

Preventing Neurotrauma: A Casebook of Evidence Based Practices

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8 The Upstate New York Shaken Baby Syndrome (SBS) Education Program

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8.1 Background

Head injuries are the leading cause of traumatic infant death in North America (American Academy of Pediatrics, 2001; Fulton, 2000). Most unsettling, however, is the fact that 95% of severe head injuries in infants less than one year of age are inflicted (Billmire & Myers, 1985; Blumenthal, 2002; King, MacKay, Sirnack, & the Canadian Shaken Baby Study Group, 2003a).

The term 'shaken baby syndrome' describes a constellation of inflicted head injuries sustained by infants and young children after being violently shaken. It is a devastating and potentially fatal form of child abuse. Shaken baby syndrome is seen predominantly in infants less

than one year of age, although it can occasionally occur in children up to the age of five (American Academy of Pediatrics, 2001; King, MacKay, & Sirnick et al., 2003a; Smith, 2003). Also referred to as infant shaken impact syndrome, shaken infant syndrome, or whiplash shaken baby syndrome, shaken baby syndrome consists of a characteristic pattern of injuries including subdural and subarachnoid hemorrhages, retinal hemorrhages, and occult long bone fractures (Kivlin, Simons, Lazoritz, & Ruttum, 2000). Violent shaking with or without head impact causes these injuries (Blumenthal, 2002; Hadley, Sonntag, Rekate, & Murphy, 1989). The American Academy of Pediatrics has stated that, “The act of shaking leading to shaken baby syndrome is so violent that individuals observing it would recognize it as dangerous and likely to kill a child” (American Academy of Pediatrics, 1993). Unfortunately, clinical findings in shaken baby syndrome are elusive; even severely shaken infants may not exhibit overt signs of trauma (American Academy of Pediatrics, 2001). Shaken baby syndrome is a profoundly severe, under-diagnosed, and under-reported form of child abuse.

Mechanism of Injury

From a developmental perspective, it is clear why infants are uniquely susceptible to the injuries observed in shaken baby syndrome. Because an infant’s skull, brain, and neck muscles are undeveloped and rapidly maturing, the mechanism, type, and threshold of injuries differ from those seen in older children and adults (Caffey, 1972). Infants possess a rapidly growing brain encased in a thin, malleable, developing skull. The brain is soft, and the neurons are largely unmyelinated, or unprotected (Fulton, 2000; Smith, 2003). The base of the skull is flat, and has not yet developed the intricate topography of an adult skull that serves to anchor the brain (Blumenthal, 2002). The infant’s neck muscles are weak, providing inadequate support during

head movements (Fulton, 2000). These characteristics leave the infant brain exceptionally susceptible to shearing injury.

When an infant is violently shaken, its disproportionately heavy brain is thrown backwards and forwards within the skull. Acceleration-deceleration forces cause the brain to rotate on its central axis, resulting in diffuse axonal injury (Case, Graham, Handy, Jentzen, & Monteleone, 2001). Bridging veins extending from the outer cortical surface to the inner dural venous sinuses are also torn, causing the characteristic subdural and subarachnoid hemorrhages (Caffey, 1972). Hypoxia (lack of oxygen) and ischemia (diminished blood supply) result from periods of apnea (cessation of breathing) or prolonged seizures after a severe shaking episode (Dias & Barthauer, 2001). The injuries become fatal when secondary metabolic imbalances lead to cerebral edema (swelling of the brain) and increased intracranial pressure, causing axonal ischemia, and finally, death (Blumenthal, 2002; Dias & Barthauer, 2001; Duhaime, Gennarelli, Thibault L.E., Bruce, D.A., Margulies, & Wiser, 1987).

Diagnosis, Clinical Findings, and Related Controversies

The majority of experts agree that retinal hemorrhages are virtually pathognomonic for the diagnosis of shaken baby syndrome, when found in conjunction with subdural or subarachnoid hemorrhages and/or occult fractures (American Academy of Ophthalmology, 2002). Retinal hemorrhages are present in 50 to 100% of infants with inflicted head injuries (Duhaime, Christian, Rorke, & Zimmerman, 1998; Lancon, Haines, & Parent, 1998; Smith, 2003) and result from a sudden rise in intraocular pressure produced at the time of shaking. They account for the high rates of permanent visual impairment, ranging from 30 to 80%, in children that

survive shaking episodes (Smith, 2003). Accurate diagnosis requires careful examination of the infant's retina by a pediatric ophthalmologist, using dilating drops. This recommendation is based on several studies demonstrating that non-pediatric ophthalmologists were more likely to overlook or misdiagnose retinal hemorrhages in head injured infants (American Academy of Ophthalmology, 2002; Kivlin et al., 2000; Morad, Kim, Mian, & et al., 2004). Because the documented presence of retinal hemorrhages can become key evidence in criminal court cases, accurate diagnosis is of great importance to the successful prosecution of perpetrators.

Retinal hemorrhages may be found in up to one third of babies in the first 24 hours of life, after any form of delivery (American Academy of Ophthalmology, 2002). These can be differentiated from retinal hemorrhages caused by abuse in appearance and location, and they typically resolve by one month of age (Duhaime et al., 1998). Retinal hemorrhages discovered beyond one month of age, especially when they are bilateral, make the diagnosis of shaken baby syndrome extremely likely. Multiple studies have shown that retinal hemorrhages are found in less than 3% of accidental infant head injuries, and only when the injuries are life-threatening, such as in a high speed motor vehicle accident (American Academy of Ophthalmology, 2002). Claims that an infant rolled off a bed or was dropped do not support the presence of retinal hemorrhages.

Provocative papers questioning the legitimacy of retinal hemorrhages as a diagnostic feature in shaken baby syndrome have recently arisen in the U.K. among a minority of experts (Geddes & Plunkett, 2004; Reece, 2004). Although the debate continues, the vast majority of medical experts agree that retinal hemorrhages are indeed a key diagnostic feature of shaken baby

syndrome. This controversy has had unfortunate implications for the provision of expert evidence in criminal trials of recent perpetrators, and research is on-going.

The rotational forces generated by violent, abusive shaking differ from the translational forces caused by linear movement of the brain during short, accidental falls. Head injuries incurred as a result of translational forces tend to be benign and do not produce the hallmark symptoms of shaken baby syndrome (Case et al., 2001). Controversy over whether or not 'rough play' or tossing an infant in the air could result in the same injuries that occur in shaken baby syndrome took place in the early stages of research. To date, this has been repeatedly shown to be false (American Academy of Pediatrics, 2001; Duhaime et al., 1998; Health Canada, 2001; Smith, 2003).

Posterior rib fractures and other occult bone fractures are commonly found in shaken infants. They are not easily detected by plain film x-rays immediately following the abuse. In a minority of cases, external injuries including bruises or scalp swelling may signal the presence of abuse to health care providers (Duhaime et al., 1998; Lancon et al., 1998). These minor injuries need to be meticulously diagnosed and documented for the infant's health as well as for future prosecution of perpetrators, although they are not required for the diagnosis of shaken baby syndrome. Overall, it has consistently been found that the most reliable indicator of abuse is a discrepancy between the account of events given by the caregiver and the infant's actual injuries (Lancon et al., 1998).

Shaken infants typically present with symptoms including lethargy, vomiting, irritability, and poor feeding (Duhaime, Christian, & Seidl, 1996; Kivlin et al., 2000). These non-specific symptoms can be mistakenly diagnosed as viral infections, gastroenteritis, or infant colic, especially when a truthful account of the circumstances surrounding the injuries is withheld (American Academy of Pediatrics, 1993; Blumenthal, 2002). Sadly, studies have revealed that 30 to 60% of infants diagnosed with shaken baby syndrome have been victims of repeated, prior shaking abuse (American Academy of Pediatrics, 2001; Dias, Backstrom, Falk, & Li, 1998; Jenny, Hymel, Ritzen, Reinert, & Hay, 1999; Kemp & Coles, 2003; King, MacKay, & Sirnick et al., 2003a; Kivlin et al., 2000; Randell, Crabbe, Yutaka, Smith, & Bennett, 1990).

When shaken baby syndrome is suspected, the diagnostic work-up should include a thorough physical exam for external injuries, CT and MRI brain imaging, a skeletal survey (including skull x-rays), fundoscopic examination by a pediatric ophthalmologist, and, in some cases, lumbar puncture (American Academy of Pediatrics, 2001; Blumenthal, 2002). A multidisciplinary team of emergency room physicians, pediatric ophthalmologists, community pediatricians, pediatric neurosurgeons, pediatric radiologists, nurses, social workers, psychologists, and law enforcement officers are essential for the optimal provision of medical, legal, and community services.

Social Risk Factors: Are there identifiable “at risk” families?

Shaken baby syndrome permeates all socio-economic and educational classes in society (American Academy of Ophthalmology, 2002; Dias & Barthauer, 2001; Health Canada, 2001; Lancon et al., 1998). Male offenders significantly outnumber females (Starling, Holden, &

Jenny, 1995). Interestingly, male infants are also more frequent victims (Ennis & Henry, 2004; Keenan et al., 2003; King, MacKay, & Sirnick et al., 2003a; Kivlin et al., 2000; Starling et al., 1995). Biological fathers and stepfathers are the most common perpetrators (56% of cases), followed by boyfriends (16%), biological mothers (15%), and babysitters (14%) (Newton & Vandeven, 2005). In all, parents and paramours comprise approximately three-quarters of all perpetrators (Lazoritz & Palusci, 2001). Race has not been found to correlate with the incidence of shaken baby syndrome (Sinal & Petree, 2000). Factors such as unemployment, poverty, young parental age, substance abuse, and behavioural problems in the parent or child do contribute to the incidence of shaken baby syndrome (Fulton, 2000; Kemp & Coles, 2003; Starling et al., 1995). Parent education level and single parent status may also be important (Goldstein, Kelly, Bruton, & Cox, 1993). Parents that harbor unrealistic expectations for the child to fulfill the parents' personal needs, or to behave beyond their age, are also at a higher risk of harming their children (Fulton, 2000; Showers, 1989). The significance of these factors, however, is debated in the literature. Because the prevalence of shaken baby syndrome is relatively low in the population, the predictive value of social characteristics is limited (Kemp & Coles, 2003). Studies have shown that shaken baby syndrome is more likely to be missed in families where the parents are married, Caucasian, and of higher socioeconomic status, due to health care provider bias (Ricci, Giantris, Merriam, Hodge, & Doyle, 2003; Sanders, Coble, Coles, & Kemp, 2003). It is therefore prudent for health care workers to maintain a uniform index of suspicion in all cases of infants with traumatic brain injury.

The Role of Crying

Incessant crying is the most powerful trigger of infant abuse (Barr, 1990; Blumenthal, 2002; Shepherd & Sampson, 2000). This is significant for the prevention of shaken baby syndrome, since 15 to 25% of healthy infants spend up to 50% of their waking hours crying inconsolably (Papousek & von Hofacker, 1998). Perpetrators classically describe, in hindsight, how an infant's relentless, inconsolable crying, compounded by various life stressors, caused them to violently and impulsively shake an infant in their care (American Academy of Ophthalmology, 2002; Fulton, 2000; Levin, 1998). Infant colic is defined in the medical literature as persistent, excessive crying in an otherwise healthy infant, and is relatively poorly understood (Deshpande, 2005). Various theories as to the cause of colic have included gastrointestinal discomfort from lactose intolerance, difficulty adjusting to a diet of breast milk, self-regulatory dysfunction of behavioural-emotional states, and an immature infant sleep-wake organization (Papousek & von Hofacker, 1998). More recently, Dr. Barr, a pediatrician with a research interest in shaken baby syndrome, has identified a 'crying curve' that represents a universal pattern of infant crying. He found that infant crying peaks at two months of age and diminishes with time. Barr contends that all infants follow this pattern, and that infants with 'colic' are merely at the end of a spectrum of normal crying behaviour (Barr, 1990).

In a German study examining the link between persistent infant crying and the mother-infant relationship, Papousek and von Hofacker found that mothers of persistent criers scored markedly higher on scales for depressed mood, exhaustion, frustration/anger, and anxious overprotection (Papousek & von Hofacker, 1998). As well, Stifter and Bono found that mothers of colicky babies reported feeling less competent as mothers (Stifter & Bono, 1998). In the U.K., a

provocative study revealed that one third of anonymously interviewed new mothers admitted to either 'feeling like' or actually shaking their babies (Shepherd & Sampson, 2000). These mothers were significantly more likely to have infants with colic. Clearly, incessant infant crying takes its toll on caregivers and predisposes infants to the risk of violent shaking.

How big is the problem?

Accurate assessment of the true incidence of shaken baby syndrome presents an exceedingly difficult challenge. First, shaken infants often lack external signs of trauma. Second, the associated symptoms, including lethargy and vomiting, may be easily misdiagnosed. Some infants may not be brought to medical attention at the time of injury but later manifest unexplained developmental delays, neurological impairments, and learning difficulties (American Academy of Pediatrics, 2001; Duhaime et al., 1996; Fulton, 2000). Even when cases are accurately identified, 'shaken baby syndrome' is often not consistently documented as an independent class of abuse in regional, state, and national child maltreatment databases. Consequently, experts suspect that documented cases of shaken baby syndrome represent a mere fraction of the total number of shaken infants per year.

It is estimated that one of every 2,600 infants will be violently shaken before reaching one year of age (Lithco, 2004). In a prospective, population-based study of the incidence of shaken baby syndrome, Barlow found a rate of 24.6 per 100 000 children under one year of age in Scotland (Barlow & Minns, 2000). Keenan *et al.* reported an incidence rate of 29.7 per 100 000 for children less than one year of age in the U.S. (Keenan et al., 2003). Thirteen to 30% of shaken infants succumb to fatal injuries (American Academy of Ophthalmology, 2002; American

Academy of Pediatrics, 2001; Dias et al., 1998; Hadley et al., 1989; King, MacKay, Sirnick, et al., 2003a). Half of the remaining infants experience blindness and various global neurological impairments, including seizures, spasticity, paralysis, and developmental delays (A. Duhaime et al., 1996; King, MacKay, Sirnick et al., 2003a). Less than 20% of shaken infants recover without permanent injury (Lancon et al., 1998). Shaken baby syndrome is an ominous form of child abuse with devastatingly high rates of morbidity and mortality.

The Role of the Legal System

Shaking an infant is a serious criminal offence. Perpetrators have been convicted of assault, manslaughter, depraved indifference assault (People v. Nix, 173 A.D.2d 285 (1991)), endangering the welfare of a child (People v. Wong, 81 N.Y.2d 600 (N.Y. Ct. App. 1993)), and criminally negligent homicide (People v. Humiston, 187 A.D.2d 990 (1992)). Unfortunately, the conviction rate of perpetrators is low. Any physician suspecting an infant has been abused is legally obligated to report the case to state or province-specific child welfare agencies. Efforts to educate health care providers about the characteristic features of shaken baby syndrome will serve to increase the detection and reporting of new cases, and hopefully increase the conviction rate of identified perpetrators.

Preventing Shaken Baby Syndrome: A Historical Overview

Radiologist Dr. Caffey first described the combination of subdural hemorrhages, retinal hemorrhages and long bone fractures in infants without external signs of injury; he named the phenomenon ‘whiplash shaken baby syndrome’ (Caffey, 1972). In his landmark article in 1972, he called for the implementation of a nation-wide prevention campaign. Unfortunately, clinical

and research efforts remained focused on intervention rather than prevention for several reasons. First, the perceived importance of educating the public about shaken baby syndrome differed among professionals. Some felt it was common knowledge that shaking an infant was dangerous, while others routinely gave advice to shake apneic infants. Second, it was believed that the impulsive act of infant shaking was not amenable to primary prevention through public education. Third, the risk factors associated with shaken baby syndrome were unclear, eliminating the possibility of targeted secondary prevention initiatives (Barron, 2003). A minority of professionals even denied the existence of shaken baby syndrome.

Prevention-based research finally began in the United States in the mid 1980's and has been steadily gaining momentum world-wide. After a 1989 survey by Showers demonstrated that 25 to 50% of adults and adolescents were unaware of the dangers of violent infant shaking, prevention efforts in the form of media campaigns, public education initiatives, male-targeted parenting classes, baby-sitting training courses, and hospital-based programs began to appear. Unfortunately, the impact these programs had on the incidence of shaken baby syndrome remained unknown because the programs were sporadic, fragmented, and unevaluated.

Preventing shaken baby syndrome is an economically favourable endeavour. Libby *et al.* report that children with non-accidental head injuries stay in hospital 52% longer and have mean total hospital costs 89% higher than children with accidental head injuries (Libby, Sills, Thurston, & Orton, 2003). Showers estimated that the initial in-patient hospitalization costs for the care of a shaken infant can approach \$70,000 USD. Health care costs incurred during the following five years may cost an additional \$300,000. In the long term, the total cost of comprehensive medical

care for a single shaken infant can exceed \$1 million (Showers, 1998). These figures do not even begin to capture the hidden costs of shaken baby syndrome, when one considers each victim's loss of societal productivity and occupational revenue, the cost of prosecuting and incarcerating perpetrators, the cost of foster care and child welfare agency involvement, and the on-going mental, physical, and educational therapy that each victim requires (Dias & Barthauer, 2001, August). In Canada, King *et al.* found that 85% of shaken baby syndrome survivors required on-going multidisciplinary care (King, MacKay, Sirnick et al., 2003a), and the U.S. National Institute of Health estimates the lifetime cost of care to approach \$1.9 million per injured child (King, MacKay, Sirnick, & the Canadian Shaken Baby Study Group, 2003b). Financial costs aside, shaken baby syndrome has devastating effects on the personal lives and emotional health of victims and affected families. Clearly, the hidden costs of treating victims of shaken baby syndrome far exceed the costs of implementing a prevention program.

Health professionals, administrators, law enforcement officers, politicians, and affected families have taken a proactive stance in disseminating information about shaken baby syndrome. This past decade witnessed the formation of the National Center on Shaken Baby Syndrome (NCSBS) in Ogden, Utah and the publication of shaken baby syndrome position papers by the American Academy of Pediatrics and the Canadian Pediatric Society (American Academy of Pediatrics, 1993; American Academy of Pediatrics, 2001; Canadian Pediatrics Society, 2001). A worldwide network of experts from diverse professional fields has been evolving and expanding since the introduction of the NCSBS National Conferences on Shaken Baby Syndrome in 1996. The conferences provide a unique opportunity for professionals from fields including medicine,

nursing, law, policing, social work, and psychology to share new research findings, discuss prevention strategies, and educate each other about shaken baby syndrome.

On a local level, many shaken baby syndrome prevention initiatives are in operation across North America. The NCSBS offers a “Dads 101” training curriculum that teaches incarcerated males about the realities of infant care and provides them with coping strategies for peacefully dealing with persistent infant crying. The program has been implemented in multiple prisons in the United States, Canada, and Australia; however, its quantifiable effectiveness in reducing the incidence of shaken baby syndrome has never been examined (Dutson, Dulfano, & Nink, 2003). In Wisconsin, the Shaken Baby Association began educating Milwaukee police officers about shaken baby syndrome in 2001. That same year, 18 Milwaukee radio stations simultaneously broadcast a public service announcement urging parents to “Never, ever shake a baby”. Following the announcement, a three month period ensued without a single reported case of shaken baby syndrome. Unfortunately, the long term effects of this initiative remain unknown (Hammel et al., 2002, Spring).

In Canada, shaken baby syndrome public education campaigns are active in virtually every province. The programs target parents, babysitters, and health professionals in a variety of educational formats, including videos, posters, information cards, pamphlets, and refrigerator magnets (Calgary Injury Prevention Coalition, 2003). Regional public health departments and the Saskatchewan Institute on Prevention of Handicaps have been instrumental in developing and disseminating educational materials to the Canadian public. Although some programs are over

six years old, however, none have been evaluated with regard to their effect on the incidence rate of shaken baby syndrome.

In the U.K., the National Society for the Prevention of Cruelty to Children distributed posters about shaken baby syndrome in hospitals, clinics, and libraries and posted billboards across the country in 1995 (National Society for the Prevention of Cruelty to Children, 2005). These were complemented by a series of television commercials in 2000, urging parents to "Stop before you cross that line" when coping with a crying infant. Similarly, no efforts were made to measure the campaign's effect on the incidence rate of shaken baby syndrome. The few public education campaigns that have been evaluated have defined their primary outcomes in relation to the magnitude of the dissemination of program materials or levels of public awareness, rather than the program's effect on peoples' behaviour and the incidence rate of shaken baby syndrome (Kemp & Coles, 2003). Without evidence of effectiveness, the impetus for governments to mandate, fund, and implement prevention programs across large jurisdictions has been minimal.

8.1.1 Shaken Baby Syndrome Parent Education Program

Pediatric neurosurgeon Dr. Mark Dias was working at the Children's Hospital of Buffalo in Western New York in the 1990's. He had extensive experience treating infants with shaken baby syndrome and had conducted a retrospective study in serial radiography for shaken baby syndrome patients. When his own son was born in 1997, Dias experienced firsthand the frustrations that parents are faced with in caring for an inconsolable infant (Lewandowski, 1999, October 14).). He realized the ease with which exasperated parents or babysitters could

impulsively direct their frustrations onto a crying child. Dias resolved to share his expertise in inflicted infant head injuries with new parents to provide them with the necessary knowledge and coping skills to prevent a bout of frustration from resulting in a case of shaken baby syndrome.

Dias' original study provided six years of reliable incidence data for shaken baby syndrome cases in Western New York. The Children's Hospital of Buffalo, the sole tertiary referral centre for pediatric neurosurgical cases in the region, provided an ideal location for launching his envisioned program. It was to be a comprehensive, hospital-based, universal prevention program that educated parents at the time of the infant's birth about the dangers of violent infant shaking. Outcome measures were defined as the regional incidence rate of shaken baby syndrome, the number of parents reached by the program, and parental pre and post-program knowledge about shaken baby syndrome. This format was intended to improve upon the multitude of fragmented, unevaluated programs previously in operation. It was also unique in being the first to determine whether improved public knowledge could translate into a reduction in the incidence rate of shaken baby syndrome.

Dias' original study revealed that a total of 33 infants were diagnosed with shaken baby syndrome at the Children's Hospital of Buffalo between 1992 and 1998, with an average incidence rate of 7.2 infants per year (Dias et al., 1998). Ranging from 1 to 26 months, the average victim age was 6.7 months. This data, along with Dias' experience in treating infants with shaken baby syndrome, shaped the following hypotheses that guided the ultimate program design:

1. Shaken baby syndrome differs from other forms of child abuse in that it seems to result from impulsive acts of adult rage due to infant crying that may be modifiable with timely parental education.
2. Education efforts must be targeted at parents, and particularly, at males, since 71% of perpetrators are parents and paramours, and males comprise the majority.
3. Due to increased public awareness about shaken baby syndrome from public education campaigns and highly publicized infant fatalities, many parents are already aware that violently shaking an infant is dangerous. Therefore, the aim of the education campaign should be to remind parents about shaken baby syndrome *at the appropriate time* – during a mother’s post-natal stay in the hospital – after which both parents will soon be immersed in the challenges of infant care.
4. Parents are optimal advocates for infant safety and care and may be most effective at disseminating information about shaken baby syndrome to caregivers that will be in contact with their child.

Dias conceived that a shaken baby syndrome education campaign could act as a “vaccine” to “inoculate” parents with information and protect infants from acquiring shaking injuries during the first years of life, when they are most susceptible. Given that the average age at which infants incur inflicted head injuries ranges from five to nine months, the goal that parents retain the program information for at least the first year of each child’s life seemed both effective and attainable (Dias & Barthauer, 2001).

Western New York Demographics

Western New York was ideal for implementing and evaluating a shaken baby syndrome education program for the following reasons: 1) accurate historical incidence data from the previous six years at the Children's Hospital of Buffalo was readily available, 2) the Children's Hospital of Buffalo is virtually the exclusive referral site for all pediatric neurosurgical cases in the region, 3) Western New York is geographically discrete, as it is bounded by Canada and Pennsylvania on three sides, and has predictable patient referral patterns, and 4) the population base is stable, with little immigration or emigration in the region (Dias, Mazur, Li, Smith, & deGuehery, 2002). In addition, a regional Perinatal Outreach Program providing tertiary infant care in conjunction with Western New York hospitals was already in full operation.

The Perinatal Outreach Program consisted of a network of nurse managers from the maternity wards of all hospitals in Western New York. It provided an effective vehicle for disseminating the intended educational materials to new parents. Nurse managers were assigned to receive and distribute the program materials within their respective hospitals. They were to be educated about inflicted infant head injuries and how to implement Dias' Shaken Baby Syndrome Parent Education Program. In turn, the nurse managers at each hospital would convey the program information to the obstetrical ward nurses.

8.1.2 Program Objectives

The program aimed to accomplish four main goals: 1) to provide educational materials about shaken baby syndrome to the parents of every new infant in Western New York, 2) to verify parents' comprehension of the dangers of violent infant shaking, 3) to track the distribution of

information through the collection of the returned commitment statements, and 4) to evaluate the program's effect on the regional incidence of shaken baby syndrome (Dias & Barthauer, 2001).

8.1.3 Educational Materials

Program materials were to be distributed by obstetrical and neonatology nurses to all new parents during their postpartum stay in hospital. All mothers and as many fathers as possible would be presented with an information pamphlet published by the American Academy of Pediatrics (*“Prevent Shaken Baby Syndrome”*, 1995). It provides suggestions for coping with infant crying, describes the dangers of shaking an infant, and urges parents to seek immediate medical attention if they suspect that their child has been shaken. In addition, parents were to watch an 11-minute video (*“Portrait of a Promise: Preventing Shaken Baby Syndrome”*, Midwest Children's Resource Center; St. Paul, MN). The video discusses the dangers of violent infant shaking, describes the mechanism of shearing brain injury, and portrays the stories of three infant victims of shaken baby syndrome. Lastly, parents would be asked to voluntarily sign a commitment statement to verify that they received the program information. All materials were to be made available in both English and Spanish (Dias et al., 2002).

In addition to providing a record of every parent's participation in the program, the commitment statement would ask parents several brief demographic questions regarding age, education level, marital status, insurance coverage, city of residence, and the zip code of the infant's primary residence. Parents would also be asked to answer the following three questions: 1) Was this information useful to you?, 2) Was this the first time you've heard that shaking an infant is dangerous?, and 3) Would you recommend that this information be given to all new parents?.

Nurses administering the materials were to sign the commitment statement to witness parents' receipt of the information, even when parents refused to sign the commitment statement themselves. The final source of information provided to parents would come from an educational poster ("*Never, Never, Never, Never Shake a Baby*", SBS Prevention Plus; Pueblo, CO). The posters were intended for display along the hallways of obstetrical wards, in full view of parents and outside visitors. Nurses would be encouraged to provide the information about shaken baby syndrome separately from other standard hospital discharge information (Dias & Barthauer, 2001).

The inclusion of the commitment statement in the program design was a key improvement over virtually all other existing shaken baby syndrome prevention programs. The commitment statement was designed to accomplish two main objectives: 1) to actively engage parents in their own education about shaken baby syndrome, and 2) to facilitate program data collection and tracking. By signing a commitment statement, parents would feel that they were entering a “social contract” with the hospital, their infant, and their community in protecting their child against shaken baby syndrome.

8.1.4 Program Tracking

Nurse coordinators at each hospital would be instructed to return all signed commitment statements to the program office on a monthly basis, where the information would be entered into a database. An exhaustive monitoring strategy for identifying new cases of shaken baby syndrome was outlined: 1) all admissions of inflicted infant head injury to the Children's Hospital of Buffalo during the program would be identified and recorded, 2) nurses at each

hospital were to notify the program coordinators of any known cases that were not referred to the Children's Hospital, 3) regular contact with regional child fatality teams, child protective services workers, law enforcement officials and medical examiners would be established, and 4) regional media sources, including television and newspapers, would be periodically reviewed (Dias et al., 2002). A child abuse specialist working at Strong Memorial Hospital in Rochester, New York was also to be regularly contacted to identify any additional new cases, in the unlikely event that Western New York patients were referred outside of the region. Based on these investigations, the incidence of inflicted infant head injury in Western New York would be calculated and compared with the historical incidence rate from the previous six years (Dias et al., 2002).

Upon identifying a case of shaken baby syndrome, the infant's birth date and birth hospital would be identified and then cross-referenced with the mother's last name. This tracking method would indicate whether the parents had participated in the program, and whether or not they had signed a commitment statement.

8.2 Resources

The Shaken Baby Syndrome Parent Education Program began in December 1998 with a two-year grant from the New York State Office of Children and Family Services. Funding came from the William B. Hoyt Memorial Children and Family Trust Fund, and allotted Dias \$8,000 in 1998 and \$11,000 in 1999 to initiate the program. The grant money was predominately used to purchase and distribute program materials to participating hospitals (Dias & Barthauer, 2001).

By 2000, more funding was required to maintain and effectively co-ordinate the program. Dias applied for and received a much larger grant from the William B. Hoyt Memorial Children and Family Trust Fund. The new four-year grant provided \$132,000 each year for the first two years, followed by a decrease in funding to 50% and 25% of the original amount in the third and fourth years, respectively. The grant was intended to finance the operation of the existing program in Western New York and also to fund a major program expansion into the adjacent Finger Lakes Region. The additional finances enabled Dias to hire two nurse project co-ordinators, registered nurses Kim Smith and Kathy deGuehery, to run the expanded program. With the anticipated involvement of 33 hospitals spanning the two regions, the total program budget reached over \$450,000. The remaining funding needs were addressed by the Matthew Eappen Foundation, the Children's Hospital of Buffalo, Strong Children's Hospital in Rochester, the State University of New York at Buffalo, the University of Rochester, and other participating hospitals in the form of various in-kind donations (Dias & Barthauer, 2001; Dias et al., 2005).

8.3 Implementation

From 1998-2000, Dias served as the sole program co-ordinator and principal investigator. He took responsibility for tracking new cases of shaken baby syndrome, building the program database and fulfilling all program roles outside of those within each specific hospital.

Participating hospitals were gradually phased into the program over the two-year period. Most nurse managers were enthusiastic and co-operative in initiating the program in their hospitals.

Within the first two months, all hospitals in Western New York were providing parents with the

program materials. Collecting and returning signed commitment statements, however, was a slower process to instill. From a logistical standpoint, smaller hospitals were able to embrace and implement the program more rapidly than larger centres, due to lower daily delivery rates and timely approval by hospital Institutional Review Boards. Dias found that personal contact with the nurse managers was essential for establishing each hospital's commitment to the program and ensuring consistent participation from hospital staff.

A survey of maternity nurses in 2000 revealed that the program was virtually unanimously well received (Dias & Barthauer, 2001). Nurses reported routinely providing program materials to new parents and having them sign the commitment statements. The video was being regularly shown in over 1/2 of the hospitals, and over 2/3 of participating hospitals were displaying the posters. Feedback from parents was also very positive; over 90% claimed that they already knew about the dangers of shaking an infant, but felt that the program information was helpful. Ninety-five percent of parents that signed a commitment statement felt that shaken baby syndrome information should be provided to all new parents. The exceedingly small proportion of parents who felt that the program information was not helpful mostly perceived it to be redundant. Only 1% of parents refused to sign a commitment statement.

The Finger Lakes Region Hospitals Join the Program

Hospitals in the Finger Lakes Region were phased in beginning in January 2001. Since the Finger Lakes Region shares many of the same population and geographical features as Western New York, the expansion effort did not require any major structural changes to the program. Strong Children's Hospital in Rochester is analogous to the Children's Hospital of Buffalo in

that it is the sole tertiary referral centre for pediatric neurosurgical cases in the region. A similar Perinatal Outreach Program was also in full operation; its staff network and hospital linkages were used to introduce and run the program. Dr. Linda Barthauer, a pediatrician specializing in child abuse from Strong Children's Hospital, was appointed to be the principal investigator (Dias & Barthauer, 2001). The two new project co-ordinators assumed many of the administrative roles that Dias had previously fulfilled.

During the expansion phase, the commitment statement was amended to include a request that parents consent to receive a follow-up call seven months after their infant's birth. The call was intended to assess parents' recollection of the information received in the hospital and to solicit program feedback. The timing of the follow-up call coincided with the midpoint in the peak incidence of shaken baby syndrome and was designed to test the hypothesis that parental retention of the program material could endure for a minimum of seven months (Dias et al., 2002).

With the addition of the Finger Lakes Region, 33 hospitals in 17 counties would be participating in the Upstate New York Shaken Baby Syndrome Parent Education Program. The following quantitative program performance goals were set at the outset of the expansion: 1) to establish a regional program including all 17 counties in Western New York and the Finger Lakes Region, 2) to educate at least 70% of new parents about shaken baby syndrome prior to discharge from the hospital, and 3) to reduce and maintain the incidence rate of shaken baby syndrome in each region to 50% of the historical baseline figures (Dias & Barthauer, 2001). The qualitative program goals remained unchanged. All other aspects of the program, including staff

infrastructure, program materials, and incidence-tracking strategies, were introduced in the same manner as in Western New York.

8.3.1 Staff Roles and Responsibilities

The two principal investigators serve as overall program co-ordinators and oversee the data tracking within their respective regions. They also act as a valuable resource for staff regarding program innovations, trouble-shooting, and the provision of feedback. Additionally, they supervise and communicate directly with the two project co-ordinators, who are responsible for the bulk of the administrative tasks associated with routine program operations. The project co-ordinators orchestrate the purchase, receipt, and delivery of all program materials to the hospitals and conduct obstetrical and perinatology nurse training sessions. Additionally, they communicate regularly with the nurse managers and assist them in tackling local logistical problems. They also monitor the monthly collection of signed commitment statements and maintain the program database. As active participants in the vigilant tracking of new shaken baby syndrome cases, project co-ordinators regularly contact hospitals, the media, and other child abuse professionals to identify new cases. They also conduct the seven-month follow-up phone calls, assist with the preparation of program data for statistical analysis, and provide program updates for a monthly newsletter distributed to all participating centres regarding ongoing concerns, progress reports, and project status. Finally, the project co-ordinators are public speakers and community advocates for the prevention of shaken baby syndrome, as requested by local public service groups, researchers, and other regions interested in replicating the program (Dias & Barthauer, 2001).

Every participating hospital has one nurse manager and a network of obstetrical and neonatal nurses that deliver the program to parents. The nurse managers are responsible for: 1) educating the maternity nurses about shaken baby syndrome and about how to implement the program; 2) receiving and delivering all program materials; 3) collecting and delivering all signed commitment statements from the maternity nurses to the project co-ordinators each month; and 4) providing the project co-ordinators with monthly delivery statistics to be used in future incidence rate calculations. Any logistical difficulties that arise are solved through direct communication with the project co-ordinators.

Maternity ward nurses are trained to educate parents, distribute program materials, and collect signed commitment statements from a maximal number of parents, especially fathers. They return signed commitment statements to the nurse managers for delivery to the project co-ordinators each month. These nurses are the “front-line” program workers, directly interacting with the target population and delivering the primary prevention information.

8.3.2 Initial Feedback

The start-up period for the Finger Lakes Region hospitals was remarkably smooth. Within several months, nearly all hospitals were fully participating and returning commitment statements to the program office. The project co-ordinators were invaluable in ensuring consistent, open communication with nurse managers, diligently tracking returned commitment statements, and providing prompt assistance for hospital staff in tackling logistical hurdles. The smooth expansion can likely be attributed to two main factors: 1) the creation of the two nearly

full-time project co-ordinator positions, and 2) the demographic similarities shared by the two participating regions.

The Finger Lakes Region program was just as well received as that in Western New York, and the program performance goals were consistently met. The seven-month follow-up questions provided valuable insight into parental retention of program information, and the feedback from parents was overwhelmingly positive. A survey of nurse managers in 2001 revealed that nearly every hospital was routinely providing brochures, posters and commitment statements to parents (Dias et al., 2002). Over half of the hospitals regularly had parents view the “Portrait of a Promise” video. Most impressively, the project co-ordinators’ persistent efforts in improving the percentages of returned commitment statements produced an increase in return rates from 46% in Western New York before 2001 to 77% from the combined Upstate New York program (Dias & Barthauer, 2001).

8.4 Outcomes

The program’s impact on the annual incidence rate of shaken baby syndrome in Upstate New York was unprecedented. Since 1998, the average annual incidence of inflicted infant head injury decreased from 8.2 to 3.8 cases per year, or from 41.5 cases per 100 000 live births to 22.2 cases per 100 000 live births (Dias et al., 2005). In all, Western New York has experienced a 47% drop in the incidence of shaken baby syndrome since the inception of the Shaken Baby Syndrome Parent Education Program (Dias et al., 2005). Of the 21 infants that did incur shaking injuries during the study period, less than half of the parents participated in the program and signed a commitment statement. Preliminary data from the Finger Lakes Region in 2003 revealed

that the number of reported cases of shaken baby syndrome had dropped by 41% (Dias et al., 2005; National Association of Children's Hospitals and Related Institutions, 2003). These results likely represent a minimum drop in incidence, due to the increased vigilance with which cases have been tracked during the program (Dias et al., 2002).

Other child abuse statistics suggest that the dramatic and temporal reduction in shaken baby syndrome cases in Western New York can be directly attributed to the Shaken Baby Syndrome Parent Education Program. The incidence rates of other forms of child maltreatment referred to the Children's Hospital of Buffalo remained stable throughout the duration of the program, and no congruent decline was observed in the number of cases of shaken baby syndrome reported in neighbouring regions of New York State. Finally, a documented sharp decline in the incidence of shaken baby syndrome is not known to have occurred in any other region in the world, as investigated by the Special Interest Group on Child Abuse (Dias et al., 2002). The results support the overall program hypothesis that a primary prevention program providing timely education about shaken baby syndrome to new parents can be effective in preventing inflicted infant head injury.

The returned commitment statements revealed that 93% of parents were previously aware of the dangers of shaking an infant, yet 95% still felt that shaken baby syndrome educational materials should be provided to all parents (Dias & Barthauer, 2001; Dias et al., 2005). Over 90% of parents found the information helpful, regardless of their level of prior knowledge about shaken baby syndrome (Dias et al., 2005). These results support an additional program hypothesis – that

most parents are already aware of shaken baby syndrome, and merely need to be reminded *at the right time* to ensure their child's safety and protection.

The seven-month follow-up calls revealed that, without prompting, nearly one in three parents in Western New York recalled receiving information about shaken baby syndrome at their infant's birth hospital (Dias et al., 2002; Dias et al., 2005). When asked directly, 98% of parents remembered receiving the program information. The video was the least remembered component of the program, although a survey revealed that less than two thirds of hospitals regularly showed the video to parents (Dias et al., 2005). This information offers valuable guidance for improving the design of the Upstate New York program for replication in other jurisdictions, and confirms that parents are retaining the program information for at least seven months, during the period of highest risk for infant abuse.

Community Reactions

The success of the Upstate New York Shaken Baby Syndrome Education Program quickly earned the attention of both the media and state politicians. After the New York Times published an article about the program's successes in 2001 (Foderaro, 2001, May 29), the project coordinators in Upstate New York were flooded with inquiries about the potential for program expansion to other regions. New York Assemblyman Sam Hoyt sponsored a bill stating that all new parents in New York State were to receive an informational leaflet detailing, "the effect of shaking infants and young children, appropriate ways to manage the causes of shaking infants and young children, and a discussion on how to reduce the risks of shaking infants and young

children” (G. Lithco,). Several other states, including Pennsylvania and Illinois, have recently introduced similar legislation.

Effective policy making has been said to require an "iron triangle": an effective lobbying organization, congressional "champions", such as Sam Hoyt, and inside help from a supportive bureaucracy (Krugman, 1999). Parent victims and health care workers in contact with shaken children have formed the most powerful lobby for the prevention of shaken baby syndrome in the United States, and it is encouraging that policy makers have been receptive to their efforts. With evidence supporting the effectiveness of a primary prevention program against shaken baby syndrome, politicians, health care providers, and affected families were eager to introduce Dias' program in their own jurisdictions.

8.5 Program Expansions

8.5.1 The Replication Model

The program involves three distinct phases, including: 1) a planning phase lasting from six to nine months, 2) a start-up phase lasting 18 to 24 months, and 3) a maintenance phase beginning in the second year of the program.

Tasks in the planning phase include establishing a staff network, eliciting program participation from hospitals, and obtaining approval from hospital Institutional Review Boards. During this phase, program materials are ordered, staff are hired and trained, and a program start date is set. Efforts are also made to establish the regional baseline incidence rate of shaken baby syndrome.

In the start-up phase, the selected staff implement and coordinate the new program. This period is devoted to solving logistical problems, communicating regularly with hospital staff, and working diligently to achieve the program performance goals. The principal investigator is most active during the planning and start-up phases, campaigning for program support and acting as the ultimate contact person for fielding questions from hospital staff and professionals.

After approximately two years, the maintenance phase begins. By this time, the program should be firmly established and consistently meeting targeted program performance goals. The role of the project co-ordinators shifts predominantly to involve data input, follow-up calling, incidence tracking, and public relations.

8.5.2 Utah

The success of the Upstate New York Shaken Baby Syndrome Parent Education Program prompted a group of professionals from the Primary Children's Medical Centre, the National Centre on Shaken Baby Syndrome, and the University of Utah's Intermountain Injury Control and Research Centre to replicate it in Utah in 2000. The program was unique in being the first to receive joint funding from private health care insurers, Utah State agencies, and Medicaid (Herman et al., 2000). The format is nearly identical to that in Upstate New York, with the exception that parents are also offered additional materials from the NCSBS, including an information card about "The Period of Purple Crying" and a video called "Elijah's Promise".

Program collaborators believe that a prevention program funded by private health insurance companies is more amenable to rapid expansion and implementation across the United States. However, the challenge in soliciting contributions from private insurers lay in the fact that the program had to be state-wide from the beginning. There is currently no law in Utah to mandate the distribution of shaken baby syndrome prevention materials in birthing hospitals, and the rates of participation and enthusiasm for the program varied greatly between hospitals. The effect the program has had on the state-wide incidence rate of shaken baby syndrome has not been consistently tracked as in New York State. However, three month follow-up phone interviews were conducted to determine how much of the program information was retained by parents, and what aspects of the program were most useful. Preliminary results suggest that the video is most remembered by parents (A. Wicks, personal communication, August, 2005). To date, the Utah program has not achieved the uniformly high levels of hospital participation as in New York. Program coordinators are optimistic, however, that this will improve with time and that their unique public-private funding arrangement will ensure the long term sustainability of the program.

8.5.3 Pennsylvania

In 2001, Dias relocated to Central Pennsylvania and personally spearheaded the Pennsylvania expansion effort. The new site was chosen based on its challenging demographic and health care system characteristics. Central Pennsylvania contains several major neurosurgical care centres with ill-defined referral patterns extending into neighbouring states and regions. It also lacks a well-organized regional Perinatal Outreach Program. Central Pennsylvania offered an opportunity to test the effectiveness and applicability of the Upstate New York Shaken Baby

Syndrome Parent Education Program in a region lacking a centralized health care system (Dias et al., 2002).

The program began in 2002 with funding from the Pennsylvania Commission on Crime and Delinquency and the Children's Miracle Network (Dias et al., 2002; National Association of Children's Hospitals and Related Institutions, 2003). All operational design aspects of the program remained unchanged, with one exception. The Central Pennsylvania Shaken Baby Syndrome Education Program formed a partnership with the Pennsylvania Department of Children, Youth and Families, which maintains a state-wide database of reported child abuse cases (Dias et al., 2002). The registry has the ability to track cases of inflicted infant head injury according to the county in which the abuse took place. This specificity is advantageous for tracking cases in a decentralized region, where it is possible for infants born in Central Pennsylvania hospitals to receive treatment in outlying regions. The database can also query cases based on several other location characteristics, including birth county, enabling the project coordinators to isolate and identify new cases arising specifically from the Central Pennsylvania region.

Legislation was passed in 2002 mandating the provision of shaken baby syndrome prevention materials to parents of newborns in all hospitals in Pennsylvania (National Association of Children's Hospitals and Related Institutions, 2003). Dias' program had been exclusively operating in Central Pennsylvania but after the legislation was introduced, all 130 hospitals in the state were required to participate. Although the full program has only been running for 1.5 years, the project coordinators have achieved an 85% commitment statement return rate, and 125

hospitals are fully participating in all aspects of the program (C. Rotman, personal communication, August, 2005). There has not yet been a substantial state-wide drop in the incidence rate of shaken baby syndrome, although this is felt to be attributable to the fact that many hospitals were only partially participating during the first year of the program. As well, many nurses had not yet been formally trained about shaken baby syndrome and how to optimally deliver the program. State-wide nurse training is now complete and it is anticipated that the number of cases of shaken baby syndrome will drop in the ensuing years as the program reaches the vast majority of Pennsylvania families. Plans are currently underway to secure funding from private health insurers. The Pennsylvania governor, the Pennsylvania State University College of Medicine, the Pennsylvania Children's Partnership, and several other state and regional child welfare agencies strongly support the program (Dias et al., 2002). With academic, governmental and community endorsement, it now represents a multi-institutional partnership that embraces the concepts of collaboration and co-operation in reducing child maltreatment.

8.5.4 Minnesota

In 2002, the Children's Hospitals and Clinics in Minneapolis formed a task force of local experts to bring the Shaken Baby Syndrome Parent Education Program to Minnesota. Program materials were translated into several languages including Hmong, Russian, Spanish, and Somali, to cater to the ethnic diversity of the target population. Efforts to determine the pre-existing incidence rate of shaken baby syndrome in the region were undertaken by the Minnesota Department of Health, funded in part by a grant from the Centers for Disease Control and Prevention (CDCP) (National Association of Children's Hospitals and Related Institutions, 2003). Although the

implementation process is in the early stages, support from the CDCP is expected to be instrumental in facilitating the accurate tracking of new cases and upholding the evidence-based component of the program.

8.5.5 Ohio

Dias' program was launched in 2002 in Columbus, Ohio by an enthusiastic group of volunteers from the Ohio chapter of the National Council of Jewish Women. Initial funding came from the Ohio Children's Trust Fund. In addition to the standard program materials, parents receive a gift bag containing educational fridge magnets, baby bibs, and brochures with the "Love Me, Never Shake Me" and "The Period of Purple Crying" slogans from the NCSBS (Lisa Carroll, personal communication, August, 2005; National Association of Children's Hospitals and Related Institutions, 2003). A media awareness campaign and community outreach component complement the hospital-based program. People in local correctional facilities, public schools, home visitor programs, and teen parenting agencies also receive information about shaken baby syndrome. Recently, incarcerated women have participated in the design, assembly and distribution of program materials to Ohio hospitals. This unique initiative aims to empower the women to make a positive contribution to society and to educate them about shaken baby syndrome, while simultaneously creating a supply of program materials. The hospital-based program is currently operating in 32 hospitals, and the founding hospital has a 97% commitment statement return rate (Lisa Carroll, personal communication, August, 2005). Some hospitals have placed the provision of program materials on the hospital discharge nursing summary sheet. On-going funding for the Ohio program has come from state agencies, the Ohio Attorney General, and private foundations. Because there is no mandate for the state-wide provision of educational

materials in Ohio, program leaders have focused on empowering parents and members of the local community to take an active role in preventing shaken baby syndrome. To date, there is no mechanism in place to track the impact of these initiatives on the Ohio incidence rate of shaken baby syndrome.

8.5.6 New York State

In 2002, Dias was successful in securing a commitment for partial funding from three Western New York insurance companies, including Blue Cross/Blue Shield, Independent Health, and Univera Healthcare (National Association of Children's Hospitals and Related Institutions, 2003). It is hoped that an on-going partnership between public and private funding sources will ensure the future sustainability of the program.

The Upstate New York region entered a new program phase in early 2004, with the addition of community pediatricians' involvement. At every infant's first visit to pediatric care providers, parents are given advice regarding how to cope with infant crying and are reminded of the dangers of infant shaking (Dias et al., 2005). They are also asked to sign a second commitment statement. It is hoped that the repeated information will help parents responsibly cope with the stresses of infant care and, ultimately, further reduce the incidence rate of shaken baby syndrome.

8.5.7 Most Recent Additions

The Shaken Baby Syndrome Parent Education Program has most recently been introduced in Grand Rapids, Michigan and Phoenix, Arizona (National Association of Children's Hospitals

and Related Institutions, 2003). Both states do not have legislation mandating the provision of program materials, and have encountered difficulties in establishing the baseline incidence rate of shaken baby syndrome. In Arizona, severe nursing staff shortages and liability concerns have prevented the formation of a hospital-based program, and so program materials are delivered primarily through private physician's offices and parent education classes (National Association of Children's Hospitals and Related Institutions, 2003). The commitment statements have also been omitted from the program. While information about shaken baby syndrome is likely valuable in any context, the lack of program centralization in the birthing hospitals and the omission of the commitment statement significantly alters the nature of the program and limits the capacity for evaluation.

In Ontario, Canada, the University of Toronto and the Ontario Neurotrauma Foundation are collaborating to implement the Shaken Baby Syndrome Parent Education Program in hospitals in Sudbury, North Bay, and the Greater Toronto Area. Monitoring the regional incidence rates of shaken baby syndrome is expected to be challenging, but it is hoped that collaboration with public health departments will facilitate the research component of the program.

8.6 Conclusions

Seven years after its inception, the Western New York Shaken Baby Syndrome Parent Education Program has emerged as a best practice in the prevention of inflicted infant head injuries. The program is fully operational in several states and is expanding into other areas of the United States and Canada. It has been well-received by the public, the media, health care workers, governments, and public and private institutions and funding agencies. It has the potential to be

successfully implemented in regions with varying demographic characteristics, provided that the necessary financial and professional resources are available.

Remarkably, the original program goals developed by Dias in 1998 are still intact: 1) the program is universally applied, operating in all maternity care hospitals within a given region, 2) information is consistently provided to parents at the same point in time – in the hospital, following the birth of their child, 3) the participation of fathers and father figures is actively sought, even though program materials are presented to both parents, 4) the commitment statements engage parents in their own educational process, and instill in them a sense of responsibility and commitment toward preventing shaken baby syndrome, 5) the dissemination of program materials is effectively tracked using the returned commitment statements, 6) the seven-month follow-up calls provide research data on parents' recollection and retention of program information, and 7) clearly defined, quantifiable outcome measures enable staff to assess the effectiveness of the program (Dias et al., 2002).

The available evidence demonstrates that this simple program saves infant lives. Conveniently, it also has the potential to save money. Cost-benefit analyses have strongly indicated that the costs of preventing shaken baby syndrome are far less than the costs of treating shaken infants. Dias estimates that the overall program costs are equivalent to \$10 USD per child, which is comparable to the cost of routine childhood immunizations. The program expenditures could be reclaimed if the average cost of caring for injured infants was \$21,925 per child per year, which is well within published estimates (Dias et al., 2005).

While Dias' program is the first to demonstrate a quantifiable decrease in the incidence rate of shaken baby syndrome, the challenges in producing this evidence cannot be overemphasized. To date, there has been minimal improvement in the area of child maltreatment surveillance. Although the International Classification of Diseases finally introduced a specific code for shaken infant syndrome in 1996, it is largely underutilized and unknown, resulting in a persistent underestimation of the magnitude of the problem (*Shaken Baby Syndrome Surveillance In Massachusetts*). The political and financial will to develop state/province-wide or national centralized databases for tracking cases of shaken baby syndrome is still largely absent, and the participation of public health departments in case-tracking has also been underutilized. Until centralized surveillance systems are functional, regions aiming to effectively prevent shaken baby syndrome will continue to encounter incredible difficulties in establishing baseline incidence rates of inflicted infant head injuries. Without this data, the long-term impact of these programs will remain unknown.

Inadequate financial support has also been a critical factor limiting program dissemination to other regions (Dias et al., 2002). Public interest and demand far outstrip available funding opportunities. Even existing programs have been unable to secure long-term funding to ensure program sustainability. States like Pennsylvania are at risk of being in a future position where program provision is required by law but funding is inadequate to support program operations. As evidence for the program's effectiveness mounts, it is hoped that the challenges of obtaining financial backing will diminish. Increased participation from private health insurers appears to be a realistic hope for the near future, with the Utah and New York programs currently benefiting from this innovative partnership. Health insurance companies stand to save a significant amount

of money by funding the program, and it is hoped that they continue to recognize the financial and social value of their support in the future.

Two key factors have been identified for successful program replication: 1) finding capable project co-ordinators, and 2) maintaining a manageable pace of program implementation. Kim Smith and Kathy deGuehery's consistent, enthusiastic, competent leadership has been vital to the long-term success of the Upstate New York program. The importance of these qualities in project staff cannot be overemphasized. Regions that have encountered the greatest difficulties in program implementation have either lacked devoted, experienced project co-ordinators or have attempted to introduce the program at an unsustainable pace.

The success of the original program has been enthusiastically embraced but the replication process has been partial, undermining the evidence for the program. Many new regions adopting the program have failed to incorporate a research component into the planning, start-up and maintenance program phases. To benefit from the proven effect of this best practice in the prevention of shaken baby syndrome, program leaders should strive to uphold the evaluation component to facilitate accurate assessment of the program's applicability and efficacy in a variety of social contexts. Rather than rest on the laurels of the success in Upstate New York, program co-ordinators must persist in effectively educating parents about shaken baby syndrome by assessing the value of their innovations in terms of its impact on the incidence rate of this tragic form of abuse. The program is unique in its proven effectiveness and can only evolve into an optimally transportable, efficacious entity with a continuous commitment to evaluation as well as innovation.

An important joint initiative is currently underway between researchers in Washington State, U.S. and British Columbia, Canada. Barr and Rivara are undertaking the first randomized controlled trial in the primary prevention of shaken baby syndrome. Their study will run from 2005-2007 and will compare the effectiveness of delivering parent education materials in various health care settings including hospital delivery wards, pediatricians' offices, and prenatal classes (U.S. National Institute of Health, 2005). Barr's approach to prevention focuses on the normalization of persistent infant crying and on encouraging parents to develop effective coping strategies to deal with the feelings of low self-efficacy, depression, and frustration that can be associated with infant crying. His materials about the "Period of PURPLE crying" describe the timing and characteristics of persistent infant crying behaviour. The first phase of the study seeks to measure the program's efficacy in terms of parent knowledge and attitudes about infant shaking, sense of parenting competence, and maternal depression. A second study phase will seek to track the program's impact on the incidence rate of shaken baby syndrome.

It is encouraging to note a progression toward increasingly evidence-based endeavours in the field of shaken baby syndrome prevention, especially in the five years following the success of Dias' best practice program. Having a variety of published studies that embody different approaches to primary prevention in the field of shaken baby syndrome will certainly stimulate future research and raise the bar on the standard of prevention work currently being conducted.

Given the success of the Upstate New York Shaken Baby Syndrome Parent Education Program, it is anticipated that regions across North America will continue to embrace and deliver this

highly effective primary prevention program to all new parents. Its goal to reduce child abuse is universally applauded, and the fact that it has produced valid, quantifiable results is immensely promising. If the efficacy of the program can be established in a variety of social venues, it is both desirable and possible for this program to capture the attention of health departments and professionals around the world and be incorporated into routine postpartum hospital visits. Clearly, the evidence suggests that it is possible to prevent this devastating form of child abuse using a simple, comprehensive parent education program.

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