Oral mucosal Bleeding: A Nurses View.

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Introduction

The Wellington Haemophilia Centre currently has 4 children registered with severe haemophilia A aged between 17months and 25months. All have experienced oral mucosal bleeding before the age of 13 months. The experience of caring for these children has prompted the author to consider the impact of oral mucosal bleeding in young children with severe haemophlia from a practical standpoint!.

Oral Mucosal Bleeding

In Freud's psychoanalytic theory, the oral stage is the earliest stage of psychosexual development (from birth - approx. 18 months) during which the infant's needs, expression, and pleasurable experiences centre on the oral zone. Oral exploration by young children, with severe haemophilia can cause injury and bleeding from the delicate oral mucosa.

This problem has been well recognised:-

- In 1966 Baehner & Strauss found 22/114 (19%) patients with severe haemophilia between 1-12 months of age had suffered oral bleeding (and this was the most common reason for bleeding in this age group) (1)
- Kulkarni et al found that 9.6% of the 404 children they followed had suffered oral mucosal bleeding as their first bleed (2)
- Kulkarni et al also found 30% of children with haemophilia between 6-19 months had had oral mucosal bleeding (2)
- Onwuzurike et al found tongue and mouth bleeding in 37/49 (75 %) children with severe haemophilia in the first 30 months of life (3)

Wellington's Recent Experience Of Oral Mucosal Bleeding In Young Children With Severe Haemophilia

4 children from separate families were born in the Wellington region in the 8 months between April 2010 and January 2011. This "little" cohort came from a mixed background of haemophilia pedigrees and with different experiences of haemophilia diagnosis. All have had oral mucosal bleeding.

	Age at diagnosis	Reason for diagnosis	First bleed	Age at first bleed	treatment of oral bleeding	Duration of this bleed
1	Birth	Mother known carrier	Frenulum	9 months, 11 days	Tranexamic acid	30 days
2	4 months, 13 days	Unexplained Bruising on torso (NFH)	Frenulum	10 months, 29 days	Tranexamic acid rFVIII	22 days
3	5 days	Bruising following delivery (NFH)	Oral bleeding	7 months, 10 days	Tranexamic acid	11 days
4	1yr 14 days	Fell with Pencil in mouth (NFH)	Fell with Pencil in mouth	1yr 14 days	rFVIII	3 days

(NFH)= No Family History of Haemophilia

Oral Bleeding was:

- The first bleeding episode In each of these patients
- The reason for first exposure to rFVIII for 2 patients.
- The event that led to the diagnosis of haemophilia for one child.
- The cause of 2 of these children being admitted to ICU.

  Both after falling with pencils in their mouths, causing sublingual bleeding and haematomaís which required intubation to maintain their airway.
- Very distressing for the parents in all cases.

Discussion

There is no easy way for a parent to discover their child has severe haemophilia, Beeton et al described the diagnosis of severe haemophilia as an "emotional shock, which caused grief, guilt and loss of self-esteem" (4). This is the case for most parents irrespective of a family history of haemophilia or not. However those with a family history do often, in the author's opinion, seem to be able to be more emotionally prepared for the trying time when their child bleeds. Whether this is due to being diagnosed earlier and so having more time, or because they are more able to envision the longer term outcomes because they have relatives who have grown out of this phase is uncertain.

However this experience has helped me consider the education and preparation I give parents after a diagnosis of severe haemophilia. Many of our early education focuses on joint and muscle bleeds and how prophylaxis aims to limit long term damage. Oral mucosal bleeding is often a parentís first experience of a bleed. Even a small bleed in this area can be visually dramatic due to a mixture of blood with saliva. A small child with oral bleeding typically presents with dried blood in their hair, on their face and on their clothes. Re-bleeding is common due to the nature of the oral environment, the activity levels and oral focus of small children and the friable nature of clots in people with haemophilia. These bleeds often go on starting and stopping for days or weeks.

It is important to prepare parents of children with severe haemophilia adequately for the possibility of oral mucosal bleeding by informing them about this common complication and providing them with and practical advice on management of this difficult to control bleeding problem.

Points to Consider

- Oral mucosal bleeding is common in the 6-18 month age group
- Oral mucosal bleeding is often a parent's first experience of bleeding in their child, and it can be very frightening due to the obvious nature of blood in the mouth and particularly with young children who dribble!
- Frenulum bleeding can be very difficult to bring under control
- The long term affects of oral mucosal bleeding are small and so it may not be something that treaters spend much time educating their patients about
- Even with a family history of haemophilia it is still very alarming to have your child bleeding in such a visual way
- The use of cold foods like ice cream and tranexamic acid are our standard initial treatment for oral bleeding that doesn't involve swelling of the sublingual space
- These bleeds can often re-occur over a number of days and weeks, significant blood loss can therefore occur without detection

1 BAEHNER RL, STRAUSS H. Hemophilia in the first year of life. NEngl J Med 1966;275:524-8

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3 ONWUZURIKE, N., WARRIER, I. and LUSHER, J. M. (1996), Types of bleeding seen during the first 30 months of life in children with severe haemophilia A and B. Haemophilia, 2:137-140. doi:10.1111/j.1365-2516.1996.tb00156.x

4 BEETON, K., NEAL, D., WATSON, T. and LEE, C. A. (2007), Parents of children with haemophilia - a transforming experience. Haemophilia, 13:570ñ579. doi:10.1111/j.1365-2516.2007.01494.x

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