EXPLORING BARRIERS AND INTERVENTIONS FOR LONG-TERM SOCIAL-EMOTIONAL IMPACTS OF ACQUIRED BRAIN INJURY ON PEDIATRIC PATIENTS IN CANADA: A NARRATIVE REVIEW

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ABSTRACT

Background: Acquired Brain Injury (ABI) refers to brain damage caused by factors such as external trauma or internal infections that occur after birth. ABI is a leading cause of death, disability, and illness in Canada. Pediatric ABI can have various long-term social-emotional impacts, such as lower cognitive abilities, challenges in social interactions, decreased levels of self-esteem and adaptive behaviour, and higher levels of loneliness and antisocial behaviour.

Objective: The objective of this review is to investigate the long-term impacts and implications of moderate to severe ABI on social-emotional development throughout childhood, and the interventions available for pediatric patients.

Methods: This review includes literature from academic databases, including Web of Science, Ovid MEDLINE, and PubMed. Grey literature from reputable sources, including Holland Bloorview Kids Rehabilitation Hospital and CanChild, were also included to provide a holistic view of ABI research. Studies focusing on children ages 6–21 with moderate to severe ABI were prioritized, particularly those conducted in Canadian contexts.

Results: Beyond injury severity and mechanism, caregiver mental health and family functioning influence a child’s post-injury trajectory. Interventions addressing social-emotional development typically focus on reintegration into learning and recreation. Persistent challenges include disjointed hospital-to-school transition, insufficient long-term care coordination, and restricted teacher or caregiver training.

Conclusions: This review underscores the need for improved, evidence-based strategies to support the social-emotional development of Canadian children with ABI. Greater collaboration among healthcare providers, educators, and families, alongside more robust longitudinal research, could bridge existing gaps, thereby enhancing continuity of care and outcomes for pediatric ABI populations.

INTRODUCTION

Acquired brain injury (ABI) is a leading cause of death and disability among children in Canada [1]. Based on the 2019 Canadian Health Survey on Children and Youth, 4.4% of children in Ontario ages 1 to 17 years reported experiencing a head injury [1]. ABI is damage to the brain that occurs any time after a person is born. There are two types of ABI: traumatic and non-traumatic [2]. Traumatic brain injury (TBI) refers to a brain injury caused by an external force that either penetrates the skull or is non-penetrating but causes damage from trauma or force [2]. Non-traumatic brain injury (nTBI) refers to damage to the brain due to internal factors, such as a lack of oxygen, tumours, or vessel occlusions [2]. TBI is the most common cause of interruption in typical child development and the leading cause of death in North America in those under the age of 19 [3]. While less common, nTBIs still place a large burden on the healthcare system. In Ontario, Canada, between 2003 and 2010, 17,977 nTBIs requiring care were reported in patients under 19 years [4].

1.1 Severities and Clinical Presentations of ABI

Brain injury severity is a primary factor in predicting the impact on an individual. The severity of a brain injury is commonly determined by the Glasgow Coma Scale (GCS) score, duration of unconsciousness, and duration of post-traumatic amnesia. Severity is categorized as mild, moderate, or severe. The vast majority (90%) of children who sustain TBI have mild brain injuries, with symptoms typically resolving within days or weeks [2,5]. Children with moderate to severe injuries often experience neurocognitive impairments, challenges with learning new information, deficits in executive function and psychosocial problems [3].

A head injury can be described as focal/localized or diffuse. Focal injury occurs when a specific location is damaged, such as with a stroke where a particular vascular territory is affected. Diffuse injury occurs when more than one area of the brain is damaged, often with acceleration/deceleration forces as well as cerebral edema and pressure effects [6].

1.2 Etiology of Pediatric ABI

Causes of pediatric ABI vary greatly depending on the patient's age and whether the injury is classified as traumatic or non-traumatic [7]. According to the Canadian Institute for Health Information's National Ambulatory Care Reporting System, in children and youth aged 5 to 19 years, the most common causes for TBI-related hospitalizations were sports (44%) and falls (24%) [8]. Other common causes of TBI include motor vehicle collisions, bike-related injuries, and acts of violence [3]. In very young children, non-accidental injury (NAI; previously Shaken Baby Syndrome) is a frequent cause of TBI [3].

According to a 2016 retrospective cohort study on children and youth in Ontario, Canada, with nTBI, the most common nTBI diagnoses were toxic effects of substances, brain tumours, and meningitis [4]. However, patient and clinical characteristics vary depending on the type of nTBI diagnosis. 76% of individuals presenting with toxic effects of substances were adolescents, while 86% of anoxic brain injury cases were infants [4].

1.3 Impact of pABI

Based on a review of children and youth with Brain Injury by CanChild, children with moderate to severe brain injuries experience multiple difficulties in function in the areas of self-care, mobility, cognition, behaviour, and speech and language [9]. The development of persistent behavioural and social disorders is a common post-injury occurrence after pediatric TBI (pTBI), affecting as many as 48% of pTBI survivors [10].

Social-emotional development is an umbrella term that describes individuals' various interpersonal and intrapersonal skills [11]. Social-emotional development entails (1) an individual's understanding of emotional experiences in the self and others, (2) the ability to express emotions in an age-appropriate way, and (3) emotional regulation capacities [11]. Social-emotional development has been found to be central for child and adolescent mental health and can protect against psychopathology and risk across development [12].

An important component of a child's social-emotional development is their participation. Participation, defined by the World Health Organization International Classification of Functioning, Disability and Health as involvement in a life situation, is thought to influence health and well-being [13,14]. Participation occurs in various contexts of a child's life, such as school, play, sport, entertainment, learning, civic life, and religious practice [14]. Therefore, exploring the participation patterns of children and youth with ABI in comparison to typically developing peers can help improve understanding of ABI on a child's social-emotional development.

This paper aims to investigate the long-term impacts and implications of moderate to severe TBI on social-emotional development throughout childhood, specifically for children and youth ages 6-21. This paper focuses on this age range as it excludes infant-toddler development, which can look markedly different from school-aged children. Additionally, restriction to school-going aged children provides multiple consistent environments, including full-time school, home environments, and healthcare settings in which interventions can be delivered. Furthermore, the paper explores existing interventions available in Canada for pediatric patients with a discussion on current gaps and potential solutions.

METHODS

The research process started with a grey literature consultation of the CanChild and Holland Bloorview Kids Rehabilitation Centre websites, as they are well-known and reputable Canadian organizations focused on treatment and research for children, youth, and adolescents with disabilities, including pABI.

This was followed by a database search on Ovid MEDLINE, Web of Science, CINAHL, and PubMed. Search terms included ABI, pediatric, Canada, long-term, social-emotional, intervention, and their modifiers (Appendix I). Articles were screened based on the following inclusion criteria: (a) the article primarily focuses on children and adolescents from ages 6-21, included under the term 'pediatric', (b) the article focuses on ABI resulting from penetrating and non-penetrating physical trauma, tumours, strokes, and infectious diseases pertaining to the head (ie, encephalitis and meningitis), (c) articles are written or translated in English, and (d) reviews, primary studies, and case studies. Although not part of a strict inclusion or exclusion criteria, Canadian papers were prioritized. As inclusion criteria was limited to Canadian research, the findings provided are likely more applicable to domestic contexts and future interventions and research. However, sources from the US that were particularly relevant to the aim of this paper were also used tosupplement the research due to the rather limited research in Canada. Studies focusing on infant-toddlers and adults, as well as studies examining acute or short-term impacts and management of pABI, were excluded as they were beyond the scope of the review.

For the purpose of this review, long-term effects of moderate to severe ABI are defined as any impact that persists or manifests after hospitalization. Additionally, social-emotional health and development is defined as the extent to which an individual's understanding, expression and regulation of emotion in both intrapersonal and interpersonal contexts is age-appropriate [11].

3.1 Long-term social-emotional impacts of pABI on patients

pABI affects the child across a multitude of domains, including the social-emotional developmental domain [9]. The long-term social-emotional outcomes of pABI manifests across multiple environments including school, outside-of-school activities, and social settings [14-15]. Difficulties faced by children who sustained a pABI can include academic underachievement, disruptive behaviours, academic exclusion, frustration, lower self-esteem, and social and behavioural difficulties [15].

A survey-based study conducted by Law et. al with the CanChild Institute at McMaster using the Children Assessment of Participation and Enjoyment (CAPE) tool investigated the participation diversity and intensity of 135 children with pABI, comparing them to 354 controls [14]. While inclusion in this study was not limited to moderate-severe ABI, there was no significant difference between the mild and non-mild groups in terms of participation level. The CAPE measure is a valid and reliable assessment tool that examines recreational, active physical, social, skill-based, and self-improvement activities outside of the school environment. The study concluded that children with ABI had a significantly lower participation level across all five activity types and participated with less intensity in recreational, physical, skill-based, and self-improvement activities [14].

Furthermore, children with TBI may have difficulties processing social information and adjusting to social environments. The theory of mind, which is the ability to understand and interpret the thoughts and feelings of others, is an important aspect of social information processing [16]. A study by Hoskinson et al. was conducted at several sites in Canada and the United States, comparing 45 children aged 8-13 against 42 controls. Data was collected using a structural MRI, the Test of Everyday Attention for Children to evaluate executive function, and three measures of various aspects of the Theory of Mind [16]. Additionally, parents rated their child's social and behavioural adjustment using the Behaviour Assessment System for Children-Second Edition. The study's conclusions highlight group differences in performance on theory of mind assessments, with children with severe TBI performing more poorly compared to controls and mild to moderate TBI patients. Additionally, severe TBI patients exhibited lower overall brain volumes in the central executive network, which is foundational to executive functioning. Similarly, they showed reduced right-hemisphere mentalizing network volume. The mentalizing network is thought to support metacognitive tasks and the ability to think about the mental states of others, which is related to the theory of mind [16].

3.2 Barriers in transition to school and work for long-term ABI

Return to school and work posed a significant barrier for adolescents receiving ABI care, as reported by a study by Lindsay et al. This study conducted semi-structured interviews with 10 adolescents with a diagnosis of ABI and 9 of their parents from the Greater Toronto Area, Ontario, Canada to explore the transition of care from pediatric to adult care following a long-term ABI [17]. 7 of the 10 adolescents from the Lindsay et al. study expressed concern over the lack of support provided for transitioning back to school and work [17]. 3 parents also mentioned that more guidance was needed for their children's educational path and in finding meaningful workplace opportunities [17].

The hospital-to-school transition for students following ABI was further investigated in a qualitative systematic review by Hartman et al [18]. Of the 20 articles included in this review, three studies originating from Canada were investigated for this current paper–two papers by Bruce et al. (2008 and 2012) and a paper by Gauvin-Lepage et al. (2010) [19–21]. The two Bruce et al. studies involved a thematic analysis of 20 and 19 participants, respectively, which highlighted the importance of a liaison between the hospitals and schools to ensure a smooth transition for the patients [19–20]. This liaison allows for clear responsibilities of the hospital and school staff, bolstering their confidence to support the student. Additionally, the Gauvin-Lapage et al. study utilized a focus group design with adolescents, parents, and professionals to conclude that social inclusion is a significant factor contributing to smooth transitions [21]. Therefore, interventions must address not only individual accommodations, but also the social surroundings that make up norms and expectations.

3.3 Barriers in transition from pediatric to adult care for long-term ABI

Of the ten adolescents who participated in the Lindsay et al. study, seven had transitioned into adult care, one was on a waitlist, and two were not yet transitioned [17]. Those who have transitioned reported an adequate continuity of care, and that all necessary medical information followed the patient in this transition process [17]. However, these patients also expressed that there was a significant difference in care that resulted in confusion and discomfort [17]. Although the logistical and administrative aspects of transitions may be well-structured, the patient experience shows that there is work to be done [17]. Three patients found the transition to be significantly challenging, even though they were 'ready' for the transition as deemed by the parents and healthcare workers [17]. Additionally, 3 of the 6 male participants felt that leaving the pediatric system at 18 was too early, as they felt they were too young to be making independent decisions [17]. The sudden change from receiving intensive pediatric care to a broader adult level of care seemed to be the most significant modulator of the transition process [17].

These barriers in the transition from pediatric to adult care have been considered a significant issue within the Canadian healthcare system [22]. A position statement by the Canadian Paediatric Society (CPS) included a call for action to improve the transition to adult care for youth with complex healthcare needs [22]. Within the call for action, the CPS recommended that there should be "flexible age cut-offs between pediatric and adult care services" [22]. Considering that growth and development within the physical, cognitive, moral, and socioemotional domains are individualized, strict age cut-offs–typically 18 in Ontario–are not the most appropriate, highlighting the importance of this recommendation [22]. By introducing systems that ready pediatric patients for adult-level care, patients may find the transition to be more manageable and comfortable [22].

3.4 Interventions and treatments for pABI

Emerging research highlights the need for and benefits of multifaceted treatment and intervention approaches, ranging from occupational therapy (OT) based programs, such as the Pathways and Resources for Engagement and Participation (PREP) intervention protocol created by CanChild, and online interventions such as the TeachABI intervention created and facilitated by Holland Bloorview Kids Rehabilitation Hospital.

The Pathways and Resources for Engagement and Participation (PREP) intervention is a strength-based intervention that focuses on enhancing participation by removing environmental barriers and having OTs support both adolescents and parents through coaching [23]. The PREP intervention includes 5 steps: Make goals, map out a plan, make it happen, measure process and outcomes and move forward [23]. In 2018, a study including 28 adolescents ages 12 to 18 with moderate physical disabilities examined the effectiveness of the PREP intervention in improving participation in community-based activities [23]. Adolescents were recruited from 5 major rehabilitation centres and 2 high schools in Greater Montreal, Quebec [23]. The findings demonstrate that participation can be improved by only changing environmental factors, which provides further evidence to support emerging therapeutic approaches that are "activity-based, goal-oriented, and ecological in nature" [23]. Due to the potential physical consequences of ABI, PREP may be an intervention that is effective for patients who have sustained an ABI.

Another intervention currently being implemented in Ontario is a training program for educators called TeachABI [24]. The TeachABI program is still in development and is intended to be a two-phased course with eLearning and in-person components [24]. A needs assessment conducted to inform the program highlighted gaps in educator training as well as the importance of school-based interventions to effectively accommodate students affected by ABI [24]. Stevens et al. (2021) used a mixed-methods approach, incorporating a survey and workshop to sample educators [24]. From there, they assessed potential resources to support educators and students with ABI in the classroom [24]. A total of 31 stakeholders were recruited, with 27 completing surveys [24]. Survey findings found that 83% of respondents reported being "somewhat knowledgeable" about pABI [24]. They acknowledged that there were significant impacts it can have on the cognitive, physical, and psychological domains in children [24]. Despite this awareness, 65% of participants reported not having experience working directly with students with ABI [24]. Additionally, the majority of participants (61%) reported feeling "not or somewhat comfortable" assisting a student's transition back to school post-ABI [24]. These findings show a disparity, as many educators had some experience working with children with ABI but had low levels of comfort assisting with reintegration post-injury [24]. Results from the workshop identified the need for a 2-part educational course for educators that emphasized building awareness and knowledge about ABI [24].

SCHOOLFirst is an evidence-based and user-driven resource that was co-created by educators, healthcare providers, youth, and families for educators to support students returning to school following a concussion [25]. In the study, educators engaged in a 90-minute workshop that combined a guided walkthrough of the online toolkit with a case-based discussion and completion of a return-to-school planning template [25]. Educators then had ongoing access to the site for classroom use, which is available today to the public. The free, self-paced online toolkit includes short videos, as well as printable planning and tip sheets [25]. This study, which included a survey taken during a concussion education and training workshop was conducted by Holland Bloorview Kids Rehabilitation Hospital and York Region District School Board [25]. Participants included 56 educators, primarily elementary and secondary school teachers, but also school administrators and child and youth workers [25]. Published in 2022, this study evaluated the usability and satisfaction of a return-to-school resource for students following concussion. This study and the associated findings concluded that educators were satisfied with the SCHOOLFirst resource and saw opportunities to use it in the future to support their students post-concussion [25]. Participants said their overall concussion knowledge, as well as knowledge of how concussions affect the return to school process and available associated resources, increased after the workshop [25]. After the workshop, most participants felt confident in their ability to support students returning to school after a concussion [25].

DISCUSSION

4.1 Summary of the research

Findings from this review suggest pABI can significantly lower participation levels and intensity across all five activity types [15]. Children with TBI exhibited poorer performance in Theory of Mind assessment and a lower overall volume in the central executive and mentalizing networks, impacting executive functioning and metacognitive tasks, respectively [16]. Furthermore, studies exploring the common barriers for pABI patients found that return to school and work posed a large barrier for adolescents receiving ABI care and struggled with the transition between pediatric and adult care [17]. Various programs and resources, including the PREP intervention, TeachABI, and SCHOOLFirst exist to address the long-term social-emotional challenges children and youth living with moderate to severe ABI may experience [23–25].

4.2 Strengths and limitations

This paper presents a novel synthesis of research of the social-emotional impacts of ABI, focusing on research and interventions conducted within Canada.

The literature consistently highlights gaps in treatment coordination, continuity of care, and standardized approaches for pABI [26]. In 2014, Munce et al. highlighted the lack of coordinated, long-term follow-up services for youth with ABI in Ontario [26]. Lack of coordinated services can exacerbate long-term social-emotional challenges for youth, especially during critical transition periods, including back to school or to adulthood [26].

Evidence-based programs including TeachABI and SCHOOLFirst demonstrate the importance of strong partnerships and communication between families and caregivers, educators, and healthcare providers in promoting continuity of care, reducing gaps in knowledge, and ensuring consistent implementation of tailored interventions [24,25] Findings and conclusions drawn from the research studies on TeachABI and SCHOOLFirst highlighted that educators typically have limited formal training on ABI [24,25]. Although many educators understand concussion or ABI symptoms, they often lack the confidence and practical strategies to implement supports and accommodations [25].

There are several limitations associated with these findings. The prioritization of Canadian research highlighted gaps in the recency and depth of local research on social-emotional development. A 2021 prospective cohort study in the United States followed 534 children (including controls) to examine outcomes post-injury and pre-injury factors that may contribute to outcome severity and variance [27]. Similar longitudinal studies such as one conducted by Ryan et al. and systematic reviews like that conducted by Li and Liu synthesize primary studies and recent, high-quality evidence [28,29]. This provides a strong foundation of evidence to understand social-emotional development in relation to ABI within the United States. While geographically close, Canada has a remarkably different education and healthcare system to the United States, necessitating local research on ABI and its impacts on patients and caregivers to effectively inform future interventions and practice. This paper is limited to a smaller pool of evidence describing social-emotional impacts of pABI. Additionally, variability in methodologies, date at which the study was conducted, and the measures of social-emotional development may reduce the generalizability of the findings. Finally, the inclusion of studies only written or translated in English may introduce language bias by excluding relevant studies written in other languages.

4.3 Future research directions

While existing Canadian literature provides valuable insights into the long-term social-emotional impacts of pediatric ABI, there are a few limitations warranting future exploration. Future studies should incorporate longitudinal designs to capture social-emotional developmental changes over time within the Canadian context. This would provide a more comprehensive understanding of the evolving needs of children's long-term social-emotional development with ABI. Additionally, while interventions such as PREP show promise, there remains a lack of large-scale, controlled trials assessing their long-term effectiveness. Future Canadian research should prioritise research designs to assess the sustainability and effectiveness of interventions, ensuring these interventions effectively address the long-term needs of children with ABI.

CONCLUSION

Key influences, including injury severity, family dynamics, and educational support, collectively shape a child's developmental trajectory. Our review indicates when these young individuals re-enter everyday contexts like classrooms, sports, or community activities, they frequently encounter academic and behavioural challenges rooted in deficits with executive functions and social cognition, including theory of mind. Targeted programs like PREP, TeachABI, and SCHOOLFirst can foster more meaningful engagement in daily activities, particularly in school settings, and potentially bolster psychosocial outcomes. These interventions also highlight the need for a multi-stakeholder approach combining school, healthcare, and family support to address these difficulties, and research consistently note gaps in service coordination and educator training.

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