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Title: Education Needs of Nurses in Thrombosis and Haemostasis: An International, mixed-methods Study

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Essentials

- **Study aimed to identify specialized bleeding/thrombosis nurses' needs to inform future education**

- **Mixed-methods approach combined qualitative and quantitative data collected in nine countries**

- **Areas of need identified: von Willebrand disease, individualizing care, thrombosis assessments**

- **Poor access to relevant education reported as a main barrier to nurses' professional development**

Brief summary for general public:

Thrombosis assessments, von Willebrand disease, and adapting care to individual patient needs have been identified as priorities to support nurses working in thrombosis and haemostasis in their continuing education efforts.

240 character social media post:

According to a new international mixed-method study, thrombosis assessments, von Willebrand disease, and guidance on individualizing care should be continuing education priorities for nurses specialized in bleeding & clotting disorders.

Abstract

Background

The need for a more integrated, multi-disciplinary approach to care for individuals with bleeding or clotting disorders has been highlighted in recent years. Evidence-based education adapted to nurses' needs is essential for a successful evolution. However, limited data currently exist on the clinical challenges nurses face in this specialty area.

Objectives

Identify barriers and challenges faced by specialty nurses, and determine possible causes, to develop appropriate educational interventions.

Methods

A mixed-methods study, combining qualitative (semi-structured interviews) and quantitative (online survey) data was conducted on the challenges experienced by haemostasis nurses in nine countries (Argentina, Australia, Canada, China, France, Germany, Spain, the UK, and the US), and deployed in five languages (English, French, German, Mandarin and Spanish). Qualitative data were analyzed using thematic analysis. Quantitative data were analyzed using frequency tables, chi-squares and standard deviations.

Results

Participants (n=234) included nurses (n=212; n=22 qualitative; n=190 quantitative); and patients receiving care for bleeding or clotting conditions or their caretakers (n=22 qualitative phase only). Through triangulated data analysis, six challenging areas emerged: 1) Understanding of von Willebrand disease (VWD); 2) Anticoagulant safety profile in specific patients; 3) Understanding the treatment of patients with inhibitors; 4) Patient risk assessments; 5) Individualization of care and communication with patients; 6) Accessing and implementing relevant professional education.

Conclusions

This needs assessment provides a comprehensive illustration of the current challenges faced by nurses in the field of bleeding and clotting disorders, and indicates where gaps in skills, knowledge or confidence would benefit from nurse-specific educational programming.

Keywords

Background

Coagulation disorders include many chronic conditions that require life-long treatments to reduce risk of hemorrhage (bleeding disorders) or of blood clotting. A multidisciplinary, approach to patients with bleeding and clotting disorders has been shown to improve clinical outcomes, decrease mortality rates, and improve cost-effectiveness in health care settings[1-3]. Nurses play a crucial role as part of the multidisciplinary team providing care to these patients. Nursing responsibilities include providing direct clinical care, patient and family support, providing clear patient education on their condition, administering treatment, providing assistance during lifestyle adjustments, monitoring for early signs of complications, taking patient history, and in many settings, participating in treatment decisions with the team[4-6].

Multiple challenges related to providing care to patients with bleeding or thrombotic disorders were identified in the literature. For example, it has been reported the diagnostic process for von Willebrand disease (VWD) is complex, and testing and assessment is challenging[7-9], due to the variety of patient profiles and multiple types and sub-types of the disease. These challenges to VWD diagnosis are further complicated by a lack of standardized diagnostic tools, especially in pediatric settings[10].

In another example, the use of direct oral anticoagulants (DOACs) for patients with thrombotic disorders poses a challenge, as it requires nurses and others on the healthcare team to adapt patient monitoring practices in order to reduce risk of adverse events and side-effects[11]. Observational data also suggest nurses' lack of understanding of the appropriate dosage of pharmacological agents in patients with thrombotic disorders, was combined with misunderstanding of the necessity of those treatments[12].

As part of a team of health care providers (HCPs), nurses may experience unique challenges when caring for patients with coagulation disorders. However, limited research is available that describes the nursing perspective in this field.

Objectives

This study aims to identify the areas where nurses experienced challenges when educating, treating, and communicating with patients with a coagulation disorder; and to identify the causes of these challenges (e.g. lack of knowledge or skills). Study findings can be applied to the future development of targeted, relevant educational programs for nurses.

Methods

Overview

A mixed-methods approach was used to assess the educational needs of nurses, combining an exploratory qualitative phase consisting of semi-structured interviews with nurses and patients / caregivers, which led to, and informed a quantitative validation phase with nurses only. A mixed-methods approach allows for triangulation of data collection methods (qualitative and quantitative) and sources (nurses and patients / caregivers) to gain a trustworthy and in-depth understanding of a problematic issue[13,14], in this case, the challenges experienced by nurses.

Recruitment

Inclusion criteria

To be eligible, participants must practice in one of nine countries (Argentina, Australia, Canada, China, France, Germany, Spain, the United Kingdom (UK), or the United States (US)), and be employed as a nurse, nurse practitioner, or registered nurse (or the local equivalent of that designation). They must have at least one year of work experience, with at least 50% of their professional time working in the field of thrombosis and haemostasis. In Australia, those who spent 20% or more of their time in thrombosis and haemostasis were deemed eligible for this study, to reach the sample quota for this country.

Nurses were recruited from the selected countries using a purposive sampling method[15] that included participants with different levels of practice experience, and various practice settings (i.e. academic, community). Nurses were contacted via the International Society on Thrombosis and Haemostasis (ISTH) database, from within the networks of AXDEV Group, and through the Global Hemostasis Nurses Alliance (GHNA). The countries included in this study were selected to represent a range of patient and nurse experiences, and to reflect the membership distribution of ISTH, WFH (World Federation of Hemophilia) and GHNA nurses, which all represent nurses and the field of thrombosis and haemostasis.

Increasing evidence supports patient involvement in the early phases of the design of evidence-based medical education[16,17]. The inclusion of patients/caregivers in this study recognizes these experiences as valuable sources for data triangulation, which is used to corroborate or broaden the nurses' voiced challenges. Eligible patients/caregivers must live in one of the nine targeted countries, and have a thrombotic or bleeding condition for which they or their child received nursing care in the past five years. This timeframe was chosen so they would have sufficient recall of the nursing care they had received. Patients/caregivers were not included in the quantitative phase of this study, as their input was used primarily to contextualize the nurses' narratives, and to understand differences in perspective.

Ethics

International ethics approval was granted by two independent ethical review boards (IRB): one for the main study protocol that involved nurses (VERITAS, QC, Canada) and one for the complementary protocol that included patients and caregivers (Chesapeake IRB, Columbia, MD, US). An informed consent agreement was read and approved by each participant before their interview or survey. Participants received financial compensation for their participation, in accordance with ethical regulations.

Data Collection and Analysis

Qualitative phase

Participants completed a 45-minute semi-structured interview. The interview guide was designed by educational experts (co-authors PL, SL, SM) based on a review of the existing

literature regarding nurses' roles in the care of patients with coagulation disorders. Interview guide topics were discussed with clinical experts (co-authors JM, RB, KK, AL, MM, TR, FN) prior to finalizing the interview guide. The interview guide was comprised of open-ended questions designed to elicit unbiased and in-depth responses. Interviews were conducted in the participants' local language (English, French, German, Mandarin, and Spanish) and recorded with the participant's consent. Interviews were transcribed and translated to English.

Patient/caregiver interview questions were designed to be applicable if participants were responding on behalf of themselves or their child. Interviews avoided the use of technical language or jargon to focus on the patient experiences[18].

All interviewers participated in a debrief session to outline emerging themes, and construct the coding "tree" for the directed content analysis[19]. Interview transcripts were coded using N-Vivo 7.0 software (QSR International, Cambridge, MA). In cases where data from the transcript did not fit into the framework, new codes were developed, and integrated thematically into the coding "tree". Interviews were transcribed and coded until data saturation was reached- when no new codes emerged from the interviews[20]. Emerging themes were contextualized and interpreted by clinical experts and educational experts (co-authors PL, SL, SM, TR). Key findings were used to construct an online quantitative survey.

Quantitative phase

Quantitative data were collected via a 20-minute online survey, designed based on the emerging themes of the qualitative phase, and with the intent of validating the reported challenges with a larger sample. Nurses were asked to use a 5-point scale to rate their own level of knowledge, skills, confidence and support, according to the level expected in their professional role. Nurses also indicated their level of agreement with certain statements, the frequency in which they perform particular tasks (and the perceived level of difficulty of those tasks), and to select barriers that most negatively impacted patient care (see Supplementary material 1).

Analysis of survey data using SPSS software (IBM SPSS 22.0 software, IBM Corporation, Armonk, NY) included frequencies and cross-tabulations. In order to identify differences between sub-groups (country; years of practice (YOP) - either 10 YOP and under, or 11 and over), Pearson chi-squares were calculated.

Final analysis and data triangulation

The educational researchers used data triangulation[21] to integrate interview and survey data, which enabled them to identify the causes of reported challenges, contextual barriers and professional needs[15]. These findings were contextualized by the steering committee, based on their clinical expertise.

Results

A total of 234 participants were included in this study (Table 1; 212 nurses and 22 patients / caregivers). Forty-four interviews were conducted (phase 1, 22 nurses and 22 patients / caregivers) and 190 different nurses completed the online survey (phase 2).

The triangulation of data led to the identification of six main findings related to challenges nurses in the field of haemostasis and thrombosis face. These challenges include: 1) the understanding of VWD; 2) anticoagulant safety in specific patient profiles; 3) understanding the treatment of haemophilia patients with inhibitors; 4) patient risk assessments; 5) individualization of care and communication with patients and families; 6) accessing and implementing relevant professional education.

1-Challenge with the understanding of von Willebrand disease

Several aspects of clinical practice regarding patients with VWD were reported as sub-optimal by nurses. Sub-optimal knowledge of "which elements of patient and family history to collect to inform a potential diagnosis of VWD" was reported by 43% of participants (Table 3). Over half of nurses (54%) also reported sub-optimal knowledge, given their professional role, of the "criteria to identify the type of VWD". Furthermore, 50% reported

sub-optimal knowledge of the criteria to determine "if the results of basic laboratory tests are consistent with VWD, and if so, which type". Finally, after a diagnosis is confirmed, half of nurses (52%) reported sub-optimal knowledge of the "safety profile of treatments for VWD".

Along with a limited understanding of VWD, were the challenges posed by changing diagnostic criteria and fluctuations in individual patient levels observed in VWD diagnostic laboratory tests. The elusive criteria of VWD is a substantive theme that emerged from qualitative data:

> *Von Willebrand disease could be challenging to diagnose. It requires multiple visits and multiple tests and sometimes the results aren't that clear. […] When you look at the new criteria for levels that constitute a current acceptable diagnosis, it doesn't fit with patients that were diagnosed a long time ago, so we're able to say that they don't really have it.*

> -Nurse, US

2-Challenges with anticoagulant safety in specific patient profiles

Sub-optimal knowledge of the "safety profile of anticoagulants" was reported by nurses in three particular patient profiles: (1) those with a history of bleeding episodes, (2) neonates and the elderly, and (3) cancer patients.

Knowledge of "the safety profile of anticoagulation medication when used by vulnerable patients" was reported to be sub-optimal by 40% of participants; while 33% reported a similar knowledge gap in relation to caring for patients treated with anticoagulation medication who also have a history of bleeding episodes or bleeding disorders (Table 2). Discomfort using anticoagulants in vulnerable patients, including in neonates and the elderly, was also recounted during interviews:

> *Regarding the anticoagulant field, I think the vulnerable population is important. Maybe elderly patients who are poorly controlled by other*

external agents are a challenge. The challenge is the most vulnerable people,
assisting both the elder and neonates.

- Nurse, Spain

"Knowledge of DOAC safety profiles in cancer patients" was reported to be sub-optimal by nearly half of participants (48%). The need for more guidance regarding the safety profile of anticoagulants in cancer patients was a substantive theme discussed by interview participants:

NICE [National Institute for Health and Care Excellence] *guidance says, on cancer-related thrombosis, that patients should have a minimal of six months of treatment […]. I guess what I would like is some kind of tool for doing that, for helping that assessment to go forward at six months, and a little bit more clear guidance on when to continue anticoagulation and when to stop anticoagulation.*

- Nurse, UK

3-Challenges understanding the treatment of patients with inhibitors

Triangulated data identified challenges related to haemophilia and inhibitors faced by nurses. Half of participants (51%; Table 2) reported sub-optimal knowledge of the "safety profiles of bypassing agents", used to treat patients with inhibitors. The knowledge gap was higher among nurses with ≤10 YOP (62%), as compared to those with >10 YOP (43%, p=0.019). Similarly, 54% reported sub-optimal knowledge of "the goals of inhibitor treatment and eradication", with higher representation among nurses with ≤10 YOP (63%), as compared to those with >10 YOP (44%, p=0.02).

Sub-optimal knowledge of "how to recognize potential inhibitor development" (53%), as well as "the inhibitor development risks for previously untreated patients" (52%) were reported. Both knowledge gaps were higher among nurses with ≤10 YOP (respectively, 68% and 65%) as compared to nurses with >10 YOP (42%, p=0.001 and 44%, p=0. 009). Treating patients with inhibitors was reported as challenging for nurses and for patients:

What is also a very big problem, especially in haemophilia, is that an inhibitor develops, and that is in fact a major challenge for the treating physician, but also for the person affected, plus their family, because it's a very, very intensive therapy, and you do really need a good compliance, and that is in fact quite tough.

- Nurse, Germany

4-Challenges with patient risk assessments

Challenges regarding multiple facets of patient risk assessments for bleeding and thrombosis disorders emerged. For bleeding disorders, 37% of nurse participants reported a sub-optimal level of knowledge of "which elements of a patient's history are essential for the identification of an inherited disorder" (Table 2). In addition, nurses reported a sub-optimal level of knowledge, given their professional role, of the signs and symptoms of late and early hemarthroses (39%), menorrhagia (32%) and the criteria to determine haemophilia severity (46%).

Regarding bleeding disorders, 42% of nurses reported sub-optimal knowledge of how to identify immune thrombocytopenia (ITP). This proportion was significantly higher among nurses with ≤10 YOP as compared to more experienced nurses (54% vs. 34%, p=0.011).

As shown in Table 3, sub-optimal skills conducting risk assessments in bleeding disorders were also reported. Nearly half of nurses (46%) reported sub-optimal skills, when "assessing the bleeding risk for patients with inherited bleeding disorders". Half of nurses (50%) reported sub-optimal skills assessing patients with potential hemarthrosis. This lack of skill was reported by nurses from Canada (72%) and Argentina (68%) in greater proportions. Additionally, nurses with ≤10 YOP reported a significantly lower skill level when conducting assessments for menorrhagia (51% of those with ≤10 YOP vs. 34% >10 YOP, p=0.028), epistaxis (40% vs. 26%, p=0.046), and hematuria (44% vs. 27%, p=0.022).

A majority of nurses (86%) agreed with the general statement: "I gather patient history very often", and this task was not perceived to be difficult: only 11% of participants agreed that

"gathering patient history is difficult". In addition, 63% of nurses agreed with the statement "I use standardized tools to collect patient history" (Figure 1).

5-Challenges related to the individualization of care and communication with patients and families

Nurses reported challenges when individualizing the way they care for patients. Forty (40%) of nurses agreed that "it is difficult to individualize patient care while respecting protocols" (Figure 1). Specifically, a majority of participants agreed that it is difficult to personalize care provided according to patient age and cognitive level (58%), and to their life-style and preferences (55%).

In addition, 57% of nurses agreed that "it is difficult to determine the exact level of information to provide to the patient on their disease". When asked to "identify the three most significant barriers to providing the best care to patients with thrombosis or bleeding disorders", the top barrier selected by respondents was "lack of awareness among the general population regarding thrombosis and haemostasis disorders or risk factors" (54%). The third most often selected barrier was the "lack of educational materials that I could provide to my patients and caregivers" (39%).

During interviews, patients substantively mentioned the unavailability of adequate information on their specific condition, especially in relation to thrombosis disorders:

> *I think nurses need to have more knowledge on the condition overall. I struggle to find any nurse at all that has a good enough knowledge of my condition. I know more than them, when it comes to nurses. When I go to my weekly appointment, they learn a lot from me, rather than the other way around.*

> - Patient (thrombosis disorder), UK

> *It would have been nice if the information had been offered upfront and visually in a pamphlet. […] The general communication could have been better all around.*

Patients described the need to self-educate using online sources in the absence of other options:

They said something about some type of substance in the blood that creates clotting. I did a little bit of research on my own as well. After I found out about the diagnosis, I looked up what it meant to try to figure out what I needed to expect […] WebMD and looking, Googling thrombosis and seeing what it meant.

6- Challenges accessing and implementing relevant professional education

Nurses perceived a need for broader educational offerings that are relevant to their profession (Figure 1). More than half (58%) of nurses agreed with the statement that "generally, the education offerings are not applicable to the daily reality of my practice", while 70% agreed with "I feel there is a lack of training for nurses regarding how to communicate properly and to use language that the patient (or caregivers) can understand", and 75% agreed that "there is a lack of training for nurses regarding how to provide psychological support to patients (or caregivers)".

Nurses reported that providing proper education on treatments is further complicated by the intensity of the patient's experience:

Families find it very traumatic and they really need a lot of nurturing and support and time to develop competency in doing this and it's not good enough to say: 'We're going to start giving your child enoxaparin and you can go home tomorrow injecting your baby.' Parents need more time than that.

Nurses face several challenges in their efforts to improve their knowledge of bleeding and clotting disorders. Nurses reported low to acceptable confidence (Figure 2) when "identifying adequate training and/or professional development resources for nurses in the field of thrombosis and haemostasis" (57%), and when "implementing clinical practice changes based on literature I read or training I have received" (61%). In addition, there is a perceived lack of support from senior clinical staff when seeking mentorship (62%), or to improve knowledge (51%).

Discussion

This study identified challenges faced by nurses in the field of coagulation disorders, highlighted areas where nurses reported having sub-optimal knowledge or skills, and uncovered marked differences between participants according to their country of practice or level of experience.

The indicators for region-specific findings, as illustrated in the tables, could be explained by variations in the nurses' educational preparation, in health systems and in practice norms, as these were reported as factors influencing their ability to personalize patient care[22]. In terms of education, formal requirements differ among countries. Specialty training for a particular area of nursing may be optional or mandatory depending on country, degree, and practice setting[22]. Other elements may offer insight into these findings, such as differences in the strength and resources provided by the country's nursing professional society, the provision of job training programs after graduation, and the adequate availability of continuing medical education programs[23].

Nurses with 10 years of practice or less reported higher gaps in skills and knowledge when conducting patient assessments for menorrhagia, haematuria and epistaxis, as well as when treating patients with inhibitors, as compared to more experienced nurses. This suggests that less experienced nurses entering the field of coagulation disorders would particularly benefit from specific educational interventions designed to improve patient assessment and the management of challenging patient profiles. These types of educational interventions

could take the form of peer-to-peer training between nurses with a range of experience levels, with an objective to increase skills and confidence of less experienced nurses.

Nurses reported collecting patient history often and with ease, while at the same time reporting a sub-optimal level of knowledge of *which* elements of a patient's history are important to collect. These apparently incongruous findings may reveal an unperceived need for skills and knowledge in this area, as the frequency and ease of these tasks does not appear to accompany a thorough assessment. To concretize knowledge of which elements of patient history are significant, some settings use standardized tools[24]. However, current literature is divided on the use of such tools[25]. Gathering a detailed patient history is integral for the diagnosis of bleeding disorders[26], especially inherited disorders, where symptoms may emerge periodically over the course of a patient's life[27]. A recent publication by the European Association for Haemophilia and Allied Disorders (EAHAD) favored the use of a standardized tool as a part of nursing practice[25]. Other groups have argued that the under-use of such tools is detrimental to the quality of patient documentation[28], or describe the problem as beyond simply *using* the tools. Rather, they highlight that education, cost and organizational changes are needed before beginning to use these tools, and thus are factors that undermine their practical utility[29].

Reports of challenges associated with specific patient profiles, specifically those with VWD and haemophilia patients with inhibitors, indicated two areas where nurses are in need of greater familiarity with risk factors, testing guidelines and diagnostic criteria. Specifically, there is a need to keep abreast of the changing diagnostic criteria of VWD, and develop the communication skills required to manage patient treatment expectations. In addition, a greater knowledge of what is currently known and unknown regarding the prevention, treatment, and management of patients with inhibitors will improve the provision of patient education about these conditions, and is recommended as starting goals for future educational interventions.

Nurses in this study were explicit about their need for educational offerings pertinent to their practice. In addition to a need for more learning materials aimed at nurses, situating learning activities within a clinical setting has been suggested as a way to increase competency, confidence, patient outcomes, and overall knowledge especially in newly-

graduated nurses[30,31]. A perceived lack of support from senior staff when implementing learning into practice was mentioned by participants in this needs assessment. Aside from being unsure of where to access training, our study indicates that when nurses do receive training, there is a perception they do not have the support required to implement their training and knowledge. Top down support for education and mentorship is not adequate, despite facilitators in place, such as shared professional setting, and that multidisciplinary collaborations are recommended[25,32].

Bleeding and clotting disorders have significant effects on patients' health and quality of life[33,34]. The ability for nurses to provide therapeutic care, including psychological support and education, is essential, especially given that these conditions are usually chronic, and that patient age and the severity of the disorder varies considerably. Therefore, the development of a variety of care competencies (in adherence with current treatment protocols) should be included in future education materials, with priority given to the challenges identified in this study.

Study Limitations

The sample size was appropriate for this type of exploratory mixed-methods study; however, given the study was conducted internationally, with total sample size distributed across several regions, differences between countries (reported in the tables, solely) should be interpreted only as indicators of the local educational needs of nurses in the field of thrombosis and haemostasis.

Studies using self-reported participant data always carry risks to their accuracy, and purposive sampling methods may be at risk of selection bias. To account for these limitations, the researchers used data triangulation techniques that combined quantitative and qualitative data, a grounded knowledge base of expert faculty advisors, and a review of literature to strengthen and ensure the trustworthiness of the findings.

Further research is needed to validate these findings when developing educational programs in countries not included in this study, and to further explore the applicability of this approach to other specialized areas of nursing.

Conclusion

This study offers a comprehensive illustration of the current challenges and barriers faced by nurses in the field of haemostasis and thrombosis, including main areas where skills or knowledge were reported to be sub-optimal in relation to clinical tasks and patient communication.

In order to meet the needs of nurses in this field, educational programming must consider the broad range of nursing responsibilities as well as issues specific to clinical care for bleeding and clotting disorders. Nurse-specific educational resources are limited; therefore needs assessment studies are crucial when planning successful educational programs. Operationalizing evidence-based research can help overcome the identified challenges faced by nurses in this field, and reduce the deficit of educational resources identified by this cohort of nurses.

Acknowledgements

Addendum - Author's contributions

P. Lazure supervised the study design and development of research tools, conducted interviews, as well as the quantitative and qualitative analysis and the interpretation of findings. In addition, he supervised development of the manuscript first draft, and integration of co-authors comments.

S. Labbé participated in the development of research tools, data collection, data analysis and the interpretation of findings, and contributed to the development of the manuscript. Ms. Labbe took part in critical decision making on the content of this manuscript.

S. Murray was involved in the study design and applied her expertise to the interpretation of findings.

T Reiser was involved in the study design and applied his expertise to the interpretation of findings.

J Munn, R Butler, K Khair, A Lambing, M Malone, and F Newall were part of the steering committee, and contributed their clinical expertise to this project by collaborating on research design and the interpretation of findings. The steering committee offered guidance and contextualization of data to support the creation of this manuscript.

Each co-author has contributed sufficiently to be considered an author of this article, according to the International Committee of Medical Journal Editors' (ICMJE) requirements, and each co-author critically reviewed the draft and approved the final version submitted.

Declarations

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Conflict of Interest

PL, JM, SL, SM, MM, TR and FN have no conflicts of interest to disclose. AL is employed by Bayer Healthcare as a clinical support specialist. KK is part of a nurse advisory board for Bayer EU. RB has received nurse advisory board fees from Pfizer, HEMA Biologics, and Gene-Tech, as well as faculty board fees from Indiana HTC.

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	NURSES N (%)	PATIENTS / CAREGIVERS N (%)	TOTAL N (%)
PHASES			
PHASE 1 - Interviews	22 (10%)	22 (100%)	**44** (19%)
PHASE 2 – Online Survey	190 (90%)	--	**190** (81%)
COUNTRIES			
UK	23 (11%)	3 (14%)	**26** (11%)
FRANCE	22 (10%)	2 (9%)	**24** (10%)
SPAIN	23 (11%)	2 (9%)	**25** (11%)
GERMANY	23 (11%)	3 (14%)	**26** (11%)
CANADA	23 (11%)	2 (9%)	**25** (11%)
U.S	34 (16%)	4 (18%)	**38** (16%)
AUSTRALIA	19 (9%)	2 (9%)	**21** (9%)
CHINA	22 (10%)	2 (9%)	**24** (10%)
ARGENTINA	23 (11%)	2 (9%)	**25** (11%)
YEARS OF PRACTICE			
10 YEARS OF PRACTICE OR LESS	86 (41%)	--	**86** (41%)
11 YEARS OF PRACTICE OR MORE	126 (59%)	--	**126** (59%)
PRACTICE SETTING			
COMMUNITY SETTING	58 (27%)	--	**58** (27%)

ACADEMIC SETTING OR SPECIALIZED CENTER	151 (71%)	--	**151** (71%)
OTHER	3 (1%)	--	**3** (1%)

KNOWLEDGE ITEMS	% Of PARTICIPANTS THAT REPORTED SUB-OPTIMAL KNOWLEDGE	GAPS HIGHER AMONG*…	GAPS LOWER AMONG*…	STATISTICAL SIGNIFICANCE**
ITEMS RELATED TO RISK ASSESSMENT				
Which elements of a patient's history are essential for the identification of a hereditary bleeding disorder, and to inform a diagnosis of hemophilia	37% (62)	NS	NS	NS
Signs and symptoms of early and late hemarthrosis	39% (64)	NS	NS	NS
Criteria to determine the severity level of hemophilia	46% (76)	UK (67%, 10) ARG (63%, 12)	US (27%, 7), Spain (26%, 5)	p = 0.037
Conducting an assessment for menorrhagia	32% (54)	NS	NS	NS
How to identify immune thrombocytopenia (ITP)	42% (67)	≤ 10 YoP (54%, 34)	> 10 YoP (38%, 33)	p = 0.011
Which elements of patients and family history to collect to	43% (72)	GER (74%, 14) CAN (63%, 12)	FR (18%, 3) Spain (22%, 4)	p = 0.005

inform a potential diagnosis of VWD			
If the results of basic laboratory tests are consistent with VWD, and if so, which type	50% (82)	NS	NS	NS

ITEMS RELATED TO VON WILLEBRAND DISEASE

Criteria to identify the type of von Willebrand disease	54% (87)	ARG (75%, 12) CAN (72%, 13)	China (22%, 4) Spain (32%, 6)	p = 0.011
Safety profile of treatments for von Willebrand disease	52% (84)	ARG (74%, 14) FR (67%, 10)	China (22%, 4) Spain (29%, 5)	p = 0.033
		≤ 10 YOP (62%, 42)	> 10 YOP (44%, 42)	p = 0.027

ITEMS RELATED TO ANTICOAGULATION

Safety profile of anticoagulation medication in patients who have a history of bleeding episodes or bleeding disorders	33% (60)	AUS (56%,9) GER (58%, 11)	U.S. (10%, 3) Spain (30%, 6) UK (30%, 6)	p = 0.012
Safety profile of anticoagulation medication in	40% (75)	FR (67%, 12) ARG (60%, 12)	U.S. (13%, 4) China (25%, 5)	p = 0.003

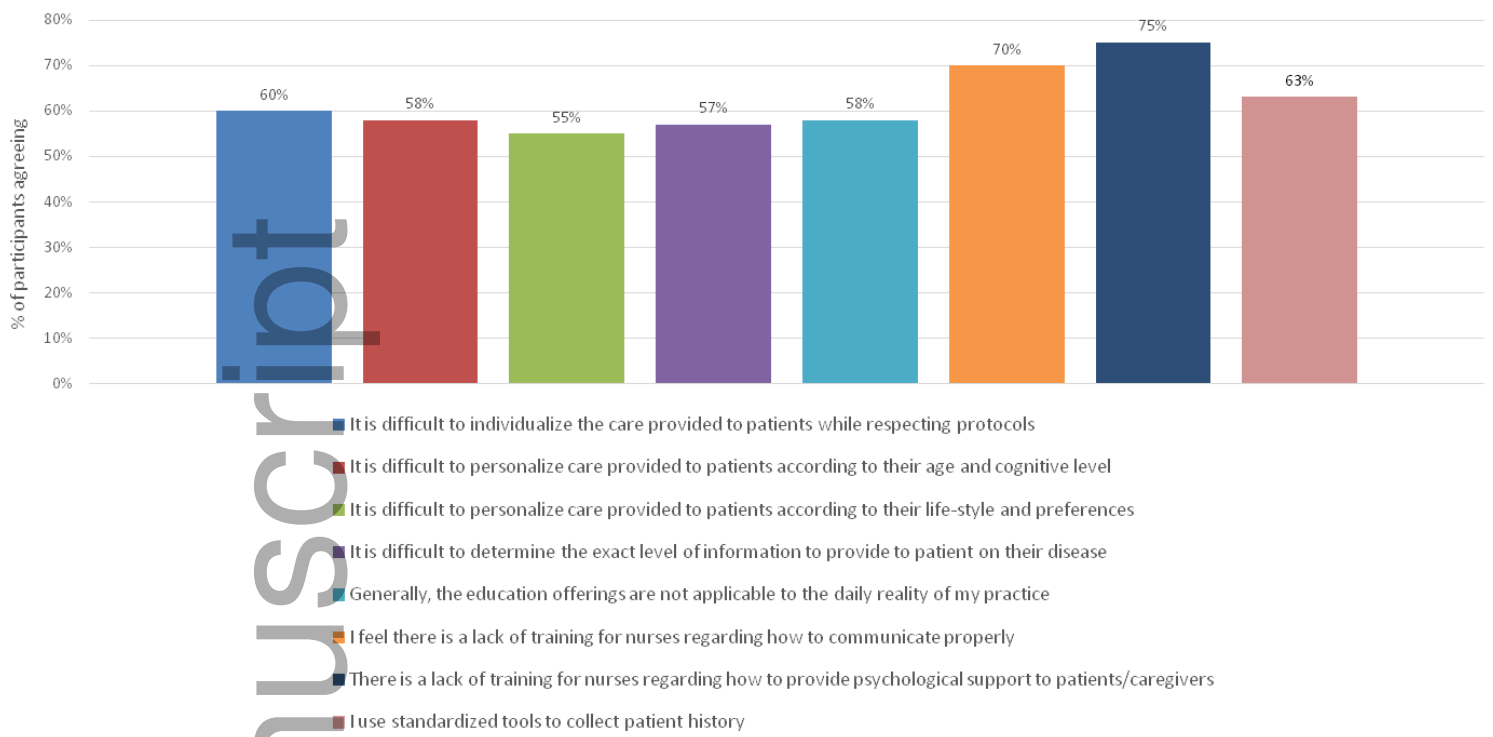|				
vulnerable patients				
Safety profile of direct oral anticoagulants (DOACs) in cancer patients	48% (86)	FR (69%, 11) ARG (68%, 13)	U.S. (20%, 6) Spain (25%, 5)	p = 0.001
ITEMS RELATED TO INHIBITORS				
Safety profile of bypassing agent	51% (82)	≤ 10 YOP (62%, 42)	> 10 YOP (43%, 40)	p = 0.019
Goals of inhibitor treatment and eradication	52% (83)	≤ 10 YOP (63%, 42)	> 10 YOP (44%, 41)	p = 0.02
How to recognize potential inhibitor development	53% (84)	≤ 10 YOP (68%, 45)	> 10 YOP (42%, 39)	p = 0.001
Inhibitor development risks for previously untreated patients	52% (84)	≤ 10 YOP (65%, 42)	> 10 YOP (44%, 42)	p = 0.009

Question: For each of the following items, please rate your <u>current knowledge level in your daily practice</u> in relation to what <u>they should be</u> given your profession.

Scale: 1=Low, 3=Acceptable, 5=Optimal, 6 = Not applicable to my practice. Data are the percentage of participants that selected 1, 2 or 3.

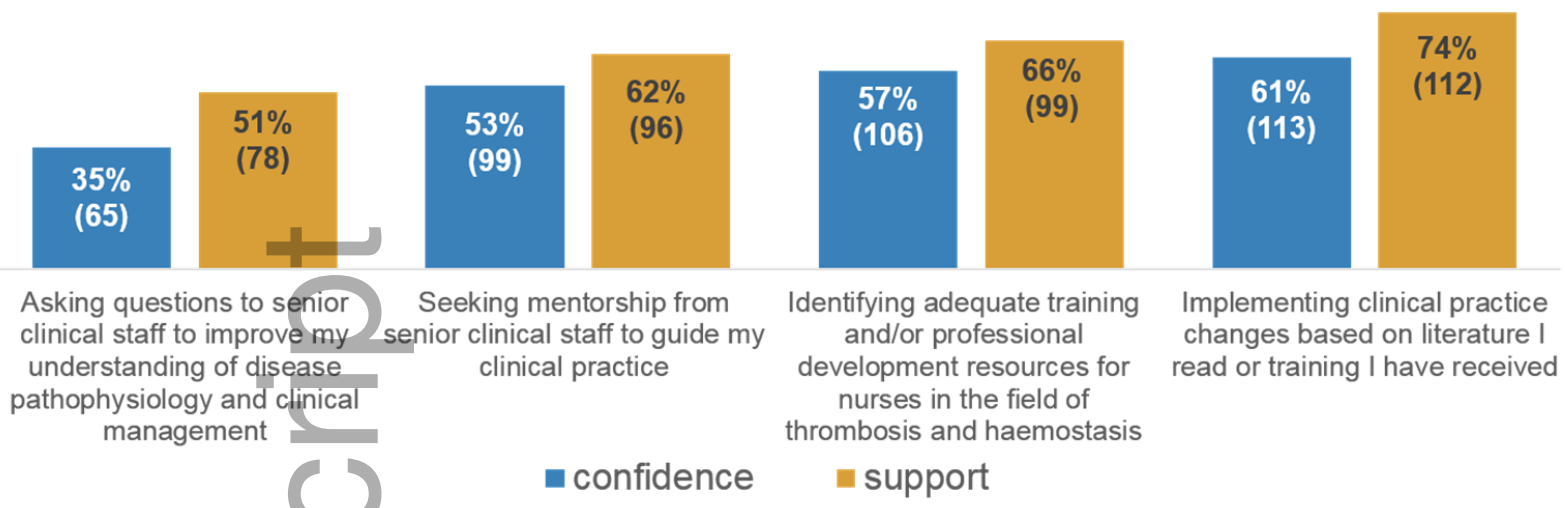*Only 2 countries with higher knowledge gaps are reported.

** Only 2 countries with lower knowledge gaps are reported.

*** Significant difference between countries or years of practice (10 years of practice or less vs. more than 10 years of practice) calculated using chi-square (p < .05).

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	Confidence	Support
Asking questions to senior clinical staff to improve my understanding of disease pathophysiology and clinical management	35% (65)	51% (78)
Seeking mentorship from senior clinical staff to guide my clinical practice	53% (99)	62% (96)
Identifying adequate training and/or professional development resources for nurses in the field of thrombosis and haemostasis	57% (106)	66% (99)
Implementing clinical practice changes based on literature I read or training I have received	61% (113)	74% (112)

■ confidence   ■ support

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