Identification of long term needs and late effects in paediatric acquired brain injury (ABI) – A collaborative approach

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Introduction

- ABI is the biggest cause of disability in children and is a lifelong concern.
- Paediatric ABI occurs on the background of development.
- Effects may be subtle and often do not become apparent until the impaired area of the brain fully matures.
- Children and Young People (CYP) with ABI referred to the Brain Injury Community Team (BICT), at The Children’s Trust, UK are often referred sometime after their ABI.
- BICT provide a consultative, non-intensive programme of support for CYP with ABI.

Patient and Methods

1. Thematic analysis of retrospective data on difficulties identified at initial assessment following referral to BICT (n=102) over a 4 year period (April 2012 - April 2016).
2. Descriptive case study (MP) of intervention provided by BICT to support long term needs.

Results

- Average length of time from time of injury to BICT referral = 2.9 years (range = 0 to 16 years) [Fig. 1].
- Following thematic analysis, 8 areas of difficulties were identified.
- Largest areas of difficulties identified were:
  - Executive dysfunction (n=240)
  - Communication difficulties (n=165)
- Multiple difficulties were often identified on initial assessment: as many as 12 deficits for a single CYP.

Case Study – MP

- Aged 0: ABI (Intraventricular Haemorrhage) at birth
- Aged 12: Referred to BICT following medico-legal case determined diagnosis of ABI
- Parents noted MP not developing the same way as peers – difficulties becoming increasingly more apparent as MP developed
- School labelled MP as ‘naughty’, ‘lazy’ and ‘stupid’ – unaware of ABI
- Issues at primary and secondary school with both learning and behaviour
- High level difficulties meant he did not meet criteria for statutory services

Multiple difficulties identified in the areas of:

- attention
- memory
- information processing
- problem-solving
- planning and organising
- flexible thinking
- fatigue
- motivation
- self-awareness
- expressive and receptive language
- cognitive communication
- emotional wellbeing

Outcomes

- Shared understanding of MP’s difficulties in relation to his ABI by all
- School now aware of ABI diagnosis and sequelae
- Recommendations and strategies implemented appropriately in school
- School’s attitude towards MP’s behaviour greatly improved. Positive strategies & language introduced vs punishment
- Child & Adolescent Scale of Participation (CASP) scores of activity and participation improved following BICT input

Multiple BICT input

- Liaison with MP, family, school, local therapy and social services
- Detailed holistic and interdisciplinary assessment (SLT, OT, Neuropsychology) including classroom observations
- Individualised ABI education, assessment findings and recommendations provided to family and school professionals together using a collaborative problem-solving approach to ensure understanding and implementation of strategies
- Comprehensive report with recommendations sent to MP and family, GP, school and health professionals involved
- Onward referrals successfully made to:
  - Community OT/ PT for assessment of physical needs
  - Child and Adolescent Mental Health Services (CAMHS)
  - Statutory Assessment & Resources Team (START) to enable Education & Health Care Plan (EHCP) assessment

Impact for Children

- An awareness and understanding of high level difficulties or hidden disability is needed in order to provide the best functional/educational outcome for CYP.
- Examples where specialist and multidisciplinary ABI services and community therapy services have worked in partnership are encouraging.

References


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