

ORALE

Neurological Patients Followed by the Pediatric Palliative Care Team in the Capital Region, Denmark

Alexandra Calmer Bungum, Martha Errebo Jacobi, Sabine Grønberg, Maja Abitz, Christina E. Hoei-Hansen and Thomas Nørrelykke Nissen

Department of Pediatric and Adolescent Medicine, University Hospital Rigshospitalet, Copenhagen, Denmark

Background: This study aimed to describe the population referred to a specialized pediatric palliative care (PPC) unit in the Capital Region of Denmark from 2016 to 2023.

Methods: We conducted a retrospective cohort study of children and young adults referred to the Pediatric Palliative Care Unit (PABU) between 2016 and 2023. Data from the Danish Palliative Database were supplemented with medical record review. Cases were categorized according to the diagnostic groups, patterns of PPC involvement, duration of care, place of death, and interdisciplinary collaboration were described.

Results: The cohort consisted of 223 patients, with a median age of three years at referral. Patients represented a broad spectrum of life-limiting and life-threatening conditions, with over 40% of cases with neurological diagnosis. The neurological group comprised of more than 40 different diagnoses. Duration of PPC involvement varied considerably, with a median of 216 days (72-540). Among children who died during follow-up, 56% died at home. Interdisciplinary involvement was extensive, with more than 94% of cases involving multiple professional disciplines. More than 95% of cases had the involvement of a social worker.

Conclusion: This study describes a diverse population receiving specialized PPC within a regional pediatric service and demonstrates the broad range of diagnoses and care trajectories encountered in clinical practice. The substantial representation of children with neurological diagnoses, encompassing more than 40 different conditions, highlights the complexity and heterogeneity of this population and the need for specialized PPC services that can accommodate diverse and evolving needs.

Navn: Ali Ateya, Morten Baltzer Houliind, John Shorter, Allan Bayat
 Afdeling: Børneafdelingen, Dansk Epilepsicenter Filadelfia

Titel: ”Er den dyre pille det værd? Fra levetiracetam til brivaracetam”

Baggrund: Levetiracetam (LEV) er et af de mest udbredte antiepileptika, men adfærdsmæssige bivirkninger begrænser ofte brugen. Brivaracetam (BRV) er foreslået som et bedre tolereret – men væsentligt dyrere – alternativ. Evidensen for dette stammer udelukkende fra voksne, og viden om børn og unge har hidtil manglet.

Formål: At studere det kliniske outcome efter overgang fra LEV til BRV, herunder anfaldshyppighed, bivirkninger samt undersøge hvilke kliniske faktorer der var associeret med et skifte fra LEV til BRV.

Metode: Et retrospektivt studie udført på Epilepsihospitalet Filadelfia og inkluderede alle børn i alderen 0-17 år samt unge voksne i alderen 18-30 år. Studiet sammenlignede patienter, der overgik fra LEV til BRV, med en kontrolgruppe som havde prøvet LEV men aldrig BRV. Patienterne blev identificeret via en intern database for terapeutisk lægemiddelmonitorering, og kliniske data blev indsamlet ved journalgennemgang.

Resultater: I alt blev 323 patienter på 30 år eller yngre inkluderet: 252 børn/unge og 71 yngre voksne. Studiegruppen bestod af 83 patienter (60 børn/unge og 23 voksne) mens kontrolgruppen bestod af 240 individer (192 børn/unge og 48 voksne). Efter overgangen var 39/83 patienter (47%) anfaldsfrie, 29 (35%) havde færre anfald men var fortsat ikke anfaldsfri, 9 (11%) havde uændret anfaldsbyrde og kun 1 patient (1,2%) fik flere anfald. 46/49 (94%) oplevede at bivirkninger fra LEV forsvandt eller blev reduceret ved overgang til BRV. Sammenlignet med kontroller havde patienter, der overgik til BRV, oftere ADHD (24,1 % vs. 13,8 %) og intellektuel funktionsnedsættelse (57,8 % vs. 40,0 %).

Konklusion: Overgang fra LEV til BRV var associeret bedre anfaldskontrol og færre bivirkninger hos mange børn, unge og yngre voksne, herunder dem med ADHD og udviklingshæmning. BRV kan være et klinisk relevant alternativ, når LEV er begrænset af bivirkninger eller utilstrækkelig anfaldskontrol.

NAVN: Sille Myrup Christensen AFDELING: Afdeling for børn og unge Rigshospitalet

NAVN: Sille Myrup Christensen

TITEL/TITLE: Increased Susceptibility to Paracetamol Among Postoperative Hospitalised Patients with Cerebral Palsy and Spinal Muscle Atrophy

BAGGRUND/BACKGROUND: The aim of this study was to investigate the pharmacokinetics and safety of paracetamol in children and adults with reduced muscle mass during postoperative care, including patients with cerebral palsy and spinal muscular atrophy.

METODE/METHODS: Thirteen patients, 8 with cerebral palsy (CP), 5 with spinal muscle atrophy (SMA) (age 14.7 ± 3.6 years), receiving weight-based dosing of paracetamol after elective surgery were included. Primary outcomes were pharmacokinetic parameters, such as total paracetamol clearance, while secondary outcomes included liver biomarkers. Results were compared with 11 healthy controls (age 25.7 ± 4.5 years) and with 12 non-hospitalised patients with SMA type II (age 18.0 ± 10.4) from a previous study.

RESULTATER/RESULTS: Paracetamol clearance was significantly reduced postoperatively in patients compared with healthy controls (10.0 ± 4.5 vs. 23.7 ± 6.1 L/h $P=3.21 \times 10^{-6}$). Paracetamol clearance was also lower compared with non-hospitalised patients with SMA type II (10.0 ± 4.5 vs 15.9 ± 5.1 $P=0.01$). Liver biomarkers were significantly elevated compared with healthy controls, with marked elevations of alanine aminotransferase observed in one patient (177 U/L).

KONKLUSION/CONCLUSION: The reduced paracetamol clearance found in this study suggests that patients with CP and SMA may have altered paracetamol disposition, especially during periods of physiological stress such as surgery. One possible mechanism is reduced glutathione availability associated with reduced muscle mass, which could limit detoxification of the toxic metabolite NAPQI and thereby increase susceptibility to hepatotoxicity.

Posters

NAVN: Kaja Andersen

AFDELING: Børneonkologisk Laboratorium, Rigshospitalet og Afdeling for Børn og Unge, Herlev Hospital

TITLE: Headache in pediatric patients with brain tumors: A systematic scoping review

BACKGROUND: Headache is one of the most prevalent symptoms reported by pediatric brain tumor patients at time of diagnosis. Identifying these patients within the larger group of primary headache patients presenting at pediatric emergency rooms and headache services is critical. Currently, lists of warning signs include progressive headaches, headaches which worsen during Valsalva maneuvers, morning headaches, concurrent vomiting, papilledema and presence of other neurological deficits. However, these characteristics generally stem from the adult brain tumor literature and expert opinions. As such, one of the goals of this review was to delineate the characteristics found in the pediatric brain tumor literature.

METODE/METHODS: A scoping review of the literature was conducted, according to the PRISMA extension for Scoping Reviews. All studies measuring headache in children with primary brain tumors from 1980 to February 2025 were included. Extracted data were synthesized across studies using descriptive statistics.

RESULTS: 99 papers recorded headache before or at time of diagnosis, but few recorded headache characteristics. Across the studies, an average of 39.4% of patients had progressive headache, 41.6% had morning headaches or headaches that were worse when lying down, 39% had headache aggravated by a Valsalva-like maneuver, 63.4% experienced vomiting, while 61.4% of patients had other neurological symptoms. In multiple studies migraine and tension-type headache were considered as differential diagnoses.

CONCLUSION: There is a general lack of literature on headache characteristics in pediatric patients with brain tumors. Across the current literature, an average of 22%-63.4% of patients experience each of the general accepted warning signs, whereas a subset of patients has headaches similar to migraine or tension type headache. More systematic research is needed to further define pediatric brain tumor headache.

TITEL/TITLE: Kognitiv adfærdsterapi mod insomni hos børn og unge – hvad viser evidensen?

NAVN: Cecilie Paulsrud AFDELING: Dansk Søvncenter for Børn og Unge, Herlev og Gentofte Hospital & Rigshospitalet

TITEL/TITLE: Kognitiv adfærdsterapi mod insomni hos børn og unge – hvad viser evidensen?

BAGGRUND/BACKGROUND: Insomni er en hyppig søvnforstyrrelse hos børn og unge og kan påvirke trivsel, læring og helbred. Samtidig er brugen af melatonin blandt danske børn og unge stigende.

Kognitiv adfærdsterapi mod insomni (CBT-I) er førstevalgsbehandling hos voksne, men anvendes fortsat kun i begrænset omfang til børn og unge i Danmark. Formålet var at sammenfatte evidensen for effekten af CBT-I hos børn og unge.

METODE/METHODS: Vi gennemgik systematiske reviews med meta-analyse, som undersøgte effekten af CBT-I hos børn og unge med insomni. Seks reviews publiceret 2018–2025 blev inkluderet og omfattede tilsammen 31 unikke primærstudier.

RESULTATER/RESULTS: CBT-I reducerede insomnisymptomer med store effektstørrelser og forkortede indsovningstiden. Der sås desuden forbedringer i søvneffektivitet og subjektiv søvnkvalitet samt mindre konsistente effekter på total søvntid og natlige opvågninger. Digitale og skolebaserede interventioner viste også positive effekter. Evidensen var primært baseret på unge, mens data for yngre børn og langtidseffekt var begrænsede.

KONKLUSION/CONCLUSION: CBT-I er en lovende ikke-farmakologisk behandling af insomni hos børn og unge. Der er behov for øget adgang til alderssvarende CBT-I i Danmark samt forskning i yngre børn, langtidseffekt og implementering i klinisk praksis.

NAME: Amanda Munk, Camilla Birgitte Sørensen, Nanette Debes Mol AFDELING: Afdeling for børn og unge, Herlev og Gentofte Hospital (HGH)

TITLE: Onset Pattern and Comorbidity in Tic and Tic-like Disorders: A Descriptive Tertiary Clinic Study

BACKGROUND: Tic and tic-like disorders are common in childhood, often accompanied by comorbidities such as attention-deficit/hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD). Differential diagnoses include functional tic-like behaviours (FTLB), stereotypies, and Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections (PANDAS).

METHODS: This retrospective cohort study included 1,089 newly referred patients to the National Tourette Syndrome Clinic, Herlev, between Dec 2019 and Mar 2025, to explore associations between tic onset pattern, comorbidity, and diagnostic outcome. Data were collected through chart review and standardised comorbidity questionnaires. Diagnostic outcome was recorded one year after initial assessment.

RESULTS: Of the total cohort, 38% were female and mean age of tic onset was 7 years. Most presented with slow onset pattern (n=942), predominantly diagnosed with a primary tic disorder, characterized by low age at onset (6.67 ± 3.20), fewer females (35.9%) and high family history of tics (27.5%). A subacute onset pattern (n=88), represented a clinically heterogeneous population, most often diagnosed with FTLB (n=31) or PANDAS (n=24). Acute onset pattern (n=43) showed high ADHD (71.4%) and OCD (66.7%) prevalence and the majority were diagnosed with PANDAS (n=19). Concordance between suspected diagnosis at referral and diagnostic outcome was 69%.

CONCLUSION: Tic onset pattern may serve as an early clinical indicator, informing diagnostic considerations and assessment scope. Diagnostic discordance underscores the need for improved clinical guidance and awareness of tic and tic-like disorders among clinicians, reducing diagnostic delay and improving treatment access.

NAVN: Sara Hvidemose Breindahl AFDELING: Dansk Søvncenter for Børn og Unge, Herlev Hospital

TITEL/TITLE: Hvad ved vi egentlig om skærmforbrug og søvn hos børn og unge?

BAGGRUND/BACKGROUND: Brugen af elektroniske enheder og sociale medier er steget markant de seneste år, samtidig med at søvnlængden blandt børn og unge er faldet. Der er en veldokumenteret sammenhæng mellem øget skærmbrug og dårligere søvn, men mekanismer og kausalitet er fortsat uklare. Denne statusartikel har til formål at gennemgå nyere forskning baseret på reviews publiceret siden 2020 samt belyse kliniske perspektiver og praktiske anbefalinger for skærmbrug og sunde søvnvaner.

METODE/METHODS: Der blev inkluderet seks systematiske reviews, to scoping reviews og ét umbrella review fra 2020-2026.

RESULTATER/RESULTS: Primærstudierne varierede betydeligt i måling af skærmbrug og søvn og anvendte oftest selv- eller forælderreporterede data; kun få anvendte objektive søvnmål. Trods metodisk heterogenitet, rapporterede de kvantitative reviews konsistente associationer mellem øget skærmbrug og kortere søvnlængde, længere indsovningstid, dårligere søvnkvalitet og øget træthed i dagtimerne. Samlet peger evidensen på en sammenhæng mellem skærmbrug omkring sengetid og utilstrækkelig søvn.

KONKLUSION/CONCLUSION: Kausaliteten er fortsat uafklaret, men sammenhængen er sandsynligvis bidirektionel og multifaktoriel. Søvnforstyrrelser og natlige forstyrrelser fra digitale enheder fremstår som plausible mekanismer, mens effekten af lys og arousal synes beskeden. Alder, type af skærmaktivitet, individuelle reguleringsstrategier og familiens rammer kan desuden påvirke sammenhængen. Klinisk bør fokus være på at identificere og reducere skærmbrug, der hos det enkelte barn bidrager til utilstrækkelig eller forstyrret søvn, frem for generelle forbud.

NAVN: Signe Vandal Pedersen AFDELING: Afdeling for Børn og Unge, Rigshospitalet

TITEL/TITLE: Describing prenatal and postnatal genetic findings in Danish children with cerebral palsy

Background: Cerebral Palsy (CP) is a heterogeneous motor disorder with multiple etiological pathways such as prematurity, asphyxia, stroke, and infections. However, in a significant proportion of cases, the cause is unknown. This has led to suggestions of a genetic component, and research has revealed several genetic causes. This study aims to comprehensively describe all genetic findings in children with CP in Denmark born between 2008–2018.

Methods: This study is a register-based retrospective cohort study. Data were extracted from national registries including the Danish Birth Register, the Danish National Patient Registry, The Danish Cerebral Palsy Follow-up Program Registry, and the Danish Cytogenetic Central Register. Genetic data were supplemented with genetic findings noted in the medical records. Only cases from East Denmark have been completed.

Results: Preliminary findings showed that approximately 35% (n=225) of children with CP living in The Capital Region or Region Zealand (n=650) had one or more genetic analyses performed. Of these, 34% (n=76) had abnormal genetic findings. This included 67% (n=51) having single nucleotide variants (SNVs) and 25% (n=19) having copy number variations (CNVs). Overall, 49 different genes with SNVs were identified, including COL4A1, ATP1A3, GNAO1, and CTNNB1, of which 53% were CP explaining. In addition, 17 different CNVs were detected including 22q11.21 deletion/duplication.

Conclusion: Uncovering genetic causes improves diagnostic certainty in 1/3 of children with CP. It provides more precise genetic counselling and opens new opportunities for personalised care and targeted therapies for children with developmental disabilities.

NAVN: Camilla Birgitte Engly Sørensen. MD, PhD-student. *Co-authors: Isabella Peña Thranow, MD; Liselotte Skov, MD, MSc; Nanette Mol Debes, MD, PhD*

AFDELING: Pediatric and Adolescent Department, Herlev and Gentofte Hospital, Herlev, Denmark

TITLE: The Hidden Burden: Caregiver experiences in childhood tic disorders and OCD

BACKGROUND: Tic disorders and obsessive-compulsive disorder (OCD) affect not only the child but the whole family. Quantitative research has documented impacts on family functioning, parental stress and quality of life, whereas qualitative studies of caregivers' experiences remain limited. We aimed to synthesize this evidence.

METHODS: PubMed, Embase, CINAHL and PsycINFO were searched following PRISMA guidelines. Qualitative studies of caregivers of children and adolescents with tic disorders and/or OCD, including Tourette syndrome, PANDAS/PANS and functional tic-like behaviors, were included. Data were synthesized using thematic synthesis and quality was assessed with the modified Critical Appraisal Skills Programme.

RESULTS: 21 studies were included. Seven descriptive themes covered the healthcare journey, parental emotions and coping, meaning-making, family life, school, and stigma and support. Four analytical themes emerged: 1) inadequate healthcare systems increase caregiver strain, 2) navigating uncertainty and disruption of prior family life, 3) seeking understanding and belonging, and 4) bearing the hidden costs of caregiving. Burden was shaped by structural factors: delayed diagnostic clarification, fragmented care pathways and limited disorder-specific expertise. Caregivers described a shift from parent towards coordinator and advocate.

CONCLUSION: Caregiver burden was driven not only by the child's symptoms but also by systemic barriers within healthcare systems. The findings emphasize the need for earlier diagnostic pathways, improved professional recognition, and holistic approaches that address both symptoms and family well-being, with caregivers recognized as essential partners in care.

Lotte Jensen¹, Hossam Saeed Khaleel Morsy², Malene Landbo Børresen¹

¹BørneUngeafdelingen Risgshospitalet, ²BørneUngeafdelingen Holbæk Sygehus.

Case: Tidlig debut af MS

4 årig pige debuterer med parese af venstre arm, over 1 døgn forværring med venstresidig facialis parese og venstresidig hemiparese. Er træt, men ikke encephalopatisk.

MR-neuroaksen med omkring ti læsioner supratentorielt i hjernen med nedsat diffusion i randen med opladning - ligner mest tumefaktive inflammatorisk/demyeliserende lidelse. Lumbalpunktur med normal celletal, protein 0,12.

På mistanke om ADEM/demyeliniserende tilstand opstartes højdosis solumedrol i 5 døgn. På dag 3 tillægges IVIG. Grundet sparsom bedring af symptomer opstartes plasmaferese dag 6. Under plasmaferese begyndende rolig bedring af symptomer.

Efterfølgende udkommer MOG og AQ4 negative. Oligoklonale bånd positive.

Klinisk forløb og parakliniske fund forenelig med MS. Patienten opstarter B-celledepleterende behandling med Rituximab.

NAVN: Sofie Kampmann Grønning AFDELING: Herlev Neuropædiatrisk Afdeling

TITEL/TITLE: Quality of Life in Children and Adolescents with Cerebral Palsy

Background: Cerebral palsy (CP) is a neurodevelopmental disorder associated with motor impairments and comorbidities that may affect health-related quality of life (HRQoL). This study aimed to investigate associations between quality of life (QoL), gross motor function and physical activity in a Danish cohort of children and adolescents with CP using the DISABKIDS questionnaire.

Methods: A cross-sectional study including 81 children and adolescents with CP from the Paediatric Department at Herlev Hospital was conducted. QoL was assessed using the generic and CP-specific DISABKIDS modules, including parent- and patient-reported questionnaires. Overall QoL scores were calculated as mean questionnaire scores. Associations between QoL, Gross Motor Function Classification System (GMFCS) level and physical activity were analysed using Kruskal–Wallis tests with Dunn's post hoc analyses and Bonferroni correction. Additional analyses explored whether specific questionnaire domains contributed more strongly to overall QoL.

Results: Lower GMFCS levels and higher physical activity were associated with higher parent-reported QoL in the generic DISABKIDS module. The largest difference was observed between GMFCS I and V. No significant associations were found in the CP-specific module. Due to limited patient responses in GMFCS II–V, additional analyses focused on GMFCS I, where emotional and social domains showed the strongest associations with QoL. Similar patterns were observed in the complete dataset. Parent and child reports were generally similar, although parents reported lower independence and physical functioning.

Conclusion: This study identified associations between motor function, physical activity and QoL in children and adolescents with CP within a Danish cohort. Emotional and social factors additionally appeared important contributors to perceived QoL.

NAVN: Amine Abdullah-Roskjær

AFDELING: Neurologisk afd. N. OUH (ph.d-studerende), Børne- og Ungeafd. H. OUH (HU-læge, aktuelt forskningsorlov)

TITEL/TITLE: Dose–response analysis of valproate, levetiracetam and lamotrigine in IGE

BAGGRUND/BACKGROUND: To evaluate dose–response relationships for valproate, levetiracetam, and lamotrigine in adults with idiopathic generalized epilepsy (IGE).

METODE/METHODS: A retrospective cohort study was conducted including 473 patients (≥ 16 years) with IGE treated at Odense University Hospital from 2015 to 2021. Patients were stratified into predefined daily dose categories for levetiracetam, lamotrigine, and valproate. The primary outcome was seizure freedom, defined as no seizures in the past 12 months or three times the longest pre-treatment inter-seizure interval. Dose–response was analyzed using chi-square tests and multivariate logistic regression adjusted for age, sex, and IGE subsyndrome.

RESULTATER/RESULTS: Valproate exhibited a linear dose–response: seizure freedom rates were 47.2% (0–1200 mg/day), 56.4% (1201–2400 mg/day), and 60.0% (>2400 mg/day, $p < 0.001$). Levetiracetam showed increasing seizure freedom up to 2000 mg/day, with a plateau at higher doses. In contrast, lamotrigine was most effective at moderate doses (201–400 mg/day; 27.7%) with decreasing efficacy at higher doses. Multivariate regression controlling for age, sex, and IGE subsyndrome confirmed these associations.

KONKLUSION/CONCLUSION: Both valproate and levetiracetam show a clear dose–response in IGE. In contrast, increasing lamotrigine doses above 400 mg/day did not confer additional effect on seizures.

NAVN: Amine Abdullah-Roskjær

AFDELING: Neurologisk afd. N. OUH (ph.d-studerende), Børne- og Ungeafd. H. OUH (HU-læge, aktuelt forskningsorlov)

TITEL/TITLE: Dose–response analysis of valproate, levetiracetam and lamotrigine in IGE

BAGGRUND/BACKGROUND: To evaluate dose–response relationships for valproate, levetiracetam, and lamotrigine in adults with idiopathic generalized epilepsy (IGE).

METODE/METHODS: A retrospective cohort study was conducted including 473 patients (≥ 16 years) with IGE treated at Odense University Hospital from 2015 to 2021. Patients were stratified into predefined daily dose categories for levetiracetam, lamotrigine, and valproate. The primary outcome was seizure freedom, defined as no seizures in the past 12 months or three times the longest pre-treatment inter-seizure interval. Dose–response was analyzed using chi-square tests and multivariate logistic regression adjusted for age, sex, and IGE subsyndrome.

RESULTATER/RESULTS: Valproate exhibited a linear dose–response: seizure freedom rates were 47.2% (0–1200 mg/day), 56.4% (1201–2400 mg/day), and 60.0% (>2400 mg/day, $p < 0.001$). Levetiracetam showed increasing seizure freedom up to 2000 mg/day, with a plateau at higher doses. In contrast, lamotrigine was most effective at moderate doses (201–400 mg/day; 27.7%) with decreasing efficacy at higher doses. Multivariate regression controlling for age, sex, and IGE subsyndrome confirmed these associations.

KONKLUSION/CONCLUSION: Both valproate and levetiracetam show a clear dose–response in IGE. In contrast, increasing lamotrigine doses above 400 mg/day did not confer additional effect on seizures.

NAVN: Ninna Brix

AFDELING: Børne- og Ungeafdelingen, Aalborg Universitetshospital

Præsenteres af yngre læge, som også er førsteforfatter: ja

TITEL

Dansk validering af QOLCE: Livskvalitet hos børn og unge med epilepsi

BAGGRUND

Der har hidtil manglet et valideret epilepsispecifikt redskab til vurdering af helbredsrelateret livskvalitet (HRQOL) hos danske børn og unge med epilepsi. Formålet var at oversætte og validere en dansk version af Quality of Life in Childhood Epilepsy (QOLCE-76) samt undersøge sammenhænge mellem livskvalitet, psykiatrisk komorbiditet og antal antiepileptika (ASM).

METODE

I alt 104 børn og unge med epilepsi fra to danske børneafdelinger indgik. Intern konsistens blev vurderet med McDonald's omega, kriterievaliditet ved korrelation mellem QOLCE-D og Strengths and Difficulties Questionnaire (SDQ) og test-retest-reliabilitet med intraclass correlation coefficient (ICC). Sammenhænge mellem QOLCE-D, psykiatrisk komorbiditet og antal ASM blev undersøgt med univariable lineære regressionsanalyser.

RESULTATER

QOLCE-D viste høj intern konsistens ($\omega=0,79-0,94$) og tilfredsstillende test-retest-reliabilitet ($ICC=0,71-0,91$). Kriterievaliditeten blev understøttet af relevante korrelationer mellem QOLCE-D og SDQ. Psykiatrisk komorbiditet var signifikant associeret med lavere livskvalitet på tværs af alle QOLCE-domæner, mens antal ASM ikke var signifikant associeret med QOLCE-D-scorerne.

KONKLUSION

QOLCE-D er et reliabelt og validt epilepsispecifikt redskab til vurdering af livskvalitet hos danske børn og unge med epilepsi. Resultaterne understreger samtidig betydningen af at identificere psykiatrisk komorbiditet som en central del af den neuropædiatriske opfølgning.

NAVN: Klara Regitze Høy Kjær

AFDELING: Department of Pediatrics and Adolescent Medicine, Copenhagen University Hospital, Herlev, Denmark

TITEL/TITLE: Genetic variants associated with pediatric migraine: A systematic review and meta-analysis

BAGGRUND/BACKGROUND:

Migraine is a complex neurological disorder involving neuronal and vascular mechanisms. It is among the most common primary headache disorders in children, but its polygenic architecture is insufficiently understood.

METODE/METHODS:

A systematic literature search was performed in three databases for studies published between 2000 and 2025. Findings were synthesized narratively, and studies were categorized as candidate-gene or hypothesis-free studies. Risk of bias was assessed using the Newcastle-Ottawa Scale. Where comparability and data permitted, a quantitative meta-analysis was performed.

RESULTATER/RESULTS:

Fifteen studies were included. One genome-wide association study identified a replicated locus at 5q33.1. The remaining 14 candidate-gene studies investigated 26 variants across 16 genes, of which 10 showed a possible association with migraine. Seven studies investigated the *MTHFR* C677T polymorphism, with mixed findings. Three studies were included in the meta-analysis, which indicated a possible association between the *MTHFR* C677T polymorphism and migraine under the recessive model, whereas no significant association was found under the dominant model. Overall, candidate-gene findings were heterogeneous, and none were replicated. The overall methodological quality of included studies was moderate.

KONKLUSION/CONCLUSION:

This review identified one replicated locus and several candidate-gene associations potentially related to pediatric migraine. A quantitative synthesis suggested an association with the *MTHFR* C677T polymorphism. Current evidence is largely based on small candidate-gene studies with variable methodological quality. Future research should prioritize large, well-characterized pediatric cohorts and genome-wide approaches to clarify the genetic architecture.

NAVN: Michelle Østergaard

AFDELING: Forskningsenheden Børn og Unge, Aalborg Universitetshospital

TITEL/TITLE: Reimagination of data collection in childhood research: “I swear, we should make research fun, too!”

BAGGRUND/BACKGROUND:

The F-words framework promotes a holistic approach to supporting children and adolescents with impairments and their families. If this perspective shapes everyday practice, why should research be any different? This Handball Check project reimagines data collection in an inclusive, active, and enjoyable environment where children can participate meaningfully, build friendships, and have fun while contributing to research.

METODE/METHODS:

Handball Check is a one-year prospective study examining how participation in an inclusive sports program for children with impairments affects health-related quality of life, physical and mental health, and sports participation. The project comprises three large-scale events at a sports college, bringing together participants from across Denmark into six teams, supported by 60 volunteers facilitating research and sports activities. A pilot phase and feedback from parents and volunteers ensured user-centered development and optimization of the format.

RESULTATER/RESULTS:

A total of 125 CWI participated in the first event, and 111 (89%) and 110 (88%) returned for the second and third events, demonstrating sustained engagement and motivation. Parents reported being pleasantly surprised by their children’s abilities, which often exceeded expectations, while children described feeling proud and empowered. The project generated several practice lessons regarding volunteer engagement, participant retention, and family-centered research design.

KONKLUSION/CONCLUSION:

Applying the F-words framework in research promotes engagement, empowerment, and inclusion, supporting participation, high-quality data, and a positive experience for CWIs and families. The principles from this project may be transferable to other pediatric research settings internationally.

A fatal case of subacute sclerosing panencephalitis (SSPE) in Denmark: Clinical manifestation and genomic characterization of measles virus from the brain

Amanda Gammelby Qvesel^{1,2,3†}, Anna Bryan Stensbøl^{4†}, **Malene Landbo Børresen⁴**, Shila Mortensen¹, Anders Frische¹, Kristina Træholt Franck¹, Olalla Urdanibia-Centelles^{5,6} and Lasse Dam Rasmussen^{1*}

1. Dep. of Virology & Microbiological Preparedness, Statens Serum Institut, Copenhagen, Denmark
2. PandemiX Center, Department of Science and Environment, Roskilde University, P.O. Box 206, DK-4000 Roskilde, Copenhagen, Denmark
3. Dep. of Health Technology, Section for Bioinformatics, Technical University of Denmark, Kgs. Lyngby, Denmark
4. Dep. of Pediatrics and Adolescent Medicine, Rigshospitalet, Copenhagen, Denmark
5. Department of Clinical Neurophysiology, Rigshospitalet, Denmark
6. University of Copenhagen, Department of Clinical Medicine, Copenhagen, Denmark

We present the clinical presentation and diagnostic investigations, including whole-genome sequencing of the measles virus from the brain biopsy of a child with only two months of progressing cerebral symptoms, before he was hospitalized and died of subacute sclerosing panencephalitis after 43 days of admission.

In order to identify mutations in the measles virus genome that may be of potential relevance to SSPE pathogenesis, the genome was compared with the closest related sequence in GenBank. Mutations in the viral genome, including matrix protein truncation, were identified. The virus was linked to suspected infection during infancy in Syria.

The case story and the findings highlight the critical importance of maintaining high measles vaccination coverage to prevent severe neurologic outcomes and deaths.