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International collaboration on prevention of shaken baby syndrome – an ongoing project/intervention

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Caring for young infants can be stressful. Non-accidental brain or head injury (shaken baby syndrome) is a result of parental stress, and a lack of knowledge of how to respond to a crying infant and the dangers of shaking a child. This article demonstrates the value of international collaboration in projects to prevent child maltreatment. It includes reports of prevention of shaken baby syndrome programmes in Australia, Hungary, Greece, Brazil and Turkey.

Keywords: Shaken baby syndrome (SBS), Prevention, International collaboration

Introduction

Shaken baby syndrome (SBS), also described as non-accidental brain injury (NABI), is a special form of child abuse caused by vigorously shaking an infant, often in anger, to make it stop crying or whining. It includes impact injuries and additional musculo-skeletal injuries. SBS commonly presents with subdural and/or subarachnoid haemorrhages, retinal haemorrhages and brain damage from oedema, bleeding, stroke, axonal injury and hypoxic-ischaemic injury. Whiplash-like shaking results in significant acceleration/deceleration force. It is thought that this causes subdural haemorrhages by tearing the dural bridging veins, and retinal haemorrhages by causing vitreoretinal traction. The incidents occur mostly in infants under 1 year of age. In the worst cases, the violent shaking causes death. It may result in severe and permanent brain injury, spinal-cord injuries, retinal haemorrhages and rib fractures.¹⁻⁴ The outcome is often devastating with 15–38% of children dying of their injuries, more than one-third having serious neurological sequelae, and two-thirds having visual impairment. Survivors often require long-term

multidisciplinary medical care and special education. SBS and its impact on child well-being is causing international concern.⁴

In most instances, the crying of an infant or toddler triggers the event. Rarely, similar symptoms are caused by unintentional actions such as tossing the infant to make him or her laugh, or by road traffic accidents. Inflicted brain injury has a poor prognosis. The safety of vulnerable children is best achieved through prevention by educating professionals, parents and carers,^{5,6} and, to this end, efforts to prevent SBS have been initiated in many countries.⁷

The experience of projects in four countries that have collaborated in the Western Sydney, Australia initiative is presented.

Western Sydney, Australia

The Shaken Baby Prevention Project in Western Sydney, known as 'Shaking Your Baby is Just Not the Deal', began in late 2001.⁸ The project team has developed a short animated film, posters, pamphlets and postcards to support parent and carer education. Although the staff are mostly public health employees, funds for the project were provided by KidsWest, a children's charity (www.kidswest.org.au). The organization continues to be a partner in the project,

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which is essential when public health funding for prevention is so unpredictable.

Western Sydney is multi-lingual and multi-cultural. The project sought informal assistance with translating and reviewing the film script from the International Society for Prevention of Child Abuse and Neglect (ISPCAN) members. A request for assistance was posted on the website (listserv) and the international partnerships in the prevention process began at this time. Subsequently, a master copy of the film on DVD and master versions of associated resources were provided to international colleagues who were encouraged to develop their own local and culturally appropriate projects.

The film and information sheets were formally trialled in the Children's Hospital at Westmead (CHW) and the nearby Westmead Hospital in Western Sydney. The trial demonstrated that the resources were very acceptable to parents. Approximately 90% of respondents remembered the key message that shaking is dangerous, 78% reported that they sought assistance with their crying infant in the 3 months after being shown the film. For examples of participants' comments, see Appendix 1.

Consultation and feedback with staff and parents identified implementation options to further develop associated educational strategies such as postcards and new posters. Local colleagues were also consulted in order to ascertain the best way to disseminate the information. CHW provides acute and ongoing medical, rehabilitative, psychiatric and psycho-social care for injured SBS infants. The contributing psycho-social elements in the infant's family and community were the key elements addressed in this prevention programme.

Many student social workers contributed to the project's development and to the action research. One of these research projects found that 30% of staff in several hospital and community health settings did not know that shaking an infant was dangerous. Ongoing education of all staff interacting with parents and carers is essential. The project also discovered that the extent to which the Australian community at large is educated in the dangers and prevention of SBS is very patchy.

From National Project to International Collaboration

The translated Australian film was first presented internationally in Estonia in 2004. It has subsequently been trialled as an interactive and collaborative project, encouraging local teams to develop their own translations and strategies for education in prevention.⁹

Briefly, the key elements of the project's education in prevention are: increasing parental knowledge of safe ways in which to respond to a crying infant,

providing easily understood information about the dangers of shaking an infant, and confirming that parents and carers should ask for help if they are worried about their infant's crying. These components are particularly important for parents of infants who are hard to settle.¹⁰

Hungary

In 2003, the first survey of child maltreatment and death was conducted by UNICEF in member countries of the Organisation for Economic Co-operation and Development (OECD). The study showed that, in these countries, about 3500 children under the age of 15 years die every year from abuse and maltreatment. Hungary was then ranked as the sixth worst performing country, and, over a 5-year period, 113 children were killed either by abuse or neglect.¹¹ Almost 50% of these children were <1 year of age. Around 200,000 children, equal to 10% of the whole child population, are registered by the Social Welfare System as being 'at risk'. Most of these endangered children have severe social problems. Every year, more than 3000 children suffer from physical abuse, more than 6000 from emotional abuse, and nearly 300 from sexual abuse; over 15,000 children are physically neglected and over 13,000 are emotionally neglected.¹²

An unknown number of cases remain unidentified, but the figure is estimated to be 1:25. Underlying causes are economic, social, and related to alcohol abuse, but cultural perceptions are also relevant. A study found that 80% of participating parents believed that corporal punishment is acceptable in raising children.¹³ The problem of child abuse and neglect has become a very important focus for the National Institute of Child Health in Budapest. In 2004, a protocol was published for doctors and health visitors and an educational DVD was developed. This has been followed by interdisciplinary seminars for doctors, health visitors, nurses, social workers, teachers and university students throughout the country. According to the data, half of the fatal cases were <1 year of age and 70% of them died as a result of infanticide. There were no exact data on how many children a year are killed or injured by SBS, so it was decided to focus on this aspect, including using the translated Australian educational material.¹⁴

Six conferences were organized and the programme included:

- Early mother/child attachment disorders, *post-partum* depression;
- SBS as a special form of child abuse;
- SBS cases in the accident and emergency department.
- The role of health visitors in preventing SBS.

Media involvement in this programme has led to widespread dissemination of the information and has

resulted in the involvement of all the paediatric departments and hospitals in the country. The first Hungarian website on child abuse was launched, with one subpage on SBS. The translated animated film can be watched on this webpage (www.gyermekban.talmazas.hu) and associated written material accessed.

While the impact of this programme has not yet been formally evaluated, it is hoped that a significant step has been taken towards preventing SBS in Hungary.

Brazil

Shaken baby syndrome is not very well known in Brazil. A recent literature review found only one published study on this topic in Brazil,¹⁵ and it reported an alarming fact: of 142 health professionals interviewed, 97% did not know what SBS was, and 60.8% reported that they had shaken a child.¹⁶

A North American study investigated the use of disciplinary strategies in different countries, including Brazil. In the Brazilian sample, 813 mothers were interviewed and 10% reported that in the week before the study they had shaken their children aged <2 years.¹⁷ These studies provide evidence of a possible lack of knowledge of the occurrence and severity of SBS in Brazil, highlighting the need to raise awareness in the population at large. In 2009, a partnership was established between The Western Sydney Shaken Baby Prevention Project at Westmead and the Laboratory for Violence Analysis and Prevention (LAPREV) of Universidade Federal de São Carlos (UFSCar) in São Carlos, Brazil, the Center for Integrated Studies of Childhood and Adolescence Health (CEIIAS) of Rio de Janeiro, the Zero to Six Institute in São Paulo, and the Special Interest Group in Child and Adolescent Telemedicine University Network (RUTH), resulting in three versions of the translated and adapted 'Responding to a Crying Baby' video: one in Spanish, one in Portuguese and one in Brazilian Portuguese. The pamphlet was translated into Portuguese.

In 2011, LAPREV began a research project which aimed to evaluate the effectiveness of these materials in raising parental awareness of SBS.¹⁸ The study included 82 new mothers, seven fathers of newborns and one pregnant woman in a maternity ward. They were divided into three experimental groups. The first group ('experimental video' group), watched the 'Responding to a Crying Baby' video, the second group ('pamphlet' group) read the pamphlet about SBS, and the third group ('control video' group) watched a video about child safety which did not address SBS. The participants completed the 'Crying Baby Questionnaire' and the 'Shaken Baby Syndrome Awareness Assessment' before intervention (pre-test),

immediately after intervention (post-test) and 6 months after intervention (follow-up).

The pamphlet group showed a significant increase in knowledge of the consequences of shaking an infant and of strategies to adopt when a baby is crying inconsolably or the parents are getting frustrated. In addition, on follow-up, only the pamphlet group reported leaving an infant for a while in order to deal with the crying. So, there was an increase of knowledge and a change in parental behaviour.

The experimental video group demonstrated a significant increase in awareness of the average number of hours a day of infant crying. These results indicate that SBS material seems to be effective in changing parental knowledge of this type of child maltreatment and can be used in prevention programmes and campaigns.

Following this study, a new research project was undertaken in 2013. It aims to develop a Brazilian instrument to measure awareness of SBS amongst parents and caregivers and to train health providers at Basic Health Units in its prevention. In parallel to the studies, LAPREV also held lectures and workshops for health and educational professionals of some municipalities in the state of São Paulo, sensitizing a larger number of them to the importance of preventing SBS.

Greece

In Greece, the initiative to participate in the Shaken Baby Project was taken by the Society for the Prevention of Cruelty to Children: Eliza (SPCC), a small, non-governmental organization which, since its founding in 2009, has been increasingly involved in innovative approaches to preventing child maltreatment at primary, secondary and tertiary levels (www.eliza.org.gr).

The Shaken Baby Project targeted parents of young children and health and education professionals. The project was incorporated into a 2-year campaign on prevention of child abuse implemented by the SPCC during 2011–2012.

The Shaken Baby Project has included the following stages:

- Stage 1: A detailed study of the literature and the SBS prevention educative material from Australia;
- Stage 2: The creation of a training package;
- Stage 3: The dissemination of information to health- and early childhood education professionals;
- Stage 4: Electronic access to parents of young children through Babyzone (www.babyzone.gr) and facebook.
- Stage 5: After posting the SBS video on Babyzone (www.babyzone.gr), a 5-week research project which asked mothers about their experiences related to risk factors for SBS and their coping mechanisms;
- Stage 6: Outreach to parents in maternity and paediatric hospitals.

See Appendix 2 for further details of these stages.

Seven large private hospitals with maternity and paediatric clinics were contacted within the programme's collaboration with the Intelligent Media Agency, which operates health information programmes in hospitals through television sets placed in public areas. Patients, visitors and staff have access to this information all day. The SBS video was shown twice a day for 12 months, reaching an estimated 420,000 viewers monthly.

Collaboration in this international prevention project has been a great opportunity for the SPCC to be involved in a cross-cultural exercise in parenting and prevention of child abuse. A small NGO in Greece brought to public attention a problem which is neglected even within the medical community to which it is most relevant.

The collaboration also provided an opportunity for dialogue with other professions so that a multi-sectorial and multi-disciplinary response would be seen as essential. Furthermore, the SBS package in its various usages opened a new perspective on the causes of a wide spectrum of problems of later childhood often associated with neglect, and showed that early recognition of a family's difficulties and a parent's failure to care properly for an infant can prevent an escalating spiral of violence before it is too late to treat.

One of the most valuable aspects of the approach was the provision of options for parents. In Greece, the medicalization of children's simple, everyday behaviour or 'simple problems' tends to lead to procedures which are often unnecessary, costly and anxiety-provoking for parents, especially young parents of a first child.

Feedback was requested from the different groups reached, and optional contact through a helpline directly to the programme co-ordinator or to Intelligent Media was offered. Early childhood professionals were mainly interested in acquiring more information on implementing the programme with parents as well as places for referral of cases needing support. Among the hospital population with access to the SBS video for a year, only five contacts were made to Intelligent Media for more information, and none to the helpline.

This finding may have various interpretations in a society which traditionally solves problems within the family or community and associates helplines with severe social problems requiring legal intervention. In contrast, a happy event at a maternity or paediatric hospital, such as a pregnancy, birth or a resolved paediatric problem, when there is the support of close relatives, does not seem to cause the kind of anxiety that might interfere with a positive primary relationships between mother and child or create other

predisposing factors which could lead to SBS. Another reason for limited feedback from hospitals may be that all seven hospitals where the SBS video could be shown were private, thus excluding socially and economically deprived populations who cannot afford services and could be characterized as more 'vulnerable'. Nevertheless, it should be noted that the various public insurance schemes do cover all or part of private hospital fees, thus allowing families a choice. The application of an SBS prevention programme with a different methodology to public hospitals and health centres for populations of low socio-economic status may enrich the above preliminary data.

A limitation of the Greek project was that it did not provide for pre-/post-testing and so changes of attitude and behaviour could not be evaluated.

Turkey

Although awareness of child abuse and neglect (CAN) is increasing among professionals and communities at large, SBS, a special form of CAN, is a very recent concern in Turkey. Families are not aware that shaking an infant can be harmful.

A recent study which investigated Turkish parents' knowledge of and attitudes towards SBS reported that 50.3% of parents had no idea that shaking an infant might be harmful and 24% thought that shaking an infant would not be harmful.¹⁹ SBS is not readily diagnosed by medical professionals. To our knowledge, there are only a few case reports of SBS in Turkey.^{20–22} One multi-centre study retrospectively reviewed 345 infants with subdural or sub-arachnoid bleeding, lethargy, coma, skull fracture or retinal haemorrhage: 22% of injuries were inflicted but only three of the 345 were diagnosed as SBS during their hospital stay.²³

Because there were no prevention programmes in Turkey in 2009, a member of the Turkish team contacted the Western Sydney team through ISPCAN listserv – a members' e-mail group through which members can post ideas and requests. This team generously offered their material and it was translated for use in Turkey. A study was undertaken to evaluate the effectiveness of the training in Turkey. A secondary aim of the study was to discover the most effective time at which to train mothers. This information was important in order to determine the best way to progress towards widespread, country-wide implementation.

The study was undertaken in 2010 in two different hospitals, a university and a state hospital in Ankara. A total of 545 mothers of full-term, healthy infants were included in the study. To evaluate the effect of timing of training, they were divided into three groups according to when training was given: Group 1 mothers were trained within the first

48 hours of birth, before discharge from hospital (217, 39.8%); Group 2 mothers were trained during their infant's first well-child visit 3–7 days after birth (235, 43.1%); and Group 3 mothers were trained in the Obstetrics Department during their last check-up visit (93, 17.1%).

To evaluate the effect of training on knowledge of SBS, all mothers were tested before and after training, and it was found that training was useful in all three groups. Within each group, post-test scores increased statistically significantly compared with pre-test scores: 5.0 (2.2) and 6.4 (1.7) in the pre- and post-tests, respectively ($P=0.001$). There was no statistically significant difference between the groups in the pre-test score whereas, in the post-test, the Group 1 score was significantly lower than those of the other two groups ($P=0.001$). This was interesting because most of the relevant prevention programmes suggest that training should be given in the post-partum period before discharge from hospital. The study observed that mothers in the immediate post-partum period (Group 1) were reluctant to watch the video or listen to the trainers because of their pain or problems with the infant.

In conclusion, this study demonstrated that material from the Australian project was useful for mothers in Turkey also. The study was presented at the ISPCAN Asian Regional Conference in Delhi in 2011 and at the multi-national symposium of the ISPCAN XIXth International Congress on Child Abuse and Neglect in Istanbul in 2012.²⁴ At the National Congress of Social Paediatrics in November 2012, Dr Sahin of the Turkish team gave a lecture on prevention of SBS and during her presentation the translated Western Sydney video was shown. This generated significant interest in the material and in its wider implementation. The team is now trying to extend the prevention programme through collaboration with different university hospitals. The ultimate goal is to initiate a national prevention programme.

The projects in Australia, Hungary, Brazil, Greece and Turkey demonstrate the value of international collaboration in educating professionals, parents and carers in the dangers of shaking infants and the importance of safe care of crying infants. All of the collaborating countries recognized the importance of educating professionals and parents to ensure that infants, the most vulnerable members of our communities, receive appropriate and safe care.

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Appendix 1: Participants' Comments

Examples of the participants' comments about the materials as reported in the Australian study include:

- It (the DVD film) helps if baby is crying and we are anxious and home alone.
- It was useful with information about handling the baby. I told our family that shaking the baby was harmful.
- I did not realize that shaking was so bad.
- Shaking a baby causes serious problems. I learnt what to do when the baby cries such as feed the baby first, play with them, take them out for a walk, call the helpline and they may settle.
- When you are managing a baby and all they do is screaming, in the back of your head you know not to shake them.
- My husband knew what to do if the baby was crying; not to become panicky.

Appendix 2: Further Details of the Implementation Stages of the Greece Project

Stage 1: A detailed study of the literature as well as a study of the SBS educating material from Australia.

Stage 2: A collaborative relationship was established with the Arrow advertising agency in Athens (www.arrow.gr) for the production of resource material. The training package produced included the following: (i) translation of the leaflet in to Greek following a pilot study undertaken with professionals and parents of young children, (ii) translation of the video in to Greek, with minor changes, (iii) a video for professionals, (iv) an information leaflet developed for professionals to assist them in using the project material, and (v) an accompanying letter signed by the President of the Executive Board of Foundation ELIZA and the scientific co-ordinator of the Shaken Baby Project.

Stage 3: Information was disseminated to health professionals and multi-disciplinary conference attendees. Members of professional societies involved in child care and early childhood education were contacted by email and notices were published in professional journals and parent journals.

Stage 4: A collaborative relationship was established with the media agency, Intelligent Media (www.intelligentmedia.gr), specializing in the dissemination of information on health issues to parents of young children (www.babyzone.gr). This included the following: (i) a profile of Foundation ELIZA – Against Child Abuse, (ii) a mailing of Shaken Baby to 13,000 members of Babyzone, through their electronic Newsletter, and (iii) a profile of the project on Facebook.

Stage 5: A 5-week project took place following the posting of the SBS video on Babyzone. In the section ‘Mothers Respond’, mothers were asked to answer the following questions: ‘The last time your baby was crying persistently, how did you respond? How did your child stop crying? What did you find was useful? Did you find the video useful?’ Parents were asked to share their experiences so that other parents could see what was helpful. Responses were received from 150 mothers with infants under 1 year of age. Their replies varied, but most were in accordance with the contents of the leaflet.

Stage 5: The film was shown twice a day to a hospital population of about 420,000 people per month in six hospitals in Athens and one in Larissa, which included mothers in maternity units, parents and relatives in paediatric units, visitors to outpatient departments and hospital staff of all levels.