Clinical characteristics and treatment of psychogenic nonepileptic seizures across the age span

- A. Hansen: Pediatric onset of psychogenic non-epileptic seizures: Diagnostic certainty and clinical characteristics in a Danish nationwide cohort
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**Theme**

Psychogenic nonepileptic seizures (PNES), also named functional or dissociative seizures, are associated with impairment and psychopathology both in children and adults. The similarities with epilepsy often lead to ineffective treatment with antiepileptic drugs while potential underlying psychological stressors and psychiatric comorbidity remain unaddressed. The annual cost of PNES misdiagnosed as epilepsy is up to four billion dollars in the US but decreases dramatically after the right diagnosis is made. Further studies on the clinical features of the disorder and the development of specialized interventions are important to improve diagnostics and outcome.

The presentations in this symposium will discuss recent research on clinical characteristics, multifactorial risk factors and comorbid psychopathology in pediatric PNES, the use of cognitive behavioral therapy (CBT) embedded in routine child and adolescent clinical practice for young patients with PNES and the design of a large ongoing randomized controlled trial, CODES, on CBT for adults with PNES.

**Takeaways**

Learning points: 1. Young patient with PNES have a high prevalence of psychopathology, specifically anxiety and depression, as well as anxiety sensitivity to physical sensations. 2. Knowledge about the specificity of the risk factors for comorbid psychopathology in youth with PNES might facilitate their early identification and treatment. 3. The complex biopsychosocial and distinct vulnerability profile of pediatric PNES underscores the need for screening for presence of interrelated somatopsychiatric and adversity risk factors and mental health referral for confirmation of the diagnosis and further treatment. 4. Better care pathways for patients with PNES with collaborative models between somatic and psychiatric settings are currently being developed and evaluated. 5. Cognitive behavioral therapy seems to offer a feasible approach to treatment in both children and adults, showing good compliance rates and promising outcomes.

**Chair:** Charlotte Rask Clinical Professor Aarhus University Hospital DK
Pediatric onset psychogenic non-epileptic seizures: diagnostic certainty and clinical characteristics in a Danish nationwide cohort

Aim
Five to fifteen percent of children and adolescents referred to epilepsy centers are diagnosed with psychogenic non-epileptic seizures (PNES). A misdiagnosis of epilepsy can result in potentially harmful treatment, whereas a misdiagnosis of PNES can result in lack of proper treatment with anti-epileptic drugs and risk of multiple epileptic seizures. In spite of the potential consequences of a misdiagnosis, little is known about pediatric onset PNES. This study will investigate the diagnostic certainty and clinical characteristics of pediatric PNES by utilizing the Danish healthcare registries and medical records. It is the first study conducted on a nationwide cohort of children and adolescents with incident PNES.

Methods
We will confirm the diagnosis of PNES in a nationwide sample of medical records from patients (age 5-17 years, both included) registered with one of the following ICD-10 diagnoses: F44.5 (Dissociative seizures) or R56.8G (Other and unspecified convulsions, non-epileptic) in the period 1996-2014. A clinical cohort of children and adolescents with childhood-onset of PNES will be defined by use of the criteria from the International League Against Epilepsy (ILAE). The cohort will be thoroughly described regarding a wide range of clinical characteristics.

Results
The detailed study design and preliminary results will be presented at the conference.

Conclusion
This study contributes with unique new results describing characteristic clinical features of childhood onset PNES. This knowledge can support the ability to identify this challenging disorder in clinical practice and thereby inform future strategies for the diagnostics and management of patients presenting with PNES early in life.

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Multifactorial vulnerabilities and co-morbid psychopathology in youth with Psychogenic Non-Epileptic Seizures (PNES)

Aim
To present two case control studies on multifactorial risk factors and comorbid psychopathology in PNES youth.

Methods
The risk factor study included 55 PNES cases and 35 controls (age: 8.6-18.4 yrs). The psychopathology study included 13 PNES subjects and 16 controls (age: 12-18 yrs). Psychiatric assessment was completed with the K-SADS interview and self-report measures: the Childhood Anxiety Sensitivity Index (CASI) and the Child and Adolescent Survey of Experiences (CASE).

Results
Compared to their controls, PNES probands had significantly more lifetime medical, neurological, and psychiatric problems; higher use of medications and intensive medical services; more lifetime adversities, anxiety sensitivity, practiced solitary emotional coping. Risk factors for comorbid psychopathology in controls were similar to general pediatric population, but not in PNES cases. The prevalence of any DSM-IV diagnosis (excluding conversion) was 92.3% in PNES subjects and 62.5% in controls (p < .001). Compared to controls, PNES subjects had significantly higher number of any K-SADS diagnoses (3.84 ± 1.81 vs 0.87± 0.89, p < 0.001).

Conclusion
PNES subjects have higher prevalence of psychopathology and anxiety sensitivity to physical sensations. The pediatric PNES has specific vulnerability profile and the interrelated risks included in the somatopsychiatric and adversity components. Different risk factors were related to the internalizing disorders of PNES youth compared to their siblings.

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Cognitive-behavioural treatment of functional neurological symptoms in children and adolescents

Aim
To describe a cognitive-behavioural treatment (CBT) and clinical outcomes in a series of children with functional neurological symptoms (FNS), the majority having non-epileptic seizures (NES).

Methods
Thirty-six children were assessed. Of these, 22 (13 male, 9 female) with a mean age 14.5 years (SD=2.6, range 6-17 years) completed CBT embedded in routine child and adolescent clinical/systemic practice. 13 of these had non-epileptic seizures (NES). Treatment outcomes were measured at baseline and post-intervention on the Child Global Assessment Scale (CGAS), Strengths and Difficulties Questionnaire (SDQ), Goal Based Outcomes (GBO) and Revised Child Anxiety and Depression Scale (RCADS).

Results
Scores on the CGAS improved significantly post-intervention (p<0.001) with 82% of participants showing reliable change. Individualised goals (GBO) - including return to school, social improvement and increased leisure activities – also showed clinically meaningful gains. Standard measures of emotional and behavioural symptoms (SDQ and RCADS) did not correlate well with clinical diagnoses, were usually subthreshold at baseline, and did not show significant improvement post-intervention.

Conclusion
The outcome of this pilot study suggests that CBT can be effective in the rehabilitation of young patients with FNS including those with NES. Detection of common comorbid psychiatric disorders was not assisted by use of standardised measures, although most participants were clinically anxious or depressed. More research is needed to understand why children with FNS and their parents may not endorse mental health symptoms on questionnaires, and to further evaluate interventions within randomised controlled trials.

Reference
A paper based on these data is in press in European Journal of Paediatric Neurology.

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Cognitive behavioural therapy vs standardised medical care for adults with Dissociative non-Epileptic Seizures (CODES): A UK-based pragmatic multicenter parallel arm randomised controlled trial

**Aim**
We set out to conduct an adequately powered RCT to evaluate the clinical and cost effectiveness of Cognitive Behavioural Therapy (CBT) (plus Standardised Medical Care - SMC) compared to SMC alone in adults with dissociative (i.e. psychogenic nonepileptic) seizures (DS). This presentation will reflect on the successes and challenges of running such a study.

**Methods**
We established a two-stage study whereby patients with DS were initially recruited after receipt of their DS diagnosis in neurology/specialist epilepsy clinics in England, Scotland and Wales. Participants were assessed by a Neuropsychiatrist or Liaison Psychiatrist around 3 months later and if their DS had occurred within the previous 8 weeks and met other eligibility criteria, they were consented to the RCT and provided baseline data. They were then randomised to receive either CBT+SMC or SMC alone. Follow-up data were obtained at 6 and 12 months post randomisation. In addition to collecting quantitative primary and secondary outcomes, we conducted nested qualitative studies of participants’ and healthcare professionals’ perceptions of receiving and, where relevant delivering the interventions.

**Results**
We recruited 698 people with DS to the first, observational phase of the study and randomised 368 people in the RCT. We were able to obtain good follow-up rates and compliance rates with CBT.

**Conclusion**
An RCT of this size and with this patient group poses many challenges. However, it illustrates that care pathways can be developed for this patient group and that CBT offers a feasible approach to treatment.

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