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Clinical Haemophilia

Identifying Professional Responsibilities and Designing the Optimal Curriculum for Haemophilia Nurses in Spain: A Round Table Discussion

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ABSTRACT

Introduction: There is a lack of consensus on professional competencies or educational requirements needed for registered nurses working with haemophilia patients (namely, haemophilia nurses) in thrombosis and haemostasis units in Spain. Their role is not officially recognised in many healthcare systems (HCS), including Spain.

Aim: To identify and define the optimal curriculum and professional responsibilities of haemophilia nurses in Spain.

Methods: A total of 205 items were developed through literature review, and the input was presented and rated using a 10-point Likert scale to reach posterior consensus. Items were grouped into three blocks: optimal curriculum, responsibilities in therapeutic management and follow-up, and roles in patient and family education. Consensus was defined as a mean score between 6.6 and 10. A virtual round table with final statements was held on 19 March 2024 with the participation of 13 haemophilia nurses.

Results: Agreement was reached on all items. A three-level framework (basic, advanced, expert) was proposed as a tool for knowledge of pathophysiology, laboratory procedures and therapeutic strategies. Nurses also pointed to an active role in treatment management, clinical assessment and education. Other ideal responsibilities included participation in research, education of colleagues, patients and families, and advocacy within the HCS.

Conclusion: This consensus-based proposal aimed to provide a structured, standardised framework for the education, scope, and recognition of congenital coagulopathies nurses in Spain. This framework of competencies could be the stepping stone to formal training programmes, accreditation systems, and the advancement of professional development in specialised nursing care for rare bleeding disorders.

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1 | Introduction

Congenital coagulopathies, such as haemophilia, represent a group of rare pathologies that may benefit from a specialised clinical approach. Nurses play a fundamental role in managing these conditions, particularly within multidisciplinary teams dedicated to haemophilia care [1]. The responsibilities associated with haemophilia nurses include direct clinical care, treatment management, early detection of complications, support in lifestyle adaptation, psychosocial support for patients and families, and health education [1–3]. A survey conducted by the European Association for Haemophilia and Allied Disorders (EAHAD) also identified key aspects of the haemophilia nurse role, such as patient education, care coordination, involvement in research and therapeutic management [4]. However, there are significant differences reported between countries in terms of training pathways, professional qualifications, and the scope of nursing competencies [1, 5, 6].

Despite the relevance of this professional profile, this is not formally recognised in Spain. In Spain, there are variations in the regulatory framework, care needs, and career paths from reported literature. While there are initiatives to increase competencies, such as the proposed law to regulate the prescription, use, and authorisation of certain medications by registered nurses (i.e., those who have successfully completed university-level training in nursing and have been legally authorised to practice the profession) [7], which suggests progress, this change has not yet led to formal recognition or standardisation of the specialised nursing care in congenital coagulopathies around the country. Most of the available evidence on the roles, training, and competencies of haemophilia nurses originates from the United Kingdom, the United States, and Northern European countries, among others [1–6, 8–11], without Spanish representation, which limits the applicability of these models in countries with different healthcare systems (HCS).

Spanish registered nurses are qualified to provide preventive, curative, and rehabilitative care [12] and may perform certain invasive techniques under medical indication without additional specialisation at Level 2 of our National HCS, which is equivalent to Level 6 of the European Qualification Framework [13]. There are seven nursing specialities officially recognised in Spain (gynaecological-obstetric, mental health, geriatric, occupational, medical-surgical, family and community, and paediatric nursing) that require 2 years of formal residency training within the National HCS [14]. None of these specifically address areas of specialisation such as bleeding or thrombotic disorders. According to the World Federation of Hemophilia (WFH), there are 37 haemophilia treatment centres in Spain [15], three of which are also accredited as European Haemophilia Comprehensive Care Centres by EAHAD [16]. At the national level, only four centres have been designated by the Ministry of Health as Centres, Services, and Units of Reference in Congenital Coagulopathies [17]. Due to the prevalence of these pathologies, not all healthcare facilities offer the same level of specialisation, leading to potential disparities in the care provided (depending on the patient's hospital of origin). Furthermore, although the prevalence of haemophilia influences academic curricula, the Spanish public HCS allows newly graduated nurses to work in specialised or

complex units immediately after university, without requiring further formal training.

Given these challenges, the present study aimed to identify the ideal professional competencies required for registered nurses working with haemophilia patients (hereafter named as haemophilia nurses, for simplification) in thrombosis and haemostasis units in Spain and to structure these competencies into a progressive framework. A secondary goal was to propose an evaluation and training model that can guide both newly appointed nurses and experienced professionals seeking continued development in the field.

2 | Materials and Methods

2.1 | Items and Round Table Discussion

A coordinating group led by two registered nurses working for several years in the field of coagulopathies (S.G-B. and M.A.F.) compiled a list of statements to be presented and discussed with the participants before the round table discussion. Statements for the items were developed based on a review of existing literature in PubMed (regarding the education, role, competences, responsibilities of haemophilia nurses) [1–6, 8–11, 18, 19], along with the professional experience of the coordinating group. These aimed to capture essential roles, responsibilities, tasks or competencies relevant to nursing care in congenital coagulopathies. Participants were also asked to complete an ad hoc survey (with demographic and academic data and a few daily routine activities) the day of the meeting. The document with the final statements selected was composed of 205 items and was grouped in three blocks: Block 1: Profile of the haemophilia nurses: knowledge, qualities, and characteristics; Block 2: Competencies that haemophilia nurses should have regarding therapeutic management and patient follow-up; and Block 3: Communication with the patient and their education. At the end of each block, participants were asked to stratify the items contained and define if they were basic (Level 1), intermediate (Level 2), or advanced (Level 3). The stratification of the knowledge required in three levels tried to reflect the progressive acquisition of knowledge and skills typically obtained through years of experience and professional development and based on the structure of the Spanish HCS and its regulatory framework for the health professions [20].

An email invitation was sent to 18 haemophilia nurses; however, 13 finally participated in the round table discussion. The final document was shared with participants who confirmed one week before the meeting. The proposed items were presented via a web platform (Mentimeter.com) on 19 March 2024, when they were asked to rate their level of agreement or disagreement with each item. The rating scale ranged from 1 (completely disagree) to 10 (completely agree). A consensus disagreement was reached for an item when the mean score obtained by all participants was between 0 and 3.3, while a consensus agreement was reached when it was between 6.6 and 10. Mean scores between 3.4 and 6.5 were considered indeterminate. In these cases, a debate was held to present the different viewpoints. After the round table, the results were compiled and structured for presentation.

3 | Results

3.1 | Participant Profile in the Round Table

Most participants were women (84.6%), with a majority (61.6%) between the ages of 41 and 60. Regarding maximum academic level, 69.2% had completed a university degree, and 30.8% held a master's qualification. The mean professional experience in nursing was 21.2 years (standard deviation, SD: 12.2), and specific experience in coagulopathies averaged 12.1 years (SD: 10.3).

A high percentage (84.6%) worked in centres with dedicated haemophilia/coagulopathy units, and 69.2% of them were based in referral centres receiving patients from other facilities. More than a half (66.7%) answered that their centres offered regular scheduled consultations, while 58.3% also operated on-demand appointments. However, only two of the participants worked in a centre with a formal accreditation for nurses specialising in coagulopathies. In terms of professional roles, 84.6% of the nurses engaged in teaching activities, particularly towards other nurses (81.8%) and patients (63.6%). A high percentage of participants (91.7%) reported congress attendance at national or international scientific conferences (in the form of posters, oral presentations, or attendance only). Almost all (92.3%) were involved in research, especially in participation in observational studies (75%), collaboration in clinical trials (58.3%), and contribution to scientific publications (75%).

3.2 | Items Consensus

All the items contained in the document were validated through consensus agreement. The mean consensus score for the 205 items was 9.1 (SD, 0.7). None of the items required debate to reach agreement, although some required discussion to ensure comprehension, meaning, and specification. Consensus scores and comments from participants (if any) of the meeting are presented in the [Supporting Information](#).

3.3 | Block 1: Ideal Professional Profile: Knowledge, Skills, and Competencies

Participants reached strong agreement on the comprehensive knowledge required for managing congenital coagulopathies. These ideally should include in-depth understanding of pathophysiology, inheritance patterns, diagnosis, and psychosocial aspects, particularly regarding women with bleeding disorders. Specific attention was given to the care of women carriers and those affected by bleeding disorders, and the item "women with haemophilia" was clarified to align with the updated WFH classifications. Key knowledge areas in laboratory practice validated by the panel included blood sample collection, interpretation of coagulation tests, understanding preanalytical variables, and the influence of reagents. Similarly, therapeutic management competencies included knowledge of replacement and non-replacement therapies, infusion techniques, and haemostatic planning for surgeries.

The expert panel identified a set of additional competencies for nurses specialising in coagulopathies. These were active collaborations in biomedical research related to haemophilia,

such as clinical trials, real-world studies, and observational registries. Participation in multidisciplinary research groups and the development of clinical practice recommendations were also emphasised. Continued professional development through attendance at national and international scientific congresses, either as presenters or attendees, was considered essential (mean score: 10). Also, the item "continuous training" to improve the attention to patients, families and caregivers was highly rated (mean score: 9.8). Moreover, nurses are expected to contribute to the dissemination of knowledge about haemophilia and its management through various channels, including social media, workshops, and educational courses (mean score: 8.6). Engagement with patient associations to support patient education (mean score: 9.3), as well as the training of other nurses who are going to attend the study population, was highlighted as a key component of professional leadership. It was stated that the centres should have a standardised guide for training nurses working in the area (mean score: 9.8). Finally, ensuring multidisciplinary care through effective communication with team members, acting as a liaison for referrals, and coordinating interventions outside the haemophilia service setting were also recognised as important elements of ideal nursing practice in this field. The panel defined a three-tier knowledge framework (basic, advanced, expert) across pathophysiology, laboratory skills and therapeutic management summarised in Table 1.

3.4 | Block 2: Competencies in Therapeutic Management and Follow-up

Consensus highlighted the nurse's central role in treatment preparation, administration, venepuncture, and venous access care (mean score: 9.9). Participation in treatment decisions (e.g., type, dose, switching therapies) was accepted when performed in collaboration with physicians and involving patients and families. Patient monitoring responsibilities included establishing visit frequencies, assessing venous access, and evaluating treatment adherence, satisfaction, bleeding episodes, and self-administration capacity. A checklist of tasks/actions with direct intervention of nurses for haemophilia patient follow-up assessments was identified and proposed in Table 2.

The role also extends to pharmacokinetic sampling and coordinating medication home delivery (telepharmacy), though the latter received more varied agreement due to institutional differences. Assessment of complications (e.g., inhibitor development, arthropathy, infections) had a mean score of 7.5, and the items related to the assessment of pain, physical activity, impact on daily routine, and quality of life were highly rated (mean scores: 9.2, 9.2, 9.0, and 8.9, respectively). The use of validated tools for this purpose was strongly recommended, and the principal scales (patient-reported outcomes and patient-reported outcome measures) identified are shown in Table 3. Nurses were also expected to provide support for self-care outside the hospital, tutor patients in self-treatment, and promote mobile applications for remote monitoring (mean score: 9.9).

3.5 | Block 3: Communication and Patient Education

High agreement was reached regarding the nurse's responsibility in educating patients and their families. This includes

TABLE 1 | Defined knowledge framework (basic, advanced, expert) across pathophysiology, laboratory skills, and therapeutic management.

	Disease’s pathophysiology of haemophilia and related bleeding disorders	Laboratory procedures associated with haemophilia and related bleeding disorders	Therapeutic management of haemophilia and related bleeding disorders
Level 1	Knowledge acquired during university: the coagulation cascade, the characteristics of haemophilia, bleeding in haemophilia	Knowledge acquired during university, knowing how to evaluate the quality of the sample	Knowledge acquired during university: substitutive treatments
Level 2	In-depth knowledge acquired beyond university education: types of haemophilia, severity levels, joints most prone to bleeding, traumatic versus spontaneous bleeding, and treatments along with precautions when administering them or vaccines	In-depth understanding acquired beyond basic education: methods of sample collection, determination of coagulation factor VIII levels, measurement of activated partial thromboplastin time, detection of inhibitors, surgical management, invasive procedures, and dental management of patients	In-depth understanding of treatment options: replacement therapies, subcutaneous treatments, and investigational drugs
Level 3	Comprehensive expertise acquired through advanced training and practice: understanding how coagulation factors function, the action mechanisms of monoclonal antibodies and new treatments, the damage blood causes to joints, and recognizing that haemophilia is not only a haematological disease but also a musculoskeletal disease	Extensive expertise acquired through advanced training and clinical practice: detailed understanding of proper sample collection, determination of coagulation factor VIII levels, assessment of partial thromboplastin time and prothrombin time, inhibitor detection, interpretation of coagulation analysis, pharmacokinetic monitoring, and understanding the progression to haemophilic arthropathy	Comprehensive expertise in aspects regarding treatment: detailed understanding of available therapies, treatments in clinical trials, mechanisms of action of treatments, adverse events associated with treatments, and additional precautions for treatment administration

TABLE 2 | Checklist for haemophilia patient follow-up assessments.

Assessment	Completed
Patient’s weight to explore need of dose adjustments	☐
Evaluation of the patient’s needs in relation to the current dosing regimen	☐
Explore bleeding episodes and extra dosing (to treat bleeding episodes in addition to prophylaxis)	☐
Tracking changes in analytical variables	☐
Monitoring patient adherence and satisfaction with the treatment	☐
Checking the patient’s ability to self-administer the treatment prescribed	☐
Identification of issues related to medication use	☐
Screening and management of complications (inhibitors, joint damage, or abnormal serological findings)	☐

evaluating the patient’s knowledge about their condition and treatment, especially concerning bleeding risk (mean score: 9.9), self-administration (mean score: 10), and emergency responses (mean score: 10). The use of checklists to assess patient understanding was endorsed (mean score: 8.5), with essential items covering treatment type, regimen, storage, preparation, administration technique, waste disposal, treatment risks, and adherence

importance, summarised in Table 4. The participants agreed that educational strategies must be adapted to age and cultural context. Nurses should promote healthy habits and support shared decision-making, including the use of tools such as those developed by recognised organisations such as the WFH. Although promoting disease awareness via social media received lower consensus (mean score: 7.4), the importance of structured,

TABLE 3 | Patient-reported outcomes and patient-reported outcome measures identified as ideally to be used.

Item to be measured	Tools identified by the participants to be ideally used in clinical settings
Bleeding risk	Broderick scale Annual Bleeding Rate (ABR) scale Annual Joint Bleed Rate (AJBR) scale International Society on Thrombosis and Haemostasis/Scientific Standardization Committee Bleeding Assessment Tool (ISTH BAT)
Joint condition	Hemophilia Early Arthropathy Detection with Ultrasound (HEAD-US) Hemophilia Joint Health Score (HJHS)
Pain	Visual Analog Scale (VAS) for adults In pediatrics: FLACC scale (Face, Leg, Activity, Cry, Consolability) for children between 1 month and 4 years Face scales for children between 4 and 8 years (such as the Face Pain Scale Revised, FPS-R) Numerical scales for children over 8 years
Quality of life	5-dimension EuroQoL Scale Health Assessment Questionnaire (HAQ) Patient Global Impression Severity (PGI-S) Work Productivity and Activity Impairment Questionnaire (WPAI) Hemophilia-specific quality of life index (Haemo-QoL)
Physical activity	Saltin-Grimby Physical Activity Level Scale (SGPALS) International Physical Activity Questionnaire - Short Form
Emotional impact	Goldberg Anxiety and Depression scale Hospital Anxiety and Depression (HAD) scale

TABLE 4 | Checklist for haemophilia patient education assessments.

Assessment	Completed
Type of treatment (e.g., specific replacement or non-factor therapy)	☐
The prescribed treatment regimen (prophylaxis schedule or when to take on-demand doses)	☐
Calculation of the appropriate treatment dose (for weight-based dosing, if applicable)	☐
The objective of the treatment (for example, preventing bleeds or managing a bleeding episode)	☐
Proper storage conditions for treatment products (refrigeration, protection from light, etc.)	☐
Correct preparation method for the treatment (reconstitution technique for factor concentrates, warming the vial to room temperature, etc.)	☐
Aseptic techniques to maintain sterility during administration	☐
Techniques for safe and effective home infusion or injection (e.g., finding veins, using infusion devices)	☐
Safe disposal of medical waste and sharps (needles, syringes) after administration	☐
Understanding of risks associated with treatment (such as inhibitor development, allergic reactions, or transmission of infections in older plasma-derived products)	☐
The importance of adherence to the treatment plan (and the consequences of missing doses)	☐

accurate patient education (mean score: 9.9) and continuous professional development (mean score: 9.8) was very supported by all the participants.

4 | Discussion

Given that there is currently no national consensus or regulatory framework in Spain defining the specific competencies that haemophilia nurses should have, this round table represents a first attempt to define what would be the ideal curriculum

and professional responsibilities of haemophilia nurses in Spain. In line with previous reports by groups from other countries regarding the variability of competencies among haemophilia nurses depending on the centre of origin, our group discussions detected some variability between healthcare centres in terms of role definition, access to specialised training, and professional recognition. This variability can be explained by a combination of institutional resources, regional policies and the presence or absence of specialised units. However, proposals such as those from the EAHAD [8] and the United Kingdom [10] offer robust reference points from which to adapt frameworks

to national contexts. The EAHAD model includes core topics such as applied biological sciences, treatment and management strategies, genetic considerations, care for symptomatic carriers and affected women, psychosocial impacts, research literacy, and interprofessional collaboration. It categorises competencies into two levels: competent and proficient [4]. Similarly, the adaptation by Pollard et al. from the HNA framework describes five domains: clinical knowledge, direct care, communication and support, collaborative practice, and research, differentiated into four progressive levels of expertise, from beginner to expert [10]. In alignment with these approaches, our Spanish panel proposed a three-tier system: basic, advanced, and expert levels of knowledge in the area of congenital coagulopathies. This structured evaluation proposal can serve both as a guide for newly hired nurses entering the field and as a professional development tool for experienced professionals.

Nurses are increasingly emphasising their involvement in the research process. Despite the traditionally assistive role, this round table confirms that haemophilia nurses are increasingly involved in the generation of scientific knowledge through collaboration in clinical trials and observational studies. Moreover, their involvement in the dissemination of clinical knowledge through congress attendance, collaboration with patient associations, and training of peers, demonstrates an evolving leadership role within the professional community. In addition, many of the nurses participating in this roundtable had several years of experience in the field of congenital coagulopathies, some of them with master's degree as the maximum academic level. These characteristics were identified as advanced practice by the participants in the panel discussions, but only two nurses reported working in institutions where their role was formally recognised as that of an advanced practice nurse. Although some hospitals or autonomous communities have established local accreditation systems for recognising advanced nursing roles in haemophilia care or are in the process, these remain limited in scope and lack integration into the national model. As a result, significant discrepancies persist in the formal recognition, autonomy, and development opportunities available to nurses depending on their geographical and institutional context. Also, the participants reported that healthcare centres should have a standardised guide for the training of novel haemophilia working with people with congenital disorders, so maybe the curriculum vitae and competencies proposed by the expert panel represent a response to an unmet professional development need. At a more advanced level, nurses may achieve the status of Advanced Practice Registered Nurses or Nurse Practitioners (i.e., nursing professionals with advanced training), holding master's degrees of at least 90 ECTS and demonstrating continued professional development and experience [21].

A limitation of this study is the lack of representativeness in the sample. Although the survey was distributed to 18 nurses working in haemophilia and coagulopathy units, only 13 participated in the round table. According to the WFH, there are 37 recognised haemophilia treatment centres in Spain [15]; therefore, perspectives from smaller centres may be under-represented, potentially introducing bias toward more structured or high-resource environments. Additionally, as with all consensus-based studies, the results depend on subjective expert opinion and the design of the item set, which may reflect contextual practices

despite being grounded in a literature review. However, the diversity of participants from different regions and hospitals, along with the systematic rating and discussion process, helped mitigate these limitations.

As summary, the competencies and framework developed through this consensus process may serve as a foundation for future national training programmes, formal accreditation efforts, and policy guidance, ultimately aiming to enhance both professional development and patient care across Spain.

5 | Conclusion

This framework provides a basis for determining the essential knowledge needed by new nurses and can also serve as a self-assessment tool for experienced nurses. The findings underline the urgent need for standardised training, structured professional development pathways and national accreditation. There may be nurses who, despite their knowledge, academic training and years of experience, lack formal recognition as advanced practice professionals, while other centres are certifying these professionals. Addressing this situation would help promote professional growth and ensure consistent and high-quality care for people with congenital coagulopathies in all healthcare settings.

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Ethics Statement

Ethical approval was not required for this study because it represents the opinion of haemophilia nurses about professional responsibilities and thus it did not include humans or animals.

Conflicts of Interest

SG-B has participated as a speaker in advisory boards and sponsored symposia with NovoNordisk, Bayer, Takeda, Roche, Pfizer, Biomarin, Novartis, CSL Behring, and Sobi. ACB has participated as a speaker in advisory boards and sponsored symposia with Novo Nordisk, Takeda and Roche. He also has received support for attending meetings and for travel from Novo Nordisk and Bayer. EAM has participated as a speaker, in advisory boards and sponsored symposia with Bayer, Pfizer, Takeda, Novo Nordisk, Roche, Sobi, and CSL Behring. MTG has participated as a speaker, in advisory boards and sponsored symposia with CSL Behring and Sanofi-Aventis. She has received support for attending meetings and/or travel from Roche, Sobi, and CSL Behring. NCM has participated as a speaker in advisory boards and sponsored symposia with Roche and Sobi. She also has received support for attending meetings and/or travel from Roche and Sobi. MAF has acted from Roche, Pfizer, CSL Bering and SOBI reimbursement for attending a symposium, fee for speaking, fee for organizing education, research support from organisations that might gain or lose financially through publication of the paper and fees for consulting. MRP, NP, AD, CFS, MDdD, MdCGM, and MTT declare no conflict of interest.

Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.

Table S1. Sociodemographic characteristics of the participating experts.