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Title: Childhood acquired brain injury affects adult outcomes.

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Abstract:

This special issue brings together internationally recognised experts in the field of paediatric acquired brain injury (ABI) to explore the long-term impact of ABI on adult outcomes. It is now well recognised that brain injury is a life-long condition which can lead to significant impairments across a range of cognitive, social and emotional areas. The hidden nature of brain injury means that it is a condition which is often under identified and misunderstood. Research included in this special issue attempts to highlight the many areas in which brain injuries incurred in childhood have led to poor outcomes in later life. Some of these areas include language, sleep, education, participation, standard of living and criminal justice. All of the included manuscripts call for increased training and education for those who care for children with ABI to improve long-term outcomes. We must seek to develop bespoke evidence-based interventions to support children and their families to ensure that all are given the opportunity to lead happy and successful lives.

Acquired brain injury (ABI) refers to any injury to the brain following birth (1). These include traumatic brain injuries (TBI), those sustained through infection, disease or other medical conditions. Figures for ABI are hard to come by due to the diverse nature of the definition, however, those for the more clearly defined category of TBI suggest that 17% of children will experience an injury before the age of 14 years (2). Despite such evidence TBI is perceived as a low incidence condition which receives little recognition and funding in educational, employment or criminal justice settings.

Brain injuries are classified as either mild, moderate or severe according to initial assessment via the Glasgow Coma Scale (3). Such injuries can result in deficits which impact on cognition (4), social functioning (5), behaviour (6), motor skills (7) and psychosocial functioning (8). While moderate to severe injuries are thought to lead to greater impairment there has been considerable interest given to mild injuries which are often referred to as concussions. The vast majority of all brain injuries are mild in nature (57 million) (9) and tend to resolve in days or weeks with no long-term negative consequences. However, approximately 10-15% of mild injuries are thought to lead to long-term deficits (10). Research has shown that potential serious consequences of concussion and brain injury are poorly understood by members of the public, educators and healthcare professionals (11-13).

In this special issue of *Disability and Rehabilitation* we asked international experts in the field of paediatric brain injury to share their work on the long-term outcomes of brain injury which have occurred in childhood. The diversity of topics included here demonstrates the far-reaching consequences of brain injuries sustained in childhood which negatively impact on later life. These topics include education, standard of living, participation, communication, offending, impact on sleep, and psychosocial outcomes.

Aguilar et al explored the impact of injury severity on cognitive communication competency 7-years after brain injury. Their findings form part of a larger prospective study which gathered data from children with severe and moderate TBI, together with a comparison group of children with orthopaedic injuries. Data were collected at 6, 12 and 18-months post-injury with the currently

reported data gathered at 7 years. The authors showed that children with severe TBI performed worse on all measures of discourse, with gist reasoning (i.e. abstracting meaning from large amounts of information) being the most sensitive indicator of communication competence. Aguilar et al suggest that interventions which target gist reasoning have the potential to improve communication skills, executive functioning and participation in daily activities.

Our fundamental need to sleep is examined in the work of Botchway et al who highlight the extent of sleep disturbance following paediatric TBI. Participants were part of an Australian cohort who had been followed-up at multiple time-points from the age of around 7 years. Young adults injured approximately twenty years earlier were assessed using actigraphy which estimates sleep and wake activity based on movement. This objective measure showed no significant differences between young adults with brain injury and a typically developing comparison group. However, they did show that TBI severity and being female was associated with longer sleep duration. The authors suggest that routine evaluation of sleep disturbance following childhood TBI should be introduced.

Participation has been defined by the International Classification of Functioning, Disability and Health (ICF) as 'involvement in life situations' (14) and is the subject matter of a paper by Câmara-Costa et al. The participation of children with severe TBIs was assessed 7 years post-injury as were their levels of intelligence, motor deficits, education and executive functioning. Parent reports of participation were significantly lower than those of an age and gender-matched typically developing comparison group. Children's self-report of participation levels did not differ. Participation was associated with injury related factors (severity, executive functioning, fatigue) rather than home environment. The authors recommend regular monitoring of participation in children with severe TBI using both self-report and proxy measures.

Employing structural equation modelling, Clasby et al investigated the impact of paediatric TBI on educational attainment and offending. Adolescents and young males (aged 16-18 years) detained at a young offender's centre in England were screened for the presence of TBI and post-concussion syndrome (PCS). The authors collected data on educational qualifications, criminal convictions and deprivation. Findings showed that 73.5% (n=72) self-reported a previous head injury and that PCS symptoms (e.g. headaches, dizziness, confusion etc) mediated the relationship between educational attainment and conviction frequency. Clasby et al call for the routine screening of TBI and PCS within criminal justice settings and the inclusion of a TBI category in special education provision.

The prevalence of TBI and extent of social competence among young male offenders was investigated by Linden et al in Northern Ireland. These authors collected data on Brain Injury, Hopelessness, Behavioural Regulation, Aggression and Perceived Social Support in young offenders aged between 18-21 years compared to a non-incarcerated, age and gender-matched control group. Prevalence of TBI was approximately 87% (n=54), showing a higher rate than that of Clasby et al. Offenders with TBI showed higher levels of aggression and hopelessness in addition to poorer behavioural control than the comparison group. The authors acknowledge the complexity of offender populations who often present with mental illness and substance misuse problems in addition to TBI. They suggest that training of criminal justice staff in the recognition and treatment of TBI could improve the lives of these young men and reduce rates of recidivism.

The importance of providing training to those who care for children and young people with TBI is highlighted in a study by McCart and colleagues. *In the Classroom After Concussion: Best Practices for Student Success* is an online, evidence-based training programme for educators developed in the United States. This programme employs multi-media to provide practical strategies to those working with children with brain injuries at school. The authors conducted a real-world trial on educational professionals from Washington State school in the US. Post-test measures of knowledge, knowledge application, self-efficacy and programme satisfaction showed that educators made significant improvements with knowledge and self-efficacy being maintained at 30 days follow-up. The authors suggest their programme is a cost-effective means to deliver training which could improve educational outcomes for children and young people with TBI.

The support of family is crucial following paediatric brain injury which can cause significant strain on parents. Schorr and colleagues sought to examine the impact of parenting style on the long-term outcomes of children who had sustained moderate to severe TBI. These styles have been categorised by some researchers as authoritative, permissive, and authoritarian (15). This concurrent cohort, prospective design assessed parents' ratings of their children's behavioural adjustment, social competence and executive functioning at around 7 years post injury, together with parenting style. Findings showed that permissive parenting predicted worse outcomes overall, whilst authoritative parenting predicted better executive functioning and social competence. This work suggests that support and training for parents, particularly for children with severe TBI, could significantly improve psychosocial outcomes for their children.

Parents want their children to grow up to be successful and achieve independence which can be more challenging for those who have TBI. The impact of mild and moderate to severe TBI sustained in childhood on education, employment, standards of living and receipt of government benefits was investigated by McKinlay and colleagues. Adults who had sustained their injury an average of 14 years previously were compared to a control group of individuals who had received an orthopaedic injury. Sustaining a TBI in childhood resulted in poorer outcomes in education, lower standards of living, and increased likelihood of receiving benefits when compared to the control group. Adults with a moderate to severe injury also demonstrated poorer outcomes than those with a mild TBI. McKinlay et al suggest that adults, with moderate to severe injuries sustained in childhood, should be better supported in school to improve educational attainment and supported in their efforts to maintain employment.

Many of the adverse outcomes outlined above could have been averted with appropriate and timely intervention. However, ensuring that children receive appropriate intervention requires a long-term perspective, which is difficult because children are in the process of developmental change, and it may be some time before deficits emerge. As a consequence, services may be reduced or removed before development dependent deficits emerge, resulting in the child reaching adulthood with less than optimal outcomes.

In conclusion, the research brought together in this special issue highlights the need for improved provision for children and training for those who care for their needs. The hidden nature of brain injury means that deficits are often not immediately apparent which can lead to unrealistic expectations and a lack of consideration. The long-term negative consequences of paediatric ABI

have been shown to lead to reduced quality of life, poor educational outcomes, greater reliance on state support, and in some cases, involvement with the criminal justice system. Greater awareness of the negative impact of childhood brain injury, and its long-term outcomes on these areas, is necessary if we are to adequately address the needs of this vulnerable group. We must be cognisant of the fact that children with brain injuries grow up to be adults with brain injuries who require early, targeted and ongoing intervention to fully realise their inherent potential.

Conflict of interest statement: The authors report no conflicts of interest.

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