‘Early and self-injurious behavior in young children born at-risk: a preliminary analysis’

SIR–Advances in medical and nursing care have led to the increased survival of term and preterm infants with serious medical problems who are vulnerable to later developmental delays and related problems. Among the most clinically challenging and scientifically daunting developmental problems is self-injurious behavior (SIB). Why some children with developmental disabilities repeatedly and persistently injure themselves, some so severely to the point of tissue damage and often times permanent scarring, has remained a mystery eluding a single solution. Although stereotyped movement disorders including self-injury are associated with numerous syndromes and etiologies underlying mental retardation and developmental disabilities (e.g., Lesch-Nyhan syndrome and fragile X syndrome), the ontogeny of the behavioral disorder is still poorly understood. Despite the costs associated with caring for those with chronic SIB, little is known about the behavioral and biological mechanisms associated with the initial development of the disorder and hence we are limited in our ability to prevent its occurrence or intervene early to ameliorate its consequences.

We recently reviewed our experiences with a sample of children (n=25) at risk for later developmental delay/disability and associated behaviour disorders. The perceived risk was for reasons related to medical conditions that created a need for extended hospitalization (including bronchopulmonary dysplasia, congenital airway obstruction, congenital heart disease, gastro intestinal anomalies such as short bowel syndrome, cystic fibrosis, renal impairments, and neurological anomalies). A retrospective postal survey of families was completed using the Repetitive Behavior Scales (RBS) to identify forms of early stereotypy and self-injury. The RBS consist of items designed to elicit caregiver responses in relation to the presence or absence of specific stereotyped motor movements and specific forms of self-injury, and to determine the perceived severity of these behaviors.

The children in the sample were all considered to be developmentally delayed to different degrees. Half of the children in the sample were Caucasian, one quarter were African-American, with the remaining quarter Hispanic, Native American, and Asian. Three quarters of the children were male. At time of survey, mean age of the children was 58 months (range 36–78 months), and in principle they were sufficiently mature to have developed aberrant stereotyped and/or self-injurious behavior.

Fourteen of the children were reported by parent(s) to have exhibited at least one form of stereotyped or self-injurious behavior in the previous month. The mean age of reported onset was 25 months for stereotyped behavior. Twenty-five percent of respondents suggested that the stereotyped behavior had become increasingly problematic since time of onset. Nine families reported behavior management problems related specifically to the stereotyped behavior. Seventy-one percent (n=10) of the children who were reported to engage in stereotyped behavior, did so on a daily or hourly basis. Of these 10 children, the most common forms of stereotyped movement (in order of frequency) were hand flapping, hand mouthing, head tilting, and head turning. Covering ears, head nodding, and rigid body posture were the next most common forms of repeated movements; followed by body swaying, head rolling, covering eyes, looking at hands, lip sucking, and finger wiggling. Body rocking, teeth grinding, and finger flicking occurred less frequently than once a day. Of the 10 children with daily or hourly occurrences of stereotyped movement, eight had multiple stereotyped movements that included 2 or more separate topographies or forms of behavior occurring on a daily or hourly basis. Of the four children reported to explicitly self-injure, the most common form of SIB was lip biting (n=5), followed by head banging (n=2), hand biting (n=2), self-slapping (n=2), eye poking (n=1), skin picking (n=1), and hair pulling (n=1). For self-injurious behaviour, the mean age of reported onset was 34 months.

Children who are born with medical conditions requiring extended hospitalizations may be at risk for later behavioral problems of development. Half of our sample of children were reported by primary caregivers to have some form of aberrant repetitive behavior (i.e. stereotyped and/or self-injurious) that occurred on a daily or hourly basis. It is clear that many questions germane to basic developmental and behavioral processes of this most severe behavioral disorder remain unanswered. Given the relatively small sample size, these data are descriptive and may provide an initial impetus for further research, designed to test directly hypotheses that are specific to biomedical risk factors related to the development of self-injurious behavior. In particular, it may be important to examine the relationship between qualitative differences in the quality of general movements in infancy, and quantitative differences in motor control and behavioral development.

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Management of drooling: 10 years after the Consortium on Drooling 1990

SIR—We read with interest the review contribution by Peter A Blasco1 on the therapeutic options in the management of sialorrhea. The author comes to rather pessimistic conclusions: oral medication has unacceptable side effects in one third of the patients; surgery is reserved for the worst cases; intraoral appliances could be effective, but there is a lack of practical experience and scientific data on efficacy.

The recently introduced therapy by intraglandular application of the botulinum toxin (BTX) has not received the attention in the paper we think it deserves. We believe that BTX will become a highly important contribution to the successful therapy of severe drooling. A recent query in PubMed will appear to show a child under an anesthetic mask), needle injection, aspiration pneumonia' does not necessarily follow from the exposure to invasive technology. Whether or not intraglandular botulinum injection is 'minimally invasive' is arguable. The need for topical anesthesia, general anesthesia (although it was not mentioned in the text, a picture from the article by Jongerius et al.3 appeared to show a child under an anesthetic mask), needle injection, restraint, and repeated treatment, all contribute to a picture that seems more than minimally invasive. The argument that 'this therapy might also reduce the frequency of aspiration pneumonia' does not necessarily follow from the experience reported to date. Those administering intraglandular botulinum should be aware of a case report published nine years ago, which describes a child who lost the ability to feed orally and required a surgical gastrostomy.4 In our

References
opinion, the critical element, was the thickening of secretions in a child who was functional, but in retrospect, only marginal in his ability to swallow food. The botulinum toxin studies have varied in terms of which glands were targeted. For example, Bothwell et al.\(^1\) only injected the parotid, which produces a thin secretion that is more watery than the viscous saliva of the submandibular and sublingual glands. In this setting, the propensity toward aspiration and worsening dysphagia may actually increase. This, of course, could happen with oral anticholinergics, but the drug can be stopped in a very short time if matters deteriorate. I have encountered this situation clinically: that is, the need to discontinue anticholinergic oral drugs because of worsening ability to swallow.

Intraglandular botulinum toxin has received a lot more attention than the use of intraoral appliances simply because there are now so many clinicians using it intramuscularly, and of course, it is being aggressively marketed. In contrast, there are an exceedingly small number of dentists primarily devoted to the cerebral palsy population, who are also familiar with the intraoral devices that are designed specifically for oral-motor training. I wish it were the other way around. At this point, the true value of the intraoral appliance and intraglandular botulinum toxin are yet to be demonstrated.

In the final analysis, the best comparison will be a study, probably single subject design, directly comparing these various treatments.

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