these relationships by distinguishing between primary stressors (e.g., illness severity, the need for vigilance) and secondary stressors (e.g., role conflict, social strain), which together contribute to sustained psychological distress and broader impacts on everyday functioning [13]. Although such models do not explicitly frame outcomes in terms of QoL, they provide a robust conceptual foundation for understanding how caregiver burden and emotional distress accumulate across life domains, thereby shaping caregivers' overall QoL.

Purpose of this review

The purpose of this review is to synthesise and integrate quantitative and qualitative evidence examining the impact of caregiving for individuals with FND on the QoL of informal caregivers (e.g., family members, partners, friends). The review treats caregiver burden, psychological distress, stigma, and advocacy demands as interrelated mechanisms through which caregiver QoL is shaped, rather than as outcomes separate from QoL. By integrating evidence across methodological approaches, the review aims to provide a comprehensive account of how caregiving for individuals with FND affects caregivers' lived experience, wellbeing, and everyday functioning, which may in turn influence caregivers' capacity to provide ongoing support to individuals with FND.

The aim of the review is to answer the question: "*What is the impact of caregiving for individuals with Functional Neurological Disorder on the quality of life of informal caregivers?"*.

Methods

The completion of this systematic review was informed by Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) [14, 15] guidance. The review was prospectively registered with PROSPERO (CRD420251153860).

Search Strategy

CINAHL Ultimate, Medline Ultimate, PsycINFO, PubMed Central, and Scopus were systematically searched for studies published between 1 January 2013 and 3 November 2025. This timeframe reflected contemporary conceptualisation of FND, including its introduction as a diagnostic term in the DSM-5 [16], replacing earlier terminology such as conversion disorder.

To account for evolving terminology and inconsistent indexing within FND literature, searches incorporated both current and historical terms. In PubMed, keyword-based searches restricted to title and abstract fields were used, with automatic explosion of Medical Subject Headings (MeSH) restricted due to inconsistent indexing of FND-related terms and retrieval of irrelevant records. An example of the full search strategy is provided in Appendix A.

Eligibility Criteria

Inclusion Criteria

Studies were included if published in English and involving informal caregivers (e.g., family members, partners, friends) aged 18 years or older, providing unpaid care to individuals diagnosed with FND, including subtypes such as functional seizures or functional motor symptoms. Eligible studies were required to report caregiver-related outcomes, including QoL or wellbeing, psychological impact, or caregiver burden. Quantitative, qualitative, and mixed-methods designs were eligible, including cross-sectional surveys, cohort and case-control studies, interviews, and focus groups. Randomised controlled trials were eligible if caregiver outcomes were reported. The exposure of interest was the experience of providing informal care to an individual with FND; no specific therapeutic intervention was required for inclusion.

Exclusion Criteria

Studies were excluded if they focused on formal or paid caregivers (e.g., healthcare professionals or care staff), caregivers under 18 years of age, or caregivers of individuals with conditions other than FND unless FND-specific data were reported separately. Studies reporting only patient outcomes were excluded, as were case reports, editorials, commentaries, conference abstracts without full data, and review articles.

Screening and Study Selection

All records identified through database searching and clinical expertise were imported into Rayyan [17] for de-duplication and screening. Titles and abstract were screened against inclusion criteria, followed by full-text screening of potentially eligible studies.

Title and abstract screening was conducted independently by the first and third authors, with 100% of records screened by the third author to ensure reliability. Full-text screening was also conducted independently by the third author. Few disagreements were identified at either stage; all disagreements were resolved through discussion, with escalation to the second and last authors where necessary to support a final consensus. The study selection process was conducted in accordance with PRISMA guidelines.

Data Extraction and Management

Data were extracted using a structured framework developed in line with the PROSPERO protocol. Extracted study characteristics included author, year, country, study type and design, setting, FND subtype, and (where reported) age and illness duration of the care recipient. Caregiver characteristics included age, gender, relationship to the care recipient, employment status, and time spent caregiving.

Outcome data included caregiver QoL and wellbeing, alongside related indicators such as caregiver burden and psychological impact (e.g., anxiety and depression), as well as qualitative findings relating to caregiver experiences. Quantitative outcome measures and key

findings were recorded, while qualitative studies contributed author-reported themes. Associations or predictors of caregiver outcomes were extracted where examined.

All extracted data were managed using Microsoft Excel following export from Rayyan. Where multiple quantitative publications drew on overlapping caregiver samples, these were treated as a single cohort for descriptive outcomes to avoid double-counting, with secondary publications retained for unique analyses. Given heterogeneity across study designs, populations, and outcome measures, meta-analysis was not appropriate and findings were synthesised narratively. A summary table of study characteristics and extracted data is provided in Appendix B.

Quality Assessment

Methodological quality was assessed using the Quality Appraisal of Diverse Studies (QuADS) tool [18], selected for its suitability for appraising diverse healthcare research designs. QuADS comprises 13 criteria rated from 0 (criterion not addressed) to 3 (criterion comprehensively addressed), yielding a maximum possible score of 39. Rather than categorising studies into discrete quality bands (e.g., high, medium, low), QuADS encourages transparent reporting of appraisal scores which are used to inform interpretation. Full appraisal criteria are provided in Appendix C.

Quality appraisal was conducted by the primary reviewer, with 36.36% of studies independently appraised by a second reviewer, blinded to the primary ratings, to assess consistency. Discrepancies were resolved through discussion with reference to QuADS.

Synthesis

A narrative synthesis was conducted following guidance by Popay et al. [19]. Synthesis proceeded through descriptive tabulation of study characteristics and findings to identify patterns across the evidence base, followed by exploration of relationships within and between studies. Caregiver QoL was treated as the overarching outcome of interest, with caregiver

burden, psychological distress, stigma, and advocacy demands conceptualised as interrelated mechanisms shaping QoL.

Quantitative findings were synthesised narratively to examine patterns in caregiver burden, psychological impact, QoL, and stigma, with attention to consistency and direction of associations rather than effect size. Where multiple publications reported data from overlapping caregiver samples, these were treated as a single source to avoid double-counting, with secondary analyses used to inform interpretation of associations.

Qualitative findings were synthesised thematically using author-reported themes, grouped into broader domains to explore commonalities and differences in caregiver experiences across studies. Integration of quantitative and qualitative evidence was interpretative, with qualitative findings used to contextualise and elaborate quantitative patterns. The robustness of synthesis was considered with reference to methodological quality using the QuADS tool, with study quality informing interpretation of findings.

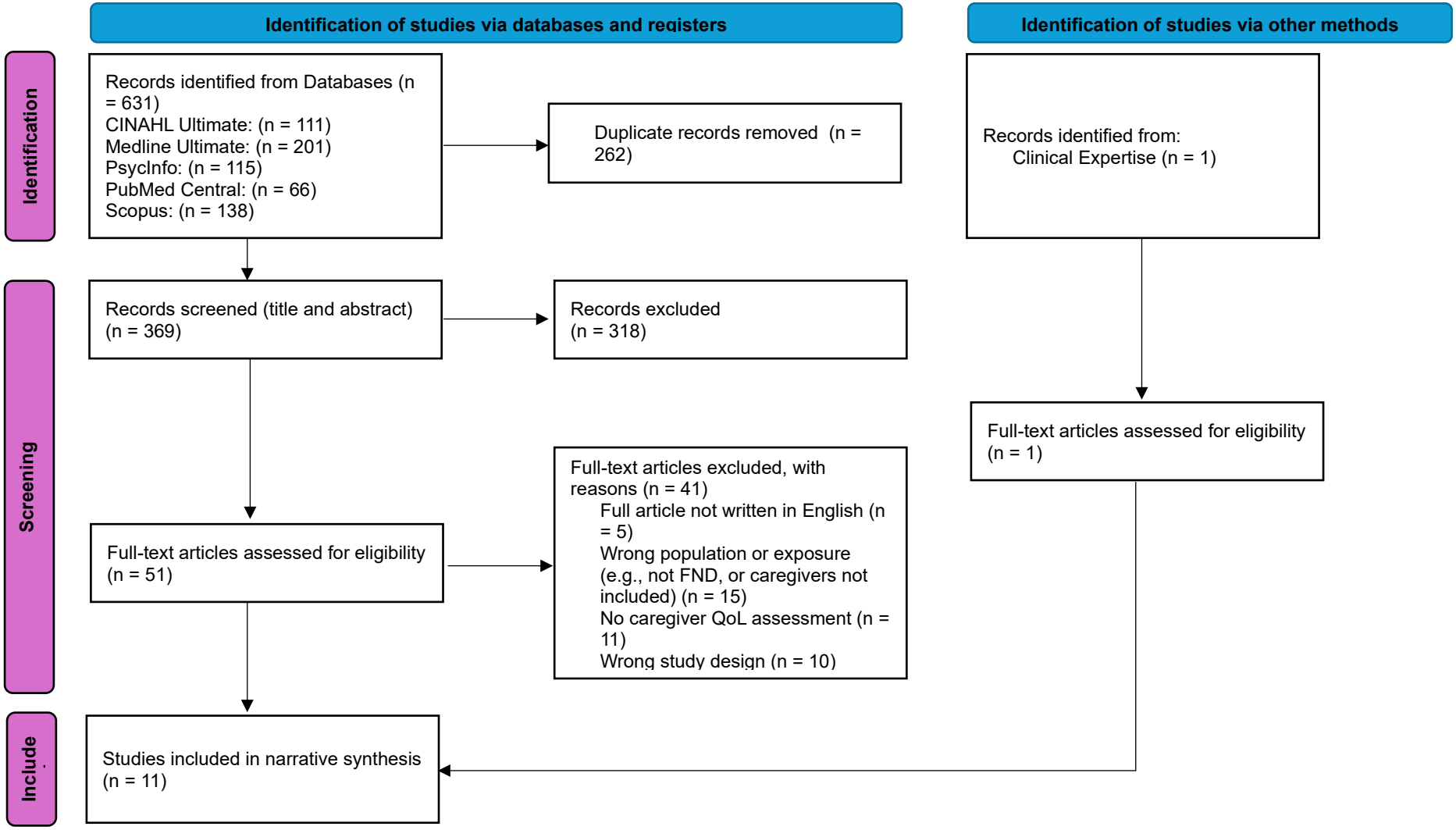
Results

Study Selection

Database searches identified 631 records, with one additional study identified through clinical expertise in the field. After removal of duplicates, 370 records remained for title and abstract screening. Following screening, 52 studies were retrieved for full-text review. Of these, 11 studies met the inclusion criteria and were included in the synthesis. The study selection process is summarised in the PRISMA flow diagram (Figure 1).

Figure 1

PRISMA flow diagram representing study selection



Summary of Study Characteristics

Eleven studies were included in the review, comprising six quantitative and five qualitative studies. A summary of characteristics is presented in Table 1.

All quantitative studies employed cross-sectional designs, while qualitative studies most commonly employed thematic analysis of interview data. Studies were conducted predominantly in the United States of America (USA) or the United Kingdom (UK), with one study conducted in Colombia. Eight studies were conducted in tertiary hospital settings, with the remainder in community contexts.

Care recipients included both adults and children diagnosed with FND, encompassing studies on functional seizures (n = 8), functional tics (n = 2), and broader conversion disorder (n = 1). Caregivers were informal and most commonly parents, partners, or other family members.

Four quantitative publications [20-23] were based on analyses of an overlapping caregiver cohort recruited from a tertiary epilepsy monitoring unit. To avoid double-counting non-independent data, these were treated as a single cohort for descriptive outcomes, with Karakis et al. [20] designated as the anchor paper. The remaining publications were retained to contribute unique analyses, including examination of associations and predictors of caregiver outcomes.

Table 1

A summary of study characteristics

Study Characteristics			Care Recipient Characteristics			Caregiver Characteristics		Outcomes examined	
Author (Year)	Country	Study Design	FND Subtype	Age	Illness Duration	Age	Relationship	Quantitative Measure(s)	Qualitative focus
Karakis, et al. (2020a)	USA	Quantitative – Cross-sectional	Functional Seizures	Mean = 36, SD = 13	Mean = 8, SD = 10	Mean = 43, SD = 12	Predominantly first-degree relatives	ZCBI, LSS, BDI, BAI	N/A
Tsamakis, et al. (2022)	USA	Quantitative – Cross-sectional	Functional Seizures	Mean = 37, SD = 14)	Mean = 9, SD = 10	Mean = 43, SD = 12	Predominantly first-degree relatives	ZCBI, LSS, BDI, BAI	N/A
Teagarden, et al. (2020)	USA	Quantitative – Cross-sectional	Functional Seizures	Mean = 36, SD = 14	Mean = 8, SD = 10	Mean = 43, SD = 12	Predominantly first-degree relatives	ZCBI, LSS, BDI, BAI	N/A
Karakis, et al. (2020b)	USA	Quantitative – Cross-sectional	Functional Seizures	Mean = 36, SD = 13	Mean = 8, SD = 10	Mean = 43, SD = 12	Predominantly first-degree relatives	ZCBI, LSS, BDI, BAI	N/A
Karakis, et al., (2014a)	USA	Quantitative – Cross-sectional	Functional Seizures	Mean = 41.84, SD = 11.44	Mean = 7.12, SD = 8.24	Mean = 47.44, SD = 9.67	Predominantly first-degree relatives	ZCBI, SF-36v2	N/A
Wardrope, et al. (2019)	UK	Quantitative – Cross-sectional	Functional Seizures	Adult patients	Not reported	Mean = 44.2, SD = 10.5	Not reported	PHQ-9, GAD-7, SF-12	N/A

McWilliams, et al. (2016)	UK	Qualitative – Thematic Analysis	Functional Seizures	Mean = 15.5	Not reported	Not reported	Predominantly first-degree relatives	N/A	Interview
Patel, et al. (2024)	USA	Qualitative – Thematic Analysis	Functional Seizures	Range = 12 – 18, Median = 14	Range = 0 - 10	Range = 33 - 51	Parents	N/A	Interview
Burn, et al. (2025)	UK	Qualitative – Thematic Analysis	Functional Tics	Mean = 15.2, Range = 12 – 18	Not reported	Not reported	Parents	N/A	Interview
Ludlow, et al. (2024)	UK	Qualitative – Thematic Analysis	Functional Tics	Mean = 13, SD = 1.3	Not reported	Mean = 43, SD = 4.9	Mothers	N/A	Interview
Mantilla and Rojas (2018)	Colombia	Qualitative – Method unclear	Conversion Disorder	Range = 9 – 17, Median = 13.5	Not reported	Not reported	Parents	N/A	Interview

ZCBI = Zarit Caregiver Burden Inventory, LSS = Liverpool Stigma Scale, BDI = Beck Depression Inventory, BAI = Beck Anxiety Inventory, SF-36v2 = Short Form 36 Version 2 Health Survey, PHQ-9 = Patient Health Questionnaire-9, GAD-7 = Generalised Anxiety Disorder-7, SF-12 = Short Form 12 Health Survey

Summary of Quality Appraisal

All studies were appraised using the QuADS tool. A second reviewer independently appraised a randomly selected four studies (36.36%). Weighted kappa indicated very strong inter-rater agreement (κ_w = .865, 95% CI [.756, .974], p < .001).

Methodological strengths and limitations varied across the evidence base. Quantitative studies generally demonstrated clear reporting of aims, appropriate use of validated outcome measures, and transparent analytic approaches. However, all employed cross-sectional designs, limiting causal inferences and assessment of change over time. The inclusion of longitudinal designs, or integration of qualitative components, would have strengthened the evidence base by enabling greater insight into caregiver experiences and stronger alignment with study aims. Sample sizes were small, often not explicitly justified, no studies reported a priori power calculations, reducing confidence in the robustness and generalisability of findings.

Qualitative studies showed variable methodological transparency. Several demonstrated clear alignment between aims, data collection, and analysis, producing rich, contextualised accounts of caregiver experiences. Common limitations included limited reflexivity, incomplete reporting of researcher positionality, and restricted demographic diversity. One qualitative study demonstrated limited and inconsistent methodological transparency, with contradictory reporting and sparse justification of analytic approach, as well as limited detail regarding coding procedures, which restricted confidence in the credibility of its findings.

In line with QuADS guidance, quality appraisal findings were used to inform interpretation rather than to categorise studies hierarchically, and no studies were excluded on the basis of quality. Detailed appraisal scores for individual studies are presented in Appendix D.

Synthesis of Findings

Impact on Measured QoL

Across the included studies, caregiving for individuals with FND was associated with meaningful impacts on caregiver QoL, particularly within psychological domains. Although only two quantitative studies examined QoL explicitly, both identified mental wellbeing as the most affected domain, indicating that psychological aspects of QoL may be especially vulnerable in this population.

Both quantitative studies drew on independent caregiver cohorts and employed different validated measures [24, 25]. Both compared caregivers of individuals with functional seizures to caregivers of individuals with epilepsy, and identified mental wellbeing as the most affected QoL domain. Karakis et al. [24] reported broadly comparable QoL between groups, with mental wellbeing more affected than physical wellbeing; Wardrope et al. [25] found poorer QoL outcomes among caregivers of individuals with functional seizures. Despite differing conclusions, both studies converge in highlighting psychological aspects of QoL as particularly vulnerable.

Qualitative studies provided richer insight into how QoL disruption manifests in daily life. Caregivers described widespread disruption, increased family stress, social isolation, and significant changes to roles and responsibilities, alongside identity disruption and loss of everyday routines as lives became organised around caregiving demands [26, 27]. Restricted participation in social, recreational, and occupational activities was commonly reported, characterised by missed opportunities, withdrawal from social life, and avoidance of activities due to symptom unpredictability and fear of escalation [27, 28]. These findings illustrate how caregiving demands translate into broader impairments in caregiver QoL beyond that captured by standardised measures like the Zarit Caregiver Burden Inventory.

One qualitative account described positive or ambivalent relational effects, including increased family closeness and a sense of unity [29]. However, these accounts coexisted with

descriptions of strain and exhaustion and did not offset broader QoL disruption. These findings arose from a study conducted in a different sociocultural context to other included studies, and with limited methodological transparency and quality, which may shape how these positive experiences are understood and interpreted.

Caregiver Burden and Psychological Distress

Caregiver burden and psychological distress emerged consistently across studies as key mechanisms through which caregiver QoL is shaped. Quantitative evidence demonstrated clinically relevant levels of caregiver burden, anxiety, and depression, while qualitative findings provided contextual insight into how this burden is experienced in everyday life.

Quantitative findings from a tertiary epilepsy monitoring unit (EMU) caregiver cohort indicated mild to moderate levels of caregiver burden alongside elevated symptoms of anxiety and depression [20]. Within this cohort, higher caregiver burden was significantly associated with greater psychological distress, highlighting emotional strain as a core contributor to reduced wellbeing. Similar patterns were observed in independent quantitative studies using distinct caregiver samples, including clinically significant anxiety and depression [25] and mild to moderate caregiver burden [24]. These findings suggest that psychological burden and distress are robust features of caregiving in FND and represent important determinants of caregiver QoL across cohorts, settings, and measurement approaches.

Qualitative studies extended these findings by illustrating how burden and distress are embedded within daily life through emotional labour, vigilance, and persistent fear and anxiety [26-28, 30]. Caregivers described living in a state of heightened alertness, characterised by fear and uncertainty regarding symptom onset, intensity, and progression. These experiences provide explanatory depth, illustrating how psychological strain translates into diminished QoL.

Several accounts framed symptom unpredictability as generating an ongoing requirement for caregivers to act as advocates on behalf of the care recipient, contributing to an ‘advocacy burden’ [26-28]. Caregivers described needing to continually explain, justify, and

seek support from wider systems, often in contexts of scepticism or misunderstanding. This persistent advocacy role was emotionally taxing and contributed to psychological strain. These findings align with quantitative evidence linking caregiver burden with psychological distress [20], suggesting that advocacy demands represent a key pathway through which uncertainty contributes to reduced QoL.

Stigma and Invalidation

Evidence of stigma and invalidation was identified primarily through qualitative studies, with limited quantitative support. Quantitative evidence from the EMU cohort indicated elevated perceived stigma among caregivers of individuals with functional seizures, measured using a stigma questionnaire developed for epilepsy [20]. Higher stigma was associated with greater caregiver burden and psychological distress, suggesting an indirect but meaningful impact on caregiver QoL.

Qualitative studies consistently described experiences of invalidation, including symptom minimisation, poor communication, and feeling blamed, discounted, or disbelieved by professionals and wider systems [26-28, 30]. These experiences were described as emotionally distressing and contributed to social isolation and ongoing advocacy demands. Together, the evidence suggests that stigma and invalidation function as contextual factors that exacerbate burden and distress, thereby shaping caregiver QoL.

Social, Relational, and Practical Consequences

Qualitative studies described caregiving for individuals with FND as involving substantial social, relational, and practical disruption with direct implications for QoL. Caregivers reported altered family roles, increased strain, and restricted social participation due to symptom unpredictability and caregiving demands [26-28]. Practical challenges included the need for clear guidance regarding school management and seizure response [30], disruption to paid employment [29], and managing poor communication between healthcare, education, and

social systems in the absence of clear care pathways [27, 28]. These findings highlight the pervasive, system-level impact of caregiving on QoL across multiple domains of everyday life.

Other Factors Associated with Caregiver Outcomes

Evidence on factors associated with caregiver outcomes was derived largely from secondary analysis of the EMU caregiver cohort, with support from independent studies. Higher caregiver burden was associated with male patient gender, poorer patient QoL, greater patient depressive symptoms, medication side effects, and higher caregiver anxiety, depression, and perceived stigma, with unemployment showing a non-significant trend towards higher burden [20-23]. Caregiver anxiety and depression were further associated with being a parent or sibling caregiver [23], and socioeconomic status (SES) showed differential associations, with higher SES linked to greater burden and poorer social functioning, and lower SES associated with higher anxiety [22].

Findings from independent cohorts supported these associations, identifying caregiver burden as the strongest correlate of poorer mental QoL [24] and highlighting anxious attachment style and poorer perceived relationship quality as predictors of psychological distress and reduced mental QoL [25]. Overall, the findings reinforce the view that caregiver QoL in FND is shaped by interacting psychological, relational, and contextual factors rather than caregiving demands alone.

Discussion

This review synthesised quantitative and qualitative evidence on the QoL of informal caregivers of individuals with FND, with particular attention to the psychological, social, and contextual factors through which QoL is shaped. Across methodologies and cohorts, caregivers consistently reported elevated psychological burden and distress alongside meaningful impacts on mental and social aspects of QoL. Rather than representing outcomes distinct from QoL, caregiver burden and psychological distress appear to function as key mechanisms through which QoL is compromised. These findings align with broader caregiver literature in

neurological conditions, where uncertainty, emotional labour, and sustained vigilance are well-established contributors to caregiver burden and reduced QoL [31-33].

Quantitative findings demonstrated mild to moderate caregiver burden and elevated symptoms of anxiety and depression across independent caregiver cohorts. Comparable levels of burden have been reported among caregivers of individuals with epilepsy [34, 35] and other chronic neurological conditions [36], where distress is frequently driven by symptom unpredictability and perceived responsibility for monitoring risk. However, caregiving in FND appears to involve additional challenges related to diagnostic ambiguity and contested legitimacy [26-28], which may amplify emotional strain and exert a disproportionate impact on caregiver QoL.

Qualitative findings extended this evidence by illustrating how caregiver burden in FND is embedded within daily life through chronic vigilance, emotional labour, and sustained advocacy demands across healthcare, education, and social systems. Caregivers frequently assumed responsibility for explaining, legitimising, and defending symptoms, often in the context of scepticism or misunderstanding. Similar patterns have been described in the wider literature on contested or poorly understood conditions, such as myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), where misunderstanding, scepticism, and dismissiveness disrupt relationships and compel caregivers to defend symptom legitimacy [37]. This conceptual overlap suggests that uncertainty and contested legitimacy may represent common mechanisms through which caregiver strain is intensified across conditions. Consistent with stress-process models of caregiving [13], these findings suggest that uncertainty, invalidation, and advocacy demands may function as secondary stressors which accumulate across relational and systemic contexts, intensifying caregiver burden and psychological distress. In keeping with broader models emphasising the role of uncertainty and reduced social support and validation in caregiving [38], advocacy burden may therefore

represent a distinctive pathway through which FND caregiving impacts psychological wellbeing and, in turn, QoL.

Explicit quantitative assessment of caregiver QoL was limited, but available evidence indicated that mental wellbeing was more adversely affected than physical domains, consistent with findings in epilepsy caregiving [39]. Qualitative accounts provided further depth, illustrating how reductions in QoL manifest through identity disruption, social withdrawal, and loss of valued roles and routines, echoing broader chronic illness caregiving literature [37].

Strengths and Limitations

A key strength of this review is the integration of quantitative and qualitative evidence to provide a comprehensive account of caregiver QoL in FND. This approach enabled both identification of caregiver outcomes and deeper understanding of the mechanisms through which QoL is shaped. The review followed a preregistered PROSPERO protocol and employed the QuADS tool, which is well suited to mixed-methods healthcare research. Methodological steps were also taken to ensure transparency and rigour, including careful management of overlapping quantitative samples to avoid double-counting non-independent data.

Several limitations should be acknowledged. All quantitative studies were cross-sectional, limiting causal inference and examination of change over time. Sample sizes were small, no studies reported a priori power calculations, and a substantial proportion of quantitative evidence was derived from a single cohort, which may disproportionately influence conclusions. Further, explicit quantitative measurement of caregiver QoL was limited, with few studies directly assessing this outcome. Qualitative studies provided rich insight but demonstrated variable methodological transparency, including limited reflexivity and incomplete reporting of analytic procedures in some cases.

Most studies were conducted in specialist settings within Western societies, and the restriction to English-language publications may have further limited the representation of non-Western perspectives within the evidence base. This may have narrowed the conceptualisation

of FND reflected in the review, as FND symptoms may be understood or conceptualised differently across cultural contexts. As a result, the generalisability of the findings to non-Western sociocultural and healthcare contexts may be limited.

Further, differences in healthcare systems may be particularly relevant when interpreting findings relating to advocacy burden and access to support, as caregivers navigating privately funded or insurance-based healthcare systems (e.g., the United States) may experience different practical and financial demands compared to those within publicly funded healthcare systems.

There was also a difference in the populations represented across study designs, with qualitative studies focusing on caregivers of children and young people with FND, while quantitative studies focused on caregivers of adults. This means that direct comparison across the evidence base should be approached cautiously, and findings should be considered with this in mind, as caregiver experiences and QoL may differ depending on the age and developmental stage of the person with FND. These limitations highlight the need for cautious interpretation while underscoring the importance of further high-quality research to strengthen the evidence base on caregiver QoL in FND.

Clinical and Research Implications

The findings highlight caregiver QoL as a key consideration in the care of individuals with FND. Caregiver burden, psychological distress, advocacy demands, and experiences of stigma emerged as interrelated mechanisms through which QoL is compromised, particularly in mental and social domains. Routine recognition of caregiver wellbeing within FND services may therefore be warranted.

Clinical practice may benefit from greater emphasis on clear communication, validation, and caregiver education, particularly around symptom explanation, prognosis, and management. Improved coordination across healthcare, education, and social care systems

may help reduce advocacy burden and uncertainty, which were consistently linked to poorer caregiver QoL.

Future research should prioritise longitudinal and mixed-methods designs to examine changes in caregiver QoL over time and clarify pathways linking burden, advocacy demands, and wellbeing. Greater use of caregiver-specific QoL measures and research across diverse healthcare contexts are needed to strengthen the evidence base. Future research should also address the differences in populations represented across study designs by quantitatively examining caregiver QoL among carers of paediatric populations and qualitatively exploring the experiences of caregivers of adults with FND. Further, given the prominence of uncertainty, advocacy demands, and system navigation in shaping caregiver QoL, there may be value in in-depth qualitative research exploring how caregivers make sense of and manage these challenges in specific contexts.

Conclusion

This review demonstrates that caring for an individual with FND is associated with meaningful impacts on caregiver QoL, particularly in mental and social domains. Caregiver burden, psychological distress, advocacy demands, and experiences of stigma emerged as interconnected mechanisms through which QoL is shaped and often compromised. By integrating quantitative outcomes with qualitative accounts, this review highlights caregiver QoL in FND as a multidimensional and contextually embedded construct, underscoring the need for caregiver-inclusive clinical approaches and further research to address the complex challenges faced by caregivers.

References

1. Mavroudis, I., Kazis, D., Kamal, F. Z., Gurzu, I.-L., Ciobica, A., Pădurariu, M., Novac, B., & Iordache, A. (2024). Understanding functional neurological disorder: Recent insights and diagnostic challenges. *International Journal of Molecular Sciences, 25*(8), 4470. https://doi.org/10.3390/ijms25084470
2. Finkelstein, S. A., Diamond, C., Carson, A., & Stone, J. (2025). Incidence and prevalence of functional neurological disorder: A systematic review. *Journal of Neurology, Neurosurgery & Psychiatry*, *96*(4), 383–395. https://doi.org/10.1136/jnnp-2024-334767
3. National Institute of Neurological Disorders and Stroke. (n.d.). *Functional neurologic disorder*. Retrieved July 4, 2024, from https://www.ninds.nih.gov/health-information/disorders/functional-neurologic-disorder
4. Chouksey, A., & Pandey, S. (2019). Functional movement disorders in elderly. *Tremor and Other Hyperkinetic Movements, 9*, 691. https://doi.org/10.7916/tohm.v0.691
5. Harris, S. R. (2019). Psychogenic movement disorders in children and adolescents: An update. *European Journal of Pediatrics*, *178*(4), 581–585. https://doi.org/10.1007/s00431-019-03317-8
6. Ani, C., Reading, R., Lynn, R., Forlee, S., & Garralda, E. (2013). Incidence and 12-month outcome of non-transient childhood conversion disorder in the UK and Ireland. *British Journal of Psychiatry*, *202*(6), 413–418. https://doi.org/10.1192/bjp.bp.112.116707
7. Raper, J., Currigan, V., Fothergill, S., Stone, J., & Forsyth, R. J. (2019). Long-term outcomes of functional neurological disorder in children. *Archives of Disease in Childhood*, *104*(12), 1155–1160. https://doi.org/10.1136/archdischild-2018-316519
8. Yong, K., Chin, R. F. M., Shetty, J., Hogg, K., Burgess, K., Lindsay, M., McLellan, A., Stone, J., KamathTallur, K., & Edinburgh Paediatric FND Study Group. (2023). Functional neurological disorder in children and young people: Incidence, clinical features, and

prognosis. *Developmental Medicine & Child Neurology*, *65*(9), 1238–1246. https://doi.org/10.1111/dmcn.15538

9. Anderson, K. E., Gruber-Baldini, A. L., Vaughan, C. G., Reich, S. G., Fishman, P. S., Weiner, W. J., & Shulman, L. M. (2007). Impact of psychogenic movement disorders versus Parkinson's on disability, quality of life, and psychopathology. *Movement Disorders*, *22*(15), 2204–2209. https://doi.org/10.1002/mds.21687
10. Patron, V. G., Rustomji, Y., Yip, C., & Jenkins, L. M. (2022). Psychiatric comorbidities in functional neurologic symptom disorder. *Practical Neurology, 21*(3), 71–75.
11. World Health Organization. (2012). *WHOQOL: Measuring quality of life*. Retrieved July 4, 2024, from https://www.who.int/tools/whoqol
12. Howson, C.-A., & McKay, E. A. (2020). Caregiving and quality of life. *The History of the Family*, *25*(2), 306–321. https://doi.org/10.1080/1081602X.2019.1666729
13. Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, *30*(5), 583–594. https://doi.org/10.1093/geront/30.5.583
14. Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & the PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *Annals of Internal Medicine, 151*(4), 264–269. https://doi.org/10.7326/0003-4819-151-4-200908180-00135
15. Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, *372*, n71. https://doi.org/10.1136/bmj.n71
16. American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed). https://doi.org/10.1176/appi.books.9780890425596

17. Ouzzani, M., Hammady, H., Fedorowicz, Z., & Elmagarmid, A. (2016). Rayyan—A web and mobile app for systematic reviews. *Systematic Reviews*, *5*(1), 210. https://doi.org/10.1186/s13643-016-0384-4

18. Harrison, R., Jones, B., Gardner, P., & Lawton, R. (2021). Quality assessment with diverse studies (QuADS): An appraisal tool for methodological and reporting quality in systematic reviews of mixed- or multi-method studies. *BMC Health Services Research*, *21*(1), 144. https://doi.org/10.1186/s12913-021-06122-y

19. Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., & Britten, N. (2006). *Guidance on the conduct of narrative synthesis in systematic reviews*. ESRC Methods Programme. https://doi.org/10.13140/2.1.1018.4643

20. Karakis, I., Morton, M. L., Janocko, N. J., Groover, O., Teagarden, D. L., Villarreal, H. K., Loring, D. W., & Drane, D. L. (2020a). Caregiver burden in psychogenic non-epileptic seizures. *Seizure*, *81*, 13–17. https://doi.org/10.1016/j.seizure.2020.07.007

21. Karakis, I., Janocko, N. J., Morton, M. L., Groover, O., Teagarden, D. L., Villarreal, H. K., Loring, D. W., & Drane, D. L. (2020b). Stigma in psychogenic nonepileptic seizures. *Epilepsy & Behavior*, *111*, 107269. https://doi.org/10.1016/j.yebeh.2020.107269

22. Teagarden, D. L., Morton, M. L., Janocko, N. J., Groover, O., Villarreal, H. K., Evans, L., Drane, D. L., & Karakis, I. (2020). Socioeconomic disparities in patients with psychogenic nonepileptic seizures and their caregivers. *Epilepsy & Behavior*, *110*, 107160. https://doi.org/10.1016/j.yebeh.2020.107160

23. Tsamakis, K., Teagarden, D. L., Villarreal, H. K., Evans, L., Morton, M. L., Janocko, N. J., Groover, O., Hewitt, K. C., Price, M. E., Loring, D. W., Drane, D. L., & Karakis, I. (2022). Depression and anxiety in caregivers of patients with functional seizures. *Epileptic Disorders*, *25*(2), 200–208. https://doi.org/10.1002/epd2.20014

24. Karakis, I., Montouris, G. D., Piperidou, C., Luciano, M. S., Meador, K. J., & Cole, A. J. (2014). Patient and caregiver quality of life in psychogenic non-epileptic seizures

compared to epileptic seizures. *Seizure*, *23*(1), 47–54. https://doi.org/10.1016/j.seizure.2013.09.011

25. Wardrope, A., Green, B., Norman, P., & Reuber, M. (2019). The influence of attachment style and relationship quality on quality of life and psychological distress in carers of people with epileptic and nonepileptic seizures. *Epilepsy & Behavior*, *93*, 16–21. https://doi.org/10.1016/j.yebeh.2019.01.028
26. Burn, O., Duncan, M., McAllister, E., Murphy, T., & Loewenberger, A. (2025). The journey to a functional tics diagnosis and experiences of post diagnostic support: Perspectives from adolescents and their parents. *Disability and Rehabilitation*, *47*(23), 6168–6179. https://doi.org/10.1080/09638288.2025.2477293
27. Ludlow, A. K., Anderson, S., Robinson, S., Owen, T., & Hedderly, T. (2024). An investigation into mothers' experiences of their children's functional tic-like behaviour and tic attacks. *PLOS ONE*, *19*(1), e0292742. https://doi.org/10.1371/journal.pone.0292742
28. McWilliams, A., Reilly, C., McFarlane, F. A., Booker, E., & Heyman, I. (2016). Nonepileptic seizures in the pediatric population: A qualitative study of patient and family experiences. *Epilepsy & Behavior*, *59*, 128–136. https://doi.org/10.1016/j.yebeh.2016.03.029
29. Mantilla, J. S. G., & Rojas, R. A. V. (2018). The visible and less visible in the suffering of a conversion disorder in children and adolescents: A qualitative study of illness explanatory models presented to caregivers of children and adolescents with conversion disorder. *Revista Colombiana de Psiquiatría (English ed.)*, *47*(3), 155–164. https://doi.org/10.1016/j.rcpeng.2018.06.002
30. Patel, H., Malave, R., Bitting, S., Weir, K., Naus, T., Shelton, L., Harris, K. W., Kerr, W. T., Van Cott, A. C., & Kirkpatrick, L. (2024). Youth and family perspectives on diagnosis

communication about pediatric functional seizures: A qualitative study. *Pediatric Neurology*, *161*, 91–98. https://doi.org/10.1016/j.pediatrneurol.2024.09.003

31. Byun, E., Riegel, B., Sommers, M., Tkacs, N., & Evans, L. (2016). Caregiving immediately after stroke: A study of uncertainty in caregivers of older adults. *The Journal of Neuroscience Nursing, 48*(6), 343–351. https://doi.org/10.1097/JNN.0000000000000238
32. Poprelka, K., Fasilis, T., Patrikelis, P., Ntinopoulou, E., Margariti, S., Verentzioti, A., Stefanatou, M., Alexoudi, A., Stavrinou, L. C., Korfias, S., & Gatzonis, S. (2025). Burden in caregivers of adults with epilepsy: A critical review. *Epilepsy & Behavior*, *164*, 110260. https://doi.org/10.1016/j.yebeh.2024.110260
33. Tramonti, F., Bonfiglio, L., Bongioanni, P., Belviso, C., Fanciullacci, C., Rossi, B., Chisari, C., & Carboncini, M. C. (2019). Caregiver burden and family functioning in different neurological diseases. *Psychology, Health & Medicine*, *24*(1), 27–34. https://doi.org/10.1080/13548506.2018.1510131
34. Karakis, I., Cole, A. J., Montouris, G. D., San Luciano, M., Meador, K. J., & Piperidou, C. (2014). Caregiver burden in epilepsy: Determinants and impact. *Epilepsy Research and Treatment*, *2014*(1), 808421. https://doi.org/10.1155/2014/808421
35. Yeni, K., Tulek, Z., Cavusoglu, A., Dunya, C. P., Erden, S. O., Bostan, N. S., Bebek, N., & Baykan, B. (2024). Caregiver burden and its predictors in adult epilepsy patients. *Epilepsy & Behavior*, *153*, 109685. https://doi.org/10.1016/j.yebeh.2024.109685
36. Pagnini, F., Rossi, G., Lunetta, C., Banfi, P., Castelnuovo, G., Corbo, M., & Molinari, E. (2010). Burden, depression, and anxiety in caregivers of people with amyotrophic lateral sclerosis. *Psychology, Health & Medicine*, *15*(6), 685–693. https://doi.org/10.1080/13548506.2010.507773
37. Catchpole, S., & Garip, G. (2021). Acceptance and identity change: An interpretative phenomenological analysis of carers' experiences in myalgic encephalopathy/chronic

fatigue syndrome. *Journal of Health Psychology*, *26*(5), 672–687. https://doi.org/10.1177/1359105319834678

38. Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. *International Journal of Nursing Sciences*, *7*(4), 438–445. https://doi.org/10.1016/j.ijnss.2020.07.012
39. Westphal-Guitti, A. C., Alonso, N. B., Migliorini, R. C. V. P., Silva, T. I. da, Azevedo, A. M., Caboclo, L. O. S. F., Sakamoto, A. C., & Yacubian, E. M. T. (2007). Quality of life and burden in caregivers of patients with epilepsy. *Journal of Neuroscience Nursing*, *39*(6), 354–361. https://doi.org/10.1097/01376517-200712000-00006

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Ethics Approval

Ethical approval was not required for this study as it involved the synthesis of previously published literature.

Chapter Three: Bridging Chapter

Chapter two highlighted the substantial impact that caring for an individual with FND may have on caregivers' quality of life (QoL). The reviewed studies suggested that caregiver QoL was at least comparable to that observed in caregivers of individuals with epilepsy, with mental wellbeing appearing particularly vulnerable (Karakis et al., 2014; Wardrope et al., 2019). Caregiver burden, psychological distress, and stigma were also commonly reported (Karakis et al., 2014, 2020a; Wardrope et al., 2019).

Qualitative findings illustrated how these difficulties manifested within everyday life, including disruption to relationships and routines, emotional distress, uncertainty associated with symptom unpredictability, advocacy demands, and experiences of stigma and invalidation within wider systems (Burn et al., 2025; Ludlow et al., 2024; Mantilla & Rojas, 2018; McWilliams et al., 2016; Patel et al., 2024). Caregivers also described practical challenges navigating healthcare, education, and employment systems, often alongside poor communication and limited understanding of FND. Although there was some indication that caregiving could strengthen relational closeness in certain circumstances (Mantilla & Rojas, 2018), this did not appear to offset the broader impact on caregiver QoL.

Despite these findings, the review also highlighted important gaps within the existing literature. Although six quantitative studies were identified, only three represented unique datasets (Karakis et al., 2020a, 2014a; Wardrope et al., 2019), with the remaining studies comprising secondary analyses of previously published samples (Karakis et al., 2020b; Teagarden et al., 2020; Tsamakis et al., 2022). While all quantitative studies focused on caregivers of individuals with functional seizures, these studies examined measurable constructs of caregiver burden, psychological distress, and stigma. Although these findings demonstrated that caregiving may have substantial psychological and emotional impacts,

quantitative approaches offered limited insight into how caregivers understood and navigated these difficulties within everyday life.

Although all identified qualitative studies explored caregiving in relation to young people, the literature remained heterogeneous in focus. Studies focused on functional seizures, functional tics, and 'conversion disorder' more broadly (Burn et al., 2025; Ludlow et al., 2024; Mantilla & Rojas, 2018; McWilliams et al., 2016; Patel et al., 2024). While these studies provided valuable insights into caregiving experiences across functional presentations, differences in symptom profiles, functional impacts, and interactions with wider systems may shape caregiving experiences in distinct ways.

Furthermore, the two identified qualitative studies focusing specifically on functional seizures explored the experiences of young people and caregivers simultaneously, with one study focusing specifically on communication of the diagnosis (Ludlow, 2024). As such, there remained limited in-depth qualitative exploration centred specifically on the lived experiences of caregivers of young people with functional, or non-epileptic seizures (NES).

Following completion of the systematic review searches, a qualitative study was published which explored the lived experiences of parents of young people with FND, including experiences of emotional distress, social challenges, and practical burdens (Ahmad et al., 2025). As this study was published after completion of the predefined systematic review search period and screening process, it was not incorporated into the formal review synthesis. This study focused more broadly on FND rather than specifically on NES, and was conducted within a Pakistani healthcare and cultural context, which may shape caregiving experiences and interactions with healthcare systems differently. As such, there remained limited qualitative exploration focused specifically on the experiences of caregivers on young people with NES within a UK context.

The following empirical study therefore seeks to explore the experiences of caregivers of young people with NES, using a qualitative approach. By focusing specifically on caregiver perspectives, the study aims to develop a richer understanding of how caregivers make sense of, respond to, and navigate the emotional, relational, and systemic challenges that may come with caring for a young person with NES. In doing so, the study hopes to contribute to the developing evidence base relating to caregiving experiences in FND and inform future clinical understanding and support for caregivers and families.

Chapter Four: Empirical Paper

Navigating Non-Epileptic Seizures in Young People: Insights from Carers

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Abstract

Caregiving for young people with Functional Neurological Disorder (FND), particularly non-epileptic seizures (NES), can involve substantial emotional and practical demands. However, research exploring carers' experiences within paediatric contexts remains limited. This study aimed to explore the experiences of carers supporting a young person with NES.

A qualitative design was employed using semi-structured interviews. Seven mothers were recruited from paediatric clinical psychology services in the East of England. Data were analysed using inductive Reflexive Thematic Analysis.

Four interconnected themes and related subthemes were developed: (1) living in uncertainty: vigilance, emotional distress, and searching for answers; (2) holding it all together; (3) systems shaping and distributing the caregiving load; and (4) relational worlds reshaped.

The findings position caregiving as an ongoing process shaped by uncertainty, system navigation, and relational adaptation. Carers described sustained vigilance, substantial emotional and practical demands, and varied experiences of support across healthcare, school, and wider systems. Although caregiving disrupted family life and relationships, accounts also reflected adaptation and resilience over time.

The findings highlight the importance of clear communication, coordinated pathways, and greater recognition of carers' support needs within paediatric FND services.

Keywords

Functional Neurological Disorder; Non-epileptic seizures; Caregiving; Paediatric; Qualitative; Reflexive Thematic Analysis; Caregiver burden.

1. Introduction

Functional Neurological Disorder (FND) is characterised by genuine symptoms affecting motor, sensory, and cognitive domains, without structural neurological abnormalities [1, 2]. FND accounts for 5-10% of new neurological consultations, and in the UK around 8,000 new diagnoses are made per year [1]. Non-epileptic seizures (NES), also called functional, dissociative, or psychogenic non-epileptic seizures (PNES) or non-epileptic attack disorder (NEAD), are a common presentation of FND [2]. They seemingly resemble epileptic seizures, but unlike epileptic seizures they are not associated with abnormal electrical activity in the brain [3].

FND is associated with high levels of impairment and disability [1, 4], with NES having a comparable impact on quality of life to epilepsy [5]. In paediatric services, young people have described impairments in educational, social, and functional domains as a result of NES [6]. Recent paediatric studies in FND estimate a prevalence of 18.3 per 100,000 children [7], though estimates vary [8, 9]. Diagnosis can be challenging in this group, due to symptom overlap with conditions such as epilepsy, and broader difficulties surrounding recognition and understanding of FND [10, 11]. Prevalence in outpatient epilepsy clinics has been estimated as high as 58% [12].

Like other conditions, FND extends beyond the individual to impact those involved in their care (termed in this paper as ‘carers’). Caregiving in chronic conditions transcends typical parenting, involving illness-specific tasks as well as relational, emotional, and systemic impacts [13, 14]. In paediatric populations, caregiving may additionally involve supporting the young person across educational and social contexts, additional practical demands, and responding to fluctuating support needs. Across paediatric conditions, caregivers commonly report uncertainty surrounding symptoms, disruption to work and family life, changes to roles and identities, and increased responsibility for navigating services and coordinating care [15-18]. Parents of children with medically unexplained or functional symptoms have similarly

described difficulties making sense of symptoms and obtaining appropriate support from services [15, 16].

Existing research relating to NES has identified substantial impacts on caregivers and family wellbeing including psychological distress, stigma, disruption to daily life, socioeconomic and caregiving burdens, and difficulties navigating care and treatment pathways [19-21]. Families have also reported feeling misunderstood or unsupported by professionals, particularly during diagnostic processes [21]. However, research specifically exploring carers' experiences within paediatric NES remains limited. Existing studies have either explored the combined experience of young people and their families, making it difficult to examine caregiving experiences in depth, or have been conducted outside UK healthcare contexts. Greater understanding of the nuanced experiences of caregivers of young people with NES may help to inform service development and identify how families and carers can be better supported within paediatric NES pathways.

The aim of the present study was therefore to explore the experience of carers supporting a young person with NES within the context of FND. In particular, the study sought to understand carers' experiences of the diagnostic process, living with and managing FND over time, and the perceived impact of caregiving on everyday life.

2. Method

2.1. Design and Theoretical Positioning

This study used a qualitative design, collecting data through semi-structured interviews and employing inductive Reflexive Thematic Analysis (RTA) for analysis, as outlined by Braun & Clarke [22]. This approach was considered appropriate given the study's focus on exploring subjective experiences, meaning making, and patterns across participants' accounts through flexible and interpretive engagement with the data.

This study was informed by a critical realist position, which recognises that experiences are shaped by both material realities and subjective interpretations [23]. While carers supported a young person experiencing FND and navigated associated demands, the meanings attributed to these experiences varied across individuals. An interpretivist stance facilitated in-depth exploration of how carers made sense of their experiences, recognising that meanings are constructed within social and emotional contexts, rather than assuming a single objective truth [24].

2.2. Patient and Public Involvement

Patient and Public Involvement (PPI) informed study development to support the relevance and acceptability of the research to those affected, aligning with NHS values [25, 26]. Three parents reviewed participant-facing materials and contributed to the development of the interview topic guide by sharing perspectives on the caregiving experience and identifying areas they considered important to explore within interviews.

2.3. Ethics

Ethical approval was granted through an NHS Research Ethics Committee, alongside Health Research Authority approval (Project ID: 348736; Appendix F). Individual site agreements were obtained from each NHS site prior to commencing recruitment. Data were securely stored on encrypted university systems accessible only to the research team, in accordance with General Data Protection Regulation (GDPR) and NHS Research Ethics Committee (REC) requirements.

2.4. Materials

Study materials (Appendix G) included a consent-to-contact form, Participant Information Sheet (PIS), consent form, semi-structured interview topic guide, and debrief sheet. Interviews were conducted, recorded, and transcribed using Microsoft Teams. Only audio

recordings were retained for analysis. Coding and data organisation were supported using Microsoft Word, OneNote and Excel.

The study was reported in accordance with Consolidated Criteria for Reporting Qualitative Research (COREQ), a 32-item checklist ensuring transparent and comprehensive reporting for interviews and focus groups [27] (Appendix H).

2.5. Procedure

Potential participants were identified by two clinical psychologists working in paediatric FND services in the East of England (who were also members of the research team). Potential participants were informed about the study either face-to-face or by telephone, during which information on the study was provided and consent to contact was sought. At this stage, individuals were informed that participation was voluntary and would have no impact on the young person's clinical care.

Where consent to contact was provided, the lead researcher (who had no prior relationship with any participants) then made contact. At this stage potential participants were provided with a PIS detailing the study and the lead researcher's role as a trainee clinical psychologist undertaking doctoral training. Signed informed consent was then obtained from those who wished to participate. Following this, interviews were arranged, conducted, and recorded virtually using Microsoft Teams, with participants joining from their own homes. No other individuals were present during the interviews. An interview topic guide, developed through clinical expertise and PPI input (see Appendix G4), supported consistency while allowing flexibility for participants to introduce relevant topics or address later questions organically during conversation.

Following interviews, participants were offered a debrief and provided with a debrief sheet, alongside a £10 e-gift card in recognition of their time.

2.6. Recruitment and Participants

Participants were recruited from paediatric clinical psychology teams across three general hospitals in the East of England. Eligibility criteria were: (1) parent/carer of a young person with FND, currently under one of the recruiting sites; (2) the young person experienced NES as a primary symptom of FND, diagnosed by a neurologist (seizures did not need to be ongoing and additional FND symptoms could be present); (3) main caregiver, defined as being involved in day-to-day care; and (4) sufficient proficiency in spoken English to participate in an in-depth research interview without the use of an interpreter.

Participants were excluded if they were not under the care of the recruiting sites, or if the young person did not have a diagnosis of FND with NES, had a concurrent diagnosis of epilepsy, or if another carer of the same young person was already participating. Individuals who did not provide regular (e.g., daily) care were also excluded.

Purposive sampling was employed. Sample size was guided by recommendations, and principles of information power in qualitative research [28, 29], further discussion of this can be found in Chapter Six. The final sample size (n = 7) was considered sufficient to achieve depth and richness of insight in relation to the study aims.

2.6.1. Participant Characteristics and Recruitment Flow

Participants were recruited between September 2025 and March 2026. One recruiting site did not identify any participants. Eleven individuals from the remaining two sites consented to be contacted regarding participation. From this, eight gave full informed consent and three did not proceed to full consent (one did not respond to contact attempts, one provided verbal agreement but did not return completed consent forms, and one withdrew prior to consenting due to health reasons). Of the eight individuals that consented to participate, seven completed an interview (one withdrew prior to interview due to difficult family circumstances).

The final sample included only mothers. Participant characteristics are presented in table 1, with minimal detail to preserve anonymity.

Table 1

Participant Characteristics

Participant Pseudonym	Relationship to young person	Gender of young person	Age of young person
Kate	Mother	Female	17
Nicole	Mother	Female	17
Louise	Mother	Female	17
Amy	Mother	Male	10
Lisa	Mother	Female	15
Sarah	Mother	Female	16
Tania	Mother	Female	16

3. Results

3.1. Reflexive Thematic Analysis

Transcripts were manually reviewed and corrected for accuracy to align with verbatim transcription. They were pseudonymised during this process, with all identifying information (e.g., names and locations) removed. Interviews lasted between 47 and 86 minutes (mean duration = 69.43 minutes).

Data were analysed using inductive RTA, following Braun and Clarke's six-phase approach [22, 30]: familiarisation, coding, development of candidate themes, reviewing and refining themes, defining and naming themes, and producing the final report. Analysis was conducted solely by the lead researcher, with supervisors contributing through discussion of coding, theme development, and reflexive dialogue.

The analytic process involved active and iterative engagement with the data, moving between data, codes, and themes. Coding was reflexive, and no inter-rater reliability was sought, in line with RTA principles [22]. The researcher maintained a reflexive log, including field notes recorded after each interview and at multiple stages of data analysis, to support ongoing critical reflection on assumptions, responses to the data, and analytic decisions (see Appendix I for example). Themes were developed as interpretive outputs rather than being treated as inherent or discoverable within the data. Further detail on the analytic process can be found in Chapter Six.

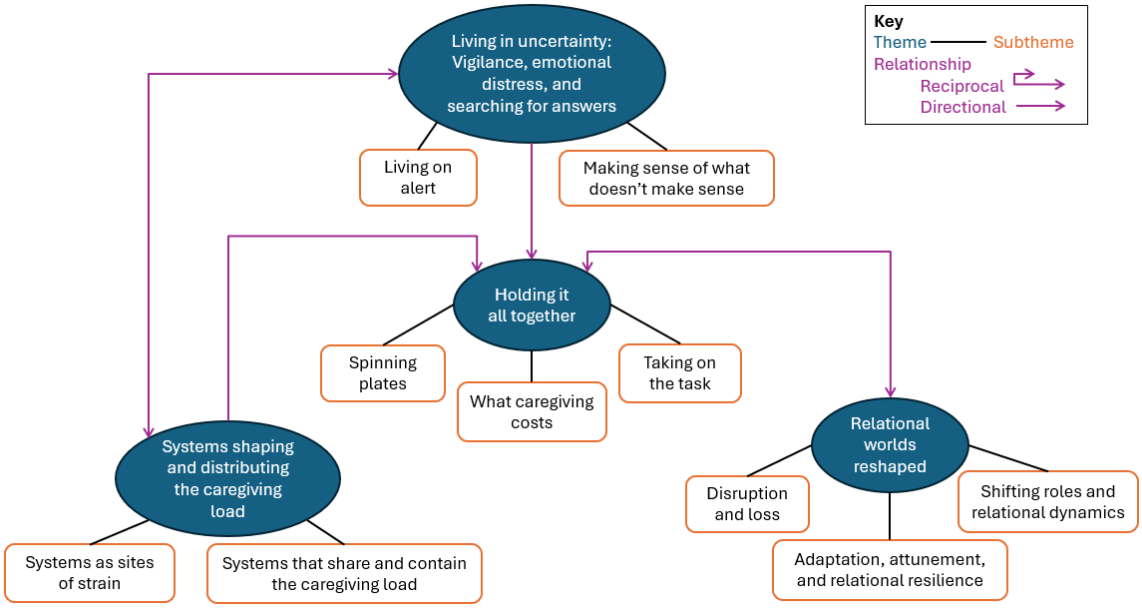
The lead researcher was a female trainee clinical psychologist undertaking doctoral-level training. She had prior qualitative research experience at undergraduate level, but no prior clinical or personal experience of FND, and therefore approached the topic with relative openness. However, her position as a trainee clinical psychologist, alongside personal experience of caregiving as a step-parent, may have shaped both data collection and interpretation, including sensitivity to caregiving demands and relational dynamics. Early PPI input may also have influenced the researcher's attunement towards advocacy-related themes.

3.2. Overview of themes

Analysis resulted in four overarching themes and associated subthemes (figure 1). These captured carers' experiences of uncertainty, caregiving demands, system interactions, and relational change. Themes were interconnected, with uncertainty shaping caregiving responses, while systems and relational contexts could intensify or alleviate the caregiving load.

Figure 1

Thematic Map



3.3. Theme 1: Living in uncertainty: vigilance, emotional distress, and searching for answers

Across interviews, carers described a pervasive sense of uncertainty spanning the caregiving journey; from symptom onset to diagnosis, and into ongoing management and the future. This was shaped by unpredictable symptoms, diagnostic ambiguity, and fears about risk and the future. Symptoms were experienced as frightening and difficult to interpret, contributing to helplessness and emotional distress. In response, carers attempted to make sense of what was happening by seeking diagnoses, information, and explanations. However, these attempts were often only partially successful, leaving carers in a sustained state of vigilance while requiring ongoing emotional and practical adjustment to uncertainty.

3.3.1. Subtheme: Living on alert

The emergence of seizures was described as frightening or "*terrifying*" (Kate), reflecting uncertainty about what was happening and the potential risk to the young person. Amy captured the shock:

“suddenly he just had a seizure [...] and I was like, “shit, what's this? What is this, I’ve never seen this happen before” (Amy).

Over time, some carers described becoming more accustomed to these experiences, with repeated exposure leading to some degree of emotional adjustment. However, this did not remove the underlying vigilance. Prolonged diagnostic journeys contributed to a sense of helplessness:

“you don't know what's going on with your child[...] you feel like... a little bit hopeless and helpless[...] because you don't know, there are no answers” (Lisa).

Even following FND diagnosis, symptoms remained unpredictable and changing, meaning uncertainty continued to shape day-to-day experiences. This led to a prolonged state of alertness, characterised by ongoing monitoring and anticipation of potential risk. Carers described *“permanently look[ing] for the what ifs”* (Tania). This vigilance extended into the future, which was often experienced as uncertain and difficult to anticipate:

“who knows what that will look like for her, in terms of independent living? And will the seizures get worse? [...] Will they become more severe? Will she injure herself? All of those things” (Louise).

For some, this uncertainty was experienced as qualitatively distinct from other health-related challenges due to the fluctuating and difficult-to-predict nature of symptoms, reinforcing a sustained sense of vigilance.

3.3.2. Subtheme: Making sense of what doesn’t make sense

Despite an FND diagnosis, carers sometimes developed their own frameworks for making sense of what was happening. They actively attempted to make sense of the young person’s symptoms in the context of ongoing uncertainty, often seeking information beyond

healthcare systems, including online searches and social media. Some constructed their own understandings of symptom onset and triggers. For example:

> *"I did a bit of research [...] I'm like, how is it possible that all of these things have started all at once... and... nobody can tell me, that they're not linked! [...] And I came up with either Lyme disease or PANS* [Paediatric Acute-Onset Neuropsychiatric Syndrome]*"* (Tania).

Carers' relationships with the diagnosis itself were central to this process. While some experienced relief that symptoms were not life-threatening, others found the diagnosis unhelpful in resolving uncertainty. For some, diagnosis was experienced as a *"double-edged sword"* (Louise), simultaneously offering reassurance while failing to fully resolve uncertainty about symptoms, prognosis, and treatment:

> "*I thought, oh, that's just another blanket term they're giving to people when they don't know what it is"* (Nicole).

Diagnosis did not always align with carers' lived experiences, particularly where available information about FND felt varied, incomplete, or inconsistent with the young person's presentation. Attempts to construct meaning did not necessarily resolve uncertainty; instead, carers were often left navigating multiple and sometimes conflicting explanations.

3.4. Theme 2: Holding it all together

Carers described becoming the person who held everything together in the context of the young person's condition. This involved managing competing demands, including everyday responsibilities alongside the practical and emotional work of caregiving. This often felt like a relentless juggle requiring constant prioritisation and sustained responsibility. Caregiving came at a personal cost, disrupting employment, valued roles, finances, and identity. Carers also took responsibility for coordinating and advocating for support, often experiencing themselves as

holding systems and care pathways together. While this role could feel burdensome and uncomfortable, some drew on prior experience and knowledge to sustain it.

3.4.1. Subtheme: Spinning plates

Caregiving was experienced as adding to already demanding lives, at times becoming a *"full-time job on top of what I was already doing"* (Kate). This was conceptualised as a 'juggle', reflecting the need to balance caregiving alongside other responsibilities:

> *"I found it incredibly difficult sometimes to be in two places at once, and I had to pick and choose [...] Yeah, just exhausting being needed by so many people at one time and having to choose which one got you"* (Kate).

Unpredictability further intensified this strain by disrupting routines and limiting carers' ability to plan. Caregiving was experienced as relentless and difficult to contain, requiring carers to continually adjust and prioritise competing needs:

> *"every day I do not know what's happening [...] I can't plan for anything"* (Tania).

The impact of this pressure was evident in carers' accounts of their own wellbeing. Some described how *"I've not coped at times"* (Nicole). In response, carers drew on a range of coping approaches. For some, this involved accessing support or using established coping strategies, while others adopted a more stoic stance, or appeared to use humour to manage otherwise difficult emotions. These approaches appeared necessary to sustain functioning in the face of ongoing demands:

> *"I've coped because I've had to cope... And that's it."* (Tania).

3.4.2. Subtheme: What caregiving costs

Caregiving was consistently experienced as coming at a personal cost, affecting both practical aspects of life and carers' sense of identity. Many described needing to adapt or reduce employment in order to meet caregiving demands, at times with financial implications:

"I stopped doing Fridays erm, at work for a little while, which is a massive impact on your income" (Amy).

Beyond these practical costs, disruptions to anticipated life trajectory and sense of self were reflected in accounts. For some, this involved recognising that their lives were different from what they had originally imagined, often linked to a loss of expected independence or identity:

"it's the time where you think, "oh, I'm now going to get my life back!"... but suddenly, Oh my God, less independence... And it was just like, oh, my God, I'm not, who am I now?" (Nicole).

These accounts highlight how caregiving reshaped both daily life and longer-term expectations, with implications for how carers understood themselves and their roles.

Carers also described emotional costs, including self-doubt and questioning their parenting, particularly during more difficult periods:

"you just think, Oh my God, I've absolutely ruined this as a parent" (Louise).

However, this was sometimes accompanied by efforts to reframe their experiences and recognise their intentions. For some, the caregiving role was anticipated to extend into the future, potentially *"forever"* (Nicole), requiring ongoing adjustment to a sustained caregiving identity.

3.4.3. Subtheme: Taking on the task

Carers actively engaged in the young person's care, often taking on responsibility for coordinating and advocating for support across healthcare and wider systems. This role was frequently framed as a 'fight', reflecting the effort required to access appropriate care. For some, this aspect of caregiving was experienced as more demanding than the condition itself:

"to be honest, the fight is actually harder [...] than actually him seizing" (Amy).

Advocacy was constructed as necessary, particularly in the context of delays or uncertainty within systems:

> *"I had had to threaten a formal complaint to the hospital [...] in the end, I did just have to say look, I've got a teenage girl here that's having multiple seizures every day. You know, her life is, is effectively on hold until we know how to cope and deal with this"* (Kate).

Carers also described advocating in response to concerns about safety, particularly where carers felt others did not fully recognise or understand risk.

Despite its importance, this role was not always comfortable. Some carers described it as *"tiring"* (Amy), *"frustrating"* (Tania), or at odds with their sense of self:

> *"that's not me at all [...] So I hated that I had to"* (Kate).

However, some drew on prior experience or professional knowledge to navigate this role more strategically, shaping how they engaged with systems and advocated for their child.

Together, these accounts illustrate how carers took on significant responsibility for coordinating care, often experiencing themselves as key drivers in ensuring systems meet the young person's needs.

3.5. Theme 3: Systems shaping and distributing the caregiving load

Wider systems were central to the caregiving experience, shaping whether it felt manageable or overwhelming. Systems were often experienced as sites of strain, with support perceived as inadequate or inaccessible. Carers described feeling dismissed or invalidated, encountering barriers to support, and receiving explanations that did not align with their lived experience. However, systems could also share the caregiving load when support was flexible, relationally attuned, and responsive to the needs of the young person and family, although responsibility often remained with carers.

3.5.1. Subtheme: Systems as sites of strain

Healthcare systems were frequently experienced as inadequate across the caregiving journey, especially during the diagnostic and post-diagnostic phases. Delays in diagnosis were experienced as contributing to uncertainty (see Theme 1) and not meeting need, with some carers describing a sense of being left without support following diagnosis:

> *"basically you're given a diagnosis and then left by yourself [...] there's no support for you and the family."* (Nicole).

Referral to psychological services was commonly described but not always understood or experienced as helpful. Some carers expressed confusion about the role of psychological input:

> *"I don't understand how Psychology can help with the non-epileptic seizures"* (Tania).

Others felt that psychological explanations contributed to misunderstanding or stigma, or were received as implicitly critical of parenting. Where support was perceived as limited or time-bound, this contributed to a sense of abandonment; requiring carers to continue seeking and coordinating support themselves (see Theme 2).

These experiences extended beyond healthcare. Decisions within school contexts, such as participation in activities, were understood to place additional responsibility on carers to manage risk and advocate for appropriate support. Schools were sometimes experienced as unable to ensure the young person's safety despite carers' efforts to coordinate support, which had emotional implications for the carer:

> *"I'm so scared about... them not looking after her [...] to this day I will never forgive that school for the way they treated her"* (Nicole).

Barriers to accessing practical support were also described, often linked to a perceived lack of recognition of FND within systems:

"there was absolutely nothing [...] because he's not autistic or ADHD, there's nothing available" (Amy).

Access to support was also experienced as uneven, shaped by personal knowledge and resources rather than need. One carer reflected that their occupational background had facilitated access to support they believed might otherwise have been inaccessible:

"it's frustrating in the fact that, if I hadn't been doing the job that I was doing, I would never have been put in touch with them" (Tania).

Carers frequently described feeling dismissed or unheard within systems. For some, these cumulative experiences generated strong emotional responses, reflecting the impact of perceived lack of support and recognition:

"I'm very angry [...] I went everywhere to fight for her... ((crying)) and no one listened" (Nicole).

Across accounts, carers also described limited support available for themselves. Informal networks were not always experienced as containing, and more formal support, such as parent groups, was not always available, accessible, or prioritised within the context of competing demands.

These accounts illustrate how systems were experienced as misaligned with need, leaving carers feeling unheard and responsible for compensating for gaps in support.

3.5.2. Subtheme: Systems that share and contain the caregiving load

Despite some carers experiencing confusion around psychological input, support was experienced as beneficial when it was responsive to the young person's needs. For example, Kate shared how psychological support *"really has done the world of good"*, particularly with strong therapeutic rapport:

"she really quickly kind of gelled with [psychologist] [...] it fits entirely around what [daughter with FND] needs" (Kate).

This highlights how support that was experienced as relationally attuned and individualised could be perceived as *"powerful"* (Louise), particularly in contrast to earlier experiences of uncertainty or misalignment.

This sense of being supported extended beyond formal services. Informal networks, such as colleagues and family members, were described as providing emotional containment and relief from caregiving demands:

"when I go into work and I need, I need to cry or I need to just rant and get angry, they're amazing [...] it's therapeutic in its own way" (Sarah).

Support that was flexible and responsive to the unpredictability of caregiving was particularly valued. For example, understanding from employers reduced concerns about job security. Similarly, adaptations within school settings helped to maintain the young person's engagement and safety. This support was experienced as helping to contain uncertainty and reduce the immediacy of caregiving demands, at times creating moments of respite:

"when he's at school, I know unless it's really bad, ((sighs)) we're alright in the meantime" (Amy).

Across accounts, support systems were often described as fundamental to sustaining the caregiving role. However, even where systems were experienced as supportive, this support was understood as limited or dependent on resource. It relied on individual relationships, flexibility, or access to resources, and did not fully remove the responsibility held by carers. This meant systems were experienced as sharing and containing aspects of the caregiving load, while overall responsibility remained with carers.

3.6. Theme 4: Relational worlds reshaped

The relational world around carers was reshaped by the young person's FND, affecting the wider family and social context. The impact was experienced through both the young person's difficulties and wider changes to family life, relationships, and social interactions. Carers navigated losses, changing roles and responsibilities, and altered relational dynamics. The young person's experiences of loss, restriction, and social disruption shaped carers' emotional and practical workload as they supported adaptation. At the same time, some accounts reflected increased understanding, closeness, and recognition of strengths.

3.6.1. Subtheme: Disruption and loss

Accounts reflected how the young person's experiences of disruption and loss shaped both their own role and the wider family context. Opportunities typically associated with the young person's developmental stage were often restricted, particularly in relation to independence and social participation:

> *"it's things at 16 years old you should be able to do [...] And at the moment, she doesn't feel able to do any of those things"* (Sarah).

Young people were also described as losing valued opportunities or activities, which were experienced as significant losses. These disruptions were often accompanied by emotional distress, positioning carers as both practical and emotional supports.

Social situations were also shaped by the condition, particularly in public contexts where symptoms could be misunderstood:

> *"sometimes people think that she's drunk or that she's taken drugs, erm, which is quite distressing for [daughter with FND] especially when she's out in public"* (Lisa).

This highlights how disruption extended into the social world, where misunderstandings and responses from others could add to the young person's distress or create situations which

the carer had to navigate, which in turn increased the emotional and practical demands on carers.

The impact extended across the wider family system, with changes to routines and activities that families could previously engage in. Siblings were frequently drawn into this disruption, with carers describing tensions in managing competing demands and associated feelings of guilt:

> *"my son got really cross… he was going to like a social at the school in the evening and erm, and I said I can't leave until your dad gets home"* (Louise).

Disruption appeared to operate as a relational process, with the effects extending across family and social contexts rather than remaining contained within the young person's experience.

3.6.2. Subtheme: Shifting roles and relational dynamics

Carers described a reorganisation of roles, responsibilities, and relationships in response to FND, reflecting how caregiving reshaped relational dynamics within the family. In some cases, carers became the preferred or primary caregiver, even where others were available:

> *"my husband can be there if she's having a seizure, but [daughter with FND]'s preference will be me"* (Louise).

Caregiving roles were shaped not only by availability but also by the young person's needs and relational preferences, which appeared at times to strengthen the bond between carer and young person. These shifts required carers to adapt their parenting approach, often becoming more responsive and collaborative, while also managing increased dependency:

> *"I've had to change my parenting to like, adapt to what she's capable of […] and us to work together"* (Lisa).

Within families, roles could become more explicitly differentiated, with particular family members taking on distinct caregiving or relational functions. While this could support family functioning, it could also contribute to tension or imbalance within relationships. Siblings were also drawn into these changing dynamics, at times taking on protective or caregiving roles; this could support carers, but also exposed siblings to emotionally challenging situations.

Despite these complexities, carers also described moments where these relational shifts highlighted strengths within the family:

> *"you learn what you have actually managed to instil into your children and how they use it"* (Sarah).

Together these accounts illustrate how caregiving involved an ongoing negotiation of roles and relationships, reshaping how family members related to one another in response to the young person's needs.

3.6.3. Subtheme: Adaptation, attunement, and relational resilience

In response to changing circumstances and relational dynamics, processes of adaptation occurred within both the family and wider social contexts, which appeared to soften the impact of disruption over time. One carer reflected how others learned to respond to seizures in ways that reduced distress:

> *"a couple of her friends were really good at not panicking [...] so these were friends that obviously had my numbers and that I had theirs so we could... you know, be OK"* (Kate).

Carers also described actively facilitating understanding, for example by exposing others to seizures through recordings, recognising that increased familiarity made it *"much easier for people to feel better about it"* (Sarah). These adaptations contributed to a sense that disruption could be softened over time:

> *"it's quite nice. Everyone's starting to understand what we're going through"* (Amy).

Within the family, this attunement was reflected in a growing ability to recognise and respond to the young person's needs, alongside a normalisation of symptoms within everyday life:

> *"the seizures just became normal. They just became part of who, who she is"* (Sarah).

This highlights a shift: from managing crises to integrating the condition into daily life. For some, this was experienced as a source of relational strength, characterised by increased understanding and closeness:

> *"we spend a lot of lovely time together ((smiles)). You know we, we laugh and we understand each other's needs"* (Louise).

These reflections were often framed as emerging through the caregiving experience itself, indicating that while caregiving involved significant challenges, it also created opportunities for connection and resilience. For some, this reframing allowed ongoing caregiving demands to be held within a broader sense of meaning:

> *"I'm blessed with great kids and this is not a burden that's beyond what I would be more than happy to carry"* (Kate).

4. Discussion

This study explored carers' experiences of supporting a young person with NES and contributes to a limited literature on caregiving for NES in the paediatric population. Four interconnected themes were identified: living in uncertainty, holding it all together, systems shaping and distributing the caregiving load, and relational worlds reshaped. These themes represent an interpretative account of carers' experiences, shaped by an iterative RTA approach. The findings position caregiving as an ongoing process of managing uncertainty, coordinating care, and adapting within relational and systemic contexts.

The pervasive nature of uncertainty was a central and enduring feature of the caregiving experience, shaped by unpredictable symptoms, ambiguity about diagnosis, and concerns

about risk and the future. Existing literature has positioned uncertainty as part of the FND [19] or NES [21] experience for carers. Findings show uncertainty persists post-diagnosis, shaping vigilance and future concerns, akin to the 'post-diagnostic limbo' felt by adults with NES [31]. Carers sought resolution of uncertainty, constructing meaning through information-seeking and personal sense-making, but these efforts were often only partially successful and at times introduced further ambiguity rather than resolution.

This may partly reflect tensions between carers' expectations of diagnosis within a Western medical model, and the realities of FND. In many medical conditions, diagnosis is associated with objective diagnostic tests, clear trajectories, and specific treatment pathways. Diagnosis in FND relies on positive clinical signs [1], rather than 'proof' from scans or bloodwork, which may leave carers questioning its validity, especially where symptoms fluctuate or do not follow a clear recovery trajectory. This cultural expectation may exacerbate uncertainty, shaping why and how they continue seeking certainty, as well as how they experience and 'fight' for support.

In response to this ongoing uncertainty, carers took on a central role in "holding it all together", managing competing demands across caregiving, family life, and everyday responsibilities, which was experienced as challenging. Similar impairments have been found in other paediatric conditions [17]. This aligns with caregiver burden models linking multiple responsibility conflict and uncertainty to strain in chronic paediatric conditions [32, 33]. Extending this, findings show caregiving demands were not limited to direct care but also included responsibility for coordinating and sustaining systems of support – a 'fight' echoed in functional tics [34], and other conditions where parents feel obligated to advocate [18]. Carers in the present study at times positioned this as more demanding than managing the young person's symptoms themselves.

Within the data, the role of wider systems was central in shaping whether caregiving felt manageable or overwhelming. Consistent with previous research (e.g., [21, 34, 35]), carers

described fragmented care, limited access to appropriate support, and experiences of feeling dismissed or misunderstood. While system-level barriers have been highlighted in lower-resource settings [19], the present findings suggest that similar challenges persist within a UK context. This indicates that the issue is not solely the availability of support, but also the nature of the support.

Carers did describe forms of support that could partially alleviate the caregiving load by sharing responsibility and providing emotional containment. Psychological support was often experienced as beneficial when it was responsive, relationally attuned, and flexible, aligning with literature emphasising the importance of the therapeutic relationship in shaping experiences of care and managing uncertainty [36]. Similarly, school environments could provide respite when they adapted to the young person's needs, although they were also described, in line with previous findings [21], as potential sites of misunderstanding and strain. These findings align with Bronfenbrenner's ecological systems theory [37], highlighting how caregiving experiences are shaped through interactions between the systems around a child: family, school, healthcare, and wider support systems. The present study's findings suggest that supportive systems can reduce aspects of caregiving burden, however caregiving remains constrained by resource and context; meaning that ultimate responsibility continues to rest with carers.

Beyond individual and systemic experiences, caregiving was embedded within relational contexts that were reshaped over time. There was disruption to family life, social participation, and anticipated developmental trajectories for both the young person and themselves; alongside shifts in roles and responsibilities within the family. These findings are consistent with previous research in FND (e.g., [19, 21]) and broader literature highlighting the relational impact of chronic conditions [16, 38].

However, while disruptions were evident, they coexisted with adaptation, attunement, and relational resilience. Accounts reflected developing sensitivity to the young person's needs

and, at times, adopting more responsive and collaborative parenting approaches. These adaptations were often accompanied by a reframing of caregiving as meaningful. This aligns with family resilience models, where reframing or meaning-making, family organisation, and communication influence an adaptive response to ongoing stress [39-41]. Importantly, these processes did not negate the challenges of caregiving, highlighting how relational adaptation functioned alongside rather than in place of ongoing caregiving demands.

4.1. Clinical Implications

While these findings should be considered in the context of a small, geographically specific sample, they offer clinically relevant insights for supporting carers within paediatric FND contexts. Persistent uncertainty highlights the importance of how information is communicated and revisited over time. Carers valued clear, consistent explanations aligned with their lived experience. Enhancing explanations of positive clinical signs at diagnosis could bridge medical model gaps, and foster acceptance. Ongoing conversations that support sense-making over time, validating carers' experiences and acknowledging uncertainty, may help to reduce distress and support engagement with care. This is consistent with literature emphasising the importance of clear communication, validation, and therapeutic rapport in FND and related conditions [31, 36, 42, 43].

Carers frequently described taking on responsibility for navigating and coordinating care across systems. These findings suggest that more consistent and coordinated pathways may reduce the extent to which carers are required to hold systems together. This has been recommended in other paediatric conditions in order to reduce family and caregiver burden [44]. Integrated working across healthcare, education, and community services may be beneficial, given the cross-contextual impact of FND. Existing recommendations for multidisciplinary and coordinated approaches to FND care [45, 46] are supported by the

present findings, which further emphasise the impact of fragmented care on caregiver burden and distress.

A key contribution of this study is the identification of carers' support needs as distinct from, but closely linked to, the young person's care. While existing interventions often focus on the young person, carers may benefit from direct psychoeducation, emotional support, and space to process the impact of caregiving. Some carers in the present study sought this privately, while others described it as something they would value if offered. Such support could reduce burden, enhance coping, and enable carers to sustain their role over time. Broader caregiving literature highlights the benefits of caregiver-focused interventions for quality of life [47], but this has received limited attention within paediatric FND contexts, suggesting an important area for service development.

The relational impact of FND, alongside processes of adaptation and attunement described by carers, suggests that interventions may benefit from a relational or family-informed approach. Studies have demonstrated that illness uncertainty can affect relationships [48]. Supporting families to adapt to changing roles, manage competing demands, and maintain relationships may warrant consideration within care. Approaches that recognise caregiving as embedded within relational and systemic contexts, such as family-based or systemic interventions, may therefore be relevant (e.g., [41]).

Finally, the findings highlight the importance of improving understanding of FND across wider systems, particularly within schools and non-specialist services. Participants had both positive and negative experiences across these contexts, suggesting that others' knowledge of FND can significantly shape the caregiving experience. Training and guidance for professionals may help to reduce misunderstanding and inconsistent responses, support more effective collaboration, and reduce the need for carers to coordinate and advocate for care. Previous literature has made similar recommendations [21].

4.2. Strengths and Limitations

This study provides an in-depth exploration of carers' experiences of supporting a young person with FND, contributing to a limited evidence base. A key strength is the focus on carers' perspectives, which enabled a detailed examination of caregiving experiences that are otherwise underrepresented within the literature. The qualitative design facilitated a rich and nuanced understanding of how caregiving is shaped across individual, relational, and systemic contexts. Consistent with the methodology, the findings represent an interpretative account shaped through the lead researcher's perspective and positioning. Reflexive practices were used throughout to support critical engagement with analytic assumptions and decisions.

However, several limitations should be considered. Recruitment through paediatric clinical psychology teams may have resulted in a sample that was more likely to engage with or access psychological support. This may have influenced the accounts provided and may limit representativeness beyond those willing to engage with psychological support. Therefore, findings cannot readily be generalised to carers who have not had contact with psychological teams or who may have experienced barriers to accessing support.

The small sample, drawn from a single geographical region in the East of England, may limit transferability of findings to other contexts. The young people cared for were largely mid-adolescent females, so accounts may be somewhat specific to caregiving for this demographic. Experiences of FND, and therefore the experience of caring for a young person with FND, may vary according to the young person's age and gender, potentially limiting the transferability of these findings to carers of young people with different demographic characteristics. Although the participation of one carer of a 10-year-old male suggests that some experiences may be shared across age and gender contexts, the limited variation in age and gender should be considered when interpreting the findings.

The demographic characteristics of the sample may also limit the transferability of findings. All participants were women and mothers, meaning that the perspectives of male carers and other caregivers, such as fathers, siblings, or extended family members, were not captured. This reflects a broader pattern in paediatric research, where fathers are often underrepresented despite making important contributions to child development [49]. The all-female and maternal composition of the sample may have shaped the accounts provided and limits the extent to which findings can be transferred to other caregiver groups. Future research may benefit from approaches designed to facilitate fathers' participation, such as explicitly inviting fathers or using father-focused recruitment strategies.

Intersectional factors (e.g., ethnicity, socioeconomic status) were not explicitly considered in the study; the final sample notably contained only White-British participants, all of whom were within a relatively narrow age range. This may partly reflect the demographic characteristics of the recruitment region, which has relatively low ethnic diversity. Consequently however, the demographics of the sample may have influenced the experiences and perspectives represented in the findings, and the findings may therefore be less transferable to those from more diverse cultural and ethnic backgrounds or different age groups.

Future studies could examine extended family perspectives (e.g., fathers, siblings), take a longitudinal approach to understand longer term adaptation, or consider the use of interventions like family therapy in supporting the family system as a whole.

4.3. Conclusion

This study explored carers' experiences of supporting a young person with FND, highlighting caregiving as an ongoing process shaped by uncertainty, system navigation, and relational change. Accounts reflected significant burden, yet also highlighted adaptation and resilience that enabled carers to sustain their role. The findings emphasise the importance of

clear communication, coordinated care, and greater recognition of carers' support needs. Addressing these areas may help services better recognise and respond to the burden experienced by carers and families navigating paediatric FND.

References

[1] Bennett K, Diamond C, Hoeritzauer I, Gardiner P, McWhirter L, Carson A, et al. A practical review of functional neurological disorder (FND) for the general physician. Clin Med (Lond). 2021;21(1):28–36. doi:10.7861/clinmed.2020-0987

[2] Hallett M, Aybek S, Dworetzky BA, McWhirter L, Staab JP, Stone J. Functional neurological disorder: new subtypes and shared mechanisms. Lancet Neurol. 2022;21(6):537–50. doi:10.1016/S1474-4422(21)00422-1

[3] Reuber M, Brown RJ. Understanding psychogenic nonepileptic seizures-phenomenology, semiology and the Integrative Cognitive Model. Seizure. 2017;44:199–205. doi:10.1016/j.seizure.2016.10.029

[4] Carson A, Stone J, Hibberd C, Murray G, Duncan R, Coleman R, et al. Disability, distress and unemployment in neurology outpatients with symptoms 'unexplained by organic disease'. J Neurol Neurosurg Psychiatry. 2011;82(7):810–3. doi:10.1136/jnnp.2010.220640

[5] Karakis I, Montouris GD, Piperidou C, Luciano MS, Meador KJ, Cole AJ. Patient and caregiver quality of life in psychogenic non-epileptic seizures compared to epileptic seizures. Seizure. 2014;23(1):47–54. doi:10.1016/j.seizure.2013.09.011

[6] Dunne A, Carolan R, Swords L, Fortune G. Patient and family perspectives of paediatric psychogenic non-epileptic seizures: a systematic review. Seizure. 2019;71:279–85. doi:10.1016/j.seizure.2019.08.014

[7] Yong K, Chin RFM, Shetty J, Hogg K, Burgess K, Lindsay M, et al. Functional neurological disorder in children and young people: incidence, clinical features, and prognosis. Dev Med Child Neurol. 2023;65(9):1238–46. doi:10.1111/dmcn.15538

[8] Ani C, Reading R, Lynn R, Forlee S, Garralda E. Incidence and 12-month outcome of non-transient childhood conversion disorder in the UK and Ireland. Br J Psychiatry. 2013 Jun;202(6):413–8. doi:10.1192/bjp.bp.112.116707

[9] Raper J, Currigan V, Fothergill S, Stone J, Forsyth RJ. Long-term outcomes of functional neurological disorder in children. Arch Dis Child. 2019;104(12):1155–60. doi:10.1136/archdischild-2018-316519

[10] Baglioni V, Esposito D, Bernardi K, Novelli M, Zaccaria V, Galosi S, et al. Misdiagnosis of functional neurological symptom disorders in paediatrics: Narrative review and relevant case report. Clinical Child Psychology and Psychiatry. 2024;29(3):1026–42. doi:10.1177/13591045241240805

[11] Filho LHP, Mutarelli EG. Diagnostic pitfalls in functional neurological disorders. Arq Neuropsiquiatr. 2022;80(Suppl 5):324–7. doi:10.1590/0004-282X-ANP-2022-S120

[12] Operto FF, Coppola G, Mazza R, Pastorino GMG, Campanozzi S, Margari L, et al. Psychogenic nonepileptic seizures in pediatric population: a review. Brain Behav. 2019;9(12):e01406. doi:10.1002/brb3.1406

[13] Eiser C. Chronic childhood disease: an introduction to psychological theory and research. New York: Cambridge University Press; 1990.

[14] Smith J, Cheater F, Bekker H. Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature. Health Expect. 2015;18(4):452–74. doi:10.1111/hex.12040

[15] Hulgaard DR, Rask CU, Risør MB, Dehlholm G. 'I can hardly breathe': exploring the parental experience of having a child with a functional disorder. J Child Healthcare. 2020;24(2):165–79. doi:10.1177/1367493519864745

[16] Morris A, Ogden J. Making sense of children's medically unexplained symptoms: managing ambiguity, authenticity and responsibility. Psychol Health Med. 2012;17(3):285–94. doi:10.1080/13548506.2011.608804

[17] Ngo D, Palmer GM, Gorrie A, Kenmuir T, Crawford M, Jaaniste T. Caregiver burden associated with pediatric chronic pain: a retrospective study using the Pediatric Electronic Persistent Pain Outcomes Collaboration database. Clin J Pain. 2024;40(3):137-44. doi:10.1097/AJP.0000000000001189

[18] Wightman A. Caregiver burden in pediatric dialysis. Pediatr Nephrol. 2020;35(9):1575–83. doi:10.1007/s00467-019-04332-5

[19] Ahmad W, Dastagir M, Azhar IA, Ahmad S, Batool S. Unseen struggles: The psychosocial toll of raising a child with functional neurological disorder. J Shalamar Med Dent Coll. 2025;6(2):71–6. doi:10.53685/jshmdc.v6i2.337

[20] Karakis I, Morton ML, Janocko NJ, Groover O, Teagarden DL, Villarreal HK, et al. Caregiver burden in psychogenic non-epileptic seizures. Seizure. 2020;81:13–7. doi:10.1016/j.seizure.2020.07.007

[21] McWilliams A, Reilly C, McFarlane FA, Booker E, Heyman I. Nonepileptic seizures in the pediatric population: a qualitative study of patient and family experiences. Epilepsy Behav. 2016;59:128–36. doi:10.1016/j.yebeh.2016.03.029

[22] Braun V, Clarke V. Thematic Analysis: A practical guide. London: SAGE Publications Ltd; 2022.

[23] Maxwell J. A realist approach to qualitative research. Thousand Oaks (CA): SAGE Publications; 2011.

[24] Alharahsheh HH, Pius A. A Review of key paradigms: positivism VS interpretivism. Glob Acad J Humanit Soc Sci. 2020;2(3):39–43.

[25] Department of Health and Social Care. The NHS Constitution for England, https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england; 2015 [accessed 10 July 2024].

[26] NHS Health Research Authority, INVOLVE. Impact of public involvement on the ethical aspects of research, https://s3.eu-west-2.amazonaws.com/www.hra.nhs.uk/media/documents/impact-public-involvement-ethical-aspects-research-updated-2016.pdf; 2016 [accessed 10 July 2024].

[27] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57. doi:10.1093/intqhc/mzm042

[28] Clarke V, Braun V. Successful qualitative research: A practical guide for beginners. London: SAGE Publications Ltd; 2013.

[29] Malterud K, Siersma V D, Guassora A D. Sample size in qualitative interview studies: guided by information power. Qual Health Res. 2016;26(13):1753–60. doi:10.1177/1049732315617444

[30] Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101. doi:10.1191/1478088706qp063oa

[31] Fairclough G, Fox J, Mercer G, Reuber M, Brown RJ. Understanding the perceived treatment needs of patients with psychogenic nonepileptic seizures. Epilepsy Behav. 2014;31:295–303. doi:10.1016/j.yebeh.2013.10.025

[32] Liu Z, Heffernan C, Tan J. Caregiver burden: a concept analysis. Int J Nurs Sci. 2020;7(4):438–45. doi:10.1016/j.ijnss.2020.07.012

[33] Doğaner F, Celen R. The effect of intolerance of uncertainty, sleep quality, and social support on caregiver burden in parents of children with chronic diseases: a cross-sectional study. J Pediatr Nurs. 2025;81:e106–12. doi:10.1016/j.pedn.2025.02.006

[34] Burn O, Duncan M, McAllister E, Murphy T, Loewenberger A. The journey to a functional tics diagnosis and experiences of post diagnostic support: perspectives from adolescents and their parents. Disabil Rehabil. 2025;47(23):6168–79. doi:10.1080/09638288.2025.2477293

[35] Walsh G, Wilson CE, Hevey D, Moore S, Flynn C, Breheny E, et al. “This is real”, “this is hard” and “I’m not making it up”: experience of diagnosis and living with non-epileptic attack disorder. Epilepsy Behav. 2024;154:109753. doi:10.1016/j.yebeh.2024.109753

[36] Kornelsen J, Atkins C, Brownell K, Woollard R. The meaning of patient experiences of medically unexplained physical symptoms. Qual Health Res. 2016;26(3):367–76. doi:10.1177/1049732314566326

[37] Bronfenbrenner U. Ecology of the family as a context for human development: research erspectives. Dev Psychol. 1986;22(6):723–42. doi:10.1037/0012-1649.22.6.723

[38] Bokharey IZ, Fahim U, Tahir K. Family conflicts are bitter splits that hurt: A qualitative inquiry toward understanding the impact of family issues in functional neurological symptom disorder. Front Psychol. 2021;12:652917. doi:10.3389/fpsyg.2021.652917

[39] Henry CS, Harrist AW. Family Resilience Theory. In: Adamsons K, Few-Demo AL, Proulx C, Roy K, editors. Sourcebook of family theories and methodologies: a dynamic approach. Cham: Springer International Publishing; 2022. p. 65–91. doi:10.1007/978-3-030-92002-9_4

[40] Kim GM, Lim JY, Kim EJ, Kim SS. A model of adaptation for families of elderly patients with dementia: focusing on family resilience. Aging Ment Health. 2018;22(10):1295–303. doi:10.1080/13607863.2017.1354972

[41] Rolland JS, Walsh F. Facilitating family resilience with childhood illness and disability. Curr Opin Pediatr. 2006;18(5):527-38. doi:10.1097/01.mop.0000245354.83454.68

[42] Patel H, Malave R, Bitting S, Weir K, Naus T, Shelton L, et al. Youth and family perspectives on diagnosis communication about pediatric functional seizures: a qualitative study. Paediatr Neurol. 2024;161;91-8. doi:10.1016/j.pediatrneurol.2024.09.003

[43] Pirard K, Stiller J, Tyndall I. A battle for validation and understanding of people with functional neurological disorder (FND): effects of stigma and actions of others on well-being and self-perception. Curr Psychol. 2026;45(6):620-9. doi:10.1007/s12144-026-09230-2

[44] Huang J, Huang X, Liu R, Dai J, Chen Y, Zhang X, et al. Experiences of burden and needs in caregivers with pediatric noninfectious uveitis: a qualitative study. BMC Nurs. 2024;23(1):929. doi:10.1186/s12912-024-02602-8

[45] British Psychological Society. Functional Neurological Disorder: Neuropsychological and psychological management in children and adults. British Psychological Society; 2024 [accessed 27 Apr 2026]. Available from: https://explore.bps.org.uk/lookup/doi/10.53841/bpsrep.2024.rep181 doi:10.53841/bpsrep.2024.rep181

[46] Edwards M, Dilley M, Golder D. Optimal clinical pathway for adults with Functional Neurological Disorder (FND), https://www.nnag.org.uk/optimal-clinical-pathway-adults-fnd-functional-neurological-disorder; National Neurosciences Advisory Group; 2023 [accessed 27 April 2026]

[47] Sheng N, Ma J, Ding W, Zhang Y. Effects of caregiver-involved interventions on the quality of life of children and adolescents with chronic conditions and their caregivers: a systematic review and meta-analysis. Qual Life Res. 2019;28(1):13–33. doi:10.1007/s11136-018-1976-3

[48] Reich JW, Olmsted ME, van Puymbroeck CM. Illness uncertainty, partner caregiver burden and support, and relationship satisfaction in fibromyalgia and osteoarthritis patients. Arthritis Care Res. 2006;55(1):86–93. doi:10.1002/art.21700

[49] Davison KK, Charles JN, Khandpur N, Nelson TJ. Fathers' perceived reasons for their underrepresentation in child health research and strategies to increase their involvement. Matern Child Health J. 2017;21(2):267–74. doi:10.1007/s10995-016-2157-z

Chapter Five: Discussion and Critical Evaluation

The purpose of this chapter is to synthesise the thesis portfolio as a whole, bringing together the findings of the systematic review (SR) and empirical paper (EP). It will also consider the portfolio's strengths and limitations, and the implications for clinical practice and future research.

Chapter one introduced functional neurological disorder (FND), including its historical development, changing terminology, and current clinical understanding. The chapter highlighted the historically uncertain position of FND between neurological and psychological understandings, and oriented readers to the current clinical landscape. It also presented the known impacts of FND on the individual and considered the role of caregiving in FND.

The SR explored the quality of life (QoL) of caregivers of individuals with FND, synthesising quantitative and qualitative evidence relating to caregiver burden, psychological distress, stigma, advocacy demands, and wider social and relational impacts. Overall, the review demonstrated that caregiving for individuals with FND is associated with meaningful impacts on caregiver QoL, particularly within psychological and social domains. The findings also highlighted that caregiver burden is shaped not only by caregiving responsibilities themselves, but also by uncertainty, experiences of invalidation, and the demands associated with navigating healthcare and wider systems, suggesting that caregiver burden emerges through ongoing interactions within wider relational, healthcare, and societal systems.

The EP explored the lived experiences of carers supporting young people with non-epileptic seizures (NES), a presentation of FND. Four interconnected themes were developed through reflexive thematic analysis: living in uncertainty; holding it all together; systems shaping and distributing the caregiving load; and relational worlds reshaped. Together, the findings positioned caregiving as an ongoing process of managing persistent uncertainty, coordinating support across systems, and adapting within changing relational contexts.

Overall Discussion

Across the thesis, findings demonstrated that the experiences of caregivers of individuals with FND are shaped by more than the task of caregiving itself. The SR highlighted elevated caregiver burden, reductions in psychological domains of quality of life, and wider social and practical impacts, while the EP provided insight into how these experiences are lived by carers of young people with NES. Together the findings suggest that caregiving is characterised not only by practical demands, but also by persistent uncertainty, advocacy demands, fragmented systems, and the need to manage and navigate a condition which does not neatly fit with dominant understandings of illness.

Uncertainty as an Ongoing Context of Caregiving

Uncertainty was evident across the thesis and often appeared to be a pervasive and enduring aspect of caregiving. Within the EP, carers described uncertainty from symptom onset through to ongoing management and concerns about the future. Accounts highlighted uncertainty regarding FND symptoms and their meaning, risk, prognosis and recovery, and how the future might look for both the young person and the carer themselves. A key finding was that uncertainty often persisted following diagnosis, as carers continued to search for explanations, develop their own interpretations, and at times struggled to reconcile professional understandings of FND with their own lived experiences. Similarly, the SR highlighted how caregiver burden and quality of life may be shaped by uncertainty (Burn et al., 2025; Ludlow et al., 2024; McWilliams et al., 2016; Patel et al., 2024). The findings therefore suggest that uncertainty in FND caregiving persists beyond diagnosis and forms part of the ongoing context in which caregiving occurs.

Within broader literature, uncertainty has frequently been positioned as a contributor to caregiver distress, especially in chronic conditions or those where symptoms are ambiguous or unpredictable and trajectories unclear (Byun et al., 2016; Chaney et al., 2016; Morris & Ogden,

2012). Mishel's Uncertainty in Illness Theory proposes that uncertainty arises where illness-related events are difficult to interpret, predict, or assign meaning to, where outcomes are unclear, or where information is limited (Mishel, 1984, 1990). Within paediatric literature, illness uncertainty has similarly been associated with increased psychological distress and poorer coping among both young people and caregivers (Chaney et al., 2016; Page et al., 2012). Szulczewski et al. (2017) additionally found that caregiver uncertainty regarding their child's chronic illness was associated with caregiver psychological functioning, coping style, anxiety, and depression, alongside the child's own psychological functioning. The findings of this thesis appear consistent with this literature, particularly in relation to carers' experiences of vigilance, emotional burden, and ongoing information-seeking in response to uncertainty.

However, the findings suggest that uncertainty in FND caregiving may extend beyond symptoms themselves. Carers often attempted to make sense of symptoms and experiences that did not always fit with dominant expectations and understandings of illness, while also navigating systems in which explanations and responses were experienced as fragmented or invalidating. Similar processes have been described within literature relating to functional tics and adult experiences of FND, where uncertainty has been shown to persist beyond diagnosis and contribute to ongoing difficulties in sense-making and validation (Burn et al., 2025; Fairclough et al., 2014; Fouché et al., 2019; Rawlings & Reuber, 2016; Walsh et al., 2024). Uncertainty appeared to extend beyond symptoms themselves into uncertainty surrounding the meaning, legitimacy, and implications of the diagnosis, aligning with NES and FND literature describing ongoing experiences of stigma and invalidation (Annandale et al., 2022; McLoughlin et al., 2024), alongside the historical ambiguity and contested legitimacy that have characterised FND (see Chapter 1).

The persistence of uncertainty following diagnosis may partly reflect tensions between carers' expectations of illness within a Western biomedical framework and the realities of FND.

Within Western healthcare systems, diagnosis is often associated with identifiable pathology, objective investigation, clear prognosis, and defined treatment pathways. In contrast, FND is diagnosed through positive clinical signs (Bennett et al., 2021) and symptoms can fluctuate over time, while recovery trajectories may be uncertain or non-linear. Within NES literature, this has been associated with patients contesting the diagnosis and continuing to seek "organic" explanations for symptoms which may feel like a more legitimate explanation (Peacock et al., 2023).

Similarly, within the EP, some carers questioned the legitimacy or usefulness of the FND diagnosis and continued to search or advocate for alternative explanations, or sought to understand more about the diagnosis in an apparent attempt to make sense of it. Referrals to psychological services were also at times experienced as confusing, irrelevant or unnecessary, or implicitly blaming based on carers' understandings of symptoms. These findings may reflect a rejection of explanations perceived as inconsistent with more traditional biomedical models of illness. They may also reflect the historically ambiguous position of FND between neurological and psychological understandings, alongside wider mind-body dualisms embedded within Western healthcare systems (Bates et al., 1997; Raynor & Baslet, 2021). Carers therefore appeared to be managing not only symptoms themselves, but also how those symptoms were interpreted and responded to by carers themselves, others and wider healthcare systems, requiring ongoing negotiation of legitimacy, meaning, and access to care.

Advocacy, Legitimacy, and Navigating Systems

Advocacy appeared to be another significant factor shaping caregiving experiences and burden across the thesis. Within the SR, caregivers described an ongoing requirement to act as advocates by explaining symptoms and seeking support, often in the face of scepticism or misunderstanding (Burn et al., 2025; Ludlow et al., 2024; McWilliams et al., 2016), alongside experiences of stigma and invalidation (Patel et al., 2024). These experiences were frequently

framed as emotionally distressing. Similarly, within the EP, carers described “fighting” throughout their journey for further investigations or treatment, support and understanding from systems such as schools, and recognition of the condition and its implications. Advocacy in this regard was often experienced as emotionally taxing and, at times, more burdensome than the symptoms themselves. Taken together, the findings indicate that caregiving in FND frequently involves substantial “advocacy work” in addition to the responsibilities of caregiving.

This advocacy burden may be closely linked to the uncertain and sometimes contested nature of FND within healthcare and wider systems. Annandale et al. (2022) found that stigma in NES is present within healthcare and social systems, while McLoughlin et al. (2024) demonstrated that this extends across FND phenotypes. This stigma was reflected in experiences of misunderstanding and dismissal, including healthcare professionals perceiving NES as “fake” or regarding patients as “time wasters” (Annandale et al., 2022). Across the thesis, because symptoms were not always perceived to be understood or recognised, carers frequently took on the role of coordinating care, explaining symptoms, and managing misunderstandings. In this way, caregiving in FND appeared to involve additional work to compensate for or mitigate responses from systems, rather than solely supporting the individual with FND.

FND is associated with high healthcare utilisation and substantial direct and indirect cost to the patient, healthcare system, and wider society (Watson et al., 2023). The thesis findings, in which carers described experiences of feeling dismissed or unheard, and where access to support was perceived as dependent on carers’ own persistence, professional knowledge, or ability to navigate systems, may reflect one reason for high healthcare utilisation through advocacy and ongoing help-seeking. Carers often described continued searching for explanations and advocating for further investigations and support even following diagnosis. This suggests that healthcare utilisation within FND may partly reflect ongoing attempts to

manage uncertainty and navigate systems experienced as insufficiently containing, rather than simply reflecting symptom need alone; particularly in paediatric populations where carers might be practically responsible for attendance in healthcare settings. Improving understanding of FND, alongside providing clear and consistent care across services, may therefore play an important role in reducing repeated healthcare utilisation and caregiver distress.

Adaptation and Relational Resilience

The thesis also highlighted processes of adaptation, attunement, and relational resilience. Although caregiving was associated with burden and disruption, carers described adapting over time, developing increased understanding of the individual's needs, and reshaping family roles and relationships around the condition. Adaptation also appeared to involve changes to carers' expectations of family life, independence, and identity over time. Within the EP, this was reflected in shifts towards more collaborative parenting approaches, increased closeness, and greater appreciation and recognition of family strengths. Similarly, within the SR, Mantilla and Rojas (2018) reported experiences of increased family closeness and unity.

However, these adaptive processes did not negate the ongoing challenges associated with caregiving. Instead, adaptation appeared to coexist with ongoing uncertainty, distress, and burden, rather than representing a resolution of these experiences. Broader literature has demonstrated that family attunement may be associated with reduced caregiver burden within neurological conditions (Tramonti et al., 2019), and within this thesis it may represent an attempt to manage the ongoing impact of FND on family life. Family resilience models emphasise the role of meaning-making and family strengths in response to ongoing adversity over time (Henry et al., 2015).Adaptation often appeared to involve families gradually integrating FND into daily life, developing shared understandings of symptoms, and reorganising roles and relationships to accommodate the condition. This suggests that caregiving in FND may be

better understood as an ongoing relational and adaptive process, rather than a static experience of burden alone. The findings therefore support more relational and systemic understandings of caregiving, where the impact of FND extends beyond the individual to shape family relationships, identities, and routines over time.

Across the thesis findings, carers frequently described experiences of misunderstanding and uncertainty, while experiences of validation and shared understanding appeared to support adaptation and reduce distress. This may highlight the potential importance of connection with others experiencing similar difficulties within caregiving experiences of FND. Although research relating specifically to peer support in FND is limited, broader literature has suggested that peer support is perceived as beneficial and may reduce distress and improve wellbeing among parents with disabilities or chronic illness (Lancaster et al., 2023; Shilling et al., 2013).

The findings also highlight the importance of caregiver wellbeing not only for the carer themselves but also for the wider family system and potentially for outcomes in the young people with FND. Broader paediatric and chronic illness literature has demonstrated associations between caregiver distress, burden, and poorer psychological and health-related outcomes in young people (Chaney et al., 2016; Pierce et al., 2017). Within adult FND, caregiver burden has been found to relate reciprocally to patient psychosocial wellbeing (Karakis et al., 2020a), while in paediatrics, family unwillingness to accept the diagnosis has been associated with poorer outcomes (Maitra et al., 2025). Across the thesis, carers' experiences often appeared interconnected with the individual with FND's adjustment, and the functioning of the wider family system. This suggests that supporting caregiver understanding and wellbeing may be an important component of supporting outcomes for people with FND.

Strengths and Limitations

The strengths and limitations of the individual SR and EP are addressed within their respective chapters. Here, the portfolio's overarching strengths and limitations are discussed.

A key strength of the portfolio is that it centres caregivers as important members of the support system surrounding the person with FND. While existing literature has largely prioritised the experiences and treatment of individuals with FND, comparatively less attention has focused on caregivers (e.g., McLoughlin et al., 2024). This portfolio contributes to a growing recognition that caregiving is both a significant component of the broader FND context and an area of substantial impact in its own right. By bringing carer experiences to the foreground, the thesis provides insight into how FND is experienced, understood, and navigated by those closely involved in supporting the individual.

A further strength lies in the integration of an SR and a qualitative EP, which allowed for both breadth and depth of understanding. The combination of quantitative and qualitative findings in the SR through a narrative synthesis, and a qualitative approach in the EP, enabled consideration of both measurable caregiver outcomes and the lived processes through which those outcomes are experienced. The SR explored a range of caregiver groups across varied age contexts, highlighting common patterns of caregiver burden, psychological distress, and reduced quality of life. The EP provided a more detailed exploration of lived experience within a specific context of caregiving for young people with NES. Together, the portfolio offers a more comprehensive account of caregiving in FND and suggests that key processes, including uncertainty, advocacy, and relational impacts, may operate across different caregiving relationships and stages of life. This strengthens the conceptual contribution of the thesis by indicating that these experiences may reflect broader features of caregiving in FND, rather than experiences confined to a single caregiving group or context.

With regard to limitations, one key consideration is the limited attention given to intersectional factors across both the SR and EP. Variables such as socioeconomic status, ethnicity, and cultural context were either inconsistently reported or not explicitly examined, despite some evidence within the reviewed literature suggesting that socioeconomic status is

associated with the caregiving experience and outcomes (Teagarden et al., 2020). Furthermore, the SR included only English-language publications, meaning that literature reflecting experiences and understandings outside predominantly Western contexts may not have been captured. This is particularly relevant given the earlier discussion surrounding Western biomedical understandings of illness, as experiences of FND, caregiving, legitimacy, and help-seeking may differ across cultural and healthcare contexts.

The empirical sample comprised White British mothers within a specific geographical region in England, meaning that the findings reflect experiences situated within particular cultural, social, and healthcare contexts. Caregiving experiences may differ significantly across contexts, particularly where understandings of illness, and access to and experiences of healthcare vary. Cultural factors have been shown to influence stigma and subsequent help-seeking and treatment in FND for the individual (McLoughlin et al., 2024), and it is likely that these factors also shape caregiving experiences. Such contextual influences may be relevant in shaping how symptoms are interpreted, responded to, and supported across different caregiving and healthcare contexts.

Although the SR included studies involving a broader range of caregivers, the empirical sample included mothers only, despite recruitment not being intentionally limited in this way. Fathers are often underrepresented in paediatric research, despite their important role in child development (Davison et al., 2017). However, caregiving experiences may differ across gendered and familial contexts, and the absence of fathers' perspectives within the EP may therefore have shaped the themes and understandings generated within the EP and across the wider thesis.

Additionally, both the literature considered in the SR and the sample recruited in the EP reflect carers who were engaged with healthcare services. As such, the experiences of those less connected to services, facing barriers to accessing care, or disengaged from care were not

represented. This may result in an incomplete understanding of the full range of caregiving experiences in FND, particularly among more marginalised or underserved groups.

Overall, the thesis provides a detailed and clinically relevant account of caregiving in FND, but the findings should be understood as offering depth of insight rather than representativeness across all caregiver populations. For example, the absence of fathers within the sample, which may reflect broader patterns or underrepresentation within paediatric research, means what potentially distinct paternal caregiving experiences were not captured within the study.

Implications for Clinical Work

The findings across the thesis highlight clear implications for clinical practice within FND services, as well as for wider systems involved in supporting individuals with FND and their families.

Uncertainty appeared to be a central feature of caregiving across both the SR and EP, suggesting that the way FND is explained, understood, and responded to within services and wider systems can significantly shape caregiver experiences and wellbeing. Clear, consistent, and ongoing explanations of FND appear important. Diagnosis may provide some reassurance, but the findings indicate that diagnosis alone is often insufficient in reducing uncertainty, especially where carers struggle to reconcile professional explanations with their lived experience of symptoms. This highlights the importance of explanation as an ongoing process rather than something localised solely to diagnosis, particularly where carers continue to seek explanations elsewhere. Providing opportunities for carers to revisit explanations or diagnosis, ask questions, and develop a shared understanding over time may support sense-making and reduce ongoing distress.

This is consistent with current British Psychological Society guidance for the management of FND, which highlights the importance of psychoeducation and family

involvement in FND care (British Psychological Society, 2024). The findings also suggest that the role and rationale of psychological input within FND services may not always be clearly understood by families. Clinical psychologists may therefore have an important role in supporting formulation, psychoeducation, and shared meaning-making within families, as well as in supporting engagement with and understanding of psychological approaches to FND. Explanations which clearly communicate symptoms as legitimate, alongside the rationale for psychological approaches, may also help to reduce confusion, self-blame, and mistrust.

The findings additionally highlight the importance of coordinated and relationally attuned support, not just in healthcare services but also across wider systems. Fragmented systems and inconsistent responses appeared to contribute to caregiver burden, often leaving carers responsible for coordinating care and advocating across healthcare, educational, and social contexts. BPS guidance emphasises the importance of multidisciplinary and whole-system approaches to FND care, including liaison across primary, secondary, and tertiary services (British Psychological Society, 2024; Edwards et al., 2023). The current findings may therefore highlight the importance of psychologically informed training and shared understanding of FND across professionals and systems involved in care, alongside greater collaboration and consistency across services. Within this context, clinical psychologists may contribute not only through direct therapeutic work, but also through consultation, formulation, liaison, and training across systems.

Given the significant role of schools within some carers' accounts in the EP, improving understanding of FND within educational settings may be particularly important. Existing guidance for schools and colleges highlights the importance of collaborative working with parents and carers, shared understandings of symptoms, psychoeducation, and consistent approaches across home and educational settings (Lumsden & Webb, 2023). The current

findings suggest that such approaches may help to reduce misunderstandings, improve consistency of support, and reduce the advocacy burden often experienced by carers.

The overall thesis findings suggest that carers themselves may require more direct recognition and support within FND care pathways. Interventions are often focused primarily on the individual with FND, but carers within both the reviewed literature and EP described substantial impacts associated with caregiving. These insights argue for approaches which directly support carers, for example through psychoeducation, emotional support, family-informed interventions, or opportunities to process uncertainty and caregiving burden within a supportive, psychologically informed context. Opportunities for connection with other families experiencing similar difficulties may also be valuable in supporting validation and promoting shared understanding.

Directions for Future Research

Longitudinal studies may help to develop a better understanding of how caregiving experiences and quality of life change over time, particularly given the ongoing and fluctuating nature of FND symptoms. Further research involving more diverse caregiver groups, including fathers, siblings, and carers from different cultural and/or socioeconomic backgrounds for example, would also strengthen understanding of how caregiving experiences may vary across contexts. Finally, given the prominence of uncertainty, advocacy demands, and psychological burden within the findings, future studies which explore caregiver-focused interventions and family-based approaches may be an important area for continued service development in FND.

Conclusions

This thesis explored caregiving in the context of FND through an SR examining caregiver QoL and an EP exploring the lived experiences of carers supporting young people with NES. Together, the findings suggest that caregiving in FND is shaped not only by caregiving responsibilities themselves, but also by persistent uncertainty, advocacy demands, fragmented

systems, and wider relational impacts. Across the portfolio, uncertainty emerged as a particularly important feature of caregiving, extending beyond symptom unpredictability into broader questions surrounding legitimacy, meaning, and explanation with the context of FND.

Overall, the thesis contributes to a broader understanding of caregiving in FND as a multidimensional and contextually embedded experience shaped through interactions between individuals, families, healthcare systems, and wider cultural understandings of illness. The findings highlight the importance of clear and ongoing communication, coordinated and psychologically informed support, and greater recognition of caregivers within FND care pathways. The thesis also highlights the need for further research exploring caregiving experiences across diverse contexts and examining approaches which more directly support caregivers and family systems within FND care.

Chapter Six: Extended Methodology for the Empirical Paper

As outlined in the empirical paper, data were analysed using an inductive reflexive thematic analysis (RTA) approach. This chapter provides additional methodological reflection to supplement the journal-style paper, including further detail regarding analytic decision-making, reflexivity, and the development of themes.

Extended Methodological Reflections

An inductive approach was selected to prioritise participants' accounts rather than applying a pre-existing framework, aligning with the exploratory aim of the study. Recruitment to the study was initially established across three Participant Identification Centres (PICs), including the development of site agreements and liaison with clinical teams. However, recruitment proved challenging and varied across sites, with one PIC not recruiting any participants during the study period. This may reflect differences in local service pathways, approaches to FND management, or opportunities for ongoing contact with families within services. During the recruitment process, one clinical supervisor also reflected on an apparent shift in referral presentations within their service, describing fewer referrals relating to NES and increasing presentations involving symptoms such as limb weakness. This may reflect the variability and changing presentations associated with FND over time.

Recruitment therefore required extension beyond the original recruitment window, at which point four participants had been recruited across two PICs. Following additional recruitment efforts, three additional participants were recruited, resulting in a final sample of seven participants. This sample size of seven was considered sufficient, informed by principles of information power (Malterud et al., 2016). The study's focused aim, specificity of the sample, and richness of the data meant that patterns were identified across participants, alongside sufficient variation to capture differences in experiences and how experienced were interpreted.

Reflexivity and Analytic Development

Reflexivity was embedded throughout data collection and analysis through the use of a reflexive log. Following each interview, the researcher recorded reflections on emotional responses to the interview process, including anticipatory feelings and how these developed during the interaction. Reflections also captured "pulls" in the interview, such as the tension between the researcher's clinical training and the role of qualitative researcher (e.g., a tendency towards a therapeutic stance). Notes were also made on aspects of participants' accounts that stood out, including how carers made sense of their experiences.

Reflexivity continued throughout coding, theme development, and the final write-up. Logs were used to document analytic decisions, including combining conceptually similar codes (e.g., "invalidation of symptoms" and "minimisation of symptoms"), refining codes, and reconsidering early assumptions. For example, an early interpretation that carers' use of medical explanations reflected doubt or misunderstanding shifted towards understanding this as a way of making sense of a complex condition. Similarly, some extracts initially coded as "financial sacrifice" were reconsidered when participants did not necessarily frame these experiences as burdensome, highlighting the influence of the researcher's own assumptions. An illustrative extract from the reflexive log is provided in Appendix I.

Reflexive engagement also informed theme development. For example, *"*positive reappraisal or learning through the experience*"* was reconsidered during analysis, as it risked functioning as a 'catch-all' category that imposed a 'silver-lining' narrative. Extracts were instead embedded within broader relational and contextual processes, such as family adaptation, changes to daily life, and future-oriented adjustment.

Analytic Process

Interviews were initially transcribed using the automatic transcription function within Microsoft Teams. The lead researcher then reviewed each transcript while listening to the corresponding audio recording, correcting inaccuracies and editing the transcript to ensure a

verbatim record. This included the addition of pauses (e.g., ((pause)) or ellipses), non-verbal expressions (e.g., ((laughs)), ((sighs))), and verbal fillers such as “erm”, to retain the naturalistic quality of participants’ speech. Each transcript was reviewed more than once during this process, which also supported the initial phase of familiarisation with the data.

Coding began with a detailed line-by-line engagement with the first transcript, generating initial codes linked directly to data extracts. This process was repeated for subsequent transcripts. Alongside this, a running list of codes was maintained in OneNote, which was updated iteratively as coding progressed. The researcher actively refined codes throughout this process, consulting the evolving code list to identify where existing codes could be applied and documenting decisions about code development and refinement through reflexive notes. Transcripts were reviewed multiple times throughout analysis, with movement back and forth across interviews as patterns, tensions, and connections developed.

Following initial coding, focused codes were developed by grouping conceptually related patterns across the dataset. Data extracts associated with initial codes were used to support the development and definition of focused codes. Where relevant, extracts were linked to focused codes within Excel, while retaining the original initial codes to preserve transparency in the analytic process.

Focused codes were subsequently organised into candidate themes. This involved an iterative and reflexive process of grouping, moving, and reorganising codes within OneNote to explore potential thematic structures. Data extracts were revisited throughout this stage to test the coherence and relevance of developing themes. Some focused codes were refined, collapsed, or removed where they did not integrate meaningfully within the developing thematic structure. In some cases, initial codes that had been grouped together were reassigned to different focused codes following further review.

Themes and subthemes were mapped based on the focused codes that comprised them, with continued reference to data extracts to clarify the central organising concept of each theme. As analysis progressed, themes were refined through processes of splitting, collapsing, and redefining to ensure internal coherence and clear distinctions between themes.

Supervision was used in the analytic process to support reflexive engagement with the data. Discussions with supervisors provided opportunities to explore and challenge developing interpretations, reflect on analytic decisions, and 'sense-check' emerging themes.

Quality and Rigour in RTA

Quality was considered in relation to principles aligned with RTA, rather than criteria associated with positivist notions of reliability or validity (Braun & Clarke, 2022). The analysis was grounded in sustained engagement with the dataset, involving repeated review of transcripts and iterative coding, which facilitated the development of themes that were closely connected to participants' accounts.

Coherence between the research question, theoretical positioning, and analytic approach was maintained throughout. The use of an inductive RTA was consistent with the study's interpretivist and critical realist orientation, supporting an exploration of how carers made sense of their experiences. Themes were developed as central organising concepts, with attention to both shared patterns and individual variation within the dataset. Care was taken to ensure that themes captured meaningful patterns across participants while also recognising differences in how experiences were understood and articulated.

Portfolio References

Ahmad, W., Dastagir, M., Azhar, I. A., Ahmad, S., & Batool, S. (2025). Unseen struggles: The psychosocial toll of raising a child with functional neurological disorder. *Journal of Shalamar Medical & Dental College*, *6*(2), 71–76. https://doi.org/10.53685/jshmdc.v6i2.337

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Anderson, K. E., Gruber-Baldini, A. L., Vaughan, C. G., Reich, S. G., Fishman, P. S., Weiner, W. J., & Shulman, L. M. (2007). Impact of psychogenic movement disorders versus Parkinson's on disability, quality of life, and psychopathology. *Movement Disorders*, *22*(15), 2204–2209. https://doi.org/10.1002/mds.21687

Annandale, M., Vilyte, G., & Pretorius, C. (2022). Stigma in functional seizures: A scoping review. *Seizure: European Journal of Epilepsy*, *99*, 131–152. https://doi.org/10.1016/j.seizure.2022.05.016

Aybek, S., & Perez, D. L. (2022). Diagnosis and management of functional neurological disorder. *BMJ*, o64. https://doi.org/10.1136/bmj.o64

Baglioni, V., Esposito, D., Bernardi, K., Novelli, M., Zaccaria, V., Galosi, S., & Pisani, F. (2024). Misdiagnosis of functional neurological symptom disorders in paediatrics: Narrative review and relevant case report. *Clinical Child Psychology and Psychiatry*, *29*(3), 1026–1042. https://doi.org/10.1177/13591045241240805

Bates, M. S., Rankin-Hill, L., & Sanchez-Ayendez, M. (1997). The effects of the cultural context of health care on treatment of and response to chronic pain and illness. *Social Science & Medicine*, *45*(9), 1433–1447. https://doi.org/10.1016/S0277-9536(97)00068-3

Bennett, K., Diamond, C., Hoeritzauer, I., Gardiner, P., McWhirter, L., Carson, A., & Stone, J. (2021). A practical review of functional neurological disorder (FND) for the general physician. *Clinical Medicine*, *21*(1), 28–36. https://doi.org/10.7861/clinmed.2020-0987

Bratanov, C., Hot, P., & Vercueil, L. (2023). The natural history of terms describing functional (neurological) disorders in the medical literature of the last 60 years. *Journal of Neurology*, *270*(4), 2010–2017. https://doi.org/10.1007/s00415-022-11526-9

Braun, V., & Clarke V. (2022). *Thematic Analysis: A practical guide*. London: SAGE Publications Ltd.

British Psychological Society. (2024). *Functional neurological disorder: Neuropsychological and psychological management in children and adults*. https://doi.org/10.53841/bpsrep.2024.rep181

Burn, O., Duncan, M., McAllister, E., Murphy, T., & Loewenberger, A. (2025). The journey to a functional tics diagnosis and experiences of post diagnostic support: Perspectives from adolescents and their parents. *Disability and Rehabilitation*, *47*(23), 6168–6179. https://doi.org/10.1080/09638288.2025.2477293

Byun, E., Riegel, B., Sommers, M., Tkacs, N., & Evans, L. (2016). Caregiving immediately after stroke: A study of uncertainty in caregivers of older adults. *The Journal of Neuroscience Nursing: Journal of the American Association of Neuroscience Nurses*, *48*(6), 343–351. https://doi.org/10.1097/JNN.0000000000000238

Carle-Toulemonde, G., Goutte, J., Do-Quang-Cantagrel, N., Mouchabac, S., Joly, C., & Garcin, B. (2023). Overall comorbidities in functional neurological disorder: A narrative review. *L'Encéphale, Functional Neurological Disorder*, *49*(4, Supplement), S24–S32. https://doi.org/10.1016/j.encep.2023.06.004

Chaney, J. M., Gamwell, K. L., Baraldi, A. N., Ramsey, R. R., Cushing, C. C., Mullins, A. J., Gillaspy, S. R., Jarvis, J. N., & Mullins, L. L. (2016). Parent perceptions of illness uncertainty and child depressive symptoms in juvenile rheumatic diseases: Examining caregiver demand and parent distress as mediators. *Journal of Pediatric Psychology*, *41*(9), 941–951. https://doi.org/10.1093/jpepsy/jsw004

Chouksey, A., & Pandey, S. (2019). Functional movement disorders in elderly. *Tremor and Other Hyperkinetic Movements*, *9*, 10.7916/tohm.v0.691. https://doi.org/10.7916/tohm.v0.691

Davison, K. K., Charles, J. N., Khandpur, N., & Nelson, T. J. (2017). Fathers' perceived reasons for their underrepresentation in child health research and strategies to increase their involvement. *Maternal and Child Health Journal*, *21*(2), 267–274. https://doi.org/10.1007/s10995-016-2157-z

Ding, J. M., & Kanaan, R. A. A. (2017). Conversion disorder: A systematic review of current terminology. *General Hospital Psychiatry*, *45*, 51–55. https://doi.org/10.1016/j.genhosppsych.2016.12.009

Dosanjh, M., Alty, J., Martin, C., Latchford, G., & Graham, C. D. (2021). What is it like to live with a functional movement disorder? An interpretative phenomenological analysis of illness experiences from symptom onset to post-diagnosis. *British Journal of Health Psychology*, *26*(2), 325–342. https://doi.org/10.1111/bjhp.12478

Edwards, M., Dilley, M., & Golder, D. (2023). *Optimal clinical pathway for adults with functional neurological disorder (FND)*. National Neurosciences Advisory Group. https://www.nnag.org.uk/optimal-clinical-pathway-adults-fnd-functional-neurological-disorder

Fairclough, G., Fox, J., Mercer, G., Reuber, M., & Brown, R. J. (2014). Understanding the perceived treatment needs of patients with psychogenic nonepileptic seizures. *Epilepsy & Behavior*, *31*, 295–303. https://doi.org/10.1016/j.yebeh.2013.10.025

Filho, L. H. P., & Mutarelli, E. G. (2022). Diagnostic pitfalls in functional neurological disorders. *Arquivos de Neuro-Psiquiatria*, *80*(S 05), 324–327. https://doi.org/10.1590/0004-282X-ANP-2022-S120

Finkelstein, S. A., Diamond, C., Carson, A., & Stone, J. (2025). Incidence and prevalence of functional neurological disorder: A systematic review. *Journal of Neurology, Neurosurgery & Psychiatry*, *96*(4), 383–395. https://doi.org/10.1136/jnnp-2024-334767

Foley, C., Kirkby, A., & Eccles, F. J. R. (2024). A meta-ethnographic synthesis of the experiences of stigma amongst people with functional neurological disorder. *Disability and Rehabilitation*, *46*(1), 1–12. https://doi.org/10.1080/09638288.2022.2155714

Fouché, M., Hartwig, L., & Pretorius, C. (2019). Management of uncertainty in the diagnosis communication of psychogenic nonepileptic seizures in a South African context. *Epilepsy & Behavior*, *98*, 45–52. https://doi.org/10.1016/j.yebeh.2019.06.009

Gelauff, J. M., Kingma, E. M., Kalkman, J. S., Bezemer, R., van Engelen, B. G. M., Stone, J., Tijssen, M. A. J., & Rosmalen, J. G. M. (2018). Fatigue, not self-rated motor symptom severity, affects quality of life in functional motor disorders. *Journal of Neurology*, *265*(8), 1803–1809. https://doi.org/10.1007/s00415-018-8915-7

Gutkin, M., McLean, L., Brown, R., & Kanaan, R. A. (2021). Systematic review of psychotherapy for adults with functional neurological disorder. *Journal of Neurology, Neurosurgery & Psychiatry*, *92*(1), 36–44. https://doi.org/10.1136/jnnp-2019-321926

Hallett, M., Aybek, S., Dworetzky, B. A., McWhirter, L., Staab, J. P., & Stone, J. (2022). Functional neurological disorder: New subtypes and shared mechanisms. *The Lancet Neurology*, *21*(6), 537–550. https://doi.org/10.1016/S1474-4422(21)00422-1

Henry, C. S., Sheffield Morris, A., & Harrist, A. W. (2015). Family resilience: Moving into the third wave. *Family Relations*, *64*(1), 22–43. https://doi.org/10.1111/fare.12106

Jones, B., Reuber, M., & Norman, P. (2016). Correlates of health-related quality of life in adults with psychogenic nonepileptic seizures: A systematic review. *Epilepsia*, *57*(2), 171–181. https://doi.org/10.1111/epi.13268

Joos, A., Herrmann, C., Lahmann, C., Flottman, M., Jansen, T., Schede, C., Maner, P., Schörner, K., von Husen, D. K., Jöbges, M., & Hartmann, A. (2023). Biopsychosocial complexity in functional neurological disorder. *General Hospital Psychiatry*, *84*, 44–46. https://doi.org/10.1016/j.genhosppsych.2023.06.011

Kanaan, R. A. (2022). A historical perspective on functional neurological disorder. In K. LaFaver, C. W. Maurer, T. R. Nicholson, & D. L. Perez (Eds.), *Functional movement disorder: An interdisciplinary case-based approach* (pp. 3–11). Springer International Publishing. https://doi.org/10.1007/978-3-030-86495-8

Karakis, I., Montouris, G. D., Piperidou, C., Luciano, M. S., Meador, K. J., & Cole, A. J. (2014). Patient and caregiver quality of life in psychogenic non-epileptic seizures compared to epileptic seizures. *Seizure*, *23*(1), 47–54. https://doi.org/10.1016/j.seizure.2013.09.011

Karakis, I., Morton, M. L., Janocko, N. J., Groover, O., Teagarden, D. L., Villarreal, H. K., Loring, D. W., & Drane, D. L. (2020a). Caregiver burden in psychogenic non-epileptic seizures. *Seizure*, *81*, 13–17. https://doi.org/10.1016/j.seizure.2020.07.007

Karakis, I., Janocko, N. J., Morton, M. L., Groover, O., Teagarden, D. L., Villarreal, H. K., Loring, D. W., & Drane, D. L. (2020b). Stigma in psychogenic nonepileptic seizures. *Epilepsy & Behavior*, *111*, 107269. https://doi.org/10.1016/j.yebeh.2020.107269

Keatley, E., & Molton, I. (2022). A shift in approach: Assessment and treatment of adults with functional neurological disorder. *Journal of Health Service Psychology*, *48*(2), 79–87. https://doi.org/10.1007/s42843-022-00061-w

Keynejad, R. C., Frodl, T., Kanaan, R., Pariante, C., Reuber, M., & Nicholson, T. R. (2019). Stress and functional neurological disorders: Mechanistic insights. *Journal of Neurology, Neurosurgery & Psychiatry*, *90*(7), 813–821. https://doi.org/10.1136/jnnp-2018-318297

Kirkwood, B., & Mark, V. W. (2022). Consistency of inclusion criteria for functional movement disorder clinical research studies: A systematic review. *NeuroRehabilitation*, *50*(2), 169–178. https://doi.org/10.3233/NRE-228002

Kola, S., & LaFaver, K. (2022). Updates in Functional Movement Disorders: From Pathophysiology to Treatment Advances. *Current Neurology and Neuroscience Reports*, *22*(5), 305–311. https://doi.org/10.1007/s11910-022-01192-9

Kozlowska, K., & Scher, S. (2024). Recent advances in understanding the neurobiology of pediatric functional neurological disorder. *Expert Review of Neurotherapeutics*, *24*(5), 497–516. https://doi.org/10.1080/14737175.2024.2333390

LaFaver, K., LaFrance, W. C., Price, M. E., Rosen, P. B., & Rapaport, M. (2021). Treatment of functional neurological disorder: Current state, future directions, and a research agenda. *CNS Spectrums*, *26*(6), 607–613. https://doi.org/10.1017/S1092852920002138

Lancaster, K., Bhopti, A., Kern, M. L., Taylor, R., Janson, A., & Harding, K. (2023). Effectiveness of peer support programmes for improving well-being and quality of life in parents/carers of

children with disability or chronic illness: A systematic review. *Child: Care, Health and Development*, *49*(3), 485–496. https://doi.org/10.1111/cch.13063

Loewenberger, A., Cope, S. R., Poole, N., & Agrawal, N. (2020). An investigation into the preferred terminology for functional seizures. *Epilepsy & Behavior*, *111*, 107183. https://doi.org/10.1016/j.yebeh.2020.107183

Ludlow, A. K., Anderson, S., Robinson, S., Owen, T., & Hedderly, T. (2024). An investigation into mothers' experiences of their children's functional tic-like behaviour and tic attacks. *PLOS ONE*, *19*(1), e0292742. https://doi.org/10.1371/journal.pone.0292742

Ludwig, L., Pasman, J. A., Nicholson, T., Aybek, S., David, A. S., Tuck, S., Kanaan, R. A., Roelofs, K., Carson, A., & Stone, J. (2018). Stressful life events and maltreatment in conversion (functional neurological) disorder: Systematic review and meta-analysis of case-control studies. *The Lancet Psychiatry*, *5*(4), 307–320. https://doi.org/10.1016/S2215-0366(18)30051-8

Lumsden, V., & Webb, H. (2023). *Guidance for management of functional neurological disorders in schools & colleges*. North East London NHS Foundation Trust. https://www.kelsi.org.uk/__data/assets/pdf_file/0009/156654/Guidance-for-schools_november-2023.pdf-v13-pdf-.pdf

Maitra, R., Conti, I., Shah, A., Smythe, L., & Baig, B. (2025). Clinical outcomes in children and adolescents with functional neurological disorders. *BJPsych Open*, *11*(S1), S30–S30. https://doi.org/10.1192/bjo.2025.10116

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Mantilla, J. S. G., & Rojas, R. A. V. (2018). The visible and less visible in the suffering of a conversion disorder in children and adolescents. A qualitative study of illness explanatory models presented to caregivers of children and adolescents with conversion disorder. *Revista Colombiana de Psiquiatría (English ed.), 47*(3), 155-164. https://doi.org/10.1016/j.rcpeng.2018.06.002

Mavroudis, I., Kazis, D., Kamal, F. Z., Gurzu, I.-L., Ciobica, A., Pădurariu, M., Novac, B., & Iordache, A. (2024). Understanding functional neurological disorder: Recent insights and diagnostic challenges. *International Journal of Molecular Sciences*, *25*(8), 4470. https://doi.org/10.3390/ijms25084470

McLoughlin, C., Lee, W. H., Carson, A., & Stone, J. (2025). Iatrogenic harm in functional neurological disorder. *Brain*, *148*(1), 27–38. https://doi.org/10.1093/brain/awae283

McLoughlin, C., McWhirter, L., Pisegna, K., Tijssen, M. A. J., Tak, L. M., Carson, A., & Stone, J. (2024). Stigma in functional neurological disorder (FND) – A systematic review. *Clinical Psychology Review*, *112*, 102460. https://doi.org/10.1016/j.cpr.2024.102460

McWilliams, A., Reilly, C., McFarlane, F. A., Booker, E., & Heyman, I. (2016). Nonepileptic seizures in the pediatric population: A qualitative study of patient and family experiences. *Epilepsy & Behavior*, *59*, 128–136. https://doi.org/10.1016/j.yebeh.2016.03.029

Mishel, M. H. (1984). Perceived uncertainty and stress in illness. *Research in Nursing & Health*, *7*(3), 163–171. https://doi.org/10.1002/nur.4770070304

Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Image: The Journal of Nursing Scholarship*, *22*(4), 256–262. https://doi.org/10.1111/j.1547-5069.1990.tb00225.x

Morgan, L. A., Dvorchik, I., Williams, K. L., Jarrar, R. G., & Buchhalter, J. R. (2013). Parental ranking of terms describing nonepileptic events. *Pediatric Neurology*, *48*(5), 378–382. https://doi.org/10.1016/j.pediatrneurol.2012.12.029

Morris, A., & Ogden, J. (2012). Making sense of children's medically unexplained symptoms: Managing ambiguity, authenticity and responsibility. *Psychology, Health & Medicine*, *17*(3), 285–294. https://doi.org/10.1080/13548506.2011.608804

O'Mahony, B. W., Nelson-Sice, R., Nielsen, G., Hunter, R., Cope, S., Agarwal, N., Edwards, M. J., & Yogarajah, M. (2024). Cross-sectional evaluation of health resource use in patients with functional neurological disorders referred to a tertiary neuroscience centre. *BMJ Neurology Open*, *6*(1), e000606. https://doi.org/10.1136/bmjno-2023-000606

Page, M. C., Fedele, D. A., Pai, A. L. H., Anderson, J., Wolfe-Christensen, C., Ryan, J. L., & Mullins, L. L. (2012). The relationship of maternal and child illness uncertainty to child depressive symptomotology: A mediational model. *Journal of Pediatric Psychology*, *37*(1), 97–105. https://doi.org/10.1093/jpepsy/jsr055

Paredes-Echeverri, S., Guthrie, A. J., & Perez, D. L. (2022). Toward a possible trauma subtype of functional neurological disorder: Impact on symptom severity and physical health. *Frontiers in Psychiatry*, *13*. https://doi.org/10.3389/fpsyt.2022.1040911

Patel, H., Malave, R., Bitting, S., Weir, K., Naus, T., Shelton, L., Harris, K. W., Kerr, W. T., Van Cott, A. C., & Kirkpatrick, L. (2024). Youth and family perspectives on diagnosis communication about pediatric functional seizures: A qualitative study. *Pediatric Neurology, 161,* 91–98. https://doi.org/10.1016/j.pediatrneurol.2024.09.003

Patron, V. G., Rustomji, Y., Yip, C., & Jenkins, L. M. (2022). Psychiatric comorbidities in functional neurologic symptom disorder. *Practical Neurology (Fort Washington, Pa.)*, *21*(3), 71–75.

Peacock, M., Bissell, P., Ellis, J., Dickson, J. M., Wardrope, A., Grünewald, R., & Reuber, M. (2023). '*I just need to know what they are and if you can help me*': Medicalization and the search for legitimacy in people diagnosed with non-epileptic attack disorder. *Epilepsy & Behavior*, *148*, 109485. https://doi.org/10.1016/j.yebeh.2023.109485

Pierce, L., Hocking, M. C., Schwartz, L. A., Alderfer, M. A., Kazak, A. E., & Barakat, L. P. (2017). Caregiver distress and patient health-related quality of life: Psychosocial screening during pediatric cancer treatment. *Psycho-Oncology*, *26*(10), 1555–1561. https://doi.org/10.1002/pon.4171

Pritomanova, I., Cope, S. R., James, B., Edwards, M. J., Smith, J. G., El-Leithy, S., Vanzan, S., Hogwood, P., Golder, D., Turner, K. J., & Billings, J. (2026). The journey to diagnosis and care of functional neurological disorder (FND). *PLoS One*, *21*(4), e0328321. https://doi.org/10.1371/journal.pone.0328321

Pun, P., Frater, J., Broughton, M., Dob, R., & Lehn, A. (2020). Psychological profiles and clinical clusters of patients diagnosed with functional neurological disorder. *Frontiers in Neurology*, *11*, 580267. https://doi.org/10.3389/fneur.2020.580267

Rawlings, G. H., & Reuber, M. (2016). What patients say about living with psychogenic nonepileptic seizures: A systematic synthesis of qualitative studies. *Seizure*, *41*, 100–111. https://doi.org/10.1016/j.seizure.2016.07.014

Rawlings, G. H., & Reuber, M. (2018). Health care practitioners' perceptions of psychogenic nonepileptic seizures: A systematic review of qualitative and quantitative studies. *Epilepsia*, *59*(6), 1109–1123. https://doi.org/10.1111/epi.14189

Raynor, G., & Baslet, G. (2021). A historical review of functional neurological disorder and comparison to contemporary models. *Epilepsy & Behavior Reports*, *16*, 100489. https://doi.org/10.1016/j.ebr.2021.100489

Shilling, V., Morris, C., Thompson-Coon, J., Ukoumunne, O., Rogers, M., & Logan, S. (2013). Peer support for parents of children with chronic disabling conditions: A systematic review of quantitative and qualitative studies. *Developmental Medicine & Child Neurology*, *55*(7), 602–609. https://doi.org/10.1111/dmcn.12091

Staton, A., Dawson, D., Merdian, H., Tickle, A., & Walker, T. (2024). Functional neurological disorder: A qualitative study exploring individuals' experiences of psychological services. *Psychology and Psychotherapy: Theory, Research and Practice*, *97*(1), 138–156. https://doi.org/10.1111/papt.12504

Stone, J. (2025). Diagnostic signs in FND: Handle with care. *Practical Neurology*, *25*(3), 200–201. https://doi.org/10.1136/pn-2025-004513

Stone, J., Carson, A., Duncan, R., Roberts, R., Warlow, C., Hibberd, C., Coleman, R., Cull, R., Murray, G., Pelosi, A., Cavanagh, J., Matthews, K., Goldbeck, R., Smyth, R., Walker, J., & Sharpe, M. (2010). Who is referred to neurology clinics?—The diagnoses made in 3781 new patients. *Clinical Neurology and Neurosurgery*, *112*(9), 747–751. https://doi.org/10.1016/j.clineuro.2010.05.011

Stone, J., Wojcik, W., Durrance, D., Carson, A., Lewis, S., MacKenzie, L., Warlow, C. P., & Sharpe, M. (2002). What should we say to patients with symptoms unexplained by disease? The "number needed to offend". *BMJ*, *325*(7378), 1449–1450. https://doi.org/10.1136/bmj.325.7378.1449

Szasz, A., Korner, A., & McLean, L. (2025). Qualitative systematic review on the lived experience of functional neurological disorder. *BMJ Neurology Open*, *7*(1), e000694. https://doi.org/10.1136/bmjno-2024-000694

Szulczewski, L., Mullins, L. L., Bidwell, S. L., Eddington, A. R., & Pai, A. L. H. (2017). Meta-analysis: Caregiver and youth uncertainty in pediatric chronic illness. *Journal of Pediatric Psychology*, *42*(4), 395–421. https://doi.org/10.1093/jpepsy/jsw097

Teagarden, D. L., Morton, M. L., Janocko, N. J., Groover, O., Villarreal, H. K., Evans, L., Drane, D. L., & Karakis, I. (2020). Socioeconomic disparities in patients with psychogenic nonepileptic seizures and their caregivers. *Epilepsy & Behavior*, *110*, 107160. https://doi.org/10.1016/j.yebeh.2020.107160

Tinazzi, M., Morgante, F., Marcuzzo, E., Erro, R., Barone, P., Ceravolo, R., Mazzucchi, S., Pilotto, A., Padovani, A., Romito, L. M., Eleopra, R., Zappia, M., Nicoletti, A., Dallocchio, C., Arbasino, C., Bono, F., Pascarella, A., Demartini, B., Gambini, O., … Geroin, C. (2020). Clinical correlates of functional motor disorders: An Italian multicenter study. *Movement Disorders Clinical Practice*, *7*(8), 920–929. https://doi.org/10.1002/mdc3.13077

Tramonti, F., Bonfiglio, L., Bongioanni, P., Belviso, C., Fanciullacci, C., Rossi, B., Chisari, C., & Carboncini, M. C. (2019). Caregiver burden and family functioning in different neurological diseases. *Psychology, Health & Medicine*, *24*(1), 27–34. https://doi.org/10.1080/13548506.2018.1510131

Velazquez-Rodriquez, Y., & Fehily, B. (2023). Functional neurological disorder: Historical trends and urgent directions. *Journal of Neurology Research*, *13*(1), 12–32. https://doi.org/10.14740/jnr.v13i1.754

Walsh, G., Wilson, C. E., Hevey, D., Moore, S., Flynn, C., Breheny, E., & O'Keeffe, F. (2024). "This is real", "this is hard" and "I'm not making it up": Experience of diagnosis and living with non-epileptic attack disorder. *Epilepsy & Behavior*, *154*, 109753. https://doi.org/10.1016/j.yebeh.2024.109753

Wardrope, A., Green, B., Norman, P., & Reuber, M. (2019). The influence of attachment style and relationship quality on quality of life and psychological distress in carers of people with epileptic and nonepileptic seizures. *Epilepsy & Behavior*, *93*, 16–21. https://doi.org/10.1016/j.yebeh.2019.01.028

Watson, M., Woodward, J., & Strom, L. A. (2023). The financial burden of functional neurological disorders. *Current Neurology and Neuroscience Reports*, *23*(10), 637–643. https://doi.org/10.1007/s11910-023-01298-8

Yong, K., Chin, R. F. M., Shetty, J., Hogg, K., Burgess, K., Lindsay, M., McLellan, A., Stone, J., KamathTallur, K., & the Edinburgh Paediatric FND Study Group (2023). Functional neurological disorder in children and young people: Incidence, clinical features, and prognosis. *Developmental Medicine & Child Neurology*, *65*(9), 1238–1246. https://doi.org/10.1111/dmcn.15538

Portfolio Appendices

Systematic Review Appendices

Appendix A: Search Strategy

This is an example of the search strategy used as part of this systematic review. This search was run on MEDLINE Ultimate.

("quality of life" OR "QoL" OR "wellbeing" OR "well-being" OR "burden" OR "psychological impact" OR "experience*")

AND

("caregiver*" OR "carer*" OR "family member*" OR "informal care*" OR "parent*" OR "spouse*" OR "partner*")

AND

("functional neurological disorder" OR "FND" OR "functional symptoms" OR "functional seizures" OR "functional movement disorder" OR "FMD" OR "non-epileptic seizures" OR "dissociative seizures" OR "dissociative episodes" OR "conversion disorder" OR "psychogenic seizures" OR "psychogenic nonepileptic seizures" OR "psychogenic movement disorder" OR "psychogenic tremor" OR "psychogenic dystonia" OR "psychogenic gait disorder" OR "psychogenic weakness" OR "functional motor symptoms" OR "motor conversion disorder" OR "paroxysmal seizures" OR "paroxysmal episodes")

Appendix B: Summary Table of Study Characteristics and Extracted Data

Table B1

Extracted data from each included study, including quantitative results, qualitative findings, and any examined associations or predictors of caregiver outcomes

Author (Year)	Study Design	Key Quantitative Outcomes	Key Qualitative Themes/Findings	Associations/Predictors	Cohort
Karakis, et al. (2020a)	Quantitative – Cross-sectional	Mild to moderate caregiver burden (ZCBI) – Mean 28, SD 22; Elevated depression (BDI) – Mean 12, SD 10 and anxiety (BAI) – Mean 11, SD 10; Heightened stigma (LSS) – Mean 1.3, SD 1.1	N/A	Higher caregiver burden was associated with higher caregiver stigma, anxiety, and depression	EMU cohort; core quantitative dataset
Tsamakis, et al. (2022)	Quantitative – Cross-sectional	Depressive symptoms present in 52%; anxiety symptoms present in 50%	N/A	Psychological distress was associated with male patient gender, caregiver burden, and being a parent/sibling caregiver	EMU cohort
Teagarden, et al. (2020)	Quantitative – Cross-sectional	Burden was associated with SES differences	N/A	Higher SES was associated with greater burden and poorer social functioning;	EMU cohort

				lower SES was associated with higher anxiety	
Karakis, et al. (2020b)	Quantitative – Cross-sectional	76.5% of PNES caregivers felt stigmatised	N/A	Caregiver stigma was associated with poorer patient QoL and higher levels of patient and caregiver anxiety	EMU cohort
Karakis, et al., (2014a)	Quantitative – Cross-sectional	Mild to moderate caregiver burden (ZCBI) – Mean 23.27, SD 13.5; poorer mental component QoL than physical component QoL (SF-36v2)	N/A	Caregiver burden was the strongest correlate of poor mental component QoL	Independent cohort
Wardrope, et al. (2019)	Quantitative – Cross-sectional	Clinically significant anxiety (GAD-7) – Mean 8.2, SD 6.0, and depression (PHQ-9) – Mean 8.2, SD 6.3; Reduced QoL (SF-12), Mental component – Mean 43.2, SD 11.2, more impacted than physical component – Mean 48.6, SD 11.9	N/A	Anxious attachment and poorer perceived relationship quality was associated with greater psychological distress and poorer mental component QoL	Independent cohort
McWilliams, et al. (2016)	Qualitative – Thematic Analysis	N/A	Emotional burden and hypervigilance; Missing out (isolation); Feeling misunderstood; Confusion and	N/A	Independent cohort

			uncertainty; Less than epilepsy; Making sense and moving on		
Patel, et al. (2024)	Qualitative – Thematic Analysis	N/A	Fear about symptoms and feeling helpless; effective communication through reassurance; poor communication through minimisation and lack of compassion (invalidation); mixed perspectives on mental health link; need for practical guidance	N/A	Independent cohort
Burn, et al. (2025)	Qualitative – Thematic Analysis	N/A	Blamed, disbelieved, discounted (emotional exhaustion); Fighting for help (advocacy burden); Professional and community support; Change in identity and relationships (chronic vigilance, role strain)	N/A	Independent cohort
Ludlow, et al. (2024)	Qualitative – Thematic Analysis	N/A	Shock and anxiety about symptoms (emotional labour; challenge of managing symptoms;	N/A	Independent cohort

			psychological impact on family (identity disruption, social withdrawal); need for clear pathway		
Mantilla and Rojas (2018)	Qualitative – Method unclear	N/A	Multiple co-existing beliefs about symptoms (contextual factors); impact on daily life and relationships (mixed impact, unity vs strain); negative perception of psychological and/or psychiatric care	N/A	Independent cohort

EMU = Epilepsy Monitoring Unit, ZCBI = Zarit Caregiver Burden Inventory, LSS = Liverpool Stigma Scale, BDI = Beck Depression Inventory, BAI = Beck Anxiety Inventory, SF-36v2 = Short Form 36 Version 2 Health Survey, PHQ-9 = Patient Health Questionnaire-9, GAD-7 = Generalised Anxiety Disorder-7, SF-12 = Short Form 12 Health Survey

Appendix C: Quality Appraisal Tool Criteria

QuADS Criteria	0	1	2	3
1. Theoretical or conceptual underpinning to the research	No mention at all.	General reference to broad theories or concepts that frame the study. e.g. key concepts were identified in the introduction section.	Identification of specific theories or concepts that frame the study and how these informed the work undertaken. e.g. key concepts were identified in the introduction section and applied to the study.	Explicit discussion of the theories or concepts that inform the study, with application of the theory or concept evident through the design, materials and outcomes explored. e.g. key concepts were identified in the introduction section and the application apparent in each element of the study design.
2. Statement of research aim/s	No mention at all.	Reference to what the sought to achieve embedded within the report but no explicit aims statement.	Aims statement made but may only appear in the abstract or be lacking detail.	Explicit and detailed statement of aim/s in the main body of report.
3. Clear description of research setting and target population	No mention at all.	General description of research area but not of the specific research environment e.g. 'in primary care.'	Description of research setting is made but is lacking detail e.g. 'in primary care practices in region [x]'.	Specific description of the research setting and target population of study e.g. 'nurses and doctors from GP practices in [x] part of [x] city in [x] country.'
4. The study design is appropriate to address the stated research aim/s	No research aim/s stated or the design is entirely unsuitable e.g. a Y/N item survey for a study seeking to undertake exploratory work of lived experiences. .	The study design can only address some aspects of the stated research aim/s e.g. use of focus groups to capture data regarding the frequency and experience of a disease.	The study design can address the stated research aim/s but there is a more suitable alternative that could have been used or used in addition e.g. addition of a qualitative or	The study design selected appears to be the most suitable approach to attempt to answer the stated research aim/s.

			quantitative component could strengthen the design.	
5. Appropriate sampling to address the research aim/s	No mention of the sampling approach.	Evidence of consideration of the sample required e.g. the sample characteristics are described and appear appropriate to address the research aim/s.	Evidence of consideration of sample required to address the aim. e.g. the sample characteristics are described with reference to the aim/s.	Detailed evidence of consideration of the sample required to address the research aim/s. e.g. sample size calculation or discussion of an iterative sampling process with reference to the research aims or the case selected for study.
6. Rationale for choice of data collection tool/s	No mention of rationale for data collection tool used.	Very limited explanation for choice of data collection tool/s. e.g. based on availability of tool.	Basic explanation of rationale for choice of data collection tool/s. e.g. based on use in a prior similar study.	Detailed explanation of rationale for choice of data collection tool/s. e.g. relevance to the study aim/s, co-designed with the target population or assessments of tool quality.
7. The format and content of data collection tool is appropriate to address the stated research aim/s	No research aim/s stated and/or data collection tool not detailed.	Structure and/or content of tool/s suitable to address some aspects of the research aim/s or to address the aim/s superficially e.g. single item response that is very general or an open-response item to capture content which requires probing.	Structure and/or content of tool/s allow for data to be gathered broadly addressing the stated aim/s but could benefit from refinement. e.g. the framing of survey or interview questions are too broad or focused to one element of the research aim/s.	Structure and content of tool/s allow for detailed data to be gathered around all relevant issues required to address the stated research aim/s.
8. Description of data collection procedure	No mention of the data collection procedure.	Basic and brief outline of data collection procedure e.g. 'using a questionnaire distributed to staff'.	States each stage of data collection procedure but with limited detail or states some stages in detail but	Detailed description of each stage of the data collection procedure, including when, where and how

			omits others e.g. the recruitment process is mentioned but lacks important details.	data was gathered such that the procedure could be replicated.
9. Recruitment data provided	No mention of recruitment data.	Minimal and basic recruitment data e.g. number of people invited who agreed to take part.	Some recruitment data but not a complete account e.g. number of people who were invited and agreed.	Complete data allowing for full picture of recruitment outcomes e.g. number of people approached, recruited, and who completed with attrition data explained where relevant.
10. Justification for analytic method selected	No mention of the rationale for the analytic method chosen.	Very limited justification for choice of analytic method selected. e.g. previous use by the research team.	Basic justification for choice of analytic method selected e.g. method used in prior similar research.	Detailed justification for choice of analytic method selected e.g. relevance to the study aim/s or comment around of the strengths of the method selected.
11. The method of analysis was appropriate to answer the research aim/s	No mention at all.	Method of analysis can only address the research aim/s basically or broadly.	Method of analysis can address the research aim/s but there is a more suitable alternative that could have been used or used in addition to offer a stronger analysis.	Method of analysis selected is the most suitable approach to attempt answer the research aim/s in detail e.g. for qualitative interpretative phenomenological analysis might be considered preferable for experiences vs. content analysis to elicit frequency of occurrence of events.
12. Evidence that the research stakeholders have been considered in research design or conduct.	No mention at all.	Consideration of some the research stakeholders e.g. use of pilot study with target sample but no	Evidence of stakeholder input informing the research. e.g. use of pilot study with feedback influencing the study	Substantial consultation with stakeholders identifiable in planning of study design and in preliminary work e.g. consultation in the

		stakeholder involvement in planning stages of study design.	design/conduct or reference to a project reference group established to guide the research.	conceptualisation of the research, a project advisory group or evidence of stakeholder input informing the work.
13. Strengths and limitations critically discussed	No mention at all.	Very limited mention of strengths and limitations with omissions of many key issues. e.g. one or two strengths/limitations mentioned with limited detail.	Discussion of some of the key strengths and weaknesses of the study but not complete. e.g. several strengths/limitations explored but with notable omissions or lack of depth of explanation.	Thorough discussion of strengths and limitations of all aspects of study including design, methods, data collection tools, sample & analytic approach.

Appendix D: Appraisal Scores for Individual Studies

Table 1

QuADS appraisal scores for individual studies included in the systematic review

Author and Year	Total Score /39	Total Score as Percentage
Burn, et al. (2025)	38	97.44%
Karakis, et al. (2014)	29	74.36%
Karakis, et al. (2020a)	28	71.79%
Karakis, et al. (2020b)	30	76.92%
Ludlow, et al. (2024)	37	94.87%
Mantilla and Rojas (2018)	20	51.28%
McWilliams, et al. (2016)	33	84.62%
Patel, et al. (2024)	26	66.67%
Teagarden, et al. (2020)	28	71.79%
Tsamakis, et al. (2022)	29	74.36%
Wardrope, et al. (2019)	30	76.92%

Appendix E: Journal Guidelines

Instructions for authors

Article types

Quality of Life Research welcomes scientific articles in the following categories:

• Original Articles

Original articles are a maximum of 4,000 words, exclusive of a 250-word structured abstract, figures, tables, and references. We encourage submissions of shorter length if the empirical study can be presented concisely. We also make authors aware of the option to publish additional detail as online appendices. We are particularly interested in studies that utilize patient-reported outcomes, focusing on clinical and policy applications of (health-related) quality-of-life research; showcasing quantitative and qualitative methodological advances; and/ or describing instrument development. Articles describing qualitative research can be up to 5,000 words.

Original articles describe work that is not already published elsewhere or directly uses statements from previously published materials without appropriate acknowledgement or referencing. For example, if the submitted work forms part of a thesis dissertation or the abstract was published as part of conference proceedings, these should be acknowledged. If taking direct statements from published sources, these should be appropriately referenced.

• Registered Reports

The journal is pleased to offer Registered Reports for authors submitting to the journal. To learn more about this article type, please see the full instructions here.

• Letters to the editor

Quality of Life Research accepts on occasion letters to the editor. These letters are

published at the Co-Editors in Chief's discretion. Letters would be expected to make a substantial informative point and usually cover material such as responses to published articles or viewpoints (usually of more than an individual, e.g. patient groups, scientific societies, stakeholder organizations, international research consortia). As with commentaries, letters can also be submitted on invitation of the editors. Letters are not for general news sharing or to summarize results of articles published elsewhere. Letters to the editor will be reviewed by the Co-Editors in Chief, and if necessary, by drawing on additional editorial board members. In the case of letters that are in direct response to work published in Quality of Life Research, the original handling Associate Editor will be invited to review.

The submission format for a letter is a maximum length of 1000 words; no abstract; no sections; no graphs/figures; and no tables are permitted. The manuscript should have at most 5 references. A maximum of three authors are permitted, and only first author's main affiliation should be included

- Other Types of Articles

The journal also publishes commentaries and editorials; reviews of the literature; reviews of recent books and software advances; and conference proceedings including abstracts presented at relevant meetings. These articles should be as long as needed to convey the desired information, and no more than 5,000 words in length. To the extent that it is possible, a structured abstract is appreciated.

Language

We appreciate any efforts that you make to ensure that the language usage is corrected before submission using standard United States or United Kingdom English. This will greatly improve the legibility of your paper if English is not your first language.

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Plain English summary

All submitting authors in *Quality of Life Research* have the opportunity to include a Plain English summary in addition to the Abstract. The plain English summary is a brief summary of the study written for the general public rather than for specialists. It is not a scientific abstract. Use clear and simple language, avoiding jargon, abbreviations, technical terms, uncommon words, and long sentences wherever possible.

Please address the following questions in your summary paragraph:

1. Why is this study needed?

2. What is the key problem/issue/question this manuscript addresses?

3. What is the main point of your study?

4. What are your main results and what do they mean?

The recommended length for the summary is 100-200 words and it should not exceed 250 words. Each question above should be addressed briefly (i.e., 1-2 sentences).

Please include your plain English summary as a separate submission file, and additionally within the main body of your manuscript file. The plain English summary should be inserted immediately after the official scientific abstract within the manuscript file under the heading "Plain English summary".

By adding a plain English summary, we hope to broaden the reach of the article and bring it to the attention of a more general audience. Researchers are trained to be highly focused, specific, and conservative with extrapolation and speculation. These attributes are useful for scientific publications, but not for wider public understanding. Many non-scientists have difficulty understanding technical terms

and jargon, and the public requires more context-setting by way of introduction and more help drawing a conclusion.

An Example from the Journal of Eating Disorders

Original Manuscript

www.jeatdisord.biomedcentral.com/articles/10.1186/s40337-019-0264-0

Binge Eating Disorder is the most common eating disorder. Still, this disorder is often not addressed by the health care system, and current treatment shows poor results on a large group of these patients. Difficulties in relating to own body are linked to the development and maintenance of eating disorders in previous research and seem to influence treatment results and the risk of relapse. Basic Body Awareness Therapy is a psychomotor physiotherapeutic treatment addressing the relation to one's own body. In this study, we have explored in-depth the experiences of two patients with Binge Eating Disorder during their treatment-process with Basic Body Awareness Therapy. This study indicates that changes in how these patients related to their own bodies during the treatment processes were meaningful to them and implied a movement toward well-being and accepting one's own body. Findings from this study inspire more research on body awareness raising approaches in the treatment of patients with Binge Eating Disorder.

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Manuscript Submission

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible

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Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

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Please note that Author Contribution information and Competing Interest information must be provided at submission via the submission interface. Only the information submitted via the interface will be used in the final published version. Please make sure that if you are an editorial board member and also a listed author that you also declare this information in the Competing Interest section of the interface.

Please see the relevant sections in the submission guidelines for further information on these statements as well as possible other mandatory statements.

Statement on patient, public or community engagement (mandatory)

Please describe if and how this study involved or engaged with people with lived experience (such as patients, community members, users of health services, family members, carers) in the prioritization, design, conduct, translation, evaluation, or dissemination of the research; for example, as co-researchers/co-investigators, partners, or advisors.

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Editorial procedure

Single-blind peer review

This journal follows a single-blind reviewing procedure.

This journal also publishes special/guest-edited issues. The peer review process for these articles is the same as the peer review process of the journal in general.

Additionally, if a guest editor authors an article in their issue/collection, they will not handle the peer review process.

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Title Page

Please make sure your title page contains the following information.

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The title should be concise and informative.

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Abstract

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- Book
  Sapolsky, R. M. (2017). *Behave: The biology of humans at our best and worst*. Penguin Books.
- Book chapter
  Dillard, J. P. (2020). Currents in the study of persuasion. In M. B. Oliver, A. A. Raney,

& J. Bryant (Eds.), *Media effects: Advances in theory and research* (4th ed., pp. 115–129). Routledge.

- Online document
  Fagan, J. (2019, March 25). *Nursing clinical brain*. OER Commons. Retrieved January 7, 2020, from https://www.oercommons.org/authoring/53029-nursing-clinical-brain/view

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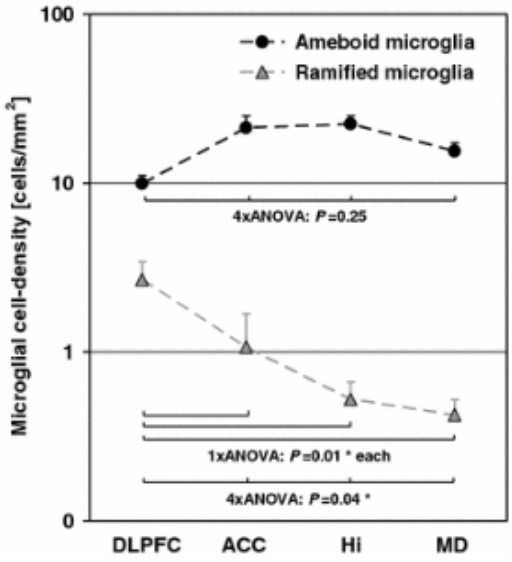
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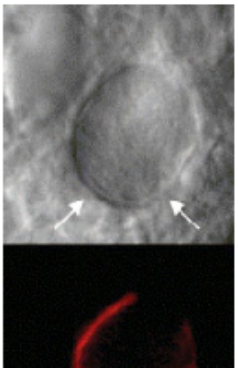
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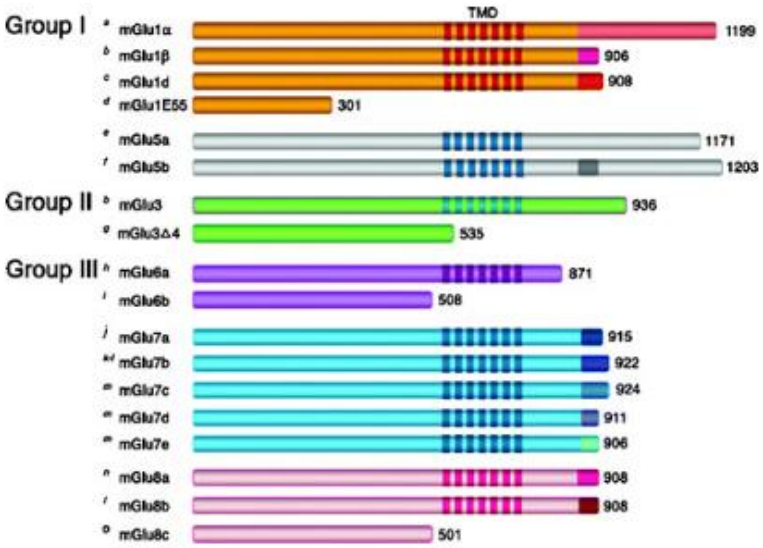
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All authors are requested to include information regarding sources of funding, financial or non-financial interests, study-specific approval by the appropriate ethics committee for research involving humans and/or animals, informed consent if the research involved human participants, and a statement on welfare of animals if the research involved animals (as appropriate).

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All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by [full name], [full name] and [full name]. The first draft of the manuscript was written by [full name] and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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A Graduate Student's Guide to Determining Authorship Credit and Authorship Order, APA Science Student Council 2006

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- Research involving Human Participants and/or Animals
- Informed consent

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It is difficult to specify a threshold at which a financial interest becomes significant,

any such figure is necessarily arbitrary, so one possible practical guideline is the following: "Any undeclared financial interest that could embarrass the author were it to become publicly known after the work was published."

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Please note that, in addition to the above requirements, funding information (given that funding is a potential competing interest (as mentioned above)) needs to be disclosed upon submission of the manuscript in the peer review system. This information will automatically be added to the Record of CrossMark, however it is **not added** to the manuscript itself. Under 'summary of requirements' (see below) funding information should be included in the '**Declarations**' section.

Summary of requirements

The above should be summarized in a statement and placed in a 'Declarations' section before the reference list under a heading of 'Funding' and/or 'Competing interests'. Other declarations include Ethics approval, Consent, Data, Material and/or Code availability and Authors' contribution statements.

Please see the various examples of wording below and revise/customize the sample statements according to your own needs.

When all authors have the same (or no) conflicts and/or funding it is sufficient to use one blanket statement.

Examples of statements to be used when funding has been received:

- Partial financial support was received from [...]
- The research leading to these results received funding from [...] under Grant Agreement No[...].
- This study was funded by [...]
- This work was supported by [...] (Grant numbers [...] and [...]

Examples of statements to be used when there is no funding:

- The authors did not receive support from any organization for the submitted work.
- No funding was received to assist with the preparation of this manuscript.
- No funding was received for conducting this study.
- No funds, grants, or other support was received.

Examples of statements to be used when there are interests to declare:

- **Financial interests:** Author A has received research support from Company A. Author B has received a speaker honorarium from Company W and owns stock in Company X. Author C is consultant to company Y.
  Non-financial interests: Author C is an unpaid member of committee Z.
- **Financial interests:** The authors declare they have no financial interests.
  Non-financial interests: Author A is on the board of directors of Y and receives no compensation as member of the board of directors.

- **Financial interests:** Author A received a speaking fee from Y for Z. Author B receives a salary from association X. X where s/he is the Executive Director.
  Non-financial interests: none.
- **Financial interests:** Author A and B declare they have no financial interests. Author C has received speaker and consultant honoraria from Company M and Company N. Dr. C has received speaker honorarium and research funding from Company M and Company O. Author D has received travel support from Company O.
  Non-financial interests: Author D has served on advisory boards for Company M, Company N and Company O.

Examples of statements to be used when authors have nothing to declare:

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Research involving human participants, their data or biological material

Ethics approval

When reporting a study that involved human participants, their data or biological material, authors should include a statement that confirms that the study was approved (or granted exemption) by the appropriate institutional and/or national research ethics committee (including the name of the ethics committee) and certify that the study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. If doubt exists whether the research was conducted in accordance with the 1964 Helsinki Declaration or comparable standards, the authors must explain the reasons for their approach, and demonstrate that an independent ethics committee or institutional review board explicitly approved the doubtful aspects of the study. If a study was granted exemption from requiring ethics approval, this should also be detailed in the manuscript (including the reasons for the exemption).

Retrospective ethics approval

If a study has not been granted ethics committee approval prior to commencing, retrospective ethics approval usually cannot be obtained and it may not be possible to consider the manuscript for peer review. The decision on whether to proceed to peer review in such cases is at the Editor's discretion.

Ethics approval for retrospective studies

Although retrospective studies are conducted on already available data or biological material (for which formal consent may not be needed or is difficult to obtain) ethics approval may be required dependent on the law and the national ethical guidelines of a country. Authors should check with their institution to make sure they are complying with the specific requirements of their country.

Ethics approval for case studies

Case reports require ethics approval. Most institutions will have specific policies on this subject. Authors should check with their institution to make sure they are

complying with the specific requirements of their institution and seek ethics approval where needed. Authors should be aware to secure informed consent from the individual (or parent or guardian if the participant is a minor or incapable) See also section on **Informed Consent**.

Cell lines

If human cells are used, authors must declare in the manuscript: what cell lines were used by describing the source of the cell line, including when and from where it was obtained, whether the cell line has recently been authenticated and by what method. If cells were bought from a life science company the following need to be given in the manuscript: name of company (that provided the cells), cell type, number of cell line, and batch of cells.

It is recommended that authors check the NCBI database for misidentification and contamination of human cell lines. This step will alert authors to possible problems with the cell line and may save considerable time and effort.

Further information is available from the International Cell Line Authentication Committee (ICLAC).

Authors should include a statement that confirms that an institutional or independent ethics committee (including the name of the ethics committee) approved the study and that informed consent was obtained from the donor or next of kin.

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Research Resource Identifiers (RRID) are persistent unique identifiers (effectively similar to a DOI) for research resources. This journal encourages authors to adopt RRIDs when reporting key biological resources (antibodies, cell lines, model organisms and tools) in their manuscripts.

Examples:

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Cell Line: RST307 cell line **RRID:CVCL_C321**

Antibody: Luciferase antibody DSHB Cat# LUC-3, **RRID:AB_2722109**

Plasmid: mRuby3 plasmid **RRID:Addgene_104005**

Software: ImageJ Version 1.2.4 **RRID:SCR_003070**

RRIDs are provided by the Resource Identification Portal. Many commonly used research resources already have designated RRIDs. The portal also provides authors links so that they can quickly register a new resource and obtain an RRID.

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The World Health Organization (WHO) definition of a clinical trial is "any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes". The WHO defines health interventions as "A health intervention is an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote or modify health, functioning or health conditions" and a health-related outcome is generally defined as a change in the health of a person or population as a result of an intervention.

To ensure the integrity of the reporting of patient-centered trials, authors must register prospective clinical trials (phase II to IV trials) in suitable publicly available repositories. For example www.clinicaltrials.gov or any of the primary registries that participate in the WHO International Clinical Trials Registry Platform.

The trial registration number (TRN) and date of registration should be included as the last line of the manuscript abstract.

For clinical trials that have not been registered prospectively, authors are encouraged to register retrospectively to ensure the complete publication of all results. The trial registration number (TRN), date of registration and the words 'retrospectively registered' should be included as the last line of the manuscript abstract.

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Observational studies (STROBE)

Systematic reviews and meta-analyses (PRISMA) and protocols (Prisma-P)

Diagnostic/prognostic studies (STARD) and (TRIPOD)

Case reports (CARE)

Clinical practice guidelines (AGREE) and (RIGHT)

Qualitative research (SRQR) and (COREQ)

Animal pre-clinical studies (ARRIVE)

Quality improvement studies (SQUIRE)

Economic evaluations (CHEERS)

Summary of requirements

The above should be summarized in a statement and placed in a 'Declarations' section before the reference list under a heading of 'Ethics approval'.

Examples of statements to be used when ethics approval has been obtained:

• All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Bioethics Committee of the Medical University of A (No. ...).

• This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of University B (Date.../No. ...).

• Approval was obtained from the ethics committee of University C. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

• The questionnaire and methodology for this study was approved by the Human Research Ethics committee of the University of D (Ethics approval number: ...).

Examples of statements to be used for a retrospective study:

• Ethical approval was waived by the local Ethics Committee of University A in view of the retrospective nature of the study and all the procedures being performed were part of the routine care.

• This research study was conducted retrospectively from data obtained for clinical

purposes. We consulted extensively with the IRB of XYZ who determined that our study did not need ethical approval. An IRB official waiver of ethical approval was granted from the IRB of XYZ.

• This retrospective chart review study involving human participants was in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The Human Investigation Committee (IRB) of University B approved this study.

Examples of statements to be used when no ethical approval is required/exemption granted:

• This is an observational study. The XYZ Research Ethics Committee has confirmed that no ethical approval is required.

• The data reproduced from Article X utilized human tissue that was procured via our Biobank AB, which provides de-identified samples. This study was reviewed and deemed exempt by our XYZ Institutional Review Board. The BioBank protocols are in accordance with the ethical standards of our institution and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Authors are responsible for correctness of the statements provided in the manuscript. See also Authorship Principles. The Editor-in-Chief reserves the right to reject submissions that do not meet the guidelines described in this section.

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Informed consent

All individuals have individual rights that are not to be infringed. Individual participants in studies have, for example, the right to decide what happens to the

(identifiable) personal data gathered, to what they have said during a study or an interview, as well as to any photograph that was taken. This is especially true concerning images of vulnerable people (e.g. minors, patients, refugees, etc) or the use of images in sensitive contexts. In many instances authors will need to secure written consent before including images.

Identifying details (names, dates of birth, identity numbers, biometrical characteristics (such as facial features, fingerprint, writing style, voice pattern, DNA or other distinguishing characteristic) and other information) of the participants that were studied should not be published in written descriptions, photographs, and genetic profiles unless the information is essential for scholarly purposes and the participant (or parent/guardian if the participant is a minor or incapable or legal representative) gave written informed consent for publication. Complete anonymity is difficult to achieve in some cases. Detailed descriptions of individual participants, whether of their whole bodies or of body sections, may lead to disclosure of their identity. Under certain circumstances consent is not required as long as information is anonymized and the submission does not include images that may identify the person.

Informed consent for publication should be obtained if there is any doubt. For example, masking the eye region in photographs of participants is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic profiles, authors should provide assurance that alterations do not distort meaning.

Exceptions where it is not necessary to obtain consent:

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will assume that the prior publication obtained the relevant information regarding consent. Authors should provide the appropriate attribution for republished images.

Consent and already available data and/or biologic material

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Data protection, confidentiality and privacy

When biological material is donated for or data is generated as part of a research project authors should ensure, as part of the informed consent procedure, that the participants are made aware what kind of (personal) data will be processed, how it will be used and for what purpose. In case of data acquired via a biobank/biorepository, it is possible they apply a broad consent which allows research participants to consent to a broad range of uses of their data and samples which is regarded by research ethics committees as specific enough to be considered "informed". However, authors should always check the specific biobank/biorepository policies or any other type of data provider policies (in case of non-bio research) to be sure that this is the case.

Consent to Participate

For all research involving human subjects, freely-given, informed consent to participate in the study must be obtained from participants (or their parent or legal guardian in the case of children under 16) and a statement to this effect should appear in the manuscript. In the case of articles describing human transplantation studies, authors must include a statement declaring that no organs/tissues were obtained from prisoners and must also name the institution(s)/clinic(s)/department(s) via which organs/tissues were obtained. For manuscripts reporting studies involving vulnerable groups where there is the potential for coercion or where consent may not

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Individuals may consent to participate in a study, but object to having their data published in a journal article. Authors should make sure to also seek consent from individuals to publish their data prior to submitting their paper to a journal. This is in particular applicable to case studies. A consent to publish form can be found

here. (Download docx, 36 kB)

Summary of requirements

The above should be summarized in a statement and placed in a 'Declarations' section before the reference list under a heading of 'Consent to participate' and/or 'Consent to publish'. Other declarations include Funding, Competing interests, Ethics approval, Consent, Data and/or Code availability and Authors' contribution statements.

Please see the various examples of wording below and revise/customize the sample statements according to your own needs.

Sample statements for **"Consent to participate"**:

Informed consent was obtained from all individual participants included in the study.

Informed consent was obtained from legal guardians.

Written informed consent was obtained from the parents.

Verbal informed consent was obtained prior to the interview.

Sample statements for **"Consent to publish"**:

The authors affirm that human research participants provided informed consent for publication of the images in Figure(s) 1a, 1b and 1c.

The participant has consented to the submission of the case report to the journal.

Patients signed informed consent regarding publishing their data and photographs.

Sample statements if identifying information about participants is available in the article:

Additional informed consent was obtained from all individual participants for whom identifying information is included in this article.

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Images will be removed from publication if authors have not obtained informed consent or the paper may be removed and replaced with a notice explaining the reason for removal.

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Data availability statements

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See our list of mandated data types.

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Empirical Paper Appendices

Appendix F: Ethical Approvals
NHS REC Approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Wales REC 4
Health and Care Research Wales
Castlebridge 5
15-19 Cowbridge Road East
CF11 9AB

Please note: This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

06 August 2025

Miss Stacey Pitcher
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ

Dear Miss Pitcher

Study title:	**Navigating Non-Epileptic Seizures in Young People: Insights from Carers**
REC reference:	**25/WA/0166**
Protocol number:	**n/a**
IRAS project ID:	**348736**

Thank you for your communication of 23/07/2025. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 22 July 2025

Documents received

The documents received were as follows:

Document	*Version*	*Date*	

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Other [Participant Information Sheet - changes highlighted]	6	23 July 2025	
Participant information sheet (PIS) [Participant Information Sheet]	6	23 July 2025	

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*	
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Employers Liability and Public and Products Liability]	1	01 August 2024	
GP/consultant information sheets or letters [Clinician Information Sheet]	4	01 July 2025	
GP/consultant information sheets or letters [Clinician Information Sheet - changes highlighted]	4	01 July 2025	
Interview schedules or topic guides for participants [Topic guide for research interview]	4	01 July 2025	
Interview schedules or topic guides for participants [Topic guide - changes highlighted]	4	01 July 2025	
IRAS Application Form [IRAS_Form_13052025]		13 May 2025	
IRAS Checklist XML [Checklist_23072025]		23 July 2025	
Letter from sponsor [Cover Letter]	1	13 May 2025	
Other [Participant Debrief Sheet]	2	27 November 2024	
Other [Thesis Proposal]	2	16 July 2024	
Other [Professional Indemnity]	1	01 August 2024	
Other [Response to the REC - table]	1	01 July 2025	
Other [Protocol - highlighted changes]	2.0	01 July 2025	
Other [Participant Information Sheet - changes highlighted]	6	23 July 2025	
Participant consent form [Consent to Contact Form]	3	10 January 2025	
Participant consent form [Participant Consent Form]	4	01 July 2025	
Participant consent form [Participant Consent Form - changes highlighted]	4	01 July 2025	
Participant consent form [16+ consent form]	1	01 July 2025	

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Participant information sheet (PIS) [Participant Information Sheet]	5	01 July 2025	
Participant information sheet (PIS) [Participant Information Sheet - changes highlighted]	5	01 July 2025	
Participant information sheet (PIS) [Participant Information Sheet]	6	23 July 2025	
Research protocol or project proposal [Protocol]	2.0	01 July 2025	
Response to Additional Conditions Met		22 July 2025	
Summary CV for Chief Investigator (CI) [SP CV]	1	11 January 2025	
Summary CV for supervisor (student research) [Supervisor CV]	1	16 January 2025	
Summary CV for supervisor (student research) [Supervisor CV]	1	20 January 2025	
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol flowchart]	2	10 January 2025	

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

IRAS Project ID: 348736 **Please quote this number on all correspondence**

Yours sincerely

agell

Anne Gell

E-mail: Wales.REC4@wales.nhs.uk

Copy to: Miss Stacey Pitcher

Lead Nation approvals@hra.nhs.uk

HRA Approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Miss Stacey Pitcher
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ

Email: HCRW.approvals@wales.nhs.uk

06 August 2025 – **Re-issued**

Dear Miss Pitcher

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Navigating Non-Epileptic Seizures in Young People: Insights from Carers**
IRAS project ID:	**348736**
Protocol number:	**n/a**
REC reference:	**25/WA/0166**
Sponsor	**University of East Anglia**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **348736**. Please quote this on all correspondence.

Yours sincerely,

agell

Anne Gell
Approvals Specialist

Email: HCRW.approvals@wales

Copy to: *Ms Katt Riley*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*	
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Employers Liability and Public and Products Liability]	1	01 August 2024	
GP/consultant information sheets or letters [Clinician Information Sheet]	4	01 July 2025	
GP/consultant information sheets or letters [Clinician Information Sheet - changes highlighted]	4	01 July 2025	
Interview schedules or topic guides for participants [Topic guide for research interview]	4	01 July 2025	
Interview schedules or topic guides for participants [Topic guide - changes highlighted]	4	01 July 2025	
IRAS Application Form [IRAS_Form_13052025]		13 May 2025	
Letter from sponsor [Cover Letter]	1	13 May 2025	
Other [Response to the REC - table]	1	01 July 2025	
Other [Protocol - highlighted changes]	2.0	01 July 2025	
Other [Participant Debrief Sheet]	2	27 November 2024	
Other [Thesis Proposal]	2	16 July 2024	
Other [PIC Agreement draft]	1	01 May 2025	
Other [Professional Indemnity]	1	01 August 2024	
Participant consent form [Consent to Contact Form]	3	10 January 2025	
Participant consent form [Participant Consent Form]	4	01 July 2025	
Participant consent form [Participant Consent Form - changes highlighted]	4	01 July 2025	
Participant consent form [16+ consent form]	1	01 July 2025	
Participant information sheet (PIS) [Participant Information Sheet - changes highlighted]	6	23 July 2025	
Research protocol or project proposal [Protocol]	2.0	01 July 2025	
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Summary CV for supervisor (student research) [Supervisor CV]	1	16 January 2025	
Summary CV for supervisor (student research) [Supervisor CV]	1	20 January 2025	
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol flowchart]	2	10 January 2025	

IRAS project ID	348736

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
Activities at NHS organisations will involve PIC activity only, including the identification of participants, database searches and the mailing out of study documentation.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study in accordance with the contracting expectations detailed. Due to the nature of the activities involved, organisations will be expected to provide that confirmation to the sponsor Within **35 days** of receipt of the local information pack After HRA/HCRW Approval has been issued. If the organisation is not able to formally confirm capacity and capability within this timeframe, they must inform the sponsor of this and provide a justification. If the sponsor is not satisfied with the justification, then the sponsor may escalate to the National Coordinating Function where the participating NHS organisation is located.	The sponsor has provided the appropriate model non-commercial PIC agreement that it intends to use as a contract between itself and NHS organisations acting as their Participant Identification Centres (PICs).	Sponsor is not providing funding to PICs	The Chief Investigator will be responsible for all study activities performed at PICs.	Where an external individual will be conducting any of the research activities that will be undertaken at this site type then they would be expected to hold a Letter of Access. This should be issued be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm Occupational Health Clearance. These should confirm standard DBS checks.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio

Appendix G: Study Materials

G1: Consent-to-contact Form

University of East Anglia

NHS Cambridgeshire and Peterborough NHS Foundation Trust

Consent to Contact for Research Purposes

Research Title: Navigating Non-Epileptic Seizures in Young People: Insights from Carers

Investigators: Stacey Pitcher, Dr Bridget Coleman, and Dr Amy Carroll

Name of participant: _____

Email: _____

Home telephone number: _____

Mobile: _____

Preferred method of contact:

Email ☐ Home telephone number ☐ Mobile (call) ☐ Mobile (text) ☐

Is it okay to leave a voicemail message on your home telephone?

Yes ☐ No ☐

Is it okay to leave a voicemail message on your mobile?

Yes ☐ No ☐

1. I give my consent to be contacted by the researcher(s) in the above research study. I understand that by signing this document I am not giving consent to participate in the study, but for the researcher to contact me to discuss the study further.
2. I give my consent for the contact details I provided above to be given to the researcher(s).
3. I give my consent for the contact details I provided above to be stored securely for the duration of the study, after which they will be destroyed.

_____	_____	_____
Name	Date	Signature
_____	_____	_____
Name of person seeking consent	Date	Signature

G2: Participant Information Sheet

University of East Anglia

PARTICIPANT INFORMATION SHEET

NHS Cambridgeshire and Peterborough NHS Foundation Trust

Study Title

Navigating Non-Epileptic Seizures in Young People: Insights from Carers

Researchers

Chief investigator: Stacey Pitcher (Trainee Clinical Psychologist)

Research Supervisors: Dr Amy Carroll (Clinical Psychologist, UEA) and Dr Bridget Coleman (Clinical Psychologist, James Paget University Hospital)

Invitation

We (the sponsor for this research, the University of East Anglia) would like to invite you to participate in the study named above. It is important first for you to fully understand the purpose of the research and what it will involve. Please take your time when reading the following information and discuss it with people you may find it helpful to. If anything remains unclear or you have any questions, please do not hesitate to contact us.

Part 1 of this information sheet provides an explanation of the study being conducted, and Part 2 offers additional information. The study is being conducted by Stacey Pitcher, a Trainee Clinical Psychologist working with Cambridgeshire and Peterborough NHS Foundation Trust and undertaking a Doctorate in Clinical Psychology at the University of East Anglia (UEA). Once you have reviewed this information, you may contact Stacey to answer any questions.

Part 1: Study Information

What is the purpose of the study?

The research area of non-epileptic seizures (NES) and functional neurological disorder (FND) is rapidly expanding, because at present there is not much research out there about the psychological aspects and impacts, particularly in children and young people. It is important to understand the real-life experiences of those affected by NES – not just the person who has the seizures, but those around them who are significantly involved in the persons' care. We know that especially in children and young people, people who look after someone who has NES are key in supporting them. We therefore wish to hear from you about your experience of caring for a young person with NES.

We would like to understand what it is like for you, and the things which you find challenging as well as the things which you may have found more positive. We wish to explore this so that we can have a better understanding of the day-to-day experiences

of those who look after young people with NES. We believe that learning such information will improve both our understanding of this unique experience, but also how we can best support caregivers of young people with NES.

Why have I been invited?

You have been invited to take part in this research as you are a parent or caregiver of a young person who experiences NES and is being seen by, or has been seen in the last year by, the paediatric psychology team at either the Norfolk and Norwich University Hospital (NNUH), the James Paget University Hospital (JPUH), or the Queen Elizabeth Hospital (QEH).

Am I eligible to take part?

You are eligible to take part as long as you are over 18 years of age, and the young person you care for is under, or has been under in the last year, a paediatric team (described above) and is 18 years or younger. The young person you care for must have had (or still be having) non-epileptic seizures as one of the main symptoms of their FND. They may have had other symptoms too. You should be able to speak English to a standard which means you can understand and engage in an in-depth interview.

Unfortunately, we are only able to invite one caregiver per young person to take part in the study, and this should be a caregiver who has a significant role in the care of the young person.

Do I have to take part?

No. The decision to take part is entirely your choice, and the care your child/the child you look after receives by their team will not be affected in any way by your decision. If you do decide to take part, you can decide to withdraw from the study at any time without giving a reason.

To do this, you can contact the researcher (Stacey) using the details provided at the end of this Information Sheet. If you withdraw before your interview data has been analysed, your data will be deleted. However, once the data has been analysed and combined with other participants' data, it may not be possible to remove your individual information.

What will happen if I decide to take part?

If you do decide to take part, the researcher will be in contact to arrange the best date and time to conduct an interview. The researcher will try to be as flexible as possible to suit your needs. You will be asked to sign and return a consent form. The interview itself will take around 1 hour, but we ask that you make time for approximately 1 hour 30 minutes to allow for housekeeping and debriefing. You will be able to pause, or stop, the interview at any time throughout the interview.

The interview will be recorded using the Microsoft Teams video conferencing software (even if the interview takes place in person), and the audio will later be transcribed using Microsoft Teams Live Transcription Service, before being manually edited for clarity. The video function will not be used for the study. The interview will be analysed, along with other interviews which take place with different participants, to look for key themes about your experiences and how they link to others. The findings will be written up into a research paper to be published – if you would like a summary of the findings, you will be given an opportunity to request this, and they will be sent to you at the end of the study. To do this, your details will need to be stored securely up until the findings are shared with you, after which point they will be deleted.

What are the possible disadvantages of taking part?

The interview will take up to 1 hour 30 minutes of your time. We are aware that it may be difficult and upsetting to talk about your child/the child you look after's NES, and we may discuss some things you find distressing. We aim to always be sensitive, supportive and considerate, and we can signpost you to services or organisations where you can get further support.

What are the possible advantages of taking part?

If you do take part, you will be contributing to the developing knowledge around NES and people's experiences. We will also gift you a £10.00 'Love2Shop' voucher as a token of appreciation for your time.

What if I decide I no longer want to take part?

You are free to withdraw your participation in the study at any time without giving a reason. This includes after you have completed the research interview. However, you can only withdraw your data up until the point at which your interview transcript is included in the analysis. This point is referred to as the "withdrawal deadline."

The reason for this deadline is that, once analysis has begun, individual transcripts are examined in relation to one another. At that stage, it becomes very difficult to fully remove one person's data without affecting the overall integrity of the analysis.

At the end of your interview, the researcher will inform you that there is a minimum 14-day period during which you may choose to withdraw your data. Once the final research interview has been conducted, you will be contacted and notified that you have a final 14 days to withdraw before analysis begins. After that point, your data will be included in the analysis and cannot be removed.

Part 2: Additional Information

How will you use information about me?

We will need to use information from you for this research project. This information will include your:

- Name
- Contact details
- Transcript of your interview if you choose to take part.

People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a pseudonym (a fake name instead of your real one) instead.

The University of East Anglia (UEA) is the sponsor of this research. The UEA is responsible for looking after your information. We will not share your information related to this research project with any other organisations.

We will keep all information about you safe and secure by:

- Storing all digital data in password protected files on the secure UEA OneDrive – the passwords will only be known to people on the research team.
- Transferring any physical data into digital data by scanning, and then immediately destroying the physical copy
- Destroying/deleting the recordings and transcripts of interviews as soon as the research is finished.
- Storing identifiable information, like your contact details, separately from any other data
- Destroying/deleting your contact details as soon as the research is finished, or when you withdraw from the study if you choose to

International transfers

Your data will not be shared outside the UK.

How will you use information about me after the study ends?

Once we have finished the study, we will keep some of the data so we can check the findings. We will write our reports in a way that no-one can work out that you took part in the study.

We will keep your study data for the minimum period of time required to complete the research project, as part of the programme of Doctorate in Clinical Psychology. The study data will then be fully anonymised and securely archived.

All personal data (e.g., name and contact details) will be deleted at the end of the study, and anonymised research data will be kept securely for up to 10 years, in line with UEA data management policies. The only reason we would keep your contact details is if you

have opted to be contacted later on about the findings – in this instance, your details would be stored separately from any other study data.

What personal information will I be asked to give?

If you are happy to take part, we will ask you to give us your name and contact details so that we can contact you. These details will be deleted once you have finished your participation in the study (unless you asked for a copy of the findings).

Will my information be kept confidential?

Your participation in the study will remain confidential, and your identity will not be disclosed in any reports or publications. What you say in the interviews will be kept strictly confidential, because the recordings will not be shared with anyone outside of the research team. By signing the consent form you agree that we can quote some of the things you say when we write up the research, but any information we use in this way will be completely anonymised. You will be given an opportunity to provide a preferred pseudonym, or one will be given to you, and this is how the things you say in the interview will be referenced.

The only time we will break confidentiality is if you share something which suggests that you or someone else was at risk of harm. In this case we would have a duty of care to raise a safeguarding concern to your child/the child you look after's team. If this were to happen, we would try to have an open conversation with you about it at the time.

How will my data and information be kept secure?

Digital data, such as the recordings and transcripts of your interview, will be kept securely in password protected files on the UEA secure OneDrive. This will only be accessible to the research team. The recordings and transcripts will be destroyed upon completion of the study. Any physical data will be scanned into digital format and stored in the same way, and the physical copy will be immediately destroyed.

Identifiable information, such as the pseudonym you choose or are given and your contact details, will be kept separately and only used for the purpose of contacting you, or for if you choose to withdraw from the study. This data will also be destroyed upon completion of the study.

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. You have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this.

What will happen if I lose capacity during the study?

If, at any point before your interview data has been analysed, you are found to lack the capacity to continue in the study (for example, due to illness), your participation will be discontinued and your data will be withdrawn and securely deleted. If analysis has already begun and your data can no longer be separated from the wider dataset, it will not be possible to remove it.

Where can I find out more about how my information is used?

You can find out more about how we use your information here:

- The Health Research Authority Patient data and research leaflet – www.hra.nhs.uk/patientdataandresearch
- By asking one of the research team
- By sending an email to the research sponsor – dataprotection@uea.ac.uk

What will happen to the findings of the research study?

Our intention is to publish the findings of the study in an academic journal, and it is likely that the findings will be presented at conferences also. If you would like a summary of the findings, or a copy of any published material that comes from the study, please let us know and we will provide them.

Who has reviewed the study?

The study has been reviewed by the Wales Research Ethics Committee 4 and has received a favourable ethical opinion.

Who is overseeing and funding the study?

The study makes part of my (Stacey) Doctorate in Clinical Psychology at UEA. The two research supervisors, named at the top of this document, are overseeing the research. The study has been internally reviewed within the Doctorate in Clinical Psychology programme department. The UEA also fund the project.

What if I have concerns or complaints?

If you have any concerns or complaints about the research project, please contact Dr Amy Carroll (Amy.Carroll@uea.ac.uk) or Dr Bridget Coleman (Bridget.Coleman@jpaget.nhs.uk).

If you wish to raise concerns or complaints independent of the research team, please contact Professor Sian Coker, Programme Director for the Doctorate in Clinical Psychology at the University of East Anglia (s.coker@uea.ac.uk).

Alternatively, you can contact the local Patient Advice and Liaison Service (PALS). PALS offers confidential advice, support, and information on health-related matters and can help resolve any problems or concerns you may have.

You can contact PALS using the details relating to the hospital the child/young person you look after is seen by:

Norfolk and Norwich University Hospital

Email: palsandcomplaints@nnuh.nhs.uk

The PALS and Complaints Manager
Norfolk and Norwich University Hospital, Colney Lane
Norwich
NR4 7UY

Telephone: 01603 289036

James Paget University Hospital

Email: PALS@jpaget.nhs.uk

PALS team
James Paget University Hospitals Foundation Trust, Lowestoft Road
Gorleston, Great Yarmouth
Norfolk
NR31 6LA

Telephone: 01493 453240

Queen Elizabeth Hospital

Email: pals@qehkl.nhs.uk

Telephone: 01553 613351 or 01553 613343

In person: Visit the PALS information desk located near the main entrance to the hospital, opposite Costa Coffee. Opening times are Monday to Friday, 9am to 5pm. Please note the office is closed at weekends and bank holidays.

What next?

If you have any questions or would like further information about the study, please contact Stacey using the following details:

Email: s.pitcher@uea.ac.uk
Work mobile: 07732397232

If you are interested in taking part in the study, please inform your child/the child you look after's paediatric psychology team/clinician. They will signpost you to a person within the team, or they will themselves provide you with a Consent to Contact form, allowing us to contact you.

Thank you for considering taking part in our study, and for taking the time to read this information sheet!

G3: Participant Consent Form

University of East Anglia

NHS Cambridgeshire and Peterborough NHS Foundation Trust

PARTICIPANT CONSENT FORM

Study Title

Navigating Non-Epileptic Seizures in Young People: Insights from Carers

Researchers

Chief investigator: Stacey Pitcher (Trainee Clinical Psychologist)

Research Supervisors: Dr Amy Carroll (Clinical Psychologist, UEA) and Dr Bridget Coleman (Clinical Psychologist, James Paget University Hospital)

Please indicate that you agree with the following statements by writing your initials in the box

1. I confirm that I have read and understood the information sheet (version 5) for the above study. I have had time to consider the information and ask any questions, and I have received satisfactory answers. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time. I understand that I will have a minimum of 14 days after my interview to withdraw my data, and that I will be contacted again once the final interview has taken place to inform me of a final 14-day withdrawal period before analysis begins. After this point, my data can no longer be withdrawn. ☐
3. I give permission for the interview to be recorded. I understand that recordings will be kept secure and will only be listened to by the research team. ☐
4. I understand that I will not be personally named in any research reports, and any of my words will be referred to by pseudonym. I understand that my personal information will remain confidential. ☐
5. I understand that if the researcher thinks that I, or someone else, might be at risk of harm, they will raise these concerns with my child/the child I look after's team. I understand that they will try to discuss this with me whenever possible. ☐
6. I give consent for the researchers to use my words in any research output. ☐
7. Would you like to receive a lay summary of the findings of the study once it is completed? Please indicate YES/NO in the box ☐

Name of participant	Signature	Date
Name of person seeking consent	Signature	Date

Other information (such as best availability)

G4: Interview Topic Guide

Topic Guide for Research Interview

1. Can you tell me a little about yourself and your family?
    a. What is your family structure?
        i. Do you have any other children?
        ii. Are you in a relationship?
        iii. Do you have close relatives or friends who you see very often?
        iv. What do you do for a living?
    b. How long ago did your child get diagnosed with FND?

2. Could you tell me a bit about your journey to your child getting an FND diagnosis?
    a. What were the symptoms you first noticed? What was it like for you to notice and witness those symptoms?
    b. Did your child receive any other diagnoses first?
    c. Can you remember what it was like for you and your family to go through that diagnosis journey?

3. How did you and your family understand the diagnosis initially?
    a. What explanations were given to you by healthcare professionals?
    b. Were the explanations you were given consistent?
    c. What resources, if any, were you given to help you understand what was happening?
    d. Of the support you received by the healthcare professionals you were involved with, what was most helpful?
    e. What were your emotional reactions to the diagnosis?
    f. How did/do you feel about the diagnosis?

4. What treatments or interventions has your child received?
    a. Were you involved in the decision-making about the treatments/interventions your child received?
    b. What were your thoughts about the treatments/interventions your child received?

5. How has your child's condition impacted your daily family life? What challenges have you faced?
    a. Did you have to change your work routines? Were they accommodating?

   b. Did your child have to change their school routines? Were they accommodating?
   c. Did/do you have to organise and work around lots of healthcare appointments?
   d. What changes were there to your role as a parent?
      i. What was it like to navigate those changes?
   e. What support have you received from your social system (e.g., friends)?
   f. How have you found other people react to your child's condition? Have you noticed any stigma?

6. How have you coped with the challenges of supporting your child?
   a. Did you do your own research about your child's condition?
   b. How have your family supported one another?
   c. Did you rely on any social support?
   d. Have you accessed, or thought about accessing, therapy or counselling for yourself since your child's diagnosis?
   e. What support systems have been most helpful to you as a parent?
   f. Are there any supports you feel are missing or not readily available?

7. What are your ongoing thoughts about your child and their condition?
   a. Do you feel like there is anything your child is missing out on?
   b. What would you like your child to be able to do more of?
   c. Do you worry about your child's future?
   d. What do you think your future looks like as a parent of a child with FND?

8. What, if anything, have you and/or your family learned through your journey?
   a. Is there anything you view differently now, compared to before?

G5: Debrief Sheet

University of East Anglia

NHS Cambridgeshire and Peterborough NHS Foundation Trust

PARTICIPANT DEBRIEF SHEET

THANK YOU!

The time that you have taken to speak to me and share your experiences is greatly appreciated. Your participation will contribute to the expansion of knowledge and understanding about carers of young people who have non-epileptic seizures, and to developing the support which services offer.

A reminder of your rights as a participant:

1. You are free to withdraw from the study, at any point up until the point at which your data becomes unidentifiable from others. If you choose to withdraw, your information will not be used in any aspects of the study and will be immediately destroyed.
2. Your interview recordings and transcripts will be anonymised, and your statements will be referred to by your chosen or given pseudonym.
3. Your information will be kept strictly confidential, unless there are concerns about the safety of yourself or someone else.

If you have any concerns or questions following your participation, please contact me at S.Pitcher@uea.ac.uk

I understand that talking about your experiences may have been challenging or distressing at times. You are free to discuss your participation in the study with your child's care team, and you can ask them for further support if you feel this is needed.

Alternatively, you may find the following resources helpful:

- FND Hope (https://fndhope.org.uk)
- FND Action – Carers Support Group UK (Facebook group)
- Carers UK (https://www.carersuk.org/)
- Carers Trust (https://carers.org/)

Further support is also available to those living in Norfolk at the following organisations:

- Norfolk NHS Talking Therapies (https://www.wellbeingnands.co.uk/)
- Carers Matter Norfolk (https://carersmatternorfolk.org.uk/)

If you find yourself experiencing high levels of distress and in need of urgent support, please contact NHS 111 and select Option 2, or dial 999.

Appendix H: COREQ Checklist

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	48
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	48
Occupation	3	What was their occupation at the time of the study?	48
Gender	4	Was the researcher male or female?	51
Experience and training	5	What experience or training did the researcher have?	51
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	48
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	48
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	51
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	46 47
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	49
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	48
Sample size	12	How many participants were in the study?	49 50
Non-participation	13	How many people refused to participate or dropped out? Reasons?	49
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	48
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	48
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	49 50
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	47 48, Append
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	No
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	48
Field notes	20	Were field notes made during and/or after the inter view or focus group?	51
Duration	21	What was the duration of the inter views or focus group?	50
Data saturation	22	Was data saturation discussed?	N/A
Transcripts returned	23	Were transcripts returned to participants for comment and/or	No

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	50
Description of the coding tree	25	Did authors provide a description of the coding tree?	N/A
Derivation of themes	26	Were themes identified in advance or derived from the data?	51
Software	27	What software, if applicable, was used to manage the data?	48
Participant checking	28	Did participants provide feedback on the findings?	No
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	52 64
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Yes
Clarity of major themes	31	Were major themes clearly presented in the findings?	52 64
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	52 64

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix I: Reflexive Log Example

At the focused coding stage, I started to notice uncertainty and vigilance as common features of caregivers' experiences. Across interviews, carers appeared to be navigating ongoing uncertainty about symptoms, diagnosis, risk, and the future, often in ways that shaped everyday decision-making and emotional wellbeing. I was also struck by how strongly responses from services, schools, and wider systems seemed to shape the caregiving experience. Alongside this, caregiving often seemed to involve loss, sacrifice, and continual adaptation. The phrase "it takes a village" came to mind during this stage, reflecting my growing sense that caregiving was experienced in relation to family, services, schools, and broader support systems.

As I moved from initial to focused codes, I noticed myself particularly drawn to narratives of uncertainty, service failures, and disruption to identity. I think my clinical training may have shaped this, in that I found myself instinctively trying to understand and "formulate" the impact of the child's symptoms and wider circumstances on carers. While these areas did seem genuinely significant within the interviews, I am mindful that I may also have been sensitised to these narratives because of assumptions about how distressing such experiences might feel if I were in a similar position.

I also reflected on my relationship to emotional material within the data. I may have been initially primed to notice distress, trauma, and burden, but during focused coding I found myself intentionally trying not to privilege emotion as a standalone analytic category. Instead, I attempted to embed emotional responses within broader patterns of meaning (e.g., uncertainty, caregiving burden, adaptation), rather than creating multiple focused codes that centred emotion alone. This felt more aligned with the accounts as lived experiences rather than reducing them to distress.

I noticed some internal tension in relation to participants' responses to psychological explanations of symptoms. While I did not assume such explanations would necessarily feel validating, I did notice moments of confusion or surprise within myself when participants described difficulty accepting these explanations. This highlighted for me how my professional familiarity with psychological models may shape my expectations about what should feel understandable or helpful. It reminded me to stay attentive to the complexity of participants' meaning-making rather than privileging explanations that align more closely with my own training.

Another area of uncertainty in my analytic process was deciding how far to separate carer experiences from child experiences. At times, it felt difficult to distinguish between what was primarily about the carer and what reflected the child's emotional or social experience. I tried to remain anchored to my research aim, focusing on how carers experienced and made sense of caring for a young person with these symptoms, while still acknowledging that their accounts were often deeply relational and intertwined.

More broadly, I noticed empathy and some identification with carers' accounts of burden, responsibility, and trying to hold things together. I am aware that, as a trainee clinical psychologist, I may have a pull toward wanting to make sense of complexity and distress, because it aligns with my professional role and because of my own values around understanding and helping. I am trying to hold this awareness in mind as I move into theme development, and remain open to patterns that may challenge my assumptions as well as those that resonate with them.

Appendix J: Journal Guidelines

About the journal

Aims and scope

Epilepsy & Behavior is the fastest-growing international journal uniquely devoted to the rapid dissemination of the most current information available on the behavioral aspects of seizures and epilepsy.

Epilepsy & Behavior presents original peer-reviewed articles based on laboratory and clinical research. Topics are drawn from a variety of fields, including clinical neurology, neurosurgery, neuropsychiatry, neuropsychology, neurophysiology, neuropharmacology, and neuroimaging.

Epilepsy & Behavior publishes papers on the study of:

- Localization of ictal and postictal behaviors
- Neuroendocrine aspects of epilepsy
- Psychiatric and psychosocial aspects of epilepsy
- Behavioral aspects of epilepsy surgery
- Cognitive and affective effects of seizure treatment
- Functional imaging
- Animal models

Letters to the Editor will only be considered if they comment on articles that were previously published in *Epilepsy & Behavior*. The journal does not publish Case Reports. Authors who submit these to *Epilepsy & Behavior* will be offered a transfer or asked to resubmit their Case Reports to the journal's companion title, *Epilepsy & Behavior Reports* .

Cited in MEDLINE/PubMed and Index Medicus, Current Contents/Clinical Medicine, Science Citation Index-Expanded, NeuroScience Citation Index, PsychINFO, and EMBASE.

Article types

Epilepsy & Behavior publishes the following types of articles:

- Original research articles (both clinical and laboratory research)
- Reviews
- Editorials
- Brief communications
- Letters
- Book reviews

• Calendar of events

Reviews: Please note that only unsolicited systematic reviews will be considered for publication. Authors are required to register the protocol for the systematic review before data extraction on an accessible, searchable site such as PROSPERO and include registration number.

Editorials: Please note that Editorials are only commissioned and they comment on articles published in *Epilepsy & Behavior*.

Letters: Please note that only letters to the Editor commenting on papers published in *Epilepsy & Behavior* will be considered for publication.

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This journal follows a single anonymized review process. Your submission will initially be assessed by our editors to determine suitability for publication in this journal. If your submission is deemed suitable, it will typically be sent to a minimum of one reviewer for an independent expert assessment of the scientific quality. The decision as to whether your article is accepted or rejected will be taken by our editors.

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- have been written by family members or colleagues.
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Special issues and article collections

The peer review process for special issues and article collections follows the same process as outlined above for regular submissions, except, a guest editor may send the submissions out to the reviewers and may recommend a decision to the journal editor. The journal editor oversees the peer review process of all special issues and article collections to ensure the high standards of publishing ethics and responsiveness are respected and is responsible for the final decision regarding acceptance or rejection of articles.

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All authors should have made substantial contributions to all of the following:

1. The conception and design of the study, or acquisition of data, or analysis and interpretation of data
2. Drafting the article or revising it critically for important intellectual content.
3. Final approval of the version to be submitted.

All authors are accountable for all aspects of the work, to ensure that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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    - Consent for publication should also be obtained.
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We ask you to provide editable source files for your entire submission (including figures, tables and text graphics). Some guidelines:

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You are required to provide a concise and factual abstract which does not exceed 250 words. The abstract should briefly state the purpose of your research, principal results and major conclusions. Some guidelines:

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- Avoid non-standard or uncommon abbreviations. If any are essential to include, ensure they are defined within your abstract at first mention.

Keywords

You are required to provide 1 to 7 keywords for indexing purposes. Keywords should be written in English. Please try to avoid keywords consisting of multiple words (using "and" or "of").

We recommend that you only use abbreviations in keywords if they are firmly established in the field.

Highlights

You are encouraged to provide article highlights at submission.

Highlights are a short collection of bullet points that should capture the novel results of your research as well as any new methods used during your study. Highlights will help increase the discoverability of your article via search engines. Some guidelines:

- Submit highlights as a separate editable file in the online submission system with the word "highlights" included in the file name.
- Highlights should consist of 3 to 5 bullet points, each a maximum of 85 characters, including spaces.

We encourage you to view example article highlights and read about the benefits of their inclusion.

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The graphical abstract summarizes the contents of your article in a concise, pictorial, professional form, highlighting important aspects of the research. It is designed to appeal to an interdisciplinary audience, and draw more attention to your online article. Some guidelines:

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- Submit your graphical abstract as a separate file in the online submission system.
- Ensure the image is 531 x 1328 pixels (h x w) or proportionally more, and is readable at a size of 5 x 13 cm.
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More information, examples and a template can be found in the graphical abstract guidelines.

Units, classifications codes and nomenclature

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This journal requires you to use the international system of units (SI) which follows internationally accepted rules and conventions. If other units are mentioned within your article, you should provide the equivalent unit in SI.

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- Submit math equations as editable text, not as images.

- Present simple formulae in line with normal text, where possible.
- Use the solidus (/) instead of a horizontal line for small fractional terms such as X/Y.
- Present variables in italics.
- Denote powers of e by exp.
- Display equations separately from your text, numbering them consecutively in the order they are referred to within your text.

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Tables must be submitted as editable text, not as images. Some guidelines:

- Place tables next to the relevant text or on a separate page(s) at the end of your article.
- Cite all tables in the manuscript text.
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[3] Strunk Jr W, White EB. The elements of style. 4th ed. New York: Longman; 2000.

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[4] Mettam GR, Adams LB. How to prepare an electronic version of your article. In: Jones BS, Smith RZ, editors. Introduction to the electronic age, New York: E-Publishing Inc; 2023, p. 281-304.

Reference to a website:

[5] Cancer Research UK. Cancer statistics reports for the UK, http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/; 2023 [accessed 13 March 2023].

Reference to a dataset:

[6] Oguro M, Imahiro S, Saito S, Nakashizuka T. Mortality data for Japanese oak wilt disease and surrounding forest compositions [dataset]. Mendeley Data. 2015. https://doi-org.uea.idm.oclc.org/10.17632/xwj98nb39r.1.

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[7] Coon E, Berndt M, Jan A, Svyatsky D, Atchley A, Kikinzon E, et al. Advanced Terrestrial Simulator (ATS). Version 0.88 [software]. Zenodo; 2020 Mar 25. https://doi-org.uea.idm.oclc.org/10.5281/zenodo.3727209.

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