

Childhood brain injury is one of the leading causes of death and disability in the UK. Acquired brain injury (ABI) refers to any non-progressive damage to the brain after a period of normal development in childhood, including injury resulting from trauma, infection, stroke, tumour, surgery or hypoxia. The term 'acquired' excludes children with brain injury due to birth trauma or genetic conditions. Studies suggest that acquired brain injury in childhood results in significant social costs in terms of child and family mental health, cognitive abilities, education and contact with the criminal justice system. However, services in the UK are limited for brain-injured children, and little is known about the ways in which the mental health needs of children with post-acquired brain injury are met. This project examines the cognitive, emotional, behavioural and social problems of children referred to a new childhood brain injury service in the East of England. We compare the needs of these children with the needs of non-brain injured children referred to the Child and Adolescent Mental Health Service (CAMHS). By doing this research, we hope to improve understanding of the needs of children with ABI.



Policy context

Studies indicate that approximately 6 children per 100,000 per year will be admitted to intensive care following traumatic brain injury alone¹. While the recommendations are clear for the early management of brain injury (NICE 2007²), recommendations for long term care are lacking, partly due to the diverse and unpredictable impact of brain injury. The Child Brain Injury Trust warns that difficulties may become worse over time, rather than better, particularly as a child approaches the teenage years³. Furthermore, 'hidden disabilities' (cognitive and emotional problems) and family adjustment issues may get missed and long term support services are limited.

In some areas the presence of brain injury is an exclusion criterion for referral to CAMHS, leaving little support for ABI children and their families. Understanding the uptake of mental health services by children with ABI could help with improving provision of rehabilitation and identifying needs sooner, post-injury, thereby potentially preventing the development of later problems, and improving cost-effectiveness of services.

The research

Data were collected for 27 children with acquired brain injury referred to a specialised regional neurorehabilitation service, and for 27 age and sex matched children without ABI referred to CAMHS. The data collected were obtained using the Strengths and Difficulties Questionnaire (SDQ), which measures childhood psychiatric symptoms in terms of emotional, conduct, attention/hyperactivity and behavioural and social problems. In addition, the SDQ records the impact of the child's problems on participation in domains including cognition, communication, physical functioning, independent living, school and relationships.

The data from the two groups were collated and statistical tests (matched sample t-tests) were carried out to test for differences between the ABI and non-ABI referrals' SDQ scores. Information on pre-injury morbidity was sought from medical records.

The results

Children with ABI referred to the service were characterised by multiple pre- and post-injury difficulties impacting on a range of domains with

cognitive and emotional problems and restrictions in peer relationships being the most common. Matched pair t-tests to detect any differences between ABI and non-ABI referrals showed there were no statistically significant differences between the two groups in overall distress or for any subscale measurement.

Both groups had similar levels of difficulties, and in both groups, parents rated over 75% of the children as experiencing a significant level of impact of their difficulties on key life domains.

Conclusions

Children with ABI are very similar to matched non-ABI controls in terms of presenting cognitive, emotional, behavioural and social problems.

There was no statistically significant difference between the two groups as measured by SDQ scores. Children with ABI have complex and heterogeneous needs. The findings in this study replicate previous findings indicating the similarity between children with ABI, and children without ABI who are referred to CAMHS.

Impact

This study raised awareness of the needs of children with ABI and it was recommended that screening for brain injury be added to the local CAMHS referral checklist. It is hoped that this will happen when all the new services and structures are in place. A brief ABI screening tool has been adopted by the Youth Offending Team.

The development of the regional neuro-rehabilitation unit has been at risk as a result of financial constraints and local priorities, but this project contributed significantly to the continuity of the service, securing provision of specialised services that were previously unavailable.

The service has been commissioned to provide early rehabilitation and support for children and families following discharge from hospital in Cambridgeshire, to help reduce the chance of ensuing mental health and psychosocial problems.

Summary and recommendations

- Knowledge of rates of childhood brain injury, and of children with ABI with mental health needs, is lacking.
- Introduction of a screening tool within CAMHS would help address this.
- Awareness of childhood brain injury, and the issue of similarity of presenting difficulties to typical CAMHS referrals, should be raised within the NHS Trust services.

A parallel project ran alongside this work, using simulation modelling to virtually explore service configurations, minimising risks and potential service costs. The use of simulation modelling was highly innovative and facilitated the development of an

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understanding of systems design in brain injury rehabilitation services. Simulation modelling or other design approaches can help develop a thorough understanding of the interplay of factors influencing a service's productivity and financial viability, and support engagement of key stakeholders in understanding complex service models.

Adoption of service design and simulation modelling for supporting both service design and development and stakeholder engagement contributed to the continuity of the service in this case, and is recommended.

References

1. Parslow Epidemiology of traumatic brain injury in children receiving intensive care in the UK Arch Dis Childhood 90(11), 1182-1187, 2005
2. <http://guidance.nice.org.uk/CG56>
3. http://www.childbraininjurytrust.org.uk/information_abi.html