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Learning Disabilities

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April 2024

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1. **Safety and efficacy of trofinetide in Rett syndrome: a systematic review and meta-analysis of randomized controlled trials**

Authors: Abbas, Abdallah;Fayoud, Aya M.;El Din Moawad, Mostafa Hossam;Hamad, Abdullah Ashraf;Hamouda, Heba and Fouad, Eman A.

Publication Date: 2024

Journal: BMC Pediatrics 24(1), pp. 206

Abstract: Introduction: Rett syndrome is a rare genetic neurodevelopmental disorder that predominantly impacts females. It presents with loss of acquired skills, impaired communication, and stereotypic hand movements. Given the limited treatment options for Rett syndrome, there is a dire need for effective interventions.; Objective: To evaluate the safety and efficacy of trofinetide in Randomized Controlled Trials (RCTs) that report on Rett syndrome patients.; Methods: We identified 109 articles from four databases (Scopus, PubMed, Web of Science, and Cochrane CENTRAL). After removing the duplicates, we narrowed them down to 59 articles for further assessment. We included RCTs that evaluated the efficacy and safety of trofinetide in patients with Rett syndrome. Three studies were eligible for inclusion. Two independent reviewers evaluated the identified studies' titles, abstracts, and full texts, extracting pertinent data. We assessed the quality of the studies using the Cochrane Risk of Bias (RoB) 2.0 tool. We then conducted a meta-analysis using the fixed effects model in the case of insignificant heterogeneity; otherwise, we used the random effects model. Based on the nature of the outcome, we analyzed the mean difference or the odds ratio. Analysis was conducted using RevMan version 5.3.; Results: Among the analyzed outcomes in 181 patients in the trofinetide group and 134 patients in the placebo group, significant improvement in Rett Syndrome Behavior Questionnaire (RSBQ) scores was observed at 200 mg dosage (overall mean difference: -3.53, $p = 0.001$). Clinical Global Impression-Improvement (CGI-I) scores improved considerably at 200 mg dosage (overall mean difference: -0.34, $p < 0.0001$). No substantial changes were observed in Motor Behavioral Assessment (MBA) or Top 3 Caregiver Concerns. We evaluated Treatment Emergent Adverse Events (TEAEs) across the various dosages and noted significant associations with diarrhea (200 mg), vomiting (200 mg), and irritability (200 mg). However, we did not find a significant association between any of the dosages and the incidence of decreased appetite.; Conclusion: Trofinetide demonstrated potential in improving RSBQ and CGI-I scores at 200 mg dosage. Although no substantial changes were found in MBA and top 3 caregiver concerns. Adverse events were linked to specific dosages. (© 2024. The Author(s).)

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2. **A Scoping Review of Wearable Technologies for Use in Individuals With Intellectual Disabilities and Diabetic Peripheral Neuropathy**

Authors: Barsotti, Ercole;Goodman, Bailey;Samuelson, Riley and Carvour, Martha L.

Publication Date: 2024

Journal: Journal of Diabetes Science and Technology , pp. 19322968241231279

Abstract: Background: Individuals with intellectual disabilities (IDs) are at risk of diabetes mellitus (DM) and diabetic peripheral neuropathy (DPN), which can lead to foot ulcers and lower-extremity amputations. However, cognitive differences and communication barriers may impede some methods for screening and prevention of DPN. Wearable and mobile technologies-such as smartphone apps and pressure-sensitive insoles-could help to offset these barriers, yet little is known about the effectiveness of these technologies among individuals with ID.; Methods: We conducted a scoping review of the databases Embase, PubMed, and Web of Science using search terms for DM, DPN, ID, and technology to diagnose or monitor DPN. Finding a lack of research in this area, we broadened our search terms to include any literature on technology to diagnose or monitor DPN and then applied these findings within the context of ID.; Results: We identified 88 articles; 43 of 88 (48.9%) articles were concerned with gait mechanics or foot pressures. No articles explicitly included individuals with ID as the target population, although three articles involved individuals with other cognitive impairments (two

among patients with a history of stroke, one among patients with hemodialysis-related cognitive changes).; Conclusions: Individuals with ID are not represented in studies using technology to diagnose or monitor DPN. This is a concern given the risk of DM complications among patients with ID and the potential for added benefit of such technologies to reduce barriers to screening and prevention. More studies should investigate how wearable devices can be used among patients with ID.; Competing Interests: Declaration of Conflicting InterestsThe author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: M.C. has provided consultative support for the Suga Project/Suga Project Foundation but has not received financial compensation for this consultative work.

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3. **A systematic review of the psychometric properties of tools for measuring depression in youths with intellectual disability**

Authors: Benarous, Xavier;Walesa, Sandy;Guilé, Jean-Marc;Cravero, Cora;Consoli, Angèle;Cohen, David;Young, Héloïse;Labelle, Real and Lahaye, Hélène

Publication Date: 2024

Journal: European Child & Adolescent Psychiatry

Abstract: While youths with intellectual disability (ID) have increased vulnerability for depressive disorders, cognitive problems and combined functional barriers make them less prone to receive adequate treatments. A systematic review of the literature was conducted (PROSPERO Registration number: CRD42022347703) based on several databases from 1980 to 2022 to examine the quality of tools for measuring depression in children and adolescents with ID. The COSMIN (COnsensus-based Standards for the selection of health status Measurement Instruments) checklist was used to assess several psychometric domains. Twelve studies evaluated the properties of six tools for measuring depression in youths with ID. The Center for Epidemiologic Studies Depression Scale-Intellectual Disability (CESD-ID) was the only scale with at least five domains of psychometric properties assessed to have strong or moderate evidence. Based on the reviewed findings, tools specifically developed for populations with developmental disabilities should be considered first in order to screen depression in youths with ID. Much work is required to confirm their validity in clinical samples with patients with a complex form of developmental disabilities. As a complement to self- and caregivers-report questionnaires, clinician rating scales were considered useful to catch the full picture of depression in youths with ID, in particular associated behavioral expressions. Their validity received little scrutiny and certainly deserve more attention to improve care practice of youths with ID. (© 2024. The Author(s), under exclusive licence to Springer-Verlag GmbH Germany.)

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4. **Clinical effectiveness of the psychological therapy Mental Health Intervention for Children with Epilepsy in addition to usual care compared with assessment-enhanced usual care alone: a multicentre, randomised controlled clinical trial in the UK**

Authors: Bennett, Sophie D.;Cross, J. H.;Chowdhury, Kashfia;Ford, Tamsin;Heyman, Isobel;Coughtrey, Anna E.;Dalrymple, Emma;Byford, Sarah;Chorpita, Bruce;Fonagy, Peter;Moss-Morris, Rona;Reilly, Colin;Smith, Jonathan A.;Stephenson, Terence;Varadkar, Sophia;Blackstone, James;Quartly, Harriet;Hughes, Tyler;Lewins, Amy;Moore, Elana, et al

Publication Date: 2024

Journal: Lancet (London, England) 403(10433), pp. 1254-1266

Abstract: Background: Mental health difficulties are common in children and young people with chronic health conditions, but many of those in need do not access evidence-based psychological treatments. The study aim was to evaluate the clinical effectiveness of integrated mental health treatment for children and young people with epilepsy, a common chronic health condition known to be associated with a particularly high rate of co-occurring mental health difficulties.; Methods: We conducted a parallel

group, multicentre, open-label, randomised controlled trial of participants aged 3-18 years, attending epilepsy clinics across England and Northern Ireland who met diagnostic criteria for a common mental health disorder. Participants were randomised (1:1; using an independent web-based system) to receive the Mental Health Intervention for Children with Epilepsy (MICE) in addition to usual care, or assessment-enhanced usual care alone (control). Children and young people in both groups received a full diagnostic mental health assessment. MICE was a modular psychological intervention designed to treat common mental health conditions in children and young people using evidence-based approaches such as cognitive behaviour therapy and behavioural parenting strategies. Usual care for mental health disorders varied by site but typically included referral to appropriate services. Participants, along with their caregivers, and clinicians were not masked to treatment allocation but statisticians were masked until the point of analysis. The primary outcome, analysed by modified intention-to-treat, was the parent-report Strengths and Difficulties Questionnaire (SDQ) at 6 months post-randomisation. The study is complete and registered with ISRCTN (57823197).; Findings: 1401 young people were potentially deemed eligible for study inclusion. Following the exclusion of 531 young people, 870 participants were assessed for eligibility and completed the SDQ, and 480 caregivers provided consent for study inclusion between May 20, 2019, and Jan 31, 2022. Between Aug 28, 2019, and Feb 21, 2022, 334 participants (mean ages 10·5 years SD 3·6] in the MICE group vs 10·3 4·0] in control group at baseline) were randomly assigned to an intervention using minimisation balanced by age, primary mental health disorder, diagnosis of intellectual disability, and autistic spectrum disorder at baseline. 168 (50%) of the participants were female and 166 (50%) were male. 166 participants were randomly assigned to the MICE group and 168 were randomly assigned to the control group. At 6 months, the mean SDQ difficulties for the 148 participants in the MICE group was 17·6 (SD 6·3) and 19·6 (6·1) for the 148 participants in the control group. The adjusted effect of MICE was -1·7 (95% CI -2·8 to -0·5; p=0·0040; Cohen's d, 0·3). 14 (8%) patients in the MICE group experienced at least one serious adverse event compared with 24 (14%) in the control group. 68% percent of serious adverse events (50 events) were admission due to seizures.; Interpretation: MICE was superior to assessment-enhanced usual care in improving symptoms of emotional and behavioural difficulties in young people with epilepsy and common mental health disorders. The trial therefore shows that mental health comorbidities can be effectively and safely treated by a variety of clinicians, utilising an integrated intervention across ages and in the context of intellectual disability and autism. The evidence from this trial suggests that such a model should be fully embedded in epilepsy services and serves as a model for other chronic health conditions in young people.; Funding: UK National Institute for Health Research Programme Grants for Applied Research programme and Epilepsy Research UK Endeavour Project Grant.; Competing Interests: Declaration of interests JB was funded in part by the National Institute for Health and Care Research (NIHR) Programme Grants for Applied Research (PGfAR) to work on the MICE project in his substantive employment as a Clinical Project Manager at the UCL Comprehensive Clinical Trials Unit. RM-M and SV were funded by NIHR PGfAR. RS was funded by NIHR PGfAR with payment going to UCL for her time on the project. SB was funded by NIHR PGfAR with payments made to her institution King's College London. SDB was funded by NIHR PGfAR to work on the MICE project in her substantive employment as Principal Research Fellow at UCL. BC has received grants from the William T Grant Foundation, Wellcome Trust, and National Institute of Mental Health as principal investigator or co-principal investigator. JHC has received grants from Stoke Therapeutics, Ultragenyx, NIHR, Great Ormond Street Hospital Children's Charity, LifeARC, Waterloo Foundation, and Action Medical Research. SDB has received grants from Epilepsy Research UK and NIHR PGfAR. SV has received grants from the NIHR. RM-M has received grants from MS Society, Crohn's and Colitis UK, and NIHR. BC receives royalties from MATCH-ADTC. PF receives royalties from books with Guildford Press, American Psychiatric Publishing, Oxford University Press. SDB and RS receive royalties from Oxford University Press. RM-M is a beneficiary of license between King's College London and Mahana Therapeutics and has received consulting fees from Mahana Therapeutics and 11 London. PF's honoraria payments for lectures, presentations, and workshops are sent to the Anna Freud centre and he does not receive direct payment for them. JHC's honoraria payments from Biocodex, Nutricia, Jazz Pharmaceuticals, Takeda, and UCB are sent to UCL. SV's honoraria payments from LivaNova for speaking engagements are sent to Great Ormond Street Hospital. RM-M has received payment or honoraria from the European Association of Psychosomatic Medicine, British Association for Behavioural and Cognitive Psychotherapies, and Central and North West London NAtional Health Service (NHS) Foundation Trust. BC received support for attending the OMNI Inventive Care Omaha conference, a children's mental health gathering. TS was reimbursed for

travel costs to the annual Royal College of Paediatrics & Child Health Meeting attending to present trial findings. RM-M has received support for attending meetings and for travel from the American Psychosomatic Society, European Association of Psychosomatic Medicine, and British Association for Behavioural and Cognitive Psychotherapies. JHC does not receive personal remuneration for participation in data safety and monitoring boards for Stoke Therapeutics. SV's remuneration for participation in data safety and monitoring boards for advisory board participation from Biocodex is sent to GOSH. BC is a board member of PracticeWise, which owns the MATCH-ADTC protocol on which the Mental Health Intervention for Children with Epilepsy programme is based. PracticeWise was paid for training and consulting during the trial setup phase, and provided supervision of the study supervisors to ensure integrity of treatment implementation. JHC is the Elected President for the International League Against Epilepsy, Chair Medical Board for Matthews Friends, Chair of Medical Board for Dravet UK, Chair of Medical Board for Hope for Hypothalamic Hamartoma, and President of Epilepsy Research UK. PF is Chief Executive of the Anna Freud National Centre for Children and Families, Director for Mental Health and Behaviour Change Programmes for UCLPartners, and National Senior Clinical Advisor for Children and Young People's mental health at NHS England. RS is a director of Bespoke Mental Health. SDB is a psychologist in private practice and a co-director of Mind and Body London. BC did not interact with participants or study therapists and was not involved in the analysis. TS was not involved with the research ethics application for this study. All other authors declare no competing interests.

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5. **Outcomes for Adults With Intellectual and Developmental Disabilities Receiving Long-Term Services and Supports: A Systematic Review of the Literature**

Authors: Carlson, Sarah R.;Munandar, Vidya and Thompson, James R.

Publication Date: 2024

Journal: Intellectual and Developmental Disabilities 62(2), pp. 137-150

Abstract: The impact of long-term services and supports on the quality of life of adults with intellectual and developmental disabilities (IDD) is not well understood given the highly complex nature of researching this topic. To support future research addressing this topic, we conducted a systematic literature review of studies addressing outcomes of adults with IDD receiving long-term services and supports. Results of this review describe current outcomes for adults with IDD who receive long-term services and supports and can be used to inform program evaluation, policy development, and future research. (©AAIDD.)

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6. **Gene Expression Studies in Down Syndrome: What Do They Tell Us about Disease Phenotypes?**

Authors: Chapman, Laura R.;Ramnarine, Isabela V. P.;Zemke, Dan;Majid, Arshad and Bell, Simon M.

Publication Date: 2024

Journal: International Journal of Molecular Sciences 25(5)

Abstract: Down syndrome is a well-studied aneuploidy condition in humans, which is associated with various disease phenotypes including cardiovascular, neurological, haematological and immunological disease processes. This review paper aims to discuss the research conducted on gene expression studies during fetal development. A descriptive review was conducted, encompassing all papers published on the PubMed database between September 1960 and September 2022. We found that in amniotic fluid, certain genes such as COL6A1 and DSCR1 were found to be affected, resulting in phenotypical craniofacial changes. Additionally, other genes such as GSTT1 , CLIC6 , ITGB2 , C21orf67 , C21orf86 and RUNX1 were also identified to be affected in the amniotic fluid. In the placenta, dysregulation of genes like MEST , SNF1LK and LOX was observed, which in turn affected

nervous system development. In the brain, dysregulation of genes DYRK1A , DNMT3L , DNMT3B , TBX1 , olig2 and AQP4 has been shown to contribute to intellectual disability. In the cardiac tissues, dysregulated expression of genes GART , ETS2 and ERG was found to cause abnormalities. Furthermore, dysregulation of XIST , RUNX1 , SON , ERG and STAT1 was observed, contributing to myeloproliferative disorders. Understanding the differential expression of genes provides insights into the genetic consequences of DS. A better understanding of these processes could potentially pave the way for the development of genetic and pharmacological therapies.

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7. **Powered or manual toothbrushes for people with disabilities - which is better?**

Authors: Conway, Felicity

Publication Date: 2024

Journal: Evidence-Based Dentistry 25(1), pp. 45-46

Abstract: Design: A systematic review.; Aim: Assess the effectiveness of manual toothbrushes (MTB) and powered toothbrushes (PTB) for people with physical or intellectual disabilities.; Data Sources and Study Selection: The following data sources (MEDLINE-PubMed, Cochrane-CENTRAL and EMBASE) were searched from the date of creation to February 2022 for papers which met the inclusion criteria. There were no language limitations set. The included studies were then hand-searched for relevant studies to be included.; Data Extraction and Synthesis: Two reviewers screened the studies from the searches using Rayyan web application (Artificial-Intelligence search engine). Studies which met the inclusion criteria were selected. The studies were independently screened for the inclusion/exclusion criteria. Disagreement was resolved by discussion and consensus, or by a third party. Studies were then classified as low/moderate/high risk of bias. Analysis was performed on four subgroups; individual performing the brushing - (1) caregiver or (2) participant, main disability of the participant - (3) physical or (4) intellectual disability. Due to insufficient numerical data, a descriptive analysis was completed in place of the planned meta-analysis.; Results: In total, 16 publications were included within the results. There was no significant difference between manual or powered toothbrushing in both disability groups for the removal of plaque or gingival health. This applied to both self-brushing and caregiver brushing.; Conclusions: There is no significant difference between powered and manual toothbrushes for effective oral hygiene maintence for people with physical or intellectual disabilities. (© 2024. The Author(s), under exclusive licence to British Dental Association.)

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8. **Common pitfalls, and how to avoid them, in child and adolescent psychopharmacology: Part II**

Authors: Cortese, Samuele;Besag, Frank Mc;Clark, Bruce;Hollis, Chris;Kilgariff, Joe;Moreno, Carmen;Nicholls, Dasha;Wilkinson, Paul;Woodbury-Smith, Marc and Sharma, Aditya

Publication Date: 2024

Journal: Journal of Psychopharmacology (Oxford, England) 38(4), pp. 318-323

Abstract: As Faculty of the British Association for Psychopharmacology course on child and adolescent psychopharmacology, we present here what we deem are the most common pitfalls, and how to avoid them, in child and adolescent psychopharmacology. In this paper, we specifically addressed common pitfalls in the pharmacological treatment of autism and intellectual disability, eating disorders, neuropsychiatric correlates of epilepsy, and psychosis. Pitfalls in relation to the treatment of other disorders are addressed in a separate paper (Part I).; Competing Interests: Declaration of conflicting interestsThe author(s) declared the following potential conflicts of interest with respect to the research, authorship and/or publication of this article: SC declares honoraria and reimbursement for travel and accommodation expenses for lectures from the following non-profit associations: Association for Child and Adolescent Central Health (ACAMH), Canadian ADHD Alliance Resource (CADDRA), British Association of Pharmacology (BAP), Medice and from Healthcare Convention for educational

activity on ADHD. HE is supported by the National Institute for Health and Care Research (NIHR). DN is supported by the National Institute for Health Research (NIHR) under the Applied Health Research (ARC) programme for Northwest London. CH is supported by a NIHR Senior Investigator Award. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health. CM has been a consultant to or has received honoraria from (has received honoraria as a consultant and/or advisor and/or for lectures) Angelini, British Association of Pharmacology (BAP), Compass, Esteve, Exeltis Janssen, Lundbeck, Neuraxpharm, Nuvelution, Otsuka, Pfizer, Servier and Sunovion outside the submitted work. The other authors declare no relevant conflicts of interest.

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9. **Perinatal healthcare for women at risk of children's social care involvement: a qualitative survey of professionals in England**

Item Type: Journal Article

Authors: Grant, Claire;Bicknell-Morel, Tamsin;Lever Taylor, Billie;Powell, Claire;Blackburn, Ruth Marion;Lacey, Rebecca and Woodman, Jenny

Publication Date: 2024

Journal: BMJ Open 14(3), pp. e082914

Abstract: Background: Women with complex health needs are more at risk of having children's social care involvement with their newborns than other mothers. Around the time of pregnancy, there are opportunities for health services to support women with these needs and mitigate the risk of mother-baby separation. Yet little is known about healthcare professionals' experiences of providing this support.; Methods: We administered an online survey to perinatal healthcare professionals across England (n=70 responders), including midwives, obstetricians, perinatal psychologists/psychiatrists and health visitors. We asked about their experiences of providing care for pregnant women with chronic physical conditions, mental health needs, intellectual/developmental disabilities and substance use disorders, who might be at risk of children's social care involvement. We conducted a framework analysis.; Results: We constructed five themes from participant data. These include (1) inaccessible healthcare for women with complex needs, (2) the challenges and importance of restoring trust, (3) services focusing on individuals, not families, (4) the necessity and caution around multidisciplinary support and (5) underfunded services inhibiting good practice.; Conclusions: Women who are at risk of children's social care involvement will likely experience perinatal healthcare inequities. Our findings suggest that current perinatal healthcare provision for this population is inadequate and national guidelines need updated to inform support.; Competing Interests: Competing interests: None declared.

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10. **Definition, assessment and management of frailty for people with intellectual disabilities: A scoping review**

Authors: Grohmann, Dominique;Wellsted, David and Mengoni, Silvana E.

Publication Date: 2024

Journal: Journal of Applied Research in Intellectual Disabilities : JARID 37(3), pp. e13219

Abstract: Background: People with intellectual disabilities may experience frailty earlier than the general population. This scoping review aimed to investigate how frailty is defined, assessed, and managed in adults with an intellectual disability; factors associated with frailty; and the potential impact of COVID-19 on frailty identification and management.; Method: Databases were searched from January 2016 to July 2023 for studies that investigated frailty in individuals with intellectual disabilities.; Results: Twenty studies met the inclusion criteria. Frailty prevalence varied between 9% and 84%. Greater severity of intellectual disability, presence of Down syndrome, older age, polypharmacy, and

group home living were associated with frailty. Multiagency working, trusted relationships and provision of evidence-based information may all be beneficial in frailty management.; Conclusion: Frailty is common for people with intellectual disabilities and is best identified with measures specifically designed for this population. Future research should evaluate interventions to manage frailty and improve lives. (© 2024 The Authors. Journal of Applied Research in Intellectual Disabilities published by John Wiley & Sons Ltd.)

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11. **Chronic constipation in people with intellectual disabilities in the community: cross-sectional study**

Authors: Laugharne, Richard;Sawhney, Indermeet;Perera, Bhathika;Wainwright, Delia;Bassett, Paul;Caffrey, Briony;O'Dwyer, Maire;Lamb, Kirsten;Wilcock, Mike;Roy, Ashok;Oak, Katy;Eustice, Sharon;Newton, Nick;Sterritt, James;Bishop, Ruth and Shankar, Rohit

Publication Date: 2024

Journal: BJPsych Open 10(2), pp. e55

Abstract: Background: One-third to half of people with intellectual disabilities suffer from chronic constipation (defined as two or fewer bowel movements weekly or taking regular laxatives three or more times weekly), a cause of significant morbidity and premature mortality. Research on risk factors associated with constipation is limited.; Aims: To enumerate risk factors associated with constipation in this population.; Method: A questionnaire was developed on possible risk factors for constipation. The questionnaire was sent to carers of people with intellectual disabilities on the case-loads of four specialist intellectual disability services in England. Data analysis focused on descriptively summarising responses and comparing those reported with and without constipation.; Results: Of the 181 people with intellectual disabilities whose carers returned the questionnaire, 42% reported chronic constipation. Constipation was significantly associated with more severe intellectual disability, dysphagia, cerebral palsy, poor mobility, polypharmacy including antipsychotics and antiseizure medication, and the need for greater toileting support. There were no associations with age or gender.; Conclusions: People with intellectual disabilities may be more vulnerable to chronic constipation if they are more severely intellectually disabled. The associations of constipation with dysphagia, cerebral palsy, poor mobility and the need for greater toileting support suggests people with intellectual disabilities with significant physical disabilities are more at risk. People with the above disabilities need closer monitoring of their bowel health. Reducing medication to the minimum necessary may reduce the risk of constipation and is a modifiable risk factor that it is important to monitor. By screening patients using the constipation questionnaire, individualised bowel care plans could be implemented.

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12. **COVID-19 in patients with Down syndrome: A systematic review**

Authors: Pitchan Velammal, Praveen,N.K.;Balasubramanian, Suryakumar;Ayoobkhan, Fathima Shehnaz;Mohan, Gautham V. K.;Aggarwal, Pearl;Rabaan, Ali A.;Khan, Syed A.;Yasmin, Farah;Koritala, Thoyaja and Surani, Salim R.

Publication Date: 2024

Journal: Immunity, Inflammation and Disease 12(3), pp. e1219

Abstract: Introduction: Down syndrome (DS) is associated with multiple comorbid conditions and chronic immune dysfunction. Persons with DS who contract COVID-19 are at high risk for complications and have a poor prognosis. We aimed to study the clinical symptoms, laboratory and biochemical profiles, radiologic findings, treatment, and outcomes of patients with DS and COVID-19.; Method: We systematically searched PubMed, MEDLINE, Web of Science, Scopus, and the Cochrane Library using the keywords COVID-19 or coronavirus or SARS-CoV-2 and DS or trisomy 21. Seventeen articles were identified: eight case reports and nine case series published from December 2019 through March 2022, with a total of 55 cases.; Results: Patients averaged 24.8 years (26 days to 60

years); 29 of the patients were male. The most common symptoms were fever, dyspnea, and cough. Gastrointestinal and upper respiratory tract symptoms were commonly reported for pediatric patients. The most common comorbidities present in patients with DS were obesity (49.0%), hypothyroidism (21.6%) and obstructive sleep apnea (15.6%). The patients were hospitalized for a mean of 14.8 days. When the patients were compared with the general COVID-19 population, the mean number of hospitalized days was higher. Most patients had leukopenia, lymphopenia, and elevated inflammatory markers (d-dimer and C-reactive protein). Bilateral infiltrations and bilateral ground-glass opacifications were frequently seen in chest radiographs and chest computed tomographic imaging. Most of the patients were treated with methylprednisolone, macrolides, and hydroxychloroquine. Of the 55 patients, 22 died. The mean age of the patients who died was 42.8 years. Mortality rate was higher in individuals with DS over 40 years of age.; Conclusion: More studies are needed to better understand COVID-19 infections among persons with DS. In addition, the study was limited by a lack of statistical analyses and a specific comparison group. (© 2024 The Authors. Immunity, Inflammation and Disease published by John Wiley & Sons Ltd.)

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13. **'Moving on' for Adults With a Learning Disability and Their Families: A Constructivist Grounded Theory Study**

Authors: Taylor, Bethany;Thompson, Jill and Ryan, Tony

Publication Date: 2024

Journal: Qualitative Health Research , pp. 10497323241232360

Abstract: Ending familial co-residence, termed 'moving on' by participants, is an increasingly relevant life transition for people with a learning disability due to increasing life expectancy and policy developments. Nevertheless, there is an absence of research exploring this transition experience in a United Kingdom (UK) context. This constructivist grounded theory study therefore aimed to explore, conceptualise, and theorise the 'moving on' experiences of adults with a learning disability and their families. This article reports the experiences of five adults with a learning disability and nine family members in England, UK. Narrative interviews and creative storybook methods were used to collect data between April 2015 and May 2016. Constant comparative methods, theoretical sampling, and memo writing were used throughout data collection and analysis. Participants with a learning disability presented personal growth and greater life fulfilment over the course of the transition; they flourished. In parallel, family members relinquished their care responsibilities. Importantly, the iterative and reciprocal relationship between flourishing and relinquishing shows that ongoing family member involvement is crucial during and following relocation. Family members identified factors that potentially inhibit relinquishing: pressure to 'let go', different perceptions of independence between family members and service providers, inadequate future investment, and rapport with professional carers. These novel insights led to the generation of the first known mid-range theory concerning this transition, entitled 'Moving on: flourishing and relinquishing'. Findings will guide future research in this field and facilitate the design of appropriate support for people with a learning disability and their families.; Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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14. **Neurodevelopmental Disorders Including Autism Spectrum Disorder and Intellectual Disability as a Risk Factor for Delayed Diagnosis of Catatonia**

Authors: Zappia, Katherine J.;Shillington, Amelle;Fosdick, Cara;Erickson, Craig A.;Lamy, Martine and Dominick, Kelli C.

Publication Date: 2024

Journal: Journal of Developmental and Behavioral Pediatrics : JDBP 45(2), pp. e137-e142

Abstract: Objective: Catatonia is a distinct and severe medical syndrome comprising motor, somatic,

and psychiatric symptoms that is reported in upwards of 17% of young patients with autism spectrum disorders. Clinical experience indicates catatonia is often under-recognized in this clinical population. Here we characterize the clinical presentation of catatonia in patients with and without neurodevelopmental disorders (NDDs) including autism, including the time from symptom onset to diagnosis of catatonia.; Method: Retrospective chart review of electronic medical records at a large, academic pediatric medical center identified 113 pediatric and young adult patients with a charted history of catatonia, as identified by an encounter diagnosis or problem list entry between September 2017 and September 2021. Workup, treatments, and diagnoses (psychiatric, neurodevelopmental, and genetic) were identified.; Results: We observed a clear and substantial delay in identification of catatonia in those with NDDs (diagnosis after 330 days for those without psychosis) compared with neurotypical patients (~16 days). Psychiatry involvement was associated with shorter delays.; Conclusion: Intellectual disability and autism are risk factors for significantly delayed diagnosis of catatonia. It is unknown whether delayed diagnosis contributes to the difficulty in treating catatonia in this patient population or whether the treatment difficulties relate instead to differential and ongoing biological mechanisms and underlying encephalopathy. Overall, these findings highlight the importance of increased recognition of catatonia symptoms in patients with NDDs and suggest early referral to psychiatric specialists may shorten the delay to diagnosis.; Competing Interests: Disclosure: The authors declare no conflict of interest.

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15. **Barriers experienced by nurses in communication for sexual health education for children with intellectual disability: a qualitative study**

Authors: Kurt, Aylin;Cirban Ekrem, Ebru;Akkoç, Betül and Dinç, Fatma

Publication Date: 2023

Journal: International Journal of Developmental Disabilities 70(2), pp. 306-314

Abstract: Nurses have important responsibilities in the development of health and care services for children with intellectual disabilities. This is because it is usually the nurse who first encounters the child in all kinds of care and treatment services. Barriers to the provision of sexual healthcare by nurses have not yet been clearly discovered. This study aimed to identify the barriers experienced by nurses regarding communication for sexual health education for children with intellectual disabilities. This study was carried out with 19 nurses through in-depth interviews. The thematic analysis method was used for data analysis. Four themes emerged related to barriers in communication for sexual health education for children with intellectual disabilities by nurses as (1) communication of nurses with their patients, (2) communication on an individual level, (3) communication on the family level, and (4) institutional factors. These barriers included the lack of knowledge of children, families, and nurses, insufficient institutional support, attitudes towards sexuality and stigmatization of the family, and the prevention of sexual health education services by the aggressive behaviors of children. It is recommended to provide sexual health education to nurses and families to minimize problems in the sexual health of children with intellectual disabilities. Nurses should also be trained on sexual health policy and how to put it into practice.; Competing Interests: No potential conflict of interest was reported by the authors. (© The British Society of Developmental Disabilities 2023.)

Sources Used:

The following databases are used in the creation of this bulletin: CINAHL and Medline.