

# THE ROLE OF THE NURSE IN HEMOPHILIA CARE

# Changing Roles of Nurses

- Varied roles due to differences in:
  - Backgrounds
  - Culture
  - Geography
  - Access to health care
  - Availability of factor replacement products
  - “Systems of Care”
    - Insurance
    - Home care services

While there are some responsibilities that are universal for all nurses, individual roles vary significantly among nurses in hemophilia care. Roles vary depending on the background and interests of the individual nurse and the culture of his or her setting. This culture includes the expectations of other members of the team, the roles of other nurses in the same medical setting, and the degree of independence that nurses are permitted. Many differences relate to geography, with nurses having varied licensure and educational requirements within countries, states, and provinces. Rural and outreach nurses will have different levels of responsibilities and independence than nurses working in urban or metropolitan areas.

Access to health care for individuals with hemophilia and availability of factor replacement products also impact how the nurse will work with the patient with hemophilia. In some areas of the world, nurses have large responsibilities related to dealing with payment and other health-related systems, including insurance and healthcare services, which may not be issues in other parts of the world.

## Current Nursing Roles

- Direct care
- Communication
- Teaching
- Counselling
- History taking and assessment
- Advocacy
- Assist in behaviour change
- Leadership

Current nursing roles include direct patient care; communication with patients, families and other healthcare professionals; teaching; counselling of patients and families, history taking and assessment of acute bleeding episodes; advocacy in the community for individuals with hemophilia and their families; assisting patients in behaviour change to achieve optimal health; and serving as a leader in the hemophilia community.

## Historical Perspective in Nursing Practice

- Florence Nightingale (1860) defined nursing as *“the act of utilizing the environment of the patient to assist him in his recovery.”*

Florence Nightingale, in 1860, defined nursing as the act of utilizing the environment of the patient to assist him in his recovery. While roles change over time and from place to place, this remains a universal tenant of nursing practice.

# Hemophilia Nursing

- Traditional roles:
  - Treat bleeding episodes
  - Teach self-infusion
- Expanded roles:
  - History taking
  - Assessment of bleeding episodes
  - Participate in treatment decisions
  - Provide more independent follow-up
  - Coordinate total care

Traditional roles of hemophilia nurses include: treating acute bleeding episodes and teaching patients and families how to infuse factor concentrates. The expanded role of the hemophilia nurse is one in which nurses generally will take a family history and the patient's individual bleeding and treatment history; participate in the assessment of acute bleeding episodes; collaborate with the team in making treatment decisions; provide independent follow-up for patients once discharged; and coordinate the total care of the patient with hemophilia.

# Hemophilia Nursing: Education

- Teaching patients and families
  - Help prevent bleeding
  - Educate about treatment choices
  - Build skills to assess and treat at home
- Teaching other nurses and physicians
- Teaching school staff and employers

Education is one of the primary roles of the nurse in the hemophilia community. Nurses are responsible for teaching patients and families about hemophilia, its genetics, and how to recognize bleeding episodes and prevent bleeding. Nurses also teach patients about the treatment choices available and help patients and families build skills to assess bleeds and treat themselves at home. Nurses also have a major role in teaching other nurses within their hospitals and communities as well as physicians and other healthcare providers about hemophilia diagnosis, genetics, complications, assessment, and treatment. Finally, nurses assist in teaching school staff and employers about hemophilia and help advocate for their patients.

# Hemophilia Nursing: Patient/Family Review

- Review of interval activities and interventions:
  - Effective dose? Activities? Response as expected? Splints, other measures used? Physician recommendations followed?
- Education/Review of plan of care
  - Review dose
  - Review product
  - Reinforce early treatment for bleeding
  - Remind family to call with questions
  - Educate community providers

When a patient presents to clinic for a follow-up evaluation, it is often the nurse that will take the interval history of how the patients has done since his last visit. The nurse will help determine if the dose used to treat bleeding was effective; whether the expected response was achieved for each treatment; how other supportive measures were used for each bleed; and whether the treatment recommendations were followed. The nurse will also use this opportunity to review the activities the patient participates in and provide guidance about activities and strategies to promote adherence.

At this time the nurse will also provide education and review the plan of care with the patient and family. This includes reviewing the dose recommended for treatment and prophylaxis, if appropriate; reviewing the factor replacement product to be used as well as the recommended schedule; reinforcing the importance of early treatment for each bleeding episode; reminding the patient and family how to contact the hemophilia team with questions and concerns; and helping plan any necessary education to community providers.

# Hemophilia Nursing: History and Assessment

- An accurate, detailed history and assessment of patients for bleeding episodes and trauma is essential for determining appropriate care
- 5 questions:
  1. What are the symptoms?
  2. How long have the symptoms been present?
  3. What treatment was given and when?
  4. Was there an injury or trauma?
  5. Did a similar problem occur in the past?
- The process is continuous from first notification of event to follow-up

The nurse often plays an important role in helping care for a patient with an acute bleeding episode. An accurate, detailed history and assessment of patients for bleeding episodes and trauma is essential for determining appropriate care. Five questions that can assist in this assessment include: what are the symptoms, how long have the symptoms been present, what treatment was given and when, was there any injury or trauma, and has a similar problem occurred in the past. This process is an important part of the communication with the patient and family. It starts from when the nurse first sees the patient or hears from the family about the bleeding episode and continues until the bleed has completely resolved.

## Hemophilia Nursing: Coordination of Team

- The HTC nurse's role is to :
  - Collaborate with medical director in development and implementation of treatment guidelines
  - Distribute information to:
    - Patients and families
    - HTC staff
    - Hospital staff
    - Community-based medical providers

A hemophilia treatment centre nurse has the responsibility of collaborating with the medical director in the development and implementation of treatment guidelines for patients with hemophilia. The nurse is usually responsible for communicating this information to patients and families, hemophilia treatment centre staff, other hospital staff, and appropriate community-based medical providers.

# Hemophilia Nursing: Research

- Data collection
  - Registry of patients
  - Treatment records
  - Surveillance of laboratory values
    - Individual patients
    - Aggregate data for patient population

In many countries, hemophilia nursing responsibilities have expanded to include research about bleeding disorders. Often hemophilia nurses are responsible for data collection for research protocols. This can include: demographic information about patients, treatment records, medications used, history of bleeding, and surveillance of laboratory values. This data can be for individual patients or may represent aggregate data for a larger patient population.

## Additional Nursing Responsibilities

- Develop/follow laboratory study protocols
  - Order routine lab studies for patients
  - Record labs/flow sheets
- Record keeping
  - Routine visit forms
  - Acute visit forms
- Research
  - Coordinate clinical research protocols

In many locations hemophilia nurses are also responsible for helping to develop laboratory study protocols. Some nurses may also be responsible for ordering routine lab studies for patients and recording laboratory results on paper or electronically. Nurses may also have some responsibility in maintaining patient records. This may include developing templates to provide better documentation, including routine visit forms and acute visit forms, as well as patient treatment logs. Nurses may also be requested to coordinate clinical research protocols for patients with bleeding disorders.

## Additional Nursing Responsibilities

- Factor Concentrates
  - Ordering
  - Home care supplies
- Monitor storage in HTC (temperature of refrigerator, alarms, etc.)
- Communicate with pharmacy or blood bank to ensure adequate supply of all appropriate factor concentrates.
- Act as resource to hospital staff about reconstitution devices, dosing, and reconstitution and administration of factor concentrates.

Often hemophilia nurses are responsible for ordering or overseeing the ordering of factor replacement concentrates for home treatment programs, as well as ancillary supplies that patients or families may need at home. Nurses may be requested to monitor the storage of factor replacement products at the hospital or the clinic. For example, the nurse may need to monitor the refrigerator temperature or check alarms in the clinic or pharmacy. The nurse may be responsible for communicating with the pharmacy or the blood bank to ensure availability of an adequate supply of all needed factor concentrates. Finally, the nurse serves as a valuable resource to many hospital staff members about infusing factor. This can include information about reconstitution devices, appropriate dosing, and how to administer factor.

## Treatment Success: The Nurse's Role

- Include patient/family in plan development
- Assess plan
- Assess family dynamics and skills
- Provide clear, written plan and schedule
- Monitor progress and provide ongoing support
- Review records for patterns, problems, progress

The nurse plays a key role in helping the team, especially the patient and family, achieve success in the treatment of hemophilia. The nurse can help promote successful treatment by including the patient and the family when the plan is developed, routinely assessing the plan and reevaluating the plan when necessary, and assessing the family dynamics and the skills of the individual family members. It is also helpful to provide clear, written plans and treatment schedules, monitor a patient's progress, remain available to provide ongoing support, and to review the patient's records with them to help identify patterns of bleeding, problems of treatment, and progress in reaching the patient's goals.

## Treatment Success: The Nurse's Role

- Acknowledge difficulty of plan
- Initiate follow-up and review of progress
- Ask about potential challenges; listen to response; collaborate on strategies
- Adjust plan to fit lifestyle of patient
- Provide thorough education and skills training
- Review skills
- Maintain professional and supportive role

To promote patient adherence to a treatment plan, it is helpful for the nurse to acknowledge to the patients and families the difficulty of the plan, to initiate follow-up between visits and review progress with the family, ask the patient and family about potential challenges ahead of time, listen carefully to their responses, and collaborate with them on developing strategies to make the plan successful. The nurse may need to work with the team to adjust the treatment plan to better fit the lifestyle of the patient and to provide thorough education and skills training to patients and appropriate family members. It is important for the nurse to routinely review these skills to help maintain the appropriate level of care at home. And, of course, the nurse should always maintain a professional and supportive role for all patients with hemophilia and their families.

# SUMMARY

- Nurses are key members of the team
- They provide the link between the patient and the medical providers
- They have an important role in:
  - Education
  - Treatment
  - Research
  - Support of patient and families to learn to live with hemophilia

In summary, nurses are key members of the hemophilia treatment team as they provide the link between the patient and the other medical providers. Nurses have a crucial role in education, treatment, research, and support of patients and families to help them learn to live with hemophilia and attain optimal health.