WHAT HAVE WE LEARNT FROM CHILD DEATH REVIEW MEETINGS (CDRM) IN THE FIRST YEAR OF A NEW CDRM PROCESS FOR CHILDREN UNDER THE CARE OF THE COMMUNITY PAEDIATRIC PALLIATIVE CARE (PPC) TEAM?

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Aims Background: A new CDRM process was introduced, aiming to achieve enhanced quality of review. Previously the process relied on collating reporting forms.

Aims: (1) To identify learning outcomes from CDRM (2) To determine if parents are aware of the CDRM meetings, invited to contribute or informed of the outcomes.

Methods Cases were identified between 1 April 2020-31 March 2021 of children who were under the care of the community PPC team. Case notes were reviewed from the electronic Child Death Overview Panel (eCDOP) database, CDRM analysis forms and Trust electronic patient records.

Results Demographics: 16 CDRM cases were reviewed; 6 were female and 10 male. The median age of death was 8 years (15 weeks – 17 years). Contributing medical conditions included; genetic disorders, childhood cancers, complex cardiac conditions, cerebral palsy, severe neurological disorders and neurometabolic conditions.

The deaths were discussed in detail by a specialist team of professionals who met virtually. Meetings were chaired by an external consultant paediatrician and cases reviewed using the 4 domains (intrinsic to child, social and physical environment, service provision) of the eCDOP analysis form [1]. Attendees included; a palliative care consultant, palliative care clinical lead specialist nurse, a member of the lead clinical team, a patient safety lead, an administrator and often a local safeguarding clinician. Learning was shared with the trust ‘mortality and deteriorating patient committee’.

Areas of good practice identified included; excellent communication between medical teams, MDT working, co-ordination of care, appropriate funding applied for, good advocacy for families by palliative care and hospice teams, and good support for family and parents. In all cases a community palliative care nurse or community nurse was assigned as ‘key worker’ for family contact [1].

In no cases was there a documented discussion informing the family of the purpose of the CDRM review, that the family had been given the opportunity to give feedback or had been notified of the outcome of the CDRM review.

Several areas of learning were identified at CDRM review; (1) difficulties with funding shared care between different organisations (2) ensuring appropriate transport for patient transfers from hospital to home (3) deaths due to long-term effects of accidents or trauma will require Coroner’s referral even if the death is expected. Prior recognition and communication to families minimises distress (4) prompt sharing of Advance Care Plans with GPs preferably by electronic means (5) difficulties with different recording systems between clinical teams (6) lack of palliative neonatal pathway (7) honorary contracts to enable hospital syringe drivers to be commenced in a community setting.

Conclusion These results demonstrate the CDRM meetings were useful, comprehensive and identified good practice and several learning themes to be shared, suggesting that the new CDRM process has led to enhanced quality of review.

An area identified for improvement was the discussion of CDRM meetings with families. An information leaflet and feedback document is being developed to facilitate this communication.

REFERENCE

Aims Attendance to hospital for children and young people with complex medical needs and autism can be frightening and stressful, due the unfamiliar setting and unknown people, communication difficulties and sensory overload. Currently at our Trust, there are no specific resources for this patient group, and we have received informal and formal feedback that the needs of these young people and their families are not being met. We aim to improve the experiences of children and young people with complex medical needs and autism at our Trust by creating a new patient pathway, involving children and families early to drive change.

Methods We designed a focus group for parents of children with complex medical needs and autism. We identified families from the neurology clinic, and wrote to them to explain the project and our aims and to invite them to take part in the focus group. We followed this up with a phone call to discuss the project further and to answer their questions. The focus group took place in September 2021.

Results Five parents and one grandparent attended the focus group. Between them, they had experience of emergency hospital attendances, inpatient admissions, outpatient appointments, paediatric intensive care, multiple investigations and care across multiple sites in the UK and abroad. Their children attended both mainstream and special schools. There was a wide range of complexity of need, and input from health, school, therapies and social care. The range of experience made for a highly insightful and interesting discussion.

Positive feedback was received for the neurology consultant, epilepsy clinical nurse specialist, play specialists and hospital school team, with a particular focus on parents knowing who to contact when they needed advice and support.

Key areas for change identified included more privacy for adolescents, a leaflet detailing what to expect during an admission, sensory toys, a patient passport and iPads for the emergency department. Families also commented that space for parents to stay overnight was limited. This was not feasible for some families, and had a negative impact on their experience. Families recommended that information about the different areas of the hospital and their layout should be improved. Some families commented that they were not aware of the presence of play specialists. They also identified that communication was an issue. They recommended that children should be helped to communicate using symbols, and we will involve the children, young people and families at every stage of our project.

Conclusion Patients and families have a much greater insight into the challenges faced than professionals, and their input is the most valuable tool to drive change. Relationships between patients and professionals have a huge impact on experience of care. We will continue to work with families in order to bring about meaningful and impactful change.

Abstracts

THE IDS-2: A NEW MEASURE OF MOTOR PERFORMANCE FOR CHILDREN AND ADULTS

Aims The Intelligence and Development Scales – 2nd Edition (IDS-2) is a broad developmental assessment containing 30 subtests across six Domains: Intelligence, Executive Functions, Psychomotor skills, Social-emotional skills, Scholastic skills, and Motivation and Attitude. The IDS-2 is used worldwide by health and education professionals. It has recently been adapted and translated into English, with the collection of UK norms for 5;0 to 20;11-year-olds. The Psychomotor skills Domain of the IDS-2 measures gross motor, fine motor and visual motor skills. Gross motor skills are assessed only in 5;0 to10;11-year-olds; fine motor and visual motor skills are assessed at all ages. Standardised tests of psychomotor performance are an important component of neurodevelopmental assessment and in particular for a diagnostic assessment for motor difficulties, including Developmental Coordination Disorder (DCD). This presentation describes the content of the IDS-2 Psychomotor skills tasks and examines aspects of reliability and validity of this new tool.

Methods Trained assessors collected data on the IDS-2 from 1367 individuals (48% male) aged 5;0 to 20;11 years across the UK. The UK standardisation data was used to assess internal consistency for fine motor and visual motor skills, as each of these contain a number of similar tasks. In a separate sub-study test-retest reliability was assessed for gross motor skills, re-testing 49 children (63% male, aged 5;1–10;9) after a mean interval of 16 days. Concurrent validity was examined by comparison of performance on the Movement ABC – 2nd Edition (MABC-2). Firstly, a parent/carer of 100 children aged 5;4–15;8 from the UK standardisation sample completed the MABC-2 Checklist. Total Checklist scores were categorised as indicating ‘no movement difficulty’ or ‘highly likely to have a movement difficulty’. The IDS-2 Psychomotor skills scores were then compared for these two groups. Secondly, the performance of 50 children (aged 6;2 to10;11) on the IDS-2 Psychomotor Domain was compared with their performance on the MABC-2 Test. Finally, differential validity was examined by comparing the performance of 25 children (aged 6;2 to10;11 ) previously diagnosed with DCD to an age and gender-matched typically developing group.

Results Reliability coefficients for the total Psychomotor skills Domain were .78 and .88 for 5–10 and 11–20 years respectively (.66–.89 for fine motor and visual motor subtests). Test-retest reliability was .89 for gross motor skills in 5 to10-year-olds. Concurrent validity with the MABC-2 was supported by (1) statistically significant differences between the two Checklist groups in all three of the IDS-2 subtests and (2) significant correlations between scores (.78, p<.001 for total scores) on the IDS-2 Psychomotor skills Domain and the MABC-2 Test in a group of 50 children. Differential validity was supported, with significantly poorer gross motor, fine motor and visual