Abusive Head Trauma: The Case For Prevention

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Executive Summary

Aims: The aim of this Fellowship was to explore international programmes related to the prevention of child maltreatment with a particular focus on the devastating form of child abuse that is Abusive Head Trauma (AHT) in infants and to gain an understanding about the wider context of the delivery of care and the systems and processes in which they are provided and commissioned. Specific outputs from the Travel Fellowship include the development of a UK based primary prevention programme.

The Fellowship has included the observation and study of the powerful programmes visited and the passionate and dedicated professionals who lead and research them. A critical analysis of the applicability of the different programmes within the UK health and social care context is considered alongside the evidence base underpinning prevention of Abusive Head Trauma and helping parents and caregivers cope with crying.

Findings: The findings highlight what makes AHT prevention programmes and child protection, family support services generally, successful. The constant forward planning for funding and rooting the programme within a secure organisational infrastructure cannot be under estimated.

The development of a multi agency co-ordinated programme that can fit into mainstream service delivery, that has a simple message, is well led and operates throughout the public health levels of prevention spectrum are key success indicators.

Careful thought should be given to measuring success of a programme from the outset including the resources involved in data collection and analysis and the need to respond to current political imperatives in order to attract funders.

A successful programme would reach more men by being hospital based then move into the community embedding its message by repeated reiteration of the essential messages throughout the first two months of a baby's life at the least and supported by accessible materials. A one size fits all programme is unlikely to work and flexibility to support local delivery whilst maintaining fidelity to the essential core message is crucial.

Recommendations:

- Gain endorsement and support from key stakeholders to design and implement a coordinated AHT prevention programme focusing on helping parents/caregivers cope with crying.
- Identify champions from each agency and within stakeholder organisations.
- Establish a multi agency steering group including parents/carers and families affected by AHT to co-design the detail of the campaign.
- Consider purchase or development of bespoke materials.
- Work with interested Universities to develop research protocol/evaluation design and bid for grant funding.
- Pilot, evaluate and roll out agreed programme.

• Disseminate through publication and conference presentations.

Literature Review

Incidence: Abusive head trauma (AHT) affects one in 4000–5000 infants every year and is one of the most serious forms of physical child abuse that has a high associated mortality and morbidity (Kemp 2011). Kesler et al (2008) showed incidence of 26 per 100,000 during the first year. Barlow and Minns in 2000 demonstrated the incidence of AHT as 24.6 per 100,000 of babies in the first year of life. Kemp (2011) describes three UK studies that give a similar incidence of between 20 -24/100,000 rising to 36/100,000 in babies under 6 months. In practice, an average sized District General Hospital can expect to see a case every 1 or 2 years. At Pennine Acute Hospitals NHS Trust, there have been 5 cases in 2 years. 2.6% of American parents in 2008 admitted to having shaken a child under the age of 2 years and 9% felt like shaking their infant. It is, therefore, possible that cases which come to the attention of clinicians are only a proportion of cases of AHT.

Demographics: Kesler et al (2008) found that males represent 70% of perpetrators. Their study also provides strong evidence that, although AHT can occur in every socio-economic groups, there are significant demographic differences between the general population and those families in which AHT occurs. Compared with the population of Pennsylvania, both mothers and fathers were more likely to be younger, less educated and unmarried. Both mothers and fathers were often Africa American and fathers more often Hispanic. Mothers more often smoked in pregnancy, sought antenatal care late and how birth weight babies. However, caution should be given to interpreting the statistics as these families are more likely to be reported for AHT (or conversely, that families conforming to other demographics are less likely to be reported). A previous study (Jenny et al 1999) found that 'missed' cases of AHT more frequently involved 'intact' and 'Caucasian' families.

Altman et al (2010) also concluded that Fathers and male surrogates are nearly 5 times as likely as mothers to shake an infant. From the parents survey only 40.4% of fathers watched the educational video that was part of the prevention package evaluated. Finding better ways to reach male caretakers should be a priority.

AHT as a Public Health Issue: AHT, as with all child abuse, is a public health issue. The prevention messages relating to AHT are clearly aligned with the public health levels of prevention which are primary (preventing a problem before it starts), secondary (intervening at the early stages of an emerging problem) and tertiary (intervening when harm has occurred to prevent further harm and limit damage). A further level which could be described as 'Supportive' would help support those families affected by AHT and foster a culture where education comes from within communities.

Berger et al (2011) show a significant increase in the rate of AHT in a 74 county region during a recession compared with the 4 year period before it. Although it isn't possible to prove a causal relationship between AHT rate and the economy, the data are compelling enough to influence policy and clinical decisions. Specifically, the presence of an association between the economy and the AHT rate should be sufficient to spur a discussion of specific stressors and mediators of these stressors and how they could be modified to decrease the risk of AHT to young children. From

a clinical perspective, this association might warrant changes in the threshold for physicians to evaluate for AHT during times of economic stress.

The relationship between recession and AHT rate might not be surprising given previous data that supported an association between poverty and all types of physical abuse. However, this is the first study to focus on a specific exposure, the recession, and a specific outcome measure – county level AHT rates.

Individual poverty wasn't assessed per se but recession as a societal level risk factor was. Although work in public health is often limited to identifying individual level risk factors to identify people at high risk, the greatest improvements in populations health are likely to derive from societal interventions, because the majority of cases of poor public health outcomes arise outside the more easily identified extremes of risk. Therefore, although targeting people at high risk can have a dramatic effect on individual risk, because only a small percentage of people are at high risk, this approach might not have a major effect on population –level rates.

Parenting Support: The notion that parents do not necessarily have an innate ability to parent effectively is now recognised and the need for "efficacy in parent education" has grown (Miller and Sambell 2003:33). Moran et al (2004) suggest the likely benefit in 'normalising parenting support as a universal right' as most parents need support at some point'. With a particular focus on parental discipline, Redman and Taylor (2006) point to the need for health professionals to provide consistent advice about alternatives to physical punishment to parents who are seeking those alternatives. This view is supported by Iwaniec (2006) who emphasises that parents who are faced with parenting difficulties should be provided with help when it is requested. The dangers of inappropriate intervention are described by Dakof and Taylor (1990) who stress that individuals who request help and don't receive it, or who receive criticism of how they are handling the situation are discouraged from seeking further help.

The problems that parents of a persistently crying baby might bring to professionals is specifically discussed by a variety of authors. Long and Johnson (2001) highlight the evidence that those parents and carers who complain to professionals that their baby cries excessively, actually do have a baby who cries more frequently and for longer than most (St. James-Roberts et al 1993; Baildam et al 1995). Bar et al (2000) confirm that babies who cry excessively will do so despite the quality and level of parenting provided and all babies have a normal crying curve which starts at 2 – 3 weeks and peakes at 5 – 6 weeks. Long and Jonson (2001) found that a baby's excessive crying can promote feelings of 'living on the edge', social isolation and 'gradual introversion' for families. They highlight the fear parents have of losing control:

"The most significant fear for parents... was the danger of non-accidental injury to the baby. Such fears, exhaustion, and the occurrence of intermittent period of especially heightened tension, led to a pattern of approaching and withdrawing from a point of total loss of control: living on the edge". (p158).

If professionals are to understand the value of their interventions aimed at helping parents cope with the stress incurred by their child's behaviours such as persistent crying, there is a need to understand the context in which taht stress manifests itself, how and why it may increase, the potential outcomes that may result and what helps increase parental coping strategies.

Parenting behaviour and stress: Stress is seen as an especially prominent antecendent in violence towards children. Stressors include background or environmental stressors such as noisy environments and in particular, uncontrollable noise (Straus 1980; Geen 1990). A crying baby can be described as uncontrollable and its effects on parents and caregivers can be powerful (long & Johnson 2001; Wade et al 2005). Smith et al (1995) found that a combination of factors were prevalent in families where there were high levels of physical punishments. Underpinning these discussions is the proposal for a model of parenting which is based on Bronfenbrenner's (1979) ecological perspective of parenting which considers parent.child interaction and behaviour amid the context of parental characteristics, child characteristics and family environment (Belsky 1984). These factors are explicit within the DH (2005) 'Framework for the Assessment of Children in Need and Their Families' and are as relevant today in the application of Early Help Assessments as they were then.

Watkins and Cousins (2005) draw attention to the interplay between situational context and structural context in which physical punishment of children occurs. Whether or not parents cross the line between legitimate and non-legitimate punishment seems to stem, in many cases, from a battle to cope beneath a constellation of stressors leading to frustration and anger.

The effect infant crying and other behaviours, such as poor sleeping patterns and difficulties in feeding, have on parents, includes reduction in coping ability, poor parent/child interaction, reduction in self-esteem, exhaustion, frustration and anger (DH 1995; Iwaniec 2006; Long and Johnson 2001). All of these behaviours can potentially be the trigger which, in some people, will manifest itself as frustration, then aggression (Berkowitz 1978). In addition inconsolable crying can trigger a series of events that may lead some parents to shake their baby with sometimes fatal consequences (Showers 1992; Reijneveld et al 2004; Barr et al 2006).

The success of any coping strategy depends on the controllability of the situation. Coping strategies relying on problem solving may lead to increased frustration and distress when used in a context where the stressor cannot be controlled and where there is no response (Folkman 1992; Compas et al 1988). Taking excessive infant crying as an example, Long and Johnson (2001) found parents eventually accepted that coping involved support through the problem rather than solving the problem (i.e. stopping the baby crying) which was frequently an impossible task. The need for a careful approach towards a responsive professional intervention that is rooted in evidence is, therefore, crucial.

In conclusion, the literature on the subject of parental coping draws attention to the need for parenting education and support which is 'normal' and the professional response to which should be 'universal'. The stress of a crying baby, which every parent will experience as the increase in infant crying is normal, can impact on parenting ability and can have a potentially negative impact on child welfare.

Cost: The cost of AHT, whether or not the baby survives, are significant potentially including initial inpatient hospitalisation (PICU), long term medical services including physio therapy, occupational therapy, speech and language therapy, special education needs input, foster care, family proceedings, criminal proceedings, prison costs, probabtion costs, Serious Case Review costs, loss of societal productivity and occupational revenue.

Peterson et al (2014) assessed 1209 patients with AHT and 5895 matched controls. Approximately 48% of patients with AHT received inpatient care within 2 days of initial diagnosis, and 25% were treated in emergency departments. AHT diagnosis was associated with significantly greater medical service use and higher inpatient, outpatient, drug, and total costs for multiple years after the diagnosis. The estimated total medical cost attributable to AHT in the 4 years after diagnosis was $47 952 per patient with AHT (2012 US dollars) and differed for commercially insured ($38 231) and Medicaid ($56 691) patients. They concluded that children continue to have substantial excess medical costs for years after AHT. These estimates exclude related nonmedical costs such as special education and disability that also are attributable to AHT.

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