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Maximising potential for children and young people with sensory loss

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Poster Abstracts

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BEST POSTER PRESENTATION

IF THEY CAN'T SPEAK, WE DON'T ASK: INADEQUACIES OF PAIN REPORTING IN NON-VERBAL CHILDREN WITH DISABILITIES

Dr Dimitra Metheniti, Dr Madhumita Mukherjee

Introduction

Pain in children with severe cerebral palsy is under-recognised and often untreated. The recent NCEPOD guideline suggests that pain scores should be used when assessing pain in non-verbal children with Cerebral Palsy (CP). The (Face, Legs, Activity, Cry and Consolability) FLACC tool has been validated and suggested as one of the observational or behavioural pain scoring tools.

Aim

To audit whether non-verbal children with cerebral palsy presenting to our Paediatric A&E department have their pain assessed using the FLACC tool as per recommendation at our local Clinical Governance meeting in November 2017.

Method

This is a retrospective study looking at our paediatric A&E attendances between December 2017 and December 2019 of 22 children with severe CP (GMFCS 4/5). Demographic and patient data were collected along with the pain scores from our local IT triage system. These were analysed with Microsoft Excel.

Results

There were 59 presentations of 22 patients in A&E over the 2 years. There was no documented pain score on 32 occasions (54.2%). On 23 occasions (38.9%) the pain score was documented as 0 with no documentation of the type of pain tool used for scoring. Informal staff survey revealed that parents' pain reporting was considered but the use of an observational tool like FLACC was minimal.

Conclusions

Pain is under-recorded in non-verbal children with CP, presenting to our A&E department, reflecting the situation nationally. We are introducing a FLACC prompt in our A&E triage system and we plan to audit its use in future. We believe that a brief and validated observational tool like FLACC should be used in every clinical encounter for this group of children and pain recording in non-verbal children should be regularly audited as a quality standard.

A FEASIBILITY STUDY TO TEST A TRAINING PACKAGE ON WAYS TO SUPPORT THE DEVELOPMENTAL STIMULATION OF CHILDREN WITH VISION IMPAIRMENT IN THEIR HOMES IN MALAWI

Paul Lynch, Melissa Gladstone

We will present the findings and a training package for caregivers which are aligned to the WHO/UNICEF Care for Child Development in Malawi on ways to support the developmental stimulation of children with vision impairment in their homes in Malawi.

We used a mixed methods approach to study 24 children with low vision and 6 blind children, aged between eight months and six years in three districts in Southern Malawi. Parents reported benefits from the programme at microsystem level and made it clear how they felt supported with the use of the training materials and involvement of community workers. Without it, many parents said that they would still be experiencing considerable barriers in supporting their children at home and in the community.

Evidence indicates that multi-sectoral collaboration, including cooperation between different governmental and non-governmental agencies, is an important component of successful early childhood initiatives. By engaging support workers from a variety of cadres to provide inter-agency early childhood development collaboration to families with disabilities, the study has provided evidence on how very basic support to families with children with visual impairment can have a positive impact on the developmental and educational prospects of these children.

AN 11 YEAR REVIEW OF NEURODISABILITY DEATHS (ND) IN BERKSHIRE: WHAT CAN WE DO TO IMPROVE END OF LIFE CARE FOR OUR NEURODISABILITY POPULATION?

Dr Hannah Nicholson, Dr Sarah Hughes

Introduction

In 2013 a RCPCH review of child death in Britain showed that, '30-40% of children who died were affected by a neurological/sensory condition…more than any other group of conditions assessed' These findings highlighted the need to review our own ND data for themes to direct us to areas of potential improvement. We hoped that insight into cause/course of death, as well as background co-morbidities would help facilitate service planning and resource allocation.

Method

Data was accessed through the Berkshire CDOP database which held records from April 2008-present. Deaths spanning 11 years, age 0-17yr were reviewed (04/2008-04/2019 inclusive). Neurodisability deaths were identified and analysed for age, gender, ethnicity, local authority, expectation of, preventability and cause of death. A more detailed review of cases was then carried out.

Results

- 161/652 (24.6%) were identified as ND
- Number of ND per year range 13-18
- Gender distribution: males (57.7%), females (42.3%)
- Peak mortality was in <1year category (40.3%) followed by 1-4years (21%).
- Out of the 6 local authorities Slough (38.5%) and Reading (20.5%) had the highest proportion of ND
- The ethnic distribution was wide with peaks in white(45.9%) and Pakistani(29%) groups
- The majority of ND were expected (68.3%), explained (94.4%), and not preventable (92.5%).
- 64.5% ND were Category 7 - chromosomal, genetic and congenital anomalies
- Respiratory infection accounted for 19.8% of deaths
- Detailed review of the deaths highlighted multiple co-morbidities and case complexity.

Conclusion

The distribution of age and gender reflects that of wider mortality data. Areas with the highest proportion of ND have higher incidence of child poverty2, emphasising the need to appropriately direct funding and services within Berkshire. The majority of deaths were expected and not preventable, highlighting the importance of Advanced Care Planning and Palliative provision early in the patient journey.

BEHAVIOURAL MANIFESTATIONS OF SENSORY IMPAIRMENT IN INDIVIDUALS WITH MODERATE-PROFOUND INTELLECTUAL DISABILITY WHO SPEAK FEW OR NO WORDS

Georgina Edwards, Joanne Tarver, Liana Potter, Priya Malhi, Laura Walker, Chris Oliver & Jane Waite

Background
Sensory processing difficulties (SPD) are prevalent in individuals with autism and/or intellectual disability (ID). SPD have been found to be associated with anxiety and behaviours that challenge in autistic children. However, there is a paucity of research exploring relationships between SPD and mental health and behaviour in individuals with ID who are minimally verbal.

Objectives
To explore sensory impairment and its association with anxiety and mood, behaviours that challenge, repetitive behaviour and anxiety and mood in minimally verbal children and young adults.

Methods
Parents/carers completed an online questionnaire battery including subscales from the Sensory Profile-II, the Anxiety, Depression and Mood Scale (ADAMS), the Repetitive Behaviour Questionnaire-2 (RBQ) and the Challenging Behaviour Questionnaire (CBQ).

Results
To date, 37 parents/carers of individuals with ID (51.4% male; Mage =16.57 years (SD=6.2), range: 4-25) of heterogeneous aetiology have participated. Diagnoses included a range of genetic syndromes (n=21), idiopathic autism (n=10), or autism and a diagnosis of a genetic syndrome (n=6).

Sensory processing difficulties were associated with general anxiety (auditory: $rs=.512$, $p<0.01$; visual: $rs=.392$, $p<0.05$; tactile: $rs=.406$, $p<0.05$), but not mood.

Tactile sensory difficulties were correlated with the motor sensory subscale of the RBQ ($rs=.668$, $p<0.01$) and sensory difficulties were correlated with insistence on sameness (auditory: $rs=.556$, $p<0.01$; visual: $rs=.478$, $p<0.01$; tactile: $rs=.341$, $p<0.01$).

Anxiety and difficulties with auditory sensory processing were correlated with severity of temper outbursts ($rs=.540$, $p<0.05$; $rs=.601$, $p<0.01$). Furthermore, difficulties with visual sensory processing were correlated with the severity of destruction of property ($rs=.619$, $p<0.05$).

Conclusions
Preliminary analyses suggest SPD are associated with anxiety, repetitive behaviour and temper outbursts in individuals who speak few or no words. Clinicians should consider a comprehensive sensory assessment for individuals presenting with these concerns. By March 2020, we will present data from 70 families to allow group comparisons between autism and rare syndrome groups.

DEVELOPMENTAL VISION CLINIC REFERRALS

Dr Mary Doyle, Dr Jenefer Sargent

Severe congenital visual impairment leads to developmental vulnerability and slow developmental progress and is common in the preschool years. Low levels of vision can however be developmentally useful and there is evidence that active vision promotion leads to improved visual levels. Research also shows that children with the lowest level of vision are at the greatest developmental risk.

The Developmental vision clinic at Great Ormond Street Hospital provides assessment of functional vision and of development. Assessment findings guide recommendations to promote vision and development and add to advice already in place from the local team. The service accepts referrals of children with significant visual impairment and developmental questions. Comprehensive information about the child is required at the out set and compliments assessment.

We reviewed accepted referrals over a 12 month period to ascertain whether all relevant information was included, specifically: specifies a clear referral question; provides information about Ophthalmological diagnosis; vision assessment and everyday functional vision skills; confirms support from Qualified Teacher of Visual impairment (QVTI); describes other educational support.

Of a total of 51 referrals received from Paediatricians and Ophthalmologists, only 34% (17/51) mentioned involvement of the QTVI and only 10% (5/51) described educational provision. It was not clear, therefore, to what extent referring doctor and QTVI were working together to provide support and optimise developmental progress and family wellbeing.

Furthermore, only 37% (19/51) enclosed information from Ophthalmology and only 46% (23/51) gave any description of everyday functional vision. The reasons for this may be complex, however improved communication between Ophthalmology and Paediatrics is a good starting point in improving professional knowledge and lay foundations for joint working.

Clinical history taking with parents and some simple clinic-based observations can provide highly useful information about a child's level of functional vision, which forms the basis for simple vision promotion programmes.

DOWN'S SYNDROME – DON'T FORGET DENTITION

Dr Julia Paul, Dr Vesna Augustic, Dr Joanna Coghill

Background

Down's Syndrome is the commonest chromosomal abnormality in paediatrics and its association with Congenital Heart Disease (CHD) is well established. The incidence of CHD ranges between 40-60%. Ensuring sufficient access to appropriate dental services and effective measures to optimise dental hygiene at home are of key importance to this cohort of patients. Low-grade repeated bacteremia can occur frequently with teeth brushing with increased incidence in patients with poor dental hygiene. Sub-optimal dental hygiene places these patients at increased risk of Infective Endocarditis caused by the higher cumulative incidence of low-grade bacteremia encountered in daily life.

Aims

- To identify current dental hygiene being practiced by Down's Syndrome patients in a Community Paediatric Service.
- To explore parental understanding of the significance of dental hygiene and knowledge of infective endocarditis.

Methods

All children with Down's syndrome under clinic follow up and new patients were identified from System 1. Parents were contacted with a questionnaire containing 13 questions conducted via telephone.

Results

Total patients (n=49). Patients contacted (n=41). Patients with dentition (n=40). 45% (n=18) of patients did not have previous dental surveillance, similarly 45% (n=18) were not enrolled at a dental practice at time of interview. Of the 41 patients contacted 20 were diagnosed with CHD. In the group with CHD 45% (n=9) had not previously seen a dentist; 40% are not currently enrolled at a dental practice (n=8). Only 37.5% (n=15) of children were meeting the recommendation of brushing teeth twice daily.

Conclusion

A significant number of Down's syndrome patients are receiving sub-optimal oral health surveillance and dental hygiene which is consistent throughout those with and without CHD. Health professionals need to ensure adequate parental education on dentition to ensure dental care for patients with Down's Syndrome improves. This is of key importance, particularly for those with CHD.

EARLY ONSET ROD-CONE RETINAL DYSTROPHY: WORKING TOGETHER TO IDENTIFY AND MANAGE SYSTEMIC FEATURES

Jenefer Sargent, Eleanor Yule, Alka Sobti

Early onset rod-cone dystrophy is a rare genetic condition but a relatively common cause of severe congenital visual impairment (VI). An association with renal disease and abnormal brain imaging is recognised. The term Leber's amaurosis was used although heterogeneity was recognised; now more than 20 genes are known and diagnostic terminology is changing. Joubert syndrome is a related condition with brain abnormalities a central feature.

Children with severe VI are at risk of developmental impairment and early support is crucial. Specialist teachers for VI play a crucial role in providing advice to parents to optimise developmental outcomes. A retrospective audit of all children seen by a tertiary developmental team over a 4 year period recorded as having retinal dystrophy or Joubert syndrome was conducted. The goal was to examine the consistency of attention to potential systemic features of renal and brain involvement, and at the status of genetic testing.

43 patients were identified including 7 with Joubert. 25 had no documentation of renal screening. Of the rest, various tests were completed and two had significant disease. 38 had brain imaging. Local imaging was sometimes obtained for specialist review and the diagnosis had been missed in two cases. Regarding genetic testing, all Joubert cases had genetic diagnoses, just over half of the rest had genetic diagnoses, a fifth were untested, and others were awaiting results from 100,000 Genomes. 25% had not been referred to clinical genetics.

Conclusion
Renal abnormalities can carry significant morbidity but screening status was unknown for over half the cohort. Knowledge of the underlying genetic diagnosis can guide additional investigations. A checklist was compiled for use for all children seen with this condition so that all children undergo relevant investigation. Ophthalmologists and paediatricians should work together to ensure all diagnostic tests are completed and potential co-morbidities addressed.

EMBEDDING A TACTILE SIGNING SYSTEM IN A RESIDENTIAL SPECIALIST SCHOOL FOR CHILDREN AND YOUNG PEOPLE (CYP) WITH PROFOUND AND COMPLEX LEARNING DISABILITIES

Ciara Knox, Katrina Moore, Maruzaan Hanlon

Aim

CYP with PMLD and multi-sensory impairment often experience restrictions in meaningful interactions, understanding routines for learning and preparing for changes. Tactile signing systems are often used to support an effective total communication approach. Tactile cue use however can be inconsistent due to variations and techniques across the multi-disciplinary team (MDT) and signs often limited to basic communication functions. A quality improvement (QI) project has been undertaken to investigate how to implement a whole school approach to tactile signing in a specialist residential school.

Methods

Once cycle of plan, do, study, act (PDSA) was completed. The project set out to explore 3 key practice areas: preparing for transitions; increasing tactile communication signs; enabling opportunities for anticipation and participation in routines for learning. Planning phase formed a working party of AHPs and teaching staff, searching literature and reviewing evidenced-bases. Tassels tactile signing system was selected. Do phase supported introduction through whole-school training and a staff survey established MDT readiness for implementation. Study allowed for reflection of survey results. Act drew findings together to agree whole-school core signs. Whole-class outcomes focused learning and learning walks offered reflections to support consistency of approach.

Results

Learning walks identified early adoption of alerting signs, supporting anticipation and whole-class use supporting meaningful transitions, such as morning greetings, finishing tasks and transfers in specialist equipment. Barriers to implementation included staff time limitations, learning multiple signs and consistency across environmental contexts including lunch hall and residential homes. Peer support and integrated MDT working in context increased sign use and consistency in approach.

Conclusion

Findings offer implementation guidance for professionals working in specialist schools when introducing a tactile signing system. A further PDSA cycle should be completed to evaluate Tassels application in a residential home context. Further work should be undertaken to integrate tactile signs into curriculum targets.

HOW DO CLINICIANS WITHIN A COMMUNITY PAEDIATRIC SERVICE RESPOND WHEN A PATIENT IS NOT BROUGHT FOR AN APPOINTMENT; AN EDUCATION-BASED SERVICE DEVELOPMENT PROJECT

James Cook, Dr Susie Pearce

The failure of patients to attend appointments is recognised as a significant issue. When it comes to children, the safeguarding implications of missed appointments are an important consideration. The impact of missed appointments, and the actions of clinicians, has been considered in various areas of practice. However, little has been written about community paediatrics. Through this service development project, we have sought to further understand how clinicians respond when a patient is not brought for an appointment with an NHS community paediatric service. Information was gathered though an analysis of patient notes alongside semi-structured interviews and questionnaires completed with clinicians. The team were also offered a targeted education package, with consideration given as to how this impacted on their practice.

Prior to the education session the terminology 'did not attend' continued to be commonly used, with the view that young people should be discharged if they miss two consecutive appointments. Clinicians consistently wrote to families where a young person was not brought, although were less likely to contact by phone. There was a difference in response between professional groups, with therapists more likely to take a formulaic approach. Time, availability of other professionals and access to information were cited as barriers when responding to a missed appointment.

The education session delivered was not observed to lead to immediate change in practice, although this varied by professional group. However, it did lead to some generalisable learning. Clinicians responded positively to a short aide memoire, prompting their actions when an appointment is not attended. They were not always fully aware of the principles within trust policy and national guidance, although there was evidence of more individualised approaches being taken. Further emphasis is required on why the use of 'was not brought', and the principles behind it, is preferential to 'did not attend'.

IMPROVING THE QUALITY OF REFERRALS TO THE AUTISM SPECTRUM DISORDER ASSESSMENT TEAM (ASDAT)

Dr F Blyth, Dr S Sivaramakrishnan

Background
Many children referred for autism spectrum disorder (ASD) assessments have additional needs. Locally, such referrals are reviewed at a multidisciplinary ASD Assessment Team (ASDAT) panel prior to acceptance onto the pathway.

Aim
To improve the quality of referrals into the ASDAT pathway by considering reasons for rejection and advising appropriate early support and interventions prior to referral. Key outcomes are to improve the quality of referrals, reduce rejections and therefore increase clinician capacity for assessment.

Method
A retrospective case note review of rejected referrals to the ASDAT pathway over a six-month period (1/1/2019 – 31/05/2019), using NICE clinical guideline CG128 as the reference by which to evaluate our local referral process. Referrals were considered in terms of information given, previous referrals to ASDAT, help and support (if any) already in place as well as reasons for non-acceptance and intervention recommendations given.

Results
Of 63 rejected referrals, a sample of 30 were reviewed; 26 (86.6%) were new referrals. 14 (46%) of children referred lived in the most deprived local demographic area. 10 (33%) of referrals were from education; the rest from a combination of other agencies including Primary Care, 0-19 Service and CAMHS. Antenatal and developmental information was available for 9 (30%) of referrals and medical history for 4 (13%). Childhood Autism Spectrum Test (CAST) scores were available for 27 children during the referral process and 15 (55%) scored between 0-14. The commonest reasons for non-acceptance included lack of referring evidence for ASD (7, 23%) and behavioural/emotional difficulties (7, 23%).

Conclusion
Other services deemed appropriate were identified and referrers signposted accordingly. Further education of referring agencies regarding early support and intervention is required and now referrals are only accepted once an Early Help Assessment has been undertaken. Future work will be to review time between referral and pathway completion.

PARTICIPATION AND BARRIERS TO SPORT IN CHILDREN WITH CEREBRAL PALSY

Dr A Merino Elia, Dr J Coghill

Background

The Department of Health recommends that children should be moderately active for at least 60 minutes every day. Despite the physical, mental and social benefits of regular exercise, children with cerebral palsy (CP) are less active than their peers. Adaptive sports are growing in popularity and have been shown to enable children with disabilities to become more active and enjoy sport.

Methods

A cohort of children with CP was identified using an existing database. Telephone and face-to-face surveys were completed to assess the current involvement in sporting activities and the perceived barriers to being able to participate in more.

Results

61 children were identified as having CP. Of 33 families that were contacted, 22 completed surveys. 82% of children currently attend mainstream schools and 73% are in primary education. 73% of children were GMFCS level 1-3 and 27% level 4-5. Ages ranged from 2-12. 77% of children participate in PE at school yet of these only 47% have a program adapted to their abilities and needs. Only 18% of surveyed children participate in any school run after-school clubs but 41% report to participate in sports outside of school.91% of families report that they would like their children to participate in more sport. The most common barriers to participation in more sports are access/inclusion problems (45%), time (27%) and need for 1:1 support (23%). Only 1 family reported finding no barriers to accessing sport.

Conclusion

Less than half of children with CP surveyed participate in any sport outside of school. However, the majority of families would like their children to participate in more sport. Logistical barriers are the most commonly perceived obstacles to accessing more sport. Schools and professionals involved with these families should be more proactive in ensuring the inclusion and participation of children with CP in sport.

SURVEY OF MULTIDISCIPLINARY HEALTHCARE PROFESSIONALS' KNOWLEDGE AND USE OF GMFCS

K Wood, Y De Alwis

Introduction
The Gross Motor Function Classification System (GMFCS) is a key descriptor of function and the recent NCEPOD report, Each and Every Need, recommended GMFCS level should be documented in every clinical communication for all children, young people and young adults with cerebral palsy, across inpatient and community care. However, there is little information about wider healthcare professionals' understanding of GMFCS. This study aimed to explore knowledge and use of GMFCS by all healthcare professionals involved in clinical care for this group.

Method
Online survey disseminated via email to paediatric clinicians, nurses and therapists in a children's hospital, relevant adult clinicians within the same hospital trust, local GPs and multidisciplinary members of the regional neurodisability network.

Results
165 surveys were completed. Overall, 46% were aware of GMFCS. 35% identified the correct description of GMFCS and 38% knew functional abilities at GMFCS V. 55% reported a GMFCS level in clinical correspondence would not convey meaning or prompt any considerations. Only 20% routinely use and/or document GMFCS.

No GPs and 13% of doctors in adult services were aware of GMFCS, having implications for transition. Only 25% of nurses had awareness of GMFCS, compromising ability to consider appropriate care needs.

Although all paediatricians within neurodisability services were aware, 29% do not use GMFCS and 14% did not think it informed clinical practice. For those familiar with GMFCS, perceived usefulness was consistent with benefits previously described; additional aspects included conveying complexity, providing understanding of baseline functioning when unwell, prompting consideration of co-morbidities & support needs and aiding clinic organisation.

Conclusion
GMFCS is not adequately understood or used by relevant healthcare professionals, leading to missed opportunities for optimising clinical management, communication between professionals & with parents and enabling reasonable adjustments. There is need for development of targeted education highlighting clinical utility for different professional groups.

THE NEURODISABILITY COMMUNITY (TNC) - AN ONLINE PLATFORM TO SUPPORT TRAINEE NETWORKING AND EDUCATION

Dr Dr Hannah Nicholson, Dr Rebecca Gumm, Dr Neil Harrower, Dr Sarah Hughes

Communication, knowledge and collaborative working are fundamental components of excellent patient care. Neurodisability has small numbers of trainees, spread nationally. It is logistically challenging for trainees to connect. We wondered if an online, sub-speciality learning portal could be the answer; to bridge the barriers, build links, share learning and enhance training experience.

Method

An anonymised survey, regarding training resources and networking, was sent out nationally via email and social media to Neurodisability and CCH trainees.

Results

40 responses were obtained.

- 85% (34) didn't know where to find essential resources on starting their post.
- Only 35%(14) found it easy to network with other sub-speciality trainees.
- 72.5% found it difficult to network across deaneries.
- 30%(12) were unsure of who to contact regarding training difficulties.
- 90% (36) felt it was very(14)/extremely(22) important to have contact with other sub-speciality trainees.
- 100% felt that a platform for shared learning, resources and research would be useful.

The results supported the need for 'The Neurodisability Community (TNC);' an online platform to support trainee networking and education.Following the success of 'The Hub' (Oxford deanery) Trello was chosen to host TNC. Two 'boards' have been created. The first covers training, courses, research, condition specific resources and an area to share projects and learning. The second is specific to START preparation. TNC is trainee-led with input from CSAC and peers. Content is populated by users; the immediate upload allows 'live' conversations. User feedback ensures information is easily updated.

Conclusion

TNC will be available to trainees in December 2019. This exciting and dynamic project aims to enhance trainee experience through networking, communication and collaboration. It will provide the basis for learning and collaboration throughout training and beyond; benefiting trainees and patients. Evaluation by follow-up survey will assess impact and facilitate improvements. We hope TNC provides a model that other sub-specialities can follow.