Canadian Association of Nurses in Hemophilia Care

Job Description

March 2006
MISSION STATEMENT

The Canadian Association of Nurses in Hemophilia Care (CANHC) recognizes the need to ensure a high standard of nursing practice, education and research. In order to achieve quality nursing care for people affected by hemophilia and other bleeding disorders, we strive to enhance professionalism through partnerships, collegiality and mentorship.

NATURE AND SCOPE OF THE HEMOPHILIA NURSE COORDINATOR

The role of the Hemophilia Nurse Coordinator is dynamic, comprehensive and expansive. The Hemophilia Nurse Coordinator is the link between the patient and members of the comprehensive care team, the community and secondary service members. He/she plays a key role in patient care management, and provides care and education to the hemophilia population and those who care for them. Thus, the nurse plays a critical role in assisting the patient’s personal health management and in improving/maintaining their quality of life. There are five key areas of practice that assist the Hemophilia Nurse Coordinator in the role: clinical practice, communication, outreach services, administration and research.

This a generic "inclusive" job description and does not replace local job descriptions or standards of practice, but was created to describe and capture the depth and breadth of hemophilia nursing care in Canada.
The Hemophilia Nurse Coordinator will display the following competencies in the knowledge base of hemophilia:

**Knowledge—Skills and Application**

- Etiology of bleeding disorders  
  - (Hemophilia; other factor deficiencies; vWD; platelet dysfunction)
- Basics of coagulation
- Diagnostic tests
- Genetics:  
  - Transmission
  - Pre-natal diagnosis
- Bleeding Symptoms i.e. bleed sites
- Assessment & treatment:  
  - According to bleeding
  - Calculation of dosage
- Knowledge of all blood products available
- Knowledge of complications:  
  - Physical (vascular; neurological)
  - Hepatitis (A, B, C, D)
  - HIV
  - Inhibitor
  - Thromboembolism
  - Allergic reactions
- Psycho-social issues
- Pain assessment & control
- Physiotherapy (w/physiotherapist):  
  - Exercises
  - Anatomy
  - Range-of-motion
- Central venous line guidelines
- Vaccination guidelines
The Hemophilia Nurse Coordinator will display the following competencies in the area of clinical practice:

Clinical Practice—Skills and Application

- Physical assessment
- Assessment of bleeding: Signs & Symptoms
- Assessment of pain (as per protocol)
- Preparation of blood products (as per protocol)
- Infusion of blood products (as per protocol):
  - IV > peripheral
  - > central line
- Infusion of DDAVP (SC & IV) (as per protocol)
- Calculation of dosages (as per protocol)
- Blood drawing technique (as per protocol)
- Administration of fibrinolysis inhibitors (as per protocol)
- Treatment with fibrin sealant (as per protocol)
- Administration of vaccines
- Central venous line:
  - Accessing a CVL with an IV system
  - Heparin “locking” a CVL
  - Blood drawing from a CVL
  - Dressing care
- Preparation of annual evaluation (as per protocol)
- Coordination & running of annual evaluation clinic
COMMUNICATION

The Hemophilia Nurse Coordinator will display the following competencies in the area of communication:

- Demonstrated ability to communicate with children and their families including stressful conditions. Collaborate and work within an interdisciplinary team.
- Active liaison between the Director of the center, patient, family, other health care professionals and the community.
- To keep accurate patient records, databases, and registry with high degree of confidentiality.
- To prepare monthly reports on clinical activities.
- Competency in telephone assessment skills; clear articulation and listening skills to patients/families.
- Coordinates and facilitates comprehensive care team meetings.
- Accurately documents assessment, plan, interventions and evaluation of client/family responses including telephone advice given in the clinical health record.
- Acts as client/family advocate in areas such as treatment plan, conflict management and client/family dissatisfaction situations.
- Represents nursing in organizational/community forums focused on the educational needs of the client population.
- Demonstrates knowledge of community resources.
- Proficiency in obtaining a health history.
- Ability to advocate for patients/families.
- Demonstrated ability to work as a member of a multi-disciplinary team.
- Ability to communicate on individual basis and conflict resolution.
- Speaks articulately and persuasively, expresses oneself clearly, concisely and with impact. Listens respectfully to the contributions of others.
- Demonstrates good communication skills (written and oral).
The Hemophilia Nurse Coordinator will display the following competencies in the area of Outreach services:

- Act in the expert role as a resource for multidisciplinary providers from emergency departments, inpatient units and community agencies in providing consistency in the quality of care.
- Maintain contact with the public, health professionals, and members of related support organizations on a local, provincial or national level.
- Meet with representatives from community agencies, school administrators, school leaders, child care providers, and various other interest groups and counterparts on other sites, and in other centers.
- To be responsible for: the follow-up of all patients, to arrange for care in the local health facility, maintain contact with patient to ensure homecare program compliance, The co-coordinator will need to make home visits where indicated
- Provide telephone advice on a regular basis to all disciplines within hospitals and community agencies.
- Provide and maintain a public source of current reference materials for distribution to patients/families.
- Support proactive strategies to enable patient self-advocacy.
- Assist local chapter / camp planners by helping to provide educational learning for patients and their families during the camp experience.
- To teach children at camp about their inherited bleeding disorder and how to self-infuse factor
- To arrange and coordinate traveling clinics in those provinces that requires this service to improve outreach care for hereditary bleeding disorders.
- To have an active role in participating in the education of nursing and other allied health students.
The Hemophilia Nurse Coordinator will display the following competencies in the area of administration:

- Hiring, training and overseeing data entry personnel
- Ensuring information to patient post annual assessment is communicated to patient and family doctor
- Ensuring that post assessment recommendations are carried out i.e. referral made to other discipline
- Initiating innovative strategies for smooth clinic function
- Advocating for appropriate clinic funding and support
- Advocating for appropriate and timely treatment for patients
- Developing systems for effective patient care in other areas or departments
- Evaluation of current systems
- Monitoring clotting protein factor usage
- Placing factor orders
- Communicating with regional blood banks on current inventory
- Communicating with regional service coordinator
- Maintaining complete and updated records
- Mailing or sending out product updates or information to patients and families, i.e. Bioset™
- Acquiring computer skills: power point; word; etc.
- Ensuring knowledge is shared with new nurses
The Hemophilia Nurse Coordinator will display the following competencies in the area of research:

- Assess bleeding disorder patients for inclusion, exclusion criteria, and appropriateness of study participation
- Explain and/or obtain informed consent (when appropriate) for each study participant, documenting refusals according to protocol. Ensures that all enrolled study patients are truly informed of the risks and benefits of study participation.
- Educates the patient, family and caregivers on issues related to clinical research
- Advocates for and ensures the fair and ethical treatment of all patients with bleeding disorders who have consented to participate in research projects.
- Acts as a liaison between the patient group and the study coordinator/principal investigator to communicate protocol changes, potential risks, benefits, adverse reactions or complications in a timely manner
- Participates in and/or facilitates the accurate and timely collection of specimens or data for input into the CHARMS database program or other ethics approved open clinical research project designed to evaluate patient care outcomes and improve quality of care for individuals with inherited bleeding disorders
- Perform as well as instructs other staff on the function of venipuncture, preparation of specimens, handling, packaging, shipping of hazardous materials to the appropriate sites
- Critically analyses interdisciplinary research literature and recommends changes in clinical practice based on valid and generalizable findings
- Promotes and implements the use of valid, relevant and current research findings into policies, procedures and standards of hemophilia nursing care.
- Actively participates in nursing research projects and collaborates in interdisciplinary projects as necessary
- Identifies researchable nursing practice questions by critically analyzing practice and relevant research.
- Disseminates specialty knowledge or research findings through presentation and/or publication at local, regional, national and international levels.
- Contributes to the existing body of nursing knowledge through presentations, conferences and journal publications.
This project was developed through a collaborative effort by the following CANHC members:

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