

REVIEW ARTICLE

Childhood brain injury: A review

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Abstract

Childhood brain injury is an important and complicated public health issue worldwide. Extensive work has been done in this field. This review highlights issues that are frequently misinterpreted or overlooked in the management of childhood brain injury. The incidence of traumatic brain injury is higher than non-traumatic brain injury. However it is frequently over-reported due to various confounding factors. In ascertaining the severity of injury, assessment of brainstem functions is important and should be included in routine clinical assessment. Most rehabilitative efforts are usually aimed at improving the physical outcome. However, non-physical sequelae are also common and may be more disabling with significant impact on the learning and functioning of the child. These areas, which include depression, cognitive functioning and health-related quality of life of children, should not be overlooked in the management of childhood brain injury. In addition to caregiver's stress, family dynamic and siblings' well-being also play a crucial role in the recovery process of the child. By highlighting the frequently missed issues in the management of childhood brain injury, it is hoped that clinicians and professionals could pay more attention to these issues and provide a comprehensive medical care for the patients and their families.

INTRODUCTION

Brain injury is one of the medical conditions that require long term health care services such as rehabilitation. There are many health implications following brain injury. While physical disability is the major health impact, there are other associative psychosocial problems such as depression¹⁻³, lower health-related quality of life (HRQoL)^{4,5} and lower cognitive functioning.⁶⁻⁸ These health conditions will have adverse effects on the rehabilitation outcomes if they are not handled well and may have long term adverse sequelae.^{9,10}

In USA, data obtained from emergency department visits, hospitalizations, and deaths estimates the incidence of traumatic brain injury (TBI) at 538.2 per 100,000 population which translates into an estimated 1,565,000 TBI cases per year in 2003. TBI rate for children aged between 0 to four years old is 1,188.5 per 100 000 population and it is also the highest rate against all age groups.¹¹ In Australia, it is estimated that one in every 45 Australians (432,700 people) had acquired brain injury in 2003, with 20,000 of them children below 15 years old.¹² Incidence of childhood head injury in 2002 and 2003 is 765

per 100,000 children population, aged 0 to 15 years old while the incidence of significant head injury is 7 per 100,000 children population.¹³ In another study by Crowe *et al.*¹⁴, the incidence of head injury in year 2004 is 2008 per 100,000 children attending the emergency department while the incidence of severe head injury is 31 per 100,000 children population attending the emergency department.

Data on incidence and prevalence of childhood brain injury in Malaysia is scarce. A study conducted in the Emergency Department, Hospital Kuala Lumpur over 3 months period found a prevalence of 4.75% (n=388) of accidental childhood head injury among children below 14 years old, against all paediatrics cases presented at the Emergency Department.¹⁵ Another study conducted in Klang Valley (in the state of Selangor in Malaysia) from January to December 1998 on road traffic accidents and focusing on motorcyclists¹⁶ found that 225.8 (54.8%) motorcyclist victims survived with injuries. Pang *et al.* did not specify the severity of the injuries among survival. Nevertheless it is expected that brain injury will be one of the main morbidities.

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This is extrapolated from the fatalities in the same study where head injury accounted for 62.9% (117 out of 186) despite the fact that safety helmet were worn in 90% of the victims.¹⁶ Therefore brain injury is one of the major public health problems. Consequently, there is an urgent need to collect data on national prevalence of brain injury in Malaysia to facilitate healthcare delivery. This will lead to rational planning of acute and rehabilitation services for the people and to improve in the quality of care and consequently the outcome of brain injury.

WHAT IS THE TRUE INCIDENCE OF TRAUMATIC AND NON-TRAUMATIC BRAIN INJURY IN CHILDREN

Most studies have concentrated on traumatic brain injury. There are relatively few studies on non-traumatic brain injury (nTBI).¹⁷⁻²⁰ Figure 1 illustrates the age specific incidence of traumatic brain injury. With the exception of the study by Rutland-Brown *et al.*¹¹, most studies show a low incidence in infants and young children. Highest incidence is observed among adolescents and young adults aged 15 to 19 years old which is attributed to increased mobility and risk taking behaviour in this population group. There is no information provided by Rutland-Brown *et al.*¹¹ to account for this difference. Crowe *et al.*¹⁴ identified sport activities as the major causes of

head injury among school aged children in their study. In nTBI, highest incidence is observed among infants and young children.^{17,19,20} The main causes of nTBI are infection and inborn error of metabolism^{17,19,20} which affect mainly infant and young children.

At a glance, the overall incidence of TBI in children is very high and much more prevalent than nTBI. Incidence of childhood TBI is 70 per 100 000 children per year²¹ while incidence of nTBI in children is six per 100 000 children per year.²⁰ However there are several pitfalls to this simplistic interpretation. Definition is an important confounding factor. There is lack of uniformity in the use of head injury and brain injury. These two terms have either been used to denote the same clinical condition or used interchangeable by many studies. Head injury, includes not only injury to the brain but also external injury. The reverse however does not apply i.e. all patients with brain injury have head injury but not vice versa. There is therefore the possibility of over inclusion of patients in studies which used head injury as the recruitment criteria. Different methods of case ascertainment may also be one of the contributing factors to this discrepancy. Retrospective studies based on hospital discharges may have overlooked transfers between hospitals hence additional inclusion of the same patients in the estimation of brain injury. Studies that used

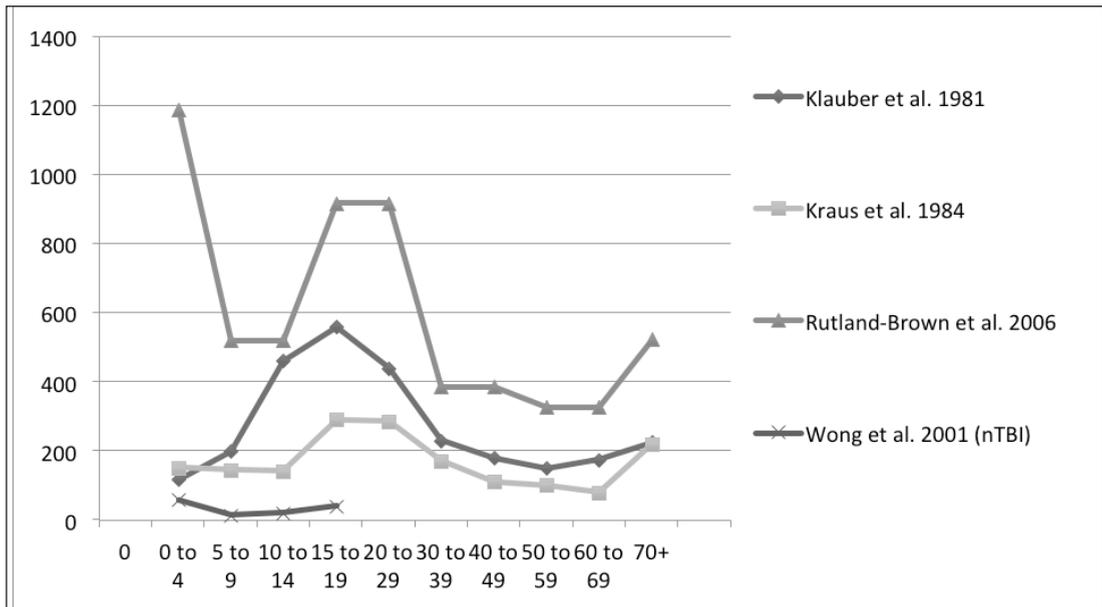


Figure 1. Age-specific incidence of brain injury. Klauber *et al.*²², Kraus *et al.*²³ and Rutland-Brown *et al.*¹¹ study refers to incidence of traumatic brain injury while Wong *et al.*²⁰ study illustrates the incidence of non-traumatic brain injury.

International Classification of Diseases (ICD) identification as recruitment criteria may also lead to multiple inclusions as injury to different part of head may be included separately and more than once. There are other confounding factors such as variations in hospital policies or different denominator used in each study. Two studies in San Diego have eloquently illustrated the influence of these confounding factors. Klauber *et al.*²², in their study of the incidence of childhood head injury in 1978 suggested an incidence in TBI of 295 per 100,000 population. However, a subsequent study by Kraus *et al.*²³ in the same region three years later found a significantly lower incidence of 180 per 100,000 population due to one or more of the reasons illustrated above such as changes to hospital admission policies within the three years and less accurate denominator used in 1978.

Another crucial factor is the use of different injury severity (of brain) as recruitment criteria. Most studies in TBI usually include patients with higher Glasgow Coma Scale (GCS) scores (<12) while nTBI studies include patients with lower GCS scores (<8) such as in Wong *et al.*²⁰ study. The incidence of severe brain injury (adult and children) in the study by Kraus was only 49 per 100,000 population, significantly lower than the overall incidence of 180 per 100,000 population.²³ In fact, subsequent analysis by Kraus *et al.*²⁴ found a further reduction in the incidence at 27 per 100 000 population. In the study by Wong *et al.*²⁰, the incidence of nTBI in children is 31 per 100,000 children, or estimated 6 per 100,000 population. The incidence of TBI and nTBI among children are therefore lower than the literature suggests with a ratio of TBI:nTBI of approximately 1:5.

ASSESSMENT OF THE SEVERITY OF BRAIN INJURY

For effective patient management, standardised measure of illness is essential and is useful in facilitating collaboration between medical or non-medical disciplines and centres. For brain injury patients, simple and accurate assessment of the level of consciousness can help to determine the immediate course of action, to monitor patients' progress, to assess effectiveness of treatment or intervention; and to ascertain prognosis. Consciousness is usually determined by the integrity of higher cortical functions, brainstem functions and reticular activating system. There are various methods or instruments that have been used to determine the conscious level in

routine clinical practice, for example, GCS, Abbreviated Injury Scale (AIS), measures of loss of consciousness (LOC), duration of posttraumatic amnesia (PTA), Adelaide Coma Scale (ACS), Grimace Scale, Seshia Scale, Blantyre Coma Scale (BCS) and computer tomography of brain lesions. These instruments assess, to varying emphasis, the integrity of the critical centres that control level of consciousness i.e. higher cortical functions, brainstem functions and reticular activating system. Most scales emphasis on higher cortical functions than the brainstem functions. However, in cases of severely comatose patients, brainstem functions may be all that's left. It is therefore important, when assessing the conscious level, to include a good assessment of brainstem function as well.

The most widely use measuring tool to assess conscious level is Glasgow Coma Scale (GCS) which was developed by Teasdale and Jenette.²⁵ GCS assesses higher cortical functions in three domains – eye opening, verbal performance and motor response independently, giving a score ranging from three to 14 in the original scale. The motor response domain was subsequently extended, giving the maximal total score of 15. However, the authors acknowledged the difficulty in the additional score and advocated the continual use of the original Glasgow Coma Scale. GCS also includes some basic brainstem functions (blood pressure, respiratory rate, heart rate and pupillary size) which are however not widely used. Most studies have used only the three domains in eye opening, verbal performance and motor response and classified GCS score of 3-8 as severe, 9-12 as moderate and 13-15 as mild.^{26,27} Although the scoring of GCS is relatively simple and straightforward, it is subjective and user-dependent especially in the borderline scores of 8-9.

Assessment for children must take into account the neurodevelopment of children. Using GCS to gauge the conscious level of children under five years old, especially with regard to the verbal response, without considering the developmental perspective of children would produce an inaccurate clinical picture. The normal top rating ('orientated') is for example unattainable by normal infants and children under five years old. Consequently many scales have been developed or modified from the GCS for use in children. Some scales have been devised for a specific purpose or condition and developed de novo such as the Lovejoy's classification for Reye Syndrome²⁸ and 'triage' classification of near-drowning patients.²⁹

Most of the paediatric coma scales proposed for general clinical use have, however, been modelled or modified from the GCS^{30,31} reflecting the wide acceptance of the GCS. Modified paediatric GCS also known as James' GCS (JGCS) is one of these scales modified based on GCS where neurodevelopment of children is accounted for. JGCS has similar scoring system as the GCS and found to have better inter-observer agreement than other scales.³²

SEQUELAE OF BRAIN INJURY

Brain injury lead to outcomes in several areas such as mobility impairments^{33,34}, neurological deficits and neuropsychological disabilities^{19,35,36} which affects functional independence of these children.^{18,34} Recovery from brain injury is a long process which does not stop at hospital discharge. Most patients have not reached optimal recovery outcomes at the point of discharge. Therefore it is important to continue the management after discharge to achieve optimum outcome. Ascertaining the states and needs of these patients at initial discharges enables appropriate planning and effective intervention according to the needs of these patients. Current resource constraint has resulted in rehabilitative services being reserved for children with more severe disabilities following brain injury. The majority of patients with mild to moderate disability do not receive any follow-up.³⁷ However, it has been reported that patient with mild to moderate head injury may still be at risk of poor outcomes although they appear to have made a good functional recovery.³⁷ In some instances, the morbidity associated with brain injury were underrated and or underreported.³⁸

A standard clinical outcome scale that is widely used is Glasgow Outcome Scales (GOS). However, GOS emphasizes more on physical aspects than cognitive, emotional or behaviour aspects.³⁹ GOS developed based on the adult sample group; it is thus less sensitive and tends to underestimate morbidity among children with neurological problems. It is important to select an assessment or instrument that is appropriate for different age group. Consequently, other outcome scales that are commonly used among children with neurologic disorder are Barthel Index⁴⁰, Neurologic Outcome Scale for Infants and Children (NOSIC)⁴¹ and King's Outcome Scale for Childhood Head Injury (KOSCHI).⁹ Crouchman *et al.* developed KOSCHI that provides robust, simple description of outcomes for children with brain injury in short, medium and long term.⁹ The administration of

KOSCHI is simple, it can be completed through direct observation or extracting data from routine medical records. This instrument emphasizes on a few aspects which are common issues among children with brain injury such as concentration, behaviour and disinhibition.⁹

There are studies suggesting strong correlations between KOSCHI and children's outcomes at discharge, injury severity based on GCS, length of hospital stay and post-traumatic amnesia.^{42,43} There is also high inter-rater reliability for assessors with different experience.⁴³ Clinicians who wish to use KOSCHI should take note that KOSCHI can predict children's physical and cognitive needs at discharge but is not a good predictor for long term outcomes more than 6 months post injury especially in the area of cognition, behaviour and emotional difficulties.⁴² Good outcome score at discharge may not necessarily imply good recovery at longer term as difficulties may surface at later stage post-injury.⁹ It is important that clinicians should not rely and categorize patients solely on the outcome score at discharge especially among children. In addition, complexity of neurodevelopment among children increases with age. Impairment at a young age may translate into disability when the demand on the child for independent living increases. This impairment may eventually handicapped the child when the child reaches the age of independence.^{9,39}

Clinicians and families of children with brain injury have traditionally concentrated on physical outcomes due to the apparent nature of physical disabilities. However, it has been found that psychological impairments are not uncommon and may be more disabling^{1,3} and these disabilities and impairments might have significant effects on the child's social participation and family life.⁴⁴ Indeed depression and diminished life satisfaction among survivors of brain injury are persistent problems that require the close attention of medical and rehabilitation professionals. Studies have shown that children with brain injury have poorer health related quality of life⁴⁵, psychological problems, social impairments and poorer psychosocial health which are observed across cultures.^{46,47} This is in addition to the concomitant cognitive impairments, which includes lower attention and executive functioning.^{6,48} Studies have reported on behaviour difficulties and personality change in children following brain injury which are more difficult for caregiver and family.^{37,49} Similarly, neurological disabilities are also observed among children with nTBI. Thirty two children out of 109 children (29%) that were followed up in Sofiah

and team's study had permanent neurological disabilities.¹⁹ Similarly, 26% among those who survived nTBI had cognitive or behavioural problems at follow-up in the study by Wong *et al.*²⁰

Even in the absence of obvious neurological problems, mild concussions can cause adverse attentional and psychosocial outcomes in later life. The duration required for patients with minor head injury to fully recover is unknown too. Children with mild head injury were found to have attention deficits and other behavioural issues few years after the insult.⁵⁰ In addition, cortical and brain stem damages with more persistent brain stem damages had been found in minor head injury than previously anticipated.⁵¹ In a group of 26 patients with minor head injury only half of the group recovered fully within six-week period. The remaining patients showed lower brain stem conduction and longer choice reaction time and some of these patients still have persistent brain stem dysfunction 6 months after the insults.⁵¹ In fact, physical, emotional and intellectual sequelae related to childhood head injury may persist up to two decades.³⁸

Studies have shown a higher recovery rate among TBI patients across all age groups^{18,34} which may be important in the expectation and management of these children. One possible explanation is that children with TBI are well before the various traumatic insults hence they have better recovery potential. In contrast, the cerebral insult in nTBI children usually occur either after a severe insults to the brain and or protracted insult in other system which eventually results in multiple organ system failure which include brain. As the children are usually severely ill by this time, their recovery potential is less. In addition, Cullen *et al.*¹⁸ also rationalised that the damage in nTBI is often more widespread and severe; ischemic and/or inflammatory damage usually co-exist and affect several parts of the brain. In contrast the lesions in most TBI are more circumscribed, unless this is complicated by secondary insult, indicating higher neuronal reserve. This allows better adaptive neuroplastic changes that lead to improved recovery and function.

Aetiology has been found to be a significant outcome prognostic factor in nTBI.^{20,34} For example, mobility improvement rate for children with brain infections and seizures was generally higher than children with anoxic brain injury in Fragala *et al.*³⁴ study. However little is known about the underlying mechanism of this

phenomenon. Further research is needed in this area to support if aetiology of brain injury is associated with outcomes and to understand the underlying mechanism. Other confounding factors such as initial cognitive level, severity of head injury, pre-existing learning difficulties, history of psychological issues or family problems have been identified and reliably predict the long term outcomes of these patients.^{38,52} These confounding factors predict or affect the outcomes following brain injury thus should not be overlooked in the management of childhood brain injury.

Non-physical morbidity following brain injury are not uncommon in TBI and nTBI; and should not be taken as secondary in terms of priority during intervention planning. Past studies have also shown that even mild to moderate brain injury has significant impact on a range of health consequences to the patients. Recovery from brain injury is indeed a long process while the duration to fully recover is unknown. Various confounding factors have been identified that complicate the recovery process of children with brain injury. It is therefore important to have sufficient follow-up with patients with brain injury to ensure they receive appropriate treatment or intervention during their recovery period.

PHYSICAL IMPAIRMENTS AND FUNCTIONAL IMPAIRMENTS IN DETAIL

Physical impairment is one of the more noticeable outcomes following brain injury. In a study, 24% of children with severe TBI had motor deficits while none of the mild to moderate TBI children had motor deficits at 6 months post injury.⁵³ However there are studies that also found mobility impairments among children with mild head injury. Following the insult of mild brain injury, these children are found to have balance deficits although most of them may perform as well as the control group children in fine and gross-motor activities.^{54,55} Anderson *et al.*⁵⁶ examined the outcomes after childhood traumatic brain injury at 6th and 30th month post-injury. Significant improvement in physical functioning was observed among the patients as a whole, with moderate to severe group patients showed most improvement. Regardless of severity of brain injury, different level of physical impairments may be seen among these patients following the insults. Physical sequelae following moderate to severe brain injury are generally more substantial but also have higher potential for recovery.

Physical outcomes are not equivalent to

functional outcomes although both terms have been used interchangeably by some researchers. In fact, functional outcomes should include broader aspects in life such as school performance, activity restrictions, and health care utilization instead of just focusing on physical health.⁵⁷ Past studies have shown children with brain injury whom eventually achieved independent ambulation still experience deficits in their physical ability such as balance and coordination imbalance or fine motor deficits in comparison to their peers.^{34,58} These deficits may appear to be mild but may be sufficient to interfere with certain daily activities. Subsequently, this could which further restrict these children from participating fully in the community. Fragala and colleagues suggested that children with brain injury who recovered and discharged at highest mobility level may still have some difficulties participating in community activity. This could be due to impairment in either advanced motor skills that are needed to perform certain activities or the presence of cognitive deficits that inhibit their interactions with peers and community.³⁴

DEPRESSION AND BEHAVIOURAL PROBLEMS

Depression is common after brain injury. Children with acquired brain injury were found to be more anxious, depressed and less resilient compared to controls.¹ In addition, children with depressive symptoms were found to have higher vulnerability and lack of resourcefulness.¹ This may degenerate into a vicious cycle whereby the lack of resourcefulness and increased vulnerability predispose them to higher risk of depression and vice versa. Max *et al.*³ observed that children with TBI usually had onset of depression within the first 6 months post injury. Factors such as age at injury, genetic factors, lesion laterality have been identified to correlate with the onset of depression post brain injury.³ It has also been found that children who are socially challenged are also at higher risk of developing depressive symptoms.² Consequently it is important for medical care providers to identify children with brain injury who might be at higher risk of developing depression.

Behavioural disturbances following TBI are common and more prevalent than other non-brain related injury.^{37,49,53,56,59} Children with TBI had been found to exhibit poorer behavioural outcomes in comparison to orthopaedic controls and the outcomes correlate with the severity of injury.^{49,56,59} The presence of behavioural problems

is not restricted to only children with pre-injury behavioural issues. Ong *et al.*⁵³ study found new behavioural disturbance among children with brain injury such as delinquency, aggressiveness and problems with socializing. These sequelae are seen more frequently in children with severe closed head injury than children with moderate head injury and their orthopaedic controls.

COGNITIVE OUTCOMES

There may be disturbance to one's attention, memory and executive functioning following brain injury regardless of the severity. These cognitive impairments may in turn result in further disturbances to more complex cognitive functions such as language development and communication.^{33,49,59,60} Tonks *et al.*³⁶ reported deficits in cognitive abilities and emotion processing domains in children with brain injury. Some children also had deficits in reading emotions, which is one of the crucial aspects of social development. Executive functioning is also affected in brain injury and is a crucial mediator between a child's resiliency and social development. Consequently, this influences the psychological health of the child as it is shown that children with brain injury are less resilient, more depressed and anxious than healthy children.¹ Botcher⁴⁸ also indicated that cognitive deficits in children with cerebral palsy are not just due to the biological constraint that affects the typical cognitive development, but also as a result of the dynamic interaction between the child and the environment.

Past studies have shown that attention deficit is one of the cognitive outcomes following brain injury. It is suggested that attention deficit hyperactivity disorder (ADHD) is a clinically important sequelae following severe TBI among children and adolescents.⁶¹ Some cognitive functions such as processing speed and selective attention may be closely linked to one's attention. As a result, slower processing speed and impaired selective attention were observed among children with TBI.^{26,62} Catale *et al.* conducted a study involving 30 children with mild traumatic brain injury and matched children without injury as control group. Test for Attentional Performance (TAP) battery was used in this study and children with brain injury were found to perform less accurately on the selective tasks than the control group children.⁶² In cases where improvements were observed in the attention domain over a longer term, memory

deficits still pose difficulties in these children's cognitive functioning.⁵⁶ Therefore, certain aspects of cognitive functioning of children with brain injury may improve over time but there are still evidences of residual deficits in longer term.

Children's academic performance is influenced significantly by their cognitive outcomes especially after the brain insult. For example, Wrightson *et al.*⁸ found children with mild head injury had lower cognitive tests performances at 6-month and 1-year post injury and subsequently had lower reading ability which is related to visual closure. Visual closure is a cognitive function that helps a person to comprehend and interpret what is being seen and it is an important foundation for one's reading ability. These cognitive impairments may only be detected few months post-injury emphasizing the importance of being vigilant even in mild traumatic brain injury. Deteriorating school performance which may be reflected in weaker math or writing skills are associated with attention problems and impaired memory in children with closed head injury.^{49,53}

HEALTH RELATED QUALITY OF LIFE (HRQoL)

International Classification of Functioning, Disability and Health (ICF) is the conceptual basis for health and disability. One's disability or functioning depends on the interactions between a person's health conditions and contextual factors which includes environmental and personal factors. ICF also classifies human's dysfunctioning into three levels: impairments, activity limitations and participation restrictions.⁶³ Disability and functioning and influence one's quality of life (QoL). WHO defines QoL as 'individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns'.⁶⁴ QoL is thereby affected by one's physical and psychological health, level of independence, social relationships, personal beliefs, and their surrounding factors.⁶⁵ Traditional outcome measures seem to exaggerate therapeutic goals, such as symptom reduction and reduced hospital admissions. However other equally important outcomes such as patients' needs and concerns, which include their actual living conditions, physical impairments, psychosocial health problems are usually overlooked. Hence HRQoL research introduces a more holistic approach as it encompasses the broader picture i.e. what a person is capable of doing, access to

resources and opportunities to use these abilities to pursue interests, and a sense of well-being.⁶⁶

In a review of children and adolescents following traumatic injury, it was observed that HRQoL of majority patients was compromised.⁶⁷ Brain injury was found specifically correlated with impaired HRQoL.^{4,5} It was found that at one year post-injury, children with TBI are found to have impaired HRQoL and HRQoL was negatively influenced by the severity of injury and other concomitant injuries such as extremity or spinal injury.⁶⁸ Furthermore, HRQoL index in children with brain injury or cerebral palsy appears to be lower among all other children with different disease clusters such as obesity, cancer, diabetes and psychiatric disorders.⁵ Consequently, HRQoL is an important aspect and should not be overlooked.

Most studies assessing HRQoL have focused on children alone, but not their parents or caregivers. This is a significant oversight given that the dynamics of parents or caregiver with children with brain injury has significant impact on the recovery process of the children. Caregivers of children with brain injury tend to report high difficulties in the physical and emotional aspects in life such as experiencing exhaustion, insomnia, feeling stressful and overall lower life satisfaction and lower HRQoL compared to the general population.⁶⁹⁻⁷¹ Single parenting also was found to negatively affect the HRQoL of the children with brain injury.⁶⁸ Therefore, assessment of HRQoL should always be conducted together for both the child and caregiver to ensure optimal recovery process which will be discussed in the next section.

CAREGIVER'S BURDEN AND WELL-BEING

Childhood brain injury is a long term health condition that may or may not improve over time. This may necessitates full time or part time caregiving from their parents or guardian. Time needed for caregiving is substantial and hence the burden and well-being of caregivers must not be overlooked. In some families, one of the parents stops working to care for the children with brain injury and the financial consequence on a family is a crucial factor. As many as half of the caregivers in Smith and Schwirian's⁷² study stopped working to care for the patients recovering from brain injury. Some caregivers who continue to work reported having trouble keeping up with their regular work schedules due to the demand

of caregiving responsibility. Caregiver burden and family financial strain happens across families with children with brain injury although it is more apparent among patients who are severely injured.^{73,74} Therefore, professional help and social support should be provided to children with brain injury and their family as appropriately to their need but not confined to children with severe brain injuries.

Not surprising caregivers of children with long term health condition have poorer psychosocial health compared to their healthy counterparts.⁷⁵⁻⁷⁷ Parents of children with cerebral palsy were more depressed, anxious, had poorer psychosocial well-being and lower life satisfaction in general.⁷⁶ Children's injury condition such as severity of brain injury, level of impairments, premorbid and post-injury behavioural problems contribute to the caregiving burden and stress in addition to parents' demographic factors such as level of maternal education.^{56,75} Caregiving burden for children with behavioural difficulty is equally heavy to caregiving for children with physical difficulty. Therefore, it is important not to overlook the behavioural sequelae during the post-injury recovery process. Besides caregiving demand, family dynamic also plays a role in affecting the parenting stress. Siblings of children with brain injury were found to have lower psychological health, more behavioural problems and impaired siblings relationships.⁷⁸ This will not only adversely affect the recovery process of the children with brain injury but also contributes to parenting stress.

The transition time shortly after discharge is crucial for family adjustment. This is the time when caregiving responsibility shifts from medical personnel to solely on the family, and compounded by other changes such as patient's emotional and behavioural difficulties and family's financial issues.⁷⁹ The initial euphoria of the family on the child having survived a severe injury may mask the awareness of a possibly persistent impact of brain trauma and associate changes or stressors that will surface within the family later on.⁸⁰ Therefore, it is important to provide professional and emotional support to caregivers of children with brain injury for smooth transition from acute care to possibly long term home care. In fact, concise health and medical information, professional and community support are few of the highly ranked needs by families with children with brain injury. Other needs that were identified were such as emotional support, reassurance, instrumental support and financial counseling.⁸¹⁻⁸⁴

Family needs have to be identified and adequately addressed to encourage recovery in patients with brain injury and to maintain healthy HRQoL of family members.

CONCLUSION

There have been quite substantial amount of work done in the area of childhood brain injury. However some aspects are occasionally overlooked. TBI, as expected is still more common than nTBI. Nevertheless its incidence may still be over reported due to various confounding factors mentioned. While assessing the severity of injury, clinicians need to include the assessment of brain stem functions as a lot of the currently used scales do not have it. One should consider recovery in both physical and non-physical domain as well. Contrary to common view, the latter may be more disabling. HRQoL of the children with brain injury as well as their caregiver are crucial and should not be overlooked.

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DISCLOSURE

Conflict of interest: None

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