

Shaken baby syndrome in Canada: clinical characteristics and outcomes of hospital cases

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Abstract

Background: Shaken baby syndrome is an extremely serious form of abusive head trauma, the extent of which is unknown in Canada. Our objective was to describe, from a national perspective, the clinical characteristics and outcome of children admitted to hospital with shaken baby syndrome.

Methods: We performed a retrospective chart review, for the years 1988–1998, of the cases of shaken baby syndrome that were reported to the child protection teams of 11 pediatric tertiary care hospitals in Canada. Shaken baby syndrome was defined as any case reported at each institution of intracranial, intraocular or cervical spine injury resulting from a substantiated or suspected shaking, with or without impact, in children aged less than 5 years.

Results: The median age of subjects was 4.6 months (range 7 days to 58 months), and 56% were boys. Presenting complaints for the 364 children identified as having shaken baby syndrome were nonspecific (seizure-like episode [45%], decreased level of consciousness [43%] and respiratory difficulty [34%]), though bruising was noted on examination in 46%. A history and/or clinical evidence of previous maltreatment was noted in 220 children (60%), and 80 families (22%) had had previous involvement with child welfare authorities. As a direct result of the shaking, 69 children died (19%) and, of those who survived, 162 (55%) had ongoing neurological injury and 192 (65%) had visual impairment. Only 65 (22%) of those who survived were considered to show no signs of health or developmental impairment at the time of discharge.

Interpretation: Shaken baby syndrome results in an extremely high degree of mortality and morbidity. Ongoing care of these children places a substantial burden on the medical system, caregivers and society.

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Abusive head trauma accounts for 95% of fatal or life-threatening injuries attributed to child abuse.^{1,2} Accidental intracranial injury is rare in children aged less than 1 year.^{3,4} In a report from the United States, child abuse cases represented 1.4% of admissions and 17% of deaths in a pediatric intensive care unit.⁵ All these children had sustained head trauma, had the youngest age (average of 9 months) and had the highest trauma severity index and mortality rate (53%) compared with other children admitted to the intensive care unit who had not been

abused. Most life-threatening cases of abusive head trauma in children aged less than 2 years have been reported to be associated with shaken baby syndrome (SBS).⁶

SBS is an extremely serious form of abusive head trauma that occurs when a child is subjected to rapid acceleration, deceleration and rotational forces, with or without impact, resulting in a unique constellation of intracranial, intraocular and cervical spinal cord injuries.^{3,7-10} Presenting complaints are often nonspecific, hence, it is important that all health care providers are able to recognize the clinical features that constitute SBS.^{9,11} The outcome is often devastating with 15%–27% of children dying as a result of their injury and more than one-third having serious neurological consequences.¹²⁻¹⁴ Survivors often require long-term multidisciplinary medical care, specialized education, adaptive housing, vocational training and the involvement of child welfare authorities.⁴ The consequences for those infants exposed to SBS who do not come to medical attention are unknown.

Our knowledge of SBS, derived from child welfare and hospital cases, has focused on relatively small populations of injured children in the United States or the United Kingdom. Barlow and Minns estimated an annual SBS incidence of 24.6 per 100 000 children aged less than 1 year.¹⁵ Estimated numbers of cases of SBS, however, represent the “tip of the iceberg” of a much larger group of injured children, because many cases, with less severe forms of injury, may not be identified or brought to medical attention. Our objective was to describe the key characteristics and outcomes of children admitted to hospital with SBS in Canada.

Methods

We evaluated all cases of SBS for the years 1988–1998 that were reported to the child protection teams at 11 tertiary care pediatric hospitals. These hospitals are responsible for a large part of pediatric care in Canada with over 90 000 admissions annually, representing an estimated 85% of tertiary care pediatric beds.¹⁶ The institutional review board of each participating centre approved the research proposal.

SBS is a recognized diagnosis.^{8,9} In this study, SBS was defined as any form of intracranial, intraocular or cervical spine injury as a result of a substantiated or suspected shaking, with or without impact, in a child aged less than 5 years. We relied on the diagnosis

assigned by the physician responsible for child protection at each hospital and/or that recorded on the discharge summary. These health care providers are responsible for managing cases of suspected child maltreatment, working in association with community child welfare authorities and the police. The diagnosis of SBS made according to the records at the treating hospital was accepted as noted. ICD-9 codes (1988 to March 1996 — 995.5, E967.0, E967.1, E967.9; April 1996 to 1998 — 995.55, 995.54, E967.0, E967.9) were also examined at each hospital to confirm that we had identified all cases.¹⁷

We used a structured data collection form developed and piloted at the Children's Hospital of Eastern Ontario (CHEO). From the medical records we reviewed and abstracted the admission history and physical examination, physician and nursing progress notes, child protection team/welfare authority notes, consultation notes and clinical reports (discharge, radiology). Data on patient demographics, clinical presentation, injury characteristics, past medical history, investigations, family composition, perpetrator and outcome were also extracted. Outcome definitions were developed for the health of the child at discharge ("well" meaning no documented health or developmental impairment; "neurological impairment" meaning documented abnormal neurological findings on physical or developmental assessment; "visual impairment" meaning documented proven or suspected visual impairment).

A single research assistant was trained to review and abstract the information from the medical charts (with the exception of data from the Hôpital Sainte-Justine, Montréal, Que., where a second research assistant abstracted the medical information documented in French) and to enter the information in duplicate into the database. Ten randomly selected cases of abusive head trauma at CHEO were reviewed by the research assistant and an independent assessor (W.J.K.) for the diagnosis of SBS, clinical features and outcome ($\kappa = 0.79$). The final data collection form was then revised and the research assistant travelled to each institution to complete the form.

We measured severity of the injury using the modified Pediatric Cerebral Performance Category (PCPC) 6-point scale (from 1 = normal to 6 = brain death).¹⁸ The PCPC scale provides outcomes for functional morbidity and cognitive impairment after critical illness or injury for pediatric intensive care patients when more extensive psychometric testing is not feasible. The scale is reliable and valid and is associated with several measures of morbidity (length of stay in the pediatric intensive care unit, total hospital costs and discharge care needs), severity of injury (pediatric trauma score) and functional outcome at 1-month and 6-month follow-up of pediatric intensive care patients.¹⁹ Ratings on the Glasgow Coma Scale (GCS) on presentation that measures patient performance in 3 areas, eye opening, verbal ability and motor ability, were also collected.^{20,21}

Summary statistics were tabulated for the whole group and for each study site. Descriptive statistics are presented for continuous variables, with frequency counts and percentages presented for categorical variables. Subjects' characteristics were compared using the Mann-Whitney test for ordinal or interval scale variables and the χ^2 test for categorical variables for children who died as a result of SBS and in cases in which the certainty of the perpetrator was coded as definite. Using results from the univariate analysis, 2 independent models were developed using backward stepwise logistic regression for the association between children who died and certainty of perpetrator with presenting complaints, injuries, previous maltreatment and outcome.

Results

The 364 children identified with SBS (median age 4.6 months, range 7 days to 58 months), 56% of whom were male, are presented by pediatric centre in Table 1. Clinical features and past medical history (Table 2) revealed nonspecific presenting complaints (seizure-like episode, decreased level of consciousness or respiratory difficulty), and most of the children (95%) did not have an underlying chronic medical or physical problem. The 307 charts containing perinatal information (mean gestation 37 weeks, mean birth weight 2880 g) noted a difficulty with the pregnancy for 16% of the children (88% were born at

Table 1: Cases of SBS by pediatric centre, 1988–1998

Pediatric centre	No. of cases
Janeway Child Health Centre, St. John's	10
IWK Health Centre, Halifax	22
Hôpital Sainte-Justine, Montréal	33
Montreal Children's Hospital, Montréal	22
Children's Hospital of Eastern Ontario, Ottawa	28
Hospital for Sick Children, Toronto	79
McMaster Children's Hospital, Hamilton	28
Children's Hospital, Winnipeg	33
Royal University Hospital, Saskatoon	27
Alberta Children's Hospital, Calgary	41
Children's and Women's Health Centre of British Columbia, Vancouver	41
Total	364

Note: SBS = shaken baby syndrome.

Table 2: Clinical features and past medical history of study subjects

Feature or history	No. (and %) of children	No. of medical records*
Clinical features		
Seizure	164 (45)	364
Decreased consciousness	157 (43)	364
Respiratory difficulty	124 (34)	364
Irritability	91 (25)	364
Lethargy	84 (23)	364
Vomiting	80 (22)	364
Apnea	76 (21)	364
Past medical history		
Previous maltreatment	170 (47)	361
Prematurity†	51 (14)	363
Excessive crying	36 (10)	362
Feeding difficulty	33 (9)	362
Developmental delay	32 (9)	361
Colic	25 (7)	363
Chronic illness	18 (5)	360

*Number of medical records with documentation.

† < 36 weeks' gestation.

< 36 weeks' gestation) and 17% were discharged from hospital after their mother.

Of the 364 children, 86% had subdural effusion, 42% had cerebral edema and 76% had retinal hemorrhages, of which 83% were bilateral (Table 3). Retinal hemorrhage was associated with more severe injury such as death (odds ratio [OR] 2.3, 95% confidence interval [CI] 1.9–2.6), subdural hemorrhage (OR 3.2, 95% CI 2.8–3.5) and neurological injury (OR 1.7, 95% CI 1.3–2.0). Cervical spine injuries were infrequently recorded (4%). The Glasgow Coma Scale on admission was documented for 86 (24%) children (median age 5.2 months, range 14 days to 38.6 months) with a median value of 6 (normal \geq 13 on a scale of 3–15). Imaging studies performed included CT scanning (96%) and MRI (24%). In 98% of cases, an abnormality was reported: subdural hemorrhage/effusion (CT: 79% of scans, MRI: 87% of images), subarachnoid hemorrhage/effusion (CT 32%, MRI 23%) and/or intracranial hemorrhage (CT 63%, MRI 44%). A skeletal survey, that is, a comprehensive radiographic evaluation, was performed in 301 children (82%) and a bone scan in 105 children (29%), as a result of which in 46% of cases and 51% respectively an abnormality was reported.

The mean household size was 3.4 people, and the mean number of children per family was 1.7. The mean age of the primary caregiver was 23.7 years (range 15–40 years), with 68% of the parents being either married or living as common-law spouses. Incomplete chart documentation did not allow an estimate of socioeconomic status, employment history or level of education. The medical chart documented poverty (undefined) in 87 families (28%), and an unsafe or inappropriate environment was noted in 73

(20%). A past medical history *and/or* clinical evidence of previous maltreatment was noted in 220 children (60%), and 80 families (22%) had had previous involvement with child welfare authorities. The biological father (43%), followed by the biological mother (26%), was most often identified as the responsible caregiver with the child at the time of the injury, even though the primary caregiver was usually the biological mother (67%), followed by "other" (35%: 18% babysitter, 17% unknown) and then the biological father (18%).

The perpetrator was identified in 240 cases (66%), with the biological father being the most common (50%), followed by the stepfather/male partner (20%) and then the biological mother (12%). Overall, the perpetrator was male in 72% of the cases; 15% of perpetrators had a previous charge or suspicion for maltreatment of a child in their care. Although the degree of certainty about the perpetrator was considered definite in 96 (40%) cases (where the perpetrator was seen to shake the child or admitted to the assault), this was not associated with the presenting complaint, injury, previous maltreatment or outcome. In almost two-thirds of cases (64%), there was an ongoing police investigation, 26% of the perpetrators had criminal charges laid and 7% were convicted for the assault.

Sixty-nine children died (19%) as a direct result of the shaking injury. Children who died were slightly older than survivors (median age 7.8 v. 4.3 months), and death was associated with a decreased level of consciousness (OR 3.2, 95% CI 2.4–4.0) or respiratory difficulty (OR 2.5, 95% CI 1.8–3.2) on presentation; bruising (OR 2.3, 95% CI 1.5–3.1) on examination; and cerebral edema (OR 3.9, 95% CI 3.1–4.7) or subdural hematoma (OR 2.5; 95% CI 1.7–3.3) on imaging. Of the 295 survivors, only 65 (22%) were felt to be "well" (absence of health or developmental impairment) at the time of discharge, with 162 (55%) having a persistent neurological deficit and 192 (65%) having visual impairment. The PCPC scale, assessed at both the time of admission and at discharge, revealed that only 21 children (7%) were rated "normal," whereas 143 children (48%) had a moderate or severe degree of disability and 34 (12%) were in a coma or vegetative state. Of the survivors, 251 (85%) required ongoing multidisciplinary care. Review of placement at discharge revealed that 42% of the children were taken into foster care, whereas 43% returned home with their biological parent(s) and a further 14% were placed with a close family member.

Interpretation

Our findings are consistent with previously published data on SBS¹⁰⁻¹³ in highlighting the young age of the victims, the slight preponderance of boys, the high rate of male perpetration and the extremely high degree of mortality and morbidity. Presenting signs and symptoms are often nonspecific, which means that health care providers must have a high index of suspicion when infants and young chil-

Table 3: Injuries of study subjects

Injury	No. (and %) of children	No. of medical records*
Subdural hematoma	313 (86)	364
Retinal hemorrhage	274 (76)	361
Bruising	167 (46)	364
Cerebral edema	152 (42)	363
No sign of external injury	146 (40)	364
Subarachnoid hematoma	135 (37)	364
Fracture		
Skull	95 (26)	364
Extremity†	82 (23)	356
Rib	80 (22)	363
Brain infarct	55 (15)	364
Abrasion	51 (14)	362
Cervical spine injury	14 (4)	350
Abdominal trauma	15 (4)	364
Burn	4 (1)	364
Oral injury	4 (1)	364

*Number of medical records with documentation.

†Extremity fractures: metaphyseal (22%), spiral (11%) and midshaft transverse or oblique (22%).

dren present with subtle neurological signs such as lethargy or decreased level of consciousness. Although a significant number of children had evidence of severe trauma with external bruising or fractures, or both, up to 40% of children had no external sign of injury.

Many of these injured children have serious neurological and developmental consequences including profound mental retardation, spastic quadriplegia or severe motor function impairment. These children require long-term involvement of multiple specialists and child welfare authorities. At the time of discharge, the PCPC scale, which is associated with functional outcome at 6-month follow-up,^{19,22-25} revealed that 60% of survivors had a moderate or greater degree of disability. This outcome, though already cause for concern, may be an underestimate, because there may be a symptom-free interval of 12–18 months before the development of neurological or developmental difficulties.²⁶ Further, the long-term outcome, especially with regard to subtle neurological injury, and for those exposed to SBS who do not come to medical attention, is unknown.

Although this study highlights the devastating effects of SBS, there are several limitations that should be noted. First, the SBS cases are a highly selected sample from admissions to tertiary care pediatric hospitals. These results may not reflect the number of shaken children in the community. Therefore, we are not able to estimate the incidence of SBS. Second, the data collection was retrospective and lacked a comparison group, making it difficult to identify factors that may be associated with SBS. Third, SBS was defined and classified at each participating hospital, and we did not perform an independent assessment to confirm the diagnosis. Fourth, the information obtained was limited to the quality of the documentation in the medical record. Many of the children described here were extremely ill when admitted, and certain elements of the admitting history may not have been reviewed in detail or documented, including sociodemographic and perinatal information. Fifth, the data collection occurred during a time period when the recognition and diagnosis of SBS was evolving and it is possible, especially early in the study, that SBS cases were not identified. Finally, while we have probably accounted for most of the more serious injuries, as these were children admitted to hospital in tertiary care pediatric centres, cases that resulted in death before hospital admission may not have been included.

A major challenge for researchers is to develop approaches to measure the incidence and risk factors for SBS, given that the injury and its circumstances are often clouded in secrecy. Our study suggests that a minimum of 40 cases of SBS occur annually in Canada, from which 8 children will die, a further 18 will have permanent neurological injury requiring life-long assistance and 17 will be taken into foster care. We also believe that this represents only the tip of the iceberg and that many other cases are not detected.¹⁴ The magnitude of this injury requires a national strategy, such as that recommended in the recently released Canadian *Joint Statement on Shaken Baby*

Syndrome.²⁷ This strategy should include population-based surveillance to establish the incidence of SBS and address risk factors by comparing SBS cases with carefully chosen controls. Prevention strategies, based on incidence data and vulnerability factors, may then be developed, implemented and assessed at the community level.

In summary, the outcome of SBS is devastating to the child; ongoing care of these children places a substantial burden on the medical system, caregivers and society. Physicians need to be aware of the nonspecific clinical presentation. Further work is required to establish the true incidence of SBS, identify vulnerable children, and to develop and evaluate prevention strategies.

This article has been peer reviewed.

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Competing interests: None declared.

Contributors: Dr. King was responsible for the study conception and design and oversaw the acquisition, analysis and interpretation of data. Ms. MacKay was involved in the study conception and design and assisted with the acquisition, analysis and interpretation of data. Dr. Sirmick was involved in the study conception and design. Dr. King drafted the manuscript; all of the authors revised the article for important intellectual content and gave final approval of the version accepted for publication. All members of the Canadian Shaken Baby Study Group were involved in the study design and data acquisition, revised the article for important intellectual content and gave final approval of the version accepted for publication.

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— D^r Douglas Perry, président, Conseil d'administration de l'AMC, 2002-2003

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