


ORIGINAL ARTICLE

Education needs of nurses in thrombosis and hemostasis: An international, mixed-methods study

Patrice Lazure MSc¹  | James Munn MS, BS, BSN, RN-BC² | Sara Labbé MSc¹ | Suzanne Murray BA¹ | Regina Butler RN-BC³ | Kate Khair RN, MSC, MCGI, PhD⁴ | Angela Lambing MSN, ANPC, GNPC⁵ | Maura Malone MSN, RN⁶ | Thomas Reiser MA⁷ | Fiona Newall PhD, MN, B.Sci(Nsg), RN^{8,9,10,11}

¹AXDEV Group, Inc., Brossard, Quebec, Canada

²University of Michigan, Ann Arbor, Michigan, USA

³Division of Hematology, Hemostasis and Thrombosis Center, Children's Hospital of Philadelphia (CHOP), Philadelphia, Pennsylvania, USA

⁴Department of Haemophilia, Great Ormond Street Hospital for Children, NHS Trust, London, UK

⁵Bayer HealthCare, Whippany, New Jersey, USA

⁶Hemophilia and Thrombosis, Dartmouth-Hitchcock USA, Lebanon, New Hampshire, USA

⁷International Society on Thrombosis and Haemostasis, Carrboro, North Carolina, USA

⁸Nursing Research, Royal Children's Hospital, Melbourne, Victoria, Australia

⁹Department of Clinical Haematology, Royal Children's Hospital, Melbourne, Australia

¹⁰Department of Nursing and Department of Paediatrics, the University of Melbourne, Melbourne, Australia

¹¹Haematology Research Group, Murdoch Children's Research Institute, Melbourne, Australia

Correspondence

Patrice Lazure, AXDEV Group, Inc., Brossard, Québec, Canada.
Email: lazurep@axdevgroup.com

Funding information

Funding for AXDEV Group to conduct this study came from International Society on Thrombosis and Haemostasis education research funds, which are supported by contributions from Bayer Healthcare Pharmaceuticals Inc.

Abstract

Background: The need for a more integrated, multidisciplinary 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 hemostasis 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: (a) Understanding of von Willebrand disease (VWD); (b) Anticoagulant safety profile in specific patients; (c) Understanding the treatment of patients with inhibitors; (d) Patient risk assessments; (e) Individualization of care and communication with patients; and (f) 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

blood coagulation disorders, clinical competence, health knowledge-practice-attitudes, nurse-patient relations, nursing care, von Willebrand disease

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2018 The Authors. *Research and Practice in Thrombosis and Haemostasis* published by Wiley Periodicals, Inc on behalf of International Society on Thrombosis and Haemostasis.

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.

1 | 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 challenging⁷⁻⁹ 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.

2 | 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 (eg, lack of knowledge or skills). Study findings can be applied to the future development of targeted, relevant educational programs for nurses.

3 | METHODS

3.1 | 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.

3.2 | Recruitment

3.2.1 | Inclusion criteria

To be eligible, participants must practice in one of nine countries (Argentina, Australia, Canada, China, France, Germany, Spain, the United Kingdom, or the United States), and be employed as a nurse, nurse practitioner, or registered nurse (or the local equivalent of that designation). They must have at least 1 year of work experience, with at least 50% of their professional time working in the field of thrombosis and hemostasis. In Australia, those who spent 20% or more of their time in thrombosis and hemostasis 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 method¹⁵ that included participants with different levels of practice experience, and various practice settings (ie, 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 in the field of thrombosis and hemostasis.

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 5 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.

3.3 | 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). 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.

3.4 | Data collection and analysis

3.4.1 | Qualitative phase

Participants completed a 45-minute semistructured interview. The interview guide was designed by educational experts (coauthors 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 (coauthors 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 (coauthors PL, SL, SM, TR). Key findings were used to construct an online quantitative survey.

3.4.2 | 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 five-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 Data S1).

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 subgroups (country; years of practice [YOP]—either 10 YOP and under, or 11 and over), Pearson chi-squares were calculated.

3.4.3 | Final analysis and data triangulation

The educational researchers used data triangulation²¹ 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.

4 | 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 hemostasis and thrombosis face. These challenges include: (a) the understanding of VWD; (b) anticoagulant safety in specific patient profiles; (c) understanding the treatment of hemophilia patients with inhibitors; (d) patient risk assessments; (e) individualization of care and communication with patients and families; and (f) accessing and implementing relevant professional education.

4.1 | Challenge with the understanding of von Willebrand disease

Several aspects of clinical practice regarding patients with VWD were reported as suboptimal by nurses. Suboptimal 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 suboptimal knowledge, given their professional role, of the "criteria to identify the type of VWD." Furthermore, 50% reported suboptimal 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 suboptimal 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

TABLE 1 Characteristics of the study final sample

	Nurses n (%)	Patients/ Caregivers n (%)	Total n (%)
Phases			
1. Interviews	22 (10)	22 (100)	44 (19)
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)
US	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 y or less	86 (41)	–	86 (41)
11 y 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)

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, USA

4.2 | Challenges with anticoagulant safety in specific patient profiles

Suboptimal knowledge of the “safety profile of anticoagulants” was reported by nurses in three particular patient profiles: (a) those with a history of bleeding episodes; (b) neonates and the elderly; and (c) cancer patients.

Knowledge of “the safety profile of anticoagulation medication when used by vulnerable patients” was reported to be suboptimal 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 suboptimal 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

4.3 | Challenges understanding the treatment of patients with inhibitors

Triangulated data identified challenges related to hemophilia and inhibitors faced by nurses. Half of participants (51%; Table 2) reported suboptimal 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 suboptimal 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%, $P = 0.02$).

Suboptimal 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

4.4 | 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 suboptimal level of knowledge

TABLE 2 Percent of participants reported sub-optimal knowledge level, according to their professional role

Knowledge items	% of participants that reported suboptimal knowledge	Gaps higher among*...	Gaps lower among**	Statistical significance**
<i>Items related to risk assessment</i>				
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 inform a potential diagnosis of VWD	43% (72)	GER (74%, 14) CAN (63%, 12)	FR (18%, 3) Spain (22%, 4)	P = 0.005
If the results of basic laboratory tests are consistent with VWD, and if so, which type	50% (82)	NS	NS	NS
<i>Items related to von Willebrand disease</i>				
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
<i>Items related to anticoagulation</i>				
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 vulnerable patients	40% (75)	FR (67%, 12) ARG (60%, 12)	U.S. (13%, 4) China (25%, 5)	P = 0.003
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
<i>Items related to inhibitors</i>				
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 = 0.020
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 current knowledge level in your daily practice in relation to what they should be 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 two countries with higher knowledge gaps are reported.

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

***Significant difference between countries or years of practice (10 y of practice or less vs more than 10 y of practice) calculated using chi-square ($P < 0.05$).

of “which elements of a patient’s history are essential for the identification of an inherited disorder” (Table 2). In addition, nurses reported a suboptimal 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 hemophilia severity (46%).

Regarding bleeding disorders, 42% of nurses reported suboptimal 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, suboptimal skills conducting risk assessments in bleeding disorders were also reported. Nearly half of nurses (46%) reported suboptimal skills, when “assessing the bleeding risk for patients with inherited bleeding disorders.” Half of nurses (50%) reported suboptimal 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).

4.5 | 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 percent 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 lifestyle 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 hemostasis 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. Caregiver (thrombosis disorder), Australia

TABLE 3 Percent of participants reported suboptimal skills level on various clinical tasks, according to their professional role

Skills items	% of participants that reported suboptimal skills	Gaps higher among...*	Gaps lower among...**	Statistical significance***
Assessing bleeding risk for patients with inherited bleeding disorders	46% (78)	NS	NS	NS
Assessing patient with potential hemarthrosis	50% (81)	CAN (72%, 13) ARG (68%, 13)	Spain (22%, 4) US (31%, 8)	$P = 0.044$
Conducting an assessment for menorrhagia	42% (69)	UK (60%, 9), FR (59%, 10) ≤ 10 YOP (51%, 36)	US (19%, 5) Spain (26%, 5) >10 YOP (34%, 33)	$P = 0.049$ $P = 0.028$
Conducting an assessment for epistaxis	32% (53)	≤ 10 YOP (40%, 28)	>10 YOP (26%, 25)	$P = 0.046$
Conducting an assessment for hematuria	34% (58)	≤ 10 YOP (44%, 31)	>10 YOP (27%, 27)	$P = 0.022$
Assessing acute bleeding episodes in patients with hemophilia	41% (70)	GER (63%, 12) ARG (62%, 13)	China (11%, 2) US (27%, 7)	$P = 0.012$
Assessing bleeding episodes in patients with von Willebrand disease (VWD)	50% (84)	≤ 10 YOP (60%, 41)	>10 YOP (43%, 43)	$P = 0.032$
Assessing bleeding risk for patients with inherited bleeding disorders	46% (78)	NS	NS	NS

Question: For each of the following items, please rate your current skill level in your daily practice in relation to what they should be 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. NS, not significant; YOP, years of practice.

*Only two countries with higher knowledge gaps are reported.

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

***Significant difference between countries or years of practice (10 y of practice or less vs more than 10 y of practice) calculated using chi-square ($P < 0.05$).

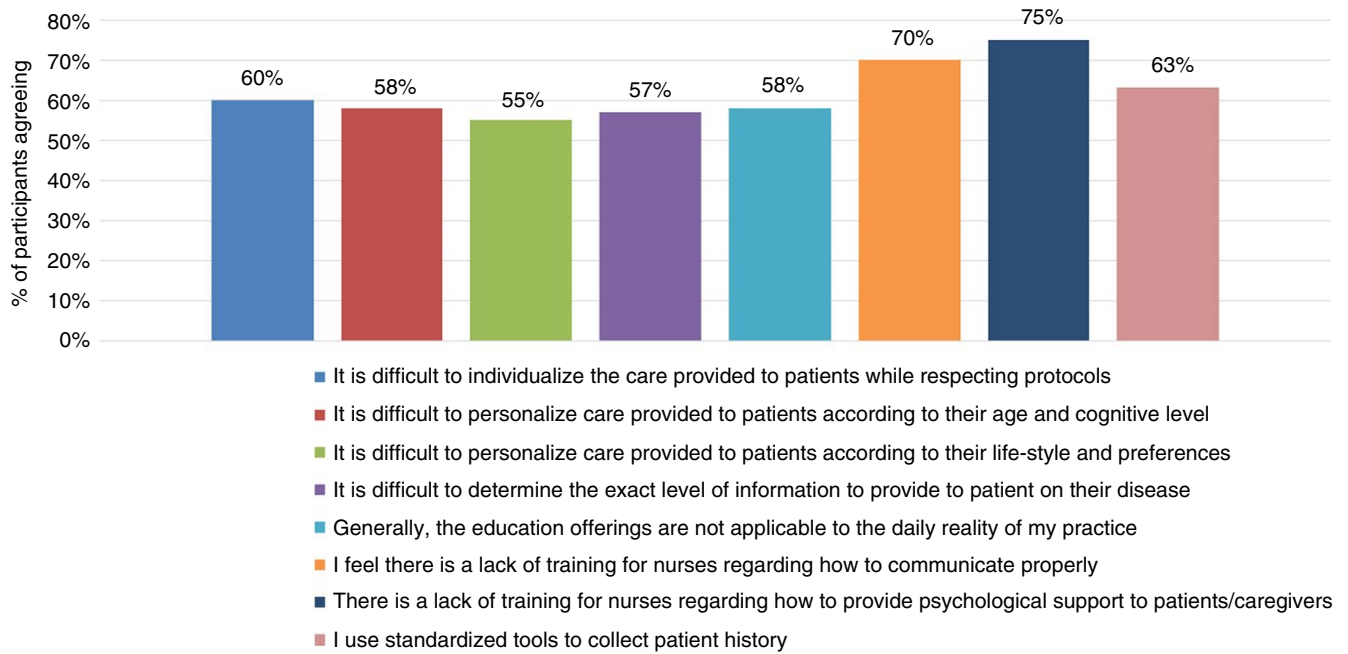


FIGURE 1 Percent of nurse participants who agree with statements regarding their practice. Question: Please rate your level of agreement with each of the following statements. Scale: 1. Completely disagree, 2. Slightly disagree, 3. Slightly agree, 4. Completely agree. Data are percentage of participants that selected 3 or 4

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.
Caregiver (thrombosis disorder), US

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. Nurse, Australia

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 hemostasis" (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%).

4.6 | 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

5 | DISCUSSION

This study identified challenges faced by nurses in the field of coagulation disorders, highlighted areas where nurses reported having suboptimal 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

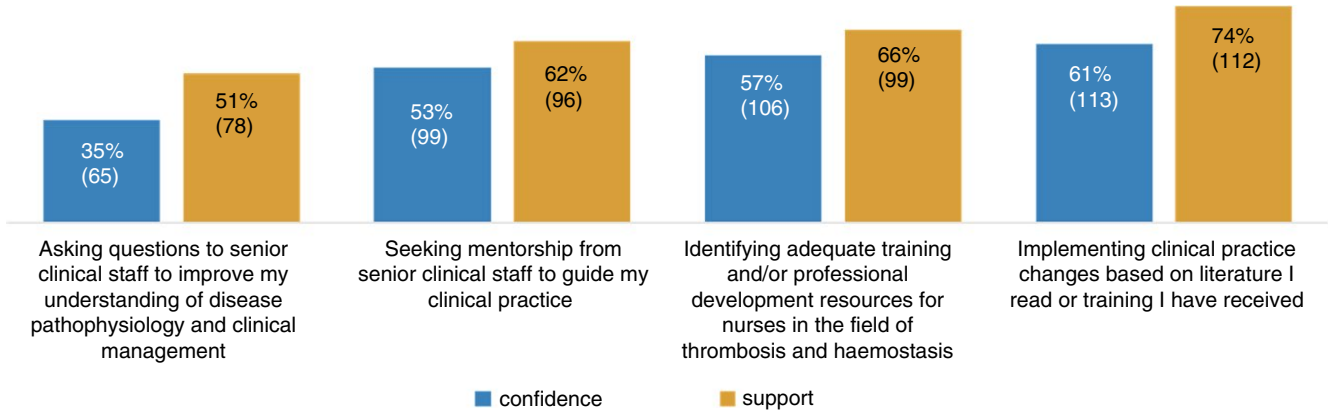


FIGURE 2 Percent and number of nurse participants who reported low to acceptable levels of confidence/support. Question: On a scale of 1-5 (1 = Low, 3 = Acceptable, 5 = Optimal), for each of the following items related to evidence-based practices in thrombosis/haemostasis management, please rate; (A) Your level of confidence; (B) The level of support you have from your clinical team and administration. Scale: 1. Low, 3. Acceptable, 5. Optimal. Data are percentage of participants that selected 1, 2 or 3

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, hematuria, 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 suboptimal 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 hemophilia 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.

5.1 | 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 hemostasis.

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.

5.2 | Conclusion

This study offers a comprehensive illustration of the current challenges and barriers faced by nurses in the field of hemostasis and thrombosis, including main areas where skills or knowledge were reported to be suboptimal 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.

ACKNOWLEDGMENTS

This study was conducted by AXDEV Group. The authors would like to acknowledge the support of Project Manager Marie-Aimée Fournier and Project Coordinator Marc Distexhe, who supported the research team and steering committee by facilitating data collection and analysis, and by coordinating communication between the many contributors to this project. Morgan Peniuta (Researcher, AXDEV Group) contributed to data collection and analysis, the design and presentation of the final findings, and to the development of this manuscript. The authors would also like to thank Gregory LeClerc (Bayer Consumer Care, AG.), Barry Sudbeck (Fleishman Hillard) and Christine Candora-Hickey (ISTH) without whom this study would

not have been possible. Finally, the authors would like to sincerely thank each nurse, patient, and caregiver for their valuable participation in this study.

RELATIONSHIP DISCLOSURE

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.

AUTHOR 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 coauthors' 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 coauthor 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.

REFERENCES

1. Mensah PK, Gooding R. Surgery in patients with inherited bleeding disorders. *Anaesthesia*. 2015;70(Suppl 1):112–20, e139–40.
2. Page D, Crymble S, Lawday K, et al. Penny wise, pound foolish: an assessment of Canadian Hemophilia/inherited bleeding disorder comprehensive care program services and resources. *Haemophilia*. 2016;22(4):531–6.
3. Pipe SW, Kessler CM. Evidence-based guidelines support integrated disease management as the optimal model of haemophilia care. *Haemophilia*. 2016;22(Suppl 3):3–5.
4. Group NW. Nurses' guide to bleeding disorders. <https://www.hemophilia.org/Researchers-Healthcare-Providers/NHF-Provider-Working-Groups/Nursing-Working-Group/Resources-for-Nurses/Nurses-Guide-to-Bleeding-Disorders>. Accessed July 4, 2018.
5. Khair K. Minimizing joint damage: the role of nurses in promoting adherence to hemophilia treatment. *Orthop Nurs*. 2010;29(3):193–200; quiz 201–192.
6. Tietze M, Gurley J. VTE prevention: development of an institutional protocol and the nurse's role. *Medsurg Nurs*. 2014;23(5):331–3, 342.

7. Ragni MV. von Willebrand disease: differential diagnosis and diagnostic approach to specific subtypes. In: Abutalib SA, Connors JM, Ragni MV, eds. *Nonmalignant Hematology*. Zion, IL: Springer International Publishing; 2016:285–93.
8. Sadler JE. Slippery criteria for von Willebrand disease type 1. *J Thromb Haemost*. 2004;2(10):1720–3.
9. Bertolotti L, Ollier E, Duvillard C, et al. Direct oral anticoagulants: current indications and unmet needs in the treatment of venous thromboembolism. *Pharmacol Res*. 2017;118:33–42.
10. Duran J, Lasky JL 3rd, Rodgers C. Use of a pediatric bleeding questionnaire in the screening of von Willebrand disease in young females at menarche in the primary care setting. *J Pediatr Health Care*. 2016;30(5):408–13.
11. Barras MA, Hughes D, Ullner M. Direct oral anticoagulants: new drugs with practical problems. How can nurses help prevent patient harm? *Nurs Health Sci*. 2016;18(3):408–11.
12. Elder S, Hobson DB, Rand CS, et al. Hidden barriers to delivery of pharmacological venous thromboembolism prophylaxis: the role of nursing beliefs and practices. *J Patient Saf*. 2016;12(2):63–8.
13. Creswell JW. Chapter 1: understanding mixed methods research. In: Creswell JW, Plano Clark VL, eds. *Designing and Conducting Mixed Methods Research*. 2nd ed. Thousand Oaks, CA: Sage Publishing; 2006:1–19.
14. Zhang W, Creswell J. The use of “mixing” procedure of mixed methods in health services research. *Med Care*. 2013;51(8):e51–7.
15. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health*. 2015;42(5):533–44.
16. Sharma M. ‘Can the patient speak?’: postcolonialism and patient involvement in undergraduate and postgraduate medical education. *Med Educ*. 2018;52(5):471–9.
17. Dijk SW. Changing the paradigm of meaningful patient involvement in medical education. *Acad Med*. 2017;92(5):576–7.
18. Berg BL. *Qualitative Research Methods for the Social Sciences*. 5th ed. Boston, MA: Pearson Education, Allyn & Bacon; 2004.
19. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277–88.
20. Morse JM. The significance of saturation. *Qual Health Res*. 1995;5(3):147–9.
21. Carter N, Bryant-Lukosius D, DiCenso A, Blythe J, Neville AJ. The use of triangulation in qualitative research. *Oncol Nurs Forum*. 2014;41(5):545–7.
22. Pulcini J, Jelic M, Gul R, Loke AY. An international survey on advanced practice nursing education, practice, and regulation. *J Nurs Scholarsh*. 2010;42(1):31–9.
23. Deng F-F. Comparison of nursing education among different countries. *Chinese Nurs Res*. 2015;2(4):96–8.
24. Neutze D, Roque J. Clinical evaluation of bleeding and bruising in primary care. *Am Fam Phys*. 2016;93(4):279–86.
25. Committee EN, Harrington C, Bedford M, et al. A European curriculum for nurses working in haemophilia. *Haemophilia*. 2016;22(1):103–9.
26. Lambing A. Bleeding disorders: patient history key to diagnosis. *Nurse Pract*. 2007;32(12):16–24; quiz 24–15.
27. Rodeghiero F, Tosetto A, Abshire T, et al. ISTH/SSC bleeding assessment tool: a standardized questionnaire and a proposal for a new bleeding score for inherited bleeding disorders. *J Thromb Haemost*. 2010;8(9):2063–5.
28. Lee TT. Nursing diagnoses: factors affecting their use in charting standardized care plans. *J Clin Nurs*. 2005;14(5):640–7.
29. Keenan GM, Yakel E, Tschannen D, Mandeville M. Documentation and the nurse care planning process. In: Hughes RG, ed. *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. Rockville, MD: Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services; 2008.
30. Liou SR, Chang CH, Tsai HM, Cheng CY. The effects of a deliberate practice program on nursing students’ perception of clinical competence. *Nurse Educ Today*. 2013;33(4):358–63.
31. Numminen O, Ruoppa E, Leino-Kilpi H, Isoaho H, Hupli M, Meretoja R. Practice environment and its association with professional competence and work-related factors: perception of newly graduated nurses. *J Nursing Manag*. 2016;24(1):e1–11.
32. Berntorp E, Dargaud Y, Hart D, et al. The second Team Haemophilia Education Meeting, 2016, Frankfurt, Germany. *Eur J Haematol*. 2017;98(Suppl 85):1–15.
33. Cutter S, Molter D, Dunn S, et al. Impact of mild to severe hemophilia on education and work by US men, women, and caregivers of children with hemophilia B: the Bridging Hemophilia B Experiences, Results and Opportunities into Solutions (B-HERO-S) study. *Eur J Haematol*. 2017;98(Suppl 86):18–24.
34. Wallis M, Autar R. Deep vein thrombosis: clinical nursing management. *Nurs Stand*. 2001;15(18):47–54; quiz 56–47.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

How to cite this article: Lazure P, Munn J, Labbé S, et al. Education needs of nurses in thrombosis and hemostasis: An international, mixed-methods study. *Res Pract Thromb Haemost*. 2019;3:99–108. <https://doi.org/10.1002/rth2.12155>