

## The role of the European haemophilia nurse

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**Background:** A broad scoping exercise was undertaken to assess and quantify haemophilia nursing care in Europe.

**Methods:** A web-based survey in English was sent to known networks of haemophilia nurses working in Europe. This survey included questions concerning the haemophilia treatment centre, educational level, work activities, gaining knowledge/expertise and development in the future.

**Results:** In total, 94 nurses in 14 countries in Europe completed the survey. Overall, the majority (62%) of the nurses had over 20 years' nursing experience, with 44% having more than 10 years' experience in haemophilia. The educational level varied; with highest educational level of attainment being 41% at non-degree level nursing entry qualification, 35% BSc and 24% MSc. 21% worked in a centre where they treat only children, 26% only adults and 53% both. All had good access to treatment. The core activities (rated >80%) of a haemophilia nurse were: prepare and administer medication, venepuncture and CVAD-use (except cannulation), providing education and telephone advice, coordination of (multidisciplinary) care and assistance with clinical trials. Furthermore, 35% stated that they initiated and performed nurse-led research. In the future, almost all nurses would like to develop their expertise and knowledge base by studying at Masters level and above, to have more responsibility, and to conduct research.

**Conclusion:** This scoping exercise provides a baseline assessment of haemophilia nursing across Europe. The results may provide a basis for a more thorough investigation of the current role and the principles of haemophilia nursing care; future opportunities, and the training requirements to develop the specialty.

**Key words:** haemophilia, haemophilia, nursing, comprehensive care, multidisciplinary

Haemophilia is a bleeding disorder in which those affected suffer repeated spontaneous or trauma-induced bleeding



Figure 1: 94 nurses in 14 countries across Europe replied to the survey.

episodes. Repeated bleeds can lead to joint damage and subsequent disabling arthropathy. For 40 years, clotting factor replacement as intravenous therapy has been administered either as prophylaxis or to treat bleeds [1,2]. The physical limitations and high degree of self-management skills needed, affect patients' autonomy and eventually quality of life [3,4]. This and the subsequent advent of comprehensive care centres and has revolutionized haemophilia care, creating the need for a highly skilled and specialized nursing workforce to deal with the complexity of haemophilia care [5,6].

Although, there are notable regional differences across Europe, the haemophilia nursing role has adapted in response to the developments in care opportunities and the associated challenges of viral contamination. In a report entitled 'An Overview of the Role of Nurses and Midwives in Health Leadership in Europe', the NHS Institute for Innovation and Improvement and the European Hospital and Healthcare Federation (HOPE), found broad consensus in the fundamental role of the nurse across

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Europe but not with most specialist nursing roles [7]. This influential report also highlights the need for a more coordinated development of nursing clinical leadership in the face of increasing health demand coupled with the pace of technological innovation.

Although a comprehensive evaluation of the role of the haemophilia nurse across Europe has not been undertaken, there have been some national initiatives such as the UK Haemophilia Nursing Association competency framework [8, 9]. There are also a number of evidence-based nursing procedures in relation to bleeding pathology that are well described in the literature [10-12]. The task for haemophilia nurses across Europe is to evaluate the specialist nurse role. The competencies and skills the haemophilia nurse needs in order to provide high quality care, are not fully defined. Therefore, a broad scoping exercise was undertaken to assess and quantify haemophilia nursing care in Europe.

### Materials and methods

A web-based survey in English was sent to known networks of haemophilia nurses working in Europe. This survey included questions concerning the haemophilia treatment centre, educational level, work activities, knowledge/ expertise, future development and characteristics of the respondents. Each nurse working with haemophilia patients and allied bleeding disorders was asked to respond to the survey. Respondents were asked to forward the survey to other nurses, to attain a high response rate.

### Analysis

Due to some missing items, percentages per answer were calculated proportional to the number of answers available per question, for the descriptive statistics. The chi-squared

test was used to compare categories with each other and observe differences. Differences were considered significant at a  $P < 0.05$ . The computer software Excel (2007 version) was used for count data and SPSS (Version 21, SPSS Inc., Chicago, IL, USA) was used for the statistical analysis.

### Results and discussion

In total, 153 nurses received the survey and were asked to forward this to their haemophilia nurse colleagues (Figure 1). Some 94 nurses in 14 countries in Europe (United Kingdom, Netherlands, Germany, Sweden, Ireland, Switzerland, Norway, Italy, France, Finland, Denmark, Belgium, Austria, and Bulgaria) replied to the survey. Characteristics of the respondents are provided in Table 1. Most (62%) of the haemophilia nurses had more than 20 years' experience as a nurse, however 85% had less than 20 years' experience in haemophilia. The educational level varied; 41% had a nursing qualification (non-degree), 35% had a Bachelors degree in nursing and 24% had a Masters degree. Not all nurses were working full time with haemophilia patients, 50% of the nurses had other nursing activities outside of haemophilia.

### Current practice

The context of where nurses worked in Europe was largely comparable; Table 2 provides a short overview of the settings in which haemophilia nurses work. Approximately 20% were in centres that treated only children and 26% in centres that treated only adults. The remainder were in centres that treated both. All reported good access to treatment, 99% of the centres offered on-demand treatment, prophylaxis and home treatment. Furthermore, the number of severe patients differed per centre.

### Core activities

Activities reported by over 80% of respondents were defined as core activities of the (European) haemophilia nurse, and have been divided in four main domains; treatment, education and support, coordination of care and research (Table 3). Most nurses prepared and administered factor replacement therapy, using different

**TABLE 1: Characteristics of nurse respondents**

Characteristics	Percentage (%)
<b>Experience (years)</b>	
0-5	4
6-10	10
11-20	24
>20	62
<b>Experience in haemophilia (years)</b>	
0-5	32
6-10	26
11-20	28
>20	14
<b>Education nurse</b>	
Nursing qualification	41
Bachelor (BSc)	34
Masters (MSc)	24
Doctorate (PhD)	1
<b>Percentage of time working in haemophilia</b>	
0-25%	4
25-50%	22
51-75%	24
76-100%	50

**TABLE 2: Characteristics of the nurses' work context**

Characteristics setting	Percentage (%)
<b>Clinic</b>	
Adults	21
Children	26
Both	53
<b>Treatment modalities</b>	
On-demand	99
Prophylaxis	99
Prophylaxis and home treatment	98
<b>Number of severe haemophilia patients</b>	
<50	43
50-100	22
>100	34

**TABLE 3: Activities of nurse respondents**

Domain	Activity	Percentage
<b>Treatment</b>		
	Prepare medication	99*
	Administer medication	98*
	Venepuncture	98*
	Care for CVADs	83*
	Cannulate	65
	Decision treat or not	45
	Decision dose	54
	Advice about dose	76
<b>Education and support</b>		
	Educate about haemophilia	95*
	Telephone consultation	95*
	Home treatment training	93*
	Educate about genetics	79
	Home visits	66
	School visits	62
	Group support	64
<b>Coordination</b>		
	Multidisciplinary care	93*
	Referral to other specialism	93*
	Organize care outside hospital	89*
<b>Research</b>		
	Assist with clinical trials	89*
	Assist with other research	80*
	Conduct nursing research	68

Items rating >80% (indicated with an asterisk\*) were defined as core activities

means of access; in some countries nurses were not permitted to cannulate. Providing education and advice also featured highly in the core activities with education about haemophilia to a range of recipients, and telephone consultation, being the most common aspects. Co-ordination of multidisciplinary care, including referral to other specialities and organizing care outside the hospital setting are tasks frequently undertaken by haemophilia

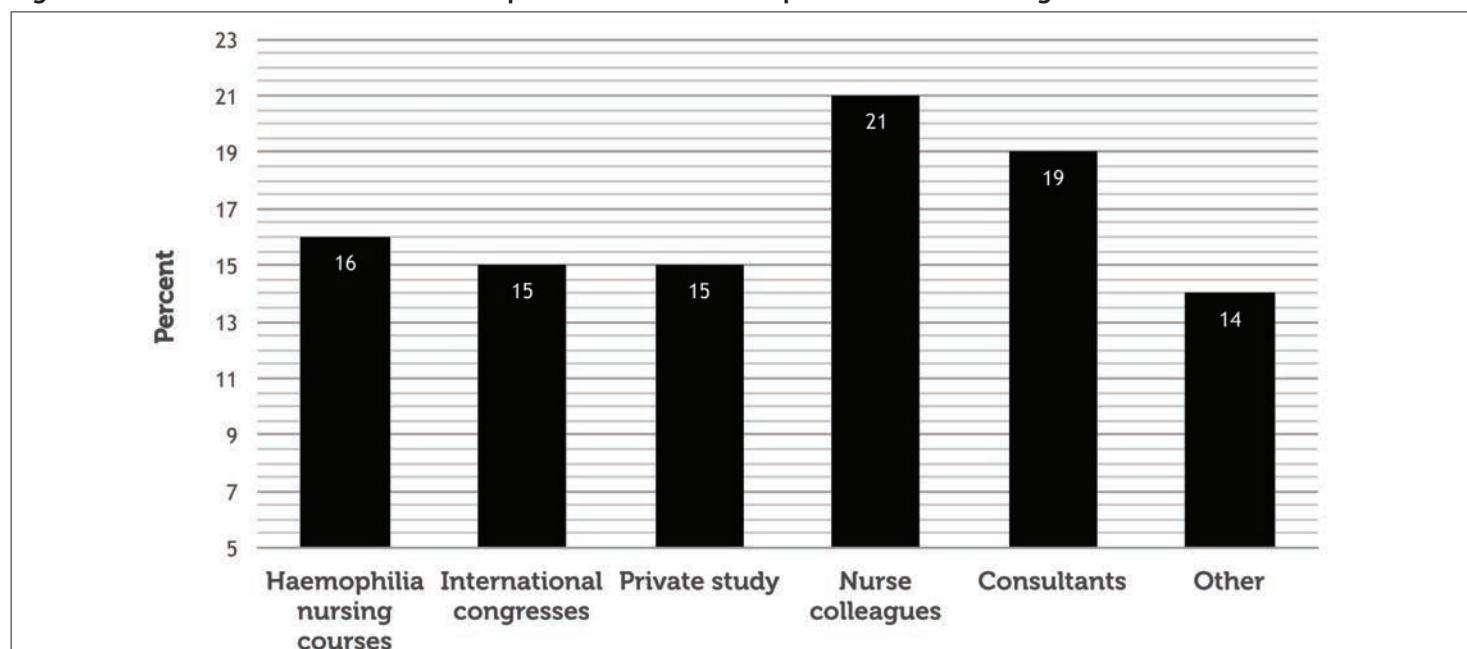
nurses. In the research domain the only element that was rated as core was assistance with clinical trials (80%), Nurse-initiated research was not a core activity but at 35% was relatively high. As expected this percentage increased amongst those nurses with an MSc (44%,  $P=0.01$ ). However these results are somewhat affected by the higher response rates from the UK and the Netherlands where most nurse-led research was reported (UK (29/47, nurses 62%) and the Netherlands (5/10, 50% nurses).

### Gaining knowledge and future development

Haemophilia nurses learned most of their expertise and knowledge from haemophilia nursing courses (16%), international congresses (15%) private study (15%) and from their nurse colleagues (21%) or haematologist (19%) (Figure 2). Almost all nurses stated that they would like to develop in their work, e.g. study at masters level have more responsibility, conduct nurse-led research and have more time to explore these activities.

### Discussion

To our knowledge, this is the first assessment of haemophilia nursing care in Europe. Nurses working in haemophilia generally had extensive experience as a registered nurse, and most had considerable experience in haemophilia care. Treatment modalities in Europe were comparable, and most nurses worked with haemophilia patients exclusively. The core activities of a haemophilia nurse were: prepare and administer medication, venepuncture and CVAD-use, providing education and telephone consultation, coordination of (multidisciplinary) care and assist with clinical trials. Furthermore, 35% stated that they initiated and performed research. Almost all nurses mentioned that they would like to grow in their

**Figure 2: Nurses' self-declared "most important" sources of expertise and knowledge**


work in the future, like studying at Masters level, to have more responsibility to conduct research.

The study had some limitations. The survey was provided only in English and it is most likely that nurses who are able to read the English language replied to the email. There was a high response from the Western European countries, but the Eastern European countries are underrepresented and so the results are probably less applicable to the eastern side of Europe. Further research on the work of haemophilia nurses in this area is necessary.

Greater understanding about the haemophilia nurse role could be obtained from the International Council of Nurses Framework for Competencies for the Nurse Specialist [13], which defined the nurse specialist as: "a nurse prepared beyond the level of a generalist and authorised to practice as a specialist with advanced expertise in a branch of the nursing field". Specialist practice includes clinical expertise, teaching, administration, research and consultant roles. These roles are comparable to those demonstrated in this study. Therefore, the authors believe that the haemophilia nurse specialist is a more proper term for nurses who work within haemophilia.

This paper serves as a starting point for haemophilia nurse delivered care and could be used as guidance for centres in Europe. Furthermore, this current practice analysis can be used to build a framework for developing a haemophilia nursing curriculum and European principles for haemophilia nursing care.

Further research is needed to explore the ratio of nurses per patient in order to set international standards. In addition, it is important to investigate specific nursing procedures that could lead to national or international standards for providing care.

## Conclusion

The role of the haemophilia nurse requires greater exploration. The present survey represents a broad scoping exercise to assess and quantify haemophilia nursing care in Europe. Most haemophilia nurses had extensive

experience as a registered nurse, and in haemophilia care. Treatment modalities in Europe were mostly comparable and most nurses saw haemophilia patients exclusively. The core activities (rated over 80%) of a haemophilia nurse were: to prepare and administer medication, venepuncture and CVAD-use, providing education and telephone consultation, coordination of (multidisciplinary) care and assist with clinical trials. Nurses have many future plans, e.g. studying at masters' level, have more responsibility, conduct nurse-led research and have more time to explore these activities. These results may serve as a starting point for developing a haemophilia nursing curriculum and eventually formalised European principles of haemophilia nursing care.

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