

HAEMOPHILIA NURSING

A core competency framework for haemophilia nurses in the UK

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The role of the nurse continues to develop, probably at greater speed than ever before. Would Florence Nightingale ever have dreamt of nurses who could manage whole episodes of patient care from diagnosis, through admission, requesting investigations, prescribing treatments and evaluating outcomes? She probably did – when she instigated the first nursing outcome measures looking at infection control. Nurses can and do, do most things. What is important is that they are appropriately trained and continue to develop skills, that are relevant both to them and the patients for whom they care. Assessing this ability, or competence, requires knowledge and skills in itself. In this paper we describe the process of defining competence in haemophilia nursing. Some of these competencies are transferable from other areas of nursing, others are haemophilia-specific. Together they provide a personal development framework for nurses who work within haemophilia as part or all of their role.

Key words: haemophilia, nursing, comprehensive care, competency

Nurses play a pivotal role in providing comprehensive care to people with haemophilia and related disorders and coordinating care with other members of the multi-disciplinary team, both within hospitals, the community and the patient's own homes.

Clinical nurse specialists in haemophilia and related disorders are advanced practitioners with extensive clinical knowledge and expertise in this specialist field. Nurses use their clinical, communication and interpersonal skills to identify the needs of people with haemophilia and related disorders and to provide care that recognises social,

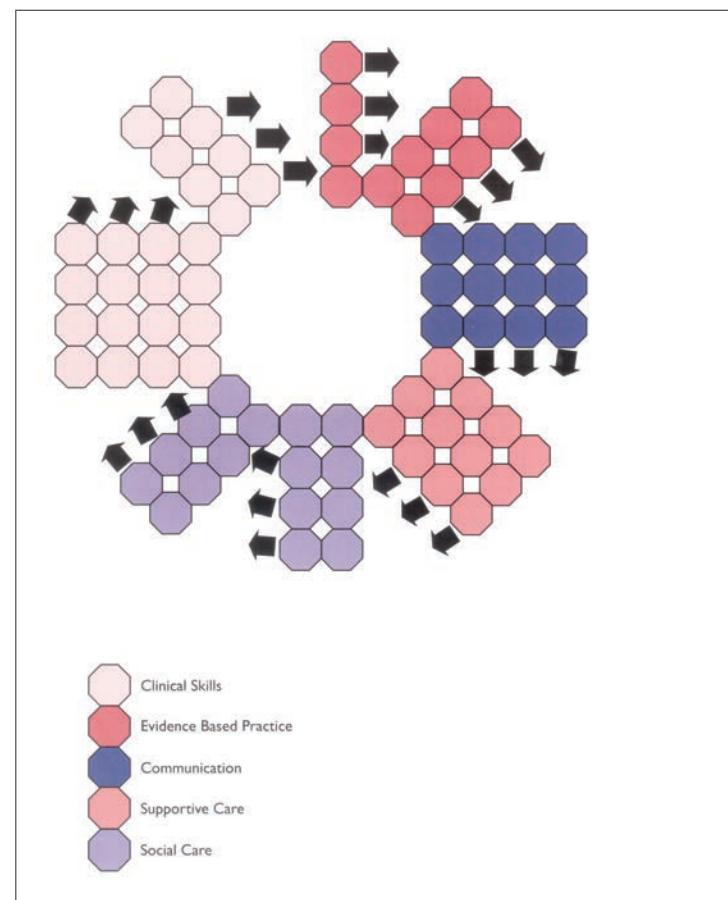


Figure 1: The Stratford Spiral

cultural and spiritual differences throughout a person's life.

Advanced nursing roles within haemophilia in the UK include advanced nurse practitioners; a role recognized by attaining a masters level in advancing nursing practice at accredited universities, clinical nurse specialists and consultant nurses. Clinical nurse specialists are recognized as having five principal functions that encompass clinical practice, advocacy, advice, education and research [1,2]. The key components of the haemophilia nurse consultant role are expert practice, leadership and consultancy, education and training and research and evaluation. To fulfill these roles nurses must be confident and competent.

Competency is the combination of attributes, knowledge and skills that underpin professional practice [3]. Development of competencies should help individuals to continually improve their performance and to work more effectively [4]. A 'competency framework' is a structure

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Competence

A specific range of skill, knowledge ability to do something successful being adequately or well qualified the condition of being capable of to meet demands, requirements

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that sets out and defines each individual competency (such as problem-solving or people management) thought to be central to effective performance and therefore required of individuals and nursing teams.

Competency-based approaches have been widely advocated both to ensure fitness for practice [5,6] and to promote professional and personal development among specialist nurses in the United Kingdom (UK)[8]. As a key part of Agenda for Change – a UK National Health Service (NHS) initiative introduced in 2004, including annual appraisal and personal development plans, linked to pay – the NHS developed a Knowledge and Skills Framework (KSF) under which all nursing staff should:

- have clear and consistent development objectives
- be helped to develop in such a way that they can apply the knowledge and skills appropriate to their level of responsibility
- be helped to identify and develop knowledge and skills that will support their career progression.

In order to help nurses fulfill their role, in 2002 members of the United Kingdom's Haemophilia Nurses' Association (HNA) devised a paper-based, hand-held core competency framework that defined differing levels of haemophilia nursing intervention in key aspects of care. This could be used for individual haemophilia nurses to inform personal development plans as well as teams of nurses in haemophilia centres to develop strategic visions for future service provision. This was subsequently revised and expanded into an electronic tool, stored on a secure website (www.haemnet.com) supported by the HNA. This paper describes the process by which the framework was developed and summarises the core attributes expected of this group of highly specialized nurses.

Analysis

Under the auspices of the HNA, a working party of experienced nurses (MB, DE, KK, NM) was convened, which reflected the plurality of experience, specialism, age focus and geographical location of haemophilia nurses in the UK. The group sought to:

- Identify an agreed theoretical premise of competency
- Describe different aspects of haemophilia nurse intervention
- Map differing levels of expertise within these aspects using descriptors drawn from nursing theory.

Benner introduced the concept that nurses develop skills and understanding of patient care over time through a sound educational base as well as experience [8]. The HNA focus group assessed clinical nursing practice using a variation of this system based on five practice domains:

- Knowledge
- Action
- Problem solving /management decision making
- Interpersonal communication
- Self-management/reflection

These were measured against four levels of practice and academic indicators derived from Benner [8]:

- Novice/advanced beginner (Level 1 certificate)
- Competent (Level 2 diploma)
- Proficient (Level 3 degree)
- Expert/specialist nurse (Masters Level and beyond)

The working party considered key events along a lifelong patient pathway and grouped these into aspects of practice. These areas were then collated into five core frames of practice (clinical skills, evidence-based practice, communication, supportive care, and social care). Each of these frames was to be considered by individual nurses in terms of their achieved levels of practice. Mapping these descriptors onto an assessment grid (known as a Stepford Spiral, Figure 1) provides individual nurses with a visual representation of their achieved competency as well as their required areas of development.

The framework was designed to be used for:

- Self-appraisal, to identify learning needs.
- Within the personal review process to help staff development.
- Strategically, to identify team skills mix.
- For quality assurance and audit purposes (locally or nationally) to define a requisite nursing profile for different types of haemophilia centre (haemophilia centre vs comprehensive care centre etc).

In 2009 the framework was revised to reflect the growing role of haemophilia clinical nurse specialists and consultant nurses [9]. The new competency framework includes additional knowledge domains in six 'satellite competencies': children and young people, inhibitor management/care, clinical care, leadership skills, genetic knowledge and skills, and women's issues.

Results and discussion

The HNA competency framework currently consists of five core domains (communication, research, education, support and treatment; Table 1) and an additional six "satellite" domains (women, children, leadership, inhibitors, genetics and physiotherapy; Table 2). Each level of the framework cites key references and links to the Department of Health Knowledge Skills Framework.

An online version of the framework is now available on Haemnet (www.haemnet.com). This allows nurses, over a period of time, to:

Table 1: The core competency domains

	Level 1	Level 2	Level 3	Level 4
COMMUNICATION				
Haemophilia MDT	Demonstrates understanding of the role of team members and communicates appropriately. Is able to observe and report accurately	Presents cases and raises issues within the team	Initiates and leads team discussions	
Liaison and referral	Liaises with referral agencies under supervision. Demonstrates a working knowledge of the range of specialist services available	Makes referral within the HMDT. Supervises care provision and requirements of individuals needing multi-agency services	Represents the HMDT in multi-agency settings	Makes referral to services outside the HMDT. Negotiates improved service provision and resource allocation for people with bleeding disorders
Interpersonal communication	Communicates effectively within familiar situations	Communicates effectively in a variety of ways and situations	Can mediate and manage conflict	Facilitates the development of others appropriate to needs of patients and their families
RESEARCH				
Audit and resource skills	Avoids wasteful use of resources. Recognises need for data collection in haemophilia management	Audits procedures, policies and protocols	Understands the implication of audit data and uses this to effectively manage resources	Develops audit procedures and uses audit data to improve service delivery
EDUCATION				
Education	Can explain basic haemophilia care and management in a one-to-one setting	Can teach and assess in clinical situations and supports other agencies	Plans and delivers teaching interventions	Strategically evaluates education needs and develops responsive programmes
Training for home therapy	Participates, under supervision, with teaching and training	Implements individual home treatment training	Manages and evaluates training programmes	Develops training programmes and facilitates best practice
SUPPORT				
Advocacy	Recognises the impact that legal and ethical concerns have on the practice of nursing e.g. reproductive choices. Supports the patient and family in the decision making process	Enables patients and their family to make informed health care decisions	Takes leadership role in patient advocacy	Recognises emerging ethical and legal issues and initiates discussion at a professional level
Cultural and spiritual	Aware of the issues that underpin individual spiritual views	Can assess the potential impact of illness on patient's lifestyle, cultural beliefs and support systems	Facilitates discussion in relation to spiritual and cultural issues	Organises appropriate support mechanisms for those involved in spiritual/cultural care
Clinical supervision	Uses clinical supervision to critically reflect upon their developing clinical expertise	Uses clinical supervision skills in the development of others		
Counselling skills	Has effective listening skills, and develops therapeutic relationships	Manages emotionally taxing situations	Is responsive to patients coping' mechanisms	Is confident to challenge dysfunctional behaviour
TREATMENT				
Diagnostic skills	Recognises signs and symptoms of bleeding at common sites	Has a detailed knowledge of pathophysiology to explain presenting symptoms	Assesses physiological functioning and develops intervention plan	Determines differential diagnoses, using examination and investigations
Factor replacement skills	Performs venepuncture in non-problematic situations	Performs venepuncture in more problematic situations. Administers coagulation factors	Formulates a care plan in liaison with other members of the HMDT. Co-ordinates more complex clinical interventions	Prescribes replacement therapy
Clinical decision making	Participates, under supervision, in decision-making	Makes decisions in predictable situations	Facilitates decision-making within the HMDT	Initiates innovative practice

Table 2: The five satellite competency domains

	Level 1	Level 2	Level 3	Level 4
CHILDREN AND YOUNG PEOPLE				
Monitoring health	Communicates with children and young people in an age/developmentally appropriate manner	Observes the behaviour of children and young people and records unexpected changes and concerns	Demonstrates listening and responds appropriately to issues raised by children and young people	Recognises child assent/consent process and acts as children and young people advocate
Enabling children and young people to understand health care needs	Discusses children and young people's views on health and well-being	Provides evidence-based care and information to children and young people and their families	Supports children and young people and their families in a partnership based model of care	Enables children and young people to communicate issues of health, treatment and care
Supporting children and young people in medicine/treatment management	Advises children and young people and their families about managing coagulation factors	Enables children and young people and families to monitor treatment planning and response	Advises children and young people and their families about factor storage, use, transportation and disposal	
Supporting adolescent transition	Provides suitable information about transition from paediatric to adult care	Provides suitable information about transition from paediatric to adult care	Reviews self-management skills of young people to support adult care after transition	Ensures smooth transition from paediatric care/hospital to adult care/hospital
INHIBITORS				
	Recognises risk factors for inhibitor development	Describes screening/detection protocols	Demonstrates detailed knowledge of presenting symptoms and laboratory results	Assesses treatment response and develops treatment plans for bleed management
	Works as part of a team promoting equity in the decision-making process. Supports and motivates other team members	Empowers, motivates and supports others to develop their clinical skills. Takes responsibility for the actions of junior staff	Develops a culture of continuing development and improvement of clinical skills. Promotes autonomy while ensuring the quality and safety of patient care. Takes responsibility for the service-wide quality of care	
CLINICAL LEADERSHIP				
History taking	Take a simple family history of common bleeding disorders and draw a family tree	Take complex history of common bleeding disorders and draw a family tree	Take history of complex bleeding disorders and draw a family tree	
Identifying those at risk	Identify patterns of inheritance in common bleeding disorders	Identify patterns of inheritance in complex bleeding disorders	Use family history to identify patients with or at risk of a bleeding disorder and refer as appropriate	
Intervention	Recognise the impact that genetic information may have on individuals and families	Explain basic modes of inheritance to patients and families	Apply detailed genetic knowledge to inform treatment in complex situations	Order genetic tests and communicate results to patients and families
WOMEN WITH BLEEDING DISORDERS AND MENORRHAGIA				
Monitoring health	Identifies the risk factors to health for women with bleeding disorders	Describes the screening tools available to assess women presenting with menorrhagia	Demonstrates detailed knowledge of presenting symptoms of menorrhagia in women with bleeding disorders	Independently assesses women with bleeding disorders, initiating appropriate screening tests and making further referrals
Education and management needs	Discusses individual's views and knowledge of their condition	Provides evidence-based care and information to women	Supports women to make informed choices regarding treatment and management	Enables women to independently manage bleeding symptoms where appropriate and provides a pathway for when further health care is required
Perinatal care and management	Recognizes the risk factors for women with bleeding disorders through the peri-natal period and understands which situations require urgent referral	Describes the ante-natal care pathways for carriers of haemophilia and women with bleeding disorders	Demonstrates detailed knowledge of the physical, psychological and emotional needs of carriers of haemophilia and women with bleeding disorders	Enables women to make informed choices about peri-natal care and to communicate their needs to other healthcare professionals

- Assess their own level of professional development
- Identify the areas in which they need to develop their skills further track their "journey" to full competence

Launched in 2010, over 200 nurses have registered on Haemnet and many UK-based nurses have used the on-line framework.

The competency framework establishes a baseline educational and practical skills forum for nurses new to haemophilia, which allows progression through personalized development and assessment, to competence at all levels of haemophilia nursing. Many aspects of the framework include transferrable skills such as communication skills, so even 'novice' haemophilia nurses are part way along the road to haemophilia competence.

This tool can be used as part of both formal (manager appraisal, objective setting etc) and informal (own assessment) development identifying areas for further education and learning. Although the UK HNA developed this tool, based on UK nurse training/education models there is no reason why it cannot be applied, perhaps in adapted forms, globally. In this journal, Schrijvers et al suggest that European haemophilia nursing curricula and European principles for haemophilia nursing care should be developed [10]. Modification of the competency framework, in line with local/national nurse education/legal programmes would go along way towards

this. As well as continuing to develop shared practice across the EU.

Conclusion

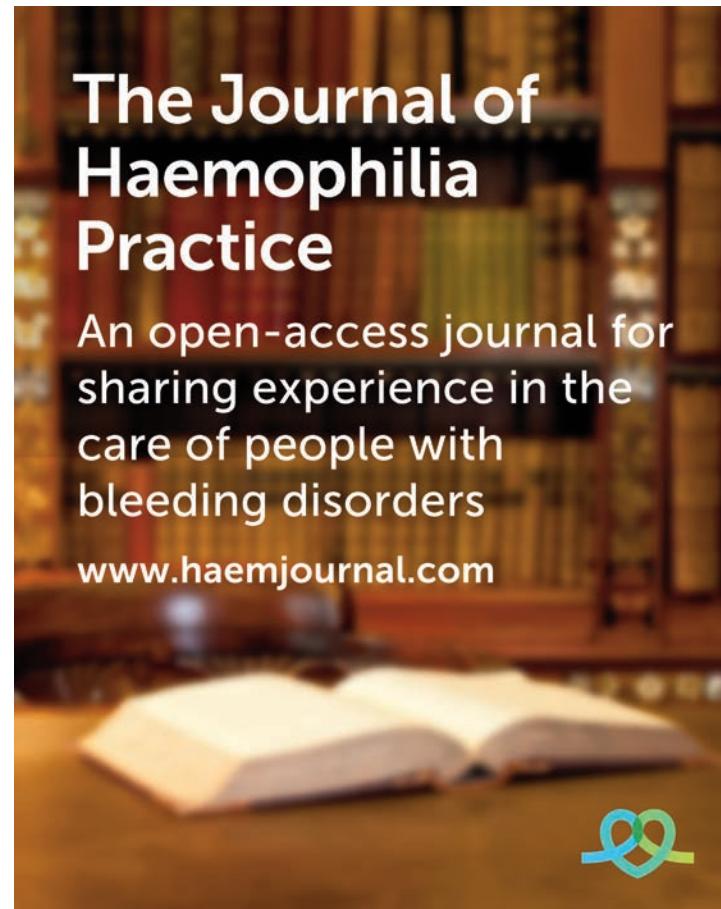
Haemophilia nursing is a complex art; weaving knowledge and skills with scientific doctrine to promote evidence based care, advocacy and self-management skills for people with bleeding disorders. Whilst many legal standards impact upon the role of the nurse across countries, we share more than we realize. The principles of nursing care for patients with bleeding disorders are the same regardless of your language; we care, support, listen, educate, advocate, research and publish. Sharing best practice with fellow nurses impacts beyond the borders of our own hospitals/treatment centres and countries leading to empowered nursing communities globally – come on join in!

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