



# Inherited Bleeding Disorders- The Nursing Experience of Patient and Family Care Needs in the Paediatric Setting.

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## Introduction

This qualitative study aims to assess the perceptions of nursing staff who care for patients with severe bleeding disorders and their families. Are we meeting their needs? Do we as nurses have more to offer in service development?

## Objectives

To determine how nurses perceive their role now, and identify, if possible, their perception of the future role of nurses in the care of these patients.

## Methods

A questionnaire was designed addressing components of 'in hospital' nursing care for patients with inherited bleeding disorders. Open ended questions were chosen to facilitate the expression of opinions, thoughts, concerns or ideas from nursing staff. Replies to the questionnaire were then divided based on length of the nurses working experience ie. > 10 years or < 10 years, to see if acquired experience had any influence on perceptions, needs and practices.

The questionnaire addresses the following-

- Identification of specific care needs for patients.
- Evaluation of whether the service is perceived by nurses to be meeting those needs? If not, why not?
- Definition of the nurse's perception of his / her role in the multidisciplinary care of these patients
- Do nurses have more to offer?

Staff were given a 2 week time frame in which to anonymously answer the questionnaire. Questions were limited to 5 to increase the likelihood of staff responding.

Number of years qualified...

Length of time working with patients with inherited bleeding disorders... \_

( if working in Emergency Department/ Theatre/ - please indicate approximate exposure to such patients, ie weekly/ once/ twice per month/ rare admissions.

Previous experience working with patients with bleeding disorders (if you have worked elsewhere/ abroad)

1 Do you think patients with bleeding disorders eg Haemophilia have any specific nursing needs as opposed to patients without bleeding disorders? Physical/ emotional/ psychological/ medicinal...If yes, please elaborate.

2 Where do you see your role in the care of a child with a bleeding disorder and family admitted to hospital, whether for treatment of acute bleed or for another unrelated procedure/ issue?

3 What is your perception of the Haemophilia Clinical Nurse Specialist role and function within the care pathway of a child with bleeding disorder and family admitted to hospital?

4 Do you feel there are service gaps or anything that hinders the implementation of your nursing care? Do you feel issues such as adequate analgesia are achieved for these patients? Does administration of Coagulation Factor Concentrate prove to be a challenge/ concern for you? Please elaborate...

5 What would you perceive is needed to help your nursing practice and help you to maintain best standards in nursing a patient with a bleeding disorder?

If you have any further opinions or comments to make in relation to nursing care, and the nurse's role in the treatment and care of children and their families with severe bleeding disorders, please feel free to elaborate below or complete additional pages...

"A significant role of the nurse is early intervention in the treatment of a bleed & safely preparing a child for a surgical procedure..."

"The CNS has a central role in the care delivery... they provide consistency within the team"



## Results

A broad cross section of nursing opinion had been sought from all wards and departments involved in any way with the care of children with inherited bleeding disorders. With a response rate of 59% divided approximately 48%/ 52% between staff with less than 10 years and greater than 10years qualified nursing experience, a good picture of varied experiences was captured by the questionnaire.

As a qualitative approach was taken, experiences and opinions were expressed in each response. Although a quantitative questionnaire may have increased the response rate, valuable opinions and experiences may not have been captured, nor an honest opinions shared by some staff .

## Discussion

The responses showed similar opinions, perceptions and attitudes irrespective of the length of time qualified, or experience in nursing the patient with an inherited bleeding disorder. All respondents cited that emotional, psychological and physical needs are more specific to children with inherited bleeding disorders as opposed to caring for children without a bleeding disorder. The chronic nature of bleeding disorders was focused on by several respondents as adding to the anxiety, educational and pain management needs of the patient.

The nurse's role is unanimously perceived as encompassing a holistic approach to the safe treatment and care for the child and their families in conjunction with the Multidisciplinary team. Also mentioned is a liaison role between the CNS and multiple disciplines involved in the child's care. Parental education and support is also cited, however a large portion of this is focused on the specific role of the CNS.

The perception of the CNS role was wholly positive with some suggestions that the role ought to be expanded. There seems to be a reliance on the CNS role by nursing staff especially in hospital areas where the care of patients with inherited bleeding disorders is infrequent or sporadic. The CNS is viewed as a link between the disciplines, a source of knowledge and support for families, patients and staff.

Cost effectiveness was mentioned as the CNS sees patients in clinic, educates families for home treatment and therefore reduce the need for hospital stays.

Interestingly, nowhere was there a mention of the perception that the CNS role deskilled the staff nurse's practice when it came to the care of these patients, but rather, the CNS was relied upon for education and practical support at ward level.

Overall the Haemophilia service in Ireland was deemed to be 'excellent', with citations that other services ought to look to the Haemophilia service as a role model for practice. Gaps in service however were thought to most likely occur out of hours. Bed shortages, which meant admitted patients being cared for on a non haematology ward, left a gap in care by experienced nursing staff, although staff in these areas did feel they knew how and where to source help and support when needed.

Suggestions relating to what was perceived to be needed to help staff in their nursing practice mainly came from staff in areas other than the haematology ward/ day unit. All respondents found the regular ward level discussions and practical sessions of great benefit, as there seems to be a perception of fear surrounding the administration of coagulation factor concentrates.

The development of a nursing care folder focusing on the nursing care needs such as pain management, and mobility was suggested because it is perceived that most resources at ward level are medical texts and policies.

A visual algorithm or diagram for pre & post operative management of a patient in theatre with a bleeding disorder was suggested as a step by step, easy to follow, flow sheet as theatre staff in particular only deal with these patients for a short portion of their hospital stay & there for many fears and uncertainties surround these patients when they arrive in the department with a CFC infusion. Fear of the inability to control bleeding being the prime fear, in conjunction with lack of understanding of CFC infusions.

These fears are also echoed in the Emergency Department, as delays may arise following triage with regards the prescription of factor and obtaining the factor from the haematology lab. This is thought to subsequently delay initiating prompt treatment of bleeds.

## Conclusion

Feedback was unanimously supportive of the service provided by the Haemophilia team in Our Lady's Children's Hospital, Crumlin. Even at times where the experience of staff was felt to be somewhat lacking or there was a question of confidence in their own nurse practice competency, there was definitive confidence in the collective support of the more experienced nursing staff working on the haematology ward and the indispensable resources provided by the CNS.

While there will always be room to expand and develop within the service, it seems the needs of nursing staff are being fundamentally met in order to safely carry out the holistic nursing care of children with an inherited bleeding disorder and their families.

Suggestions and ongoing feedback may be incorporated into reviews of nurse practice development as a whole.

" if we where to encounter more patients with bleeding disorders I would feel more confident... however I think that we are well supported"

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