

# Home infusion teaching practices at federally funded hemophilia treatment centers in the United States of America

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## Abstract

**Background:** Home management of hemophilia is standard of care in many countries. This study examined current nursing practices in teaching home infusion (HI) at hemophilia treatment centers (HTC) in the USA.

**Objectives:** The aims were to identify and compare tools and resources used, areas of unmet needs, and to discuss implications for nurses in practice.

**Methods:** An anonymous electronic survey was distributed to 574 HTC nurses; 156 responses were analyzed.

**Results:** The data demonstrated that nurses, more specifically nurse coordinators, were most responsible for teaching HI. However, many nurses lack the knowledge and confidence to do so: 23.0% responded feeling somewhat or not very confident with teaching. Of those 36.4% were staff nurses, 11.9% nurse coordinators, and 41.7% advanced practice registered nurses. The majority of nurses have worked more than 5 years as a nurse, with a mean length of time of 23.7 years (SD=11.12, range 3-47) and a mean of 12.9 years (SD=10.29, range 1-42) in a HTC. Thirty-eight and a half percent of nurses have worked less than 5 years in a HTC. Most nurses appeared to follow the Infusion Nurses Society standards when performing venipunctures. Many centers reported using a formal tool or curriculum to teach HI. Nonetheless, these curricula are not uniform and their use is inconsistent between centers and regions.

**Conclusion:** There are currently no national guidelines or standards to assist nurses in this task. The data confirmed the need to develop guidelines and a standardized curriculum to teach HI.

## KEYWORDS

hemophilia, home infusion therapy, intravenous infusion, nursing, patient education, self-administration, venipuncture

## Essentials

- Hemophilia nurses are expected to teach home infusion (HI) to patients and their caregivers.
- A survey was conducted to identify current HI teaching practices in the United States of America.
- Some nurses reported lacking confidence to teach; curricula exist but their use is not uniform.
- The study supports the development of national guidelines and a standard curricula to teach HI.

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## 1 | INTRODUCTION

According to guidelines for management of hemophilia patients, the standard of care is the use of intravenous infusions to replace missing clotting proteins to treat or prevent bleeding episodes.<sup>1,2</sup> The development of cryoprecipitate and anti-hemophilic factor (AHF) concentrates in the late 1960s and 1970s allowed for treatment to move from the clinical setting into the home.<sup>3,4</sup> Over the past 5 decades, the teaching of home infusion (HI) to hemophilia patients and their caregivers has become a standard practice in the United States of America (USA).<sup>1,4-7</sup>

Home infusion of AHF was first introduced in the literature in 1970 after a pilot program was reported to be both practical and safe.<sup>3</sup> The benefits of HI include improved adherence to prophylaxis, prompt treatment of bleeds, decreased time lost from work or school, fewer trips to the emergency room and hospitalizations, cost savings, and increased patient autonomy.<sup>6-9</sup>

Hemophilia nurses play a central role in facilitating HI education.<sup>8</sup> This undertaking can be a challenge, especially for the novice, since effective teaching of a skill requires the nurse to be confident and proficient.<sup>10</sup> Even though hemophilia nurses are expected to teach HI, most have never had the opportunity to participate in formal training either in nursing school or when they join a HTC. The University HealthSystem Consortium, an organization comprised of several of the USA's leading academic health systems focusing on quality and safety excellence, did an extensive evaluation of this matter. Barbara Wenger<sup>11</sup> reported that graduate nurse residents were asked at 3 time points to identify the top 3 skills they felt uncomfortable performing independently: the start of their residency, 6 months into practice, and again at 12 months. At each stage, venipunctures were one of the top 3 responses. Gavlak<sup>12</sup> further supported the need to reinforce these clinical skills during the orientation period. A 2013 survey conducted by the Infusion Nurses Society (INS)<sup>13</sup> found that even though 89% of nurses perform venipunctures, only 43% of them learned the skill at school. Most reported learning it on the job.

When patients are allowed to treat at home, significant medical decisions are delegated to non-medical individuals. Therefore, HI teaching should be formal and comprehensive to ensure that patients and caregivers are prepared to deal with not only routine medical situations at home, but most importantly, how to deal with emergencies and when to seek professional help.<sup>2,3,7</sup>

Although guidelines exist in other countries, there are currently no national guidelines or standards in the USA for nurses educating families about HI.<sup>8,14-16</sup> This study, the first of its kind, was conducted in an attempt to understand current teaching practices in HTCs in the USA. The aims of this study were to identify and compare tools and resources currently used, identify areas of unmet needs, and to discuss implications for nursing practice.

## 2 | MATERIALS AND METHODS

This descriptive correlational study was approved by the University of Miami Institutional Review Board.

### 2.1 | Sample population

Study participants were nurses currently working exclusively at federally funded HTCs in the USA. This included all levels of professional nurses from the lowest level licensed practical nurses (LPN), to registered nurses (RN), and advanced practice registered nurses (APRN), the highest level. In the USA, a LPN is a nurse who completes an accredited, yearlong practical nursing program and is licensed after passing a national licensure exam. This type of nurse has the lowest level of education, provides basic nursing care, and reports to other health care providers such as RNs, APRNs, and physicians.<sup>17</sup>

### 2.2 | Measurement instrument

Data was collected in 2016 using a one-time electronic, anonymous survey created through the University of Miami's Qualtrics secure web-based survey application. Potential participants received an email invitation with a unique embedded link for self-administering the survey. At the completion of the survey, participants had the option to upload educational tools and resources used at their facility.

The survey utilized was a non-validated tool developed by the authors. It consisted of: 10 demographic questions, 20 questions specific to current HI teaching practices, and 14 questions developed by the INS to explore the lack of standardization and knowledge in practices and variations among providers' skill and experience. Throughout the survey nurses were given the option to respond by selecting from choices provided including "other." Selection of this option allowed free-form text responses. Specific to HI teaching practices, participants were asked the free-form text question "What tools or resources do you think are needed?" This was the only question that did not provide preset options: nurses had to write their answers. The free-form text responses allowed for a more comprehensive assessment of current practices. Free-form entries were analyzed to identify repeated or similar responses. The estimated survey completion time was 10-15 minutes.

A survey email distribution panel list was developed using the Center for Disease Control and Prevention's (CDC) HTC directory.<sup>18</sup> This list was validated with all HTC regional coordinators and supplemented with the Partners in Bleeding Disorders Education organization's HTC nurse list.<sup>19</sup> Survey invitations were initially distributed to 587 potential participants. Thirteen surveys were omitted either because of incorrect emails or nurses who replied they no longer worked at an HTC, resulting in a calculated total of 574 surveys distributed.

The survey response data was downloaded directly from the Qualtrics Survey Software into the Statistical Package for the Social Sciences (IBM SPSS, Armonk, New York, USA), Version 22 for data computation and analysis. This included descriptive analysis on demographic information and descriptive/frequency statistics to assess for missing data. As normality test was not met, nonparametric inferential statistic was used. Educational tools shared by participants were analyzed for commonalities and differences.

### 3 | RESULTS

A total of 156 surveys were completed, yielding a 27.2% response rate. Missing data consisted of sporadic demographic information, but those surveys were included as the responses specific to HI and venipuncture were complete.

#### 3.1 | Demographics

The majority of participants were from the Great Lakes (29.5%), Southeast (18.6%), and Western States (12.2%) regions (Figure 1). Most respondents reported working at an academic HTC (61.5%); 81.0% had a Bachelor of Science in Nursing (BSN) or higher level of education (Table 1). Survey participants were predominantly female (92.3%) with an average age of 48.9 years (SD=11.2, range 24-68). Mean number of years working as a nurse was 23.7 years (SD=11.12, range 3-47) and mean length of time in a HTC was 12.9 years (SD=10.29, range 1-42), with 38.5% of nurses having worked at a HTC for less than 5 years. Participants identified themselves as nurse coordinators (54.5%), staff nurses (21.8%), and APRNs (15.4%). Eighty-eight percent (88.4%) of nurses acknowledged being responsible for pediatric patients: 30.1% cared only for children and 58.3% cared for both children and adults.

#### 3.2 | Home infusion teaching

Of the 79.5% of nurses responsible for teaching HI to patients and families, 77.0% stated strong confidence in their teaching skills (extremely or very confident). The remaining 23.0% expressed much less confidence, with 17.9% feeling somewhat confident and 5.1% not very confident, with a range of 8-41 years of nursing experience. APRNs (41.7%) were the most frequent group to report feeling “somewhat” (33.4%) or “not very” (8.3%) confident in their HI teaching skills, followed by 36.4% of staff nurses (27.3%/9.1%) and 11.9% of nurse coordinators (9.5%/2.4%) (Figure 2). While all 5 categories of nurses (58.1% nurse coordinators, 23.4% staff nurses, 12.1% APRN, 3.2% nurse educators, and 3.2% research nurses) reported responsibility for teaching HI, nurse coordinators, staff nurses, and APRNs accounted for 93.6% of all of the actual teachings.

Chi-square test of independence was calculated comparing variables by region; no significant relationships were found. Regional results appear independent of each other. We analyzed the association of confidence in teaching HI to patients and families with characteristics including years as a nurse, years working at a HTC, current position, patient population served (adult, pediatric, or both), and the use of a formal curriculum, as shown in Table 2. A significant association was found between: years as a nurse ( $\chi^2(8)=24.17, P=.002$ ); years

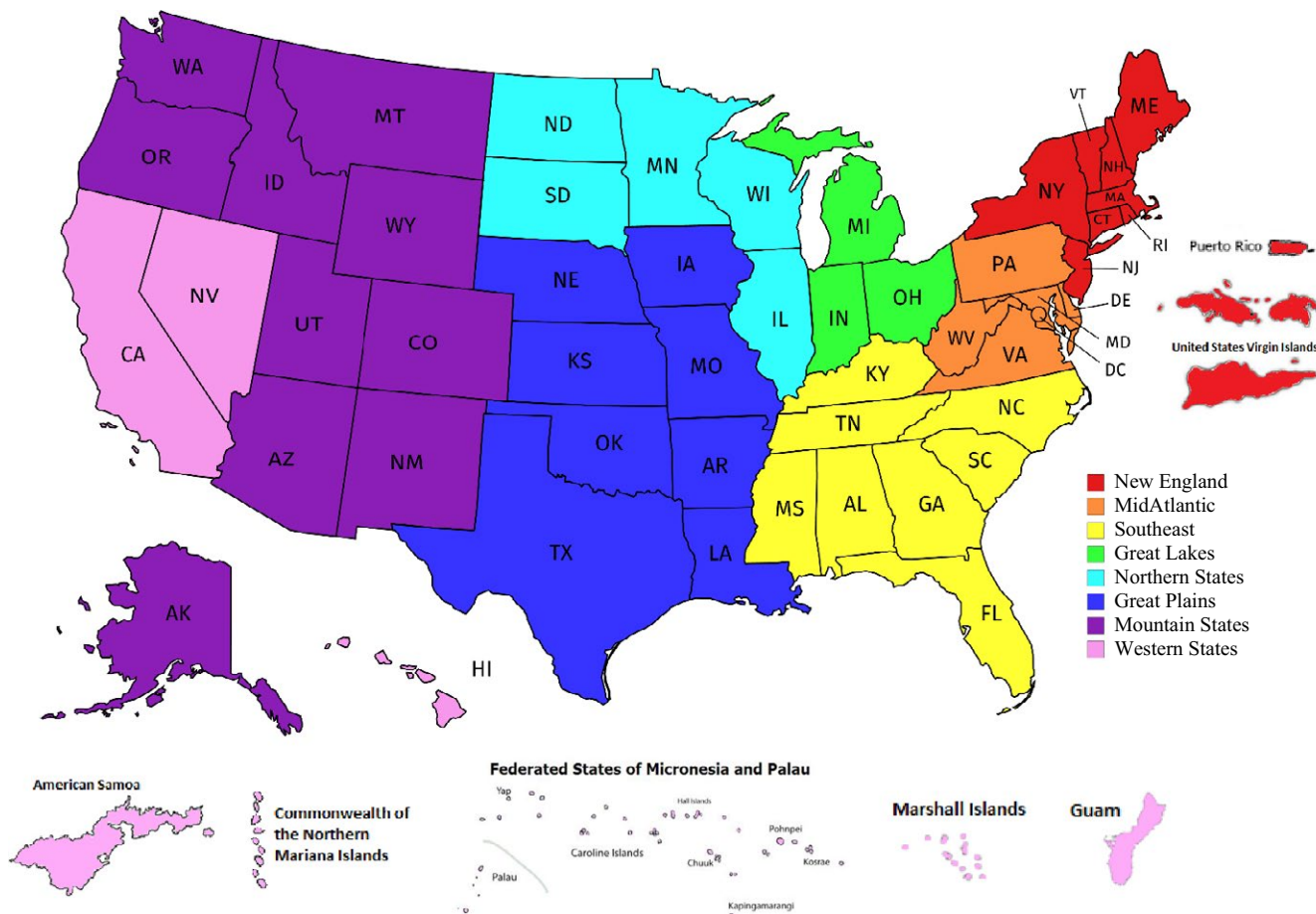


FIGURE 1 Hemophilia treatment centers by region

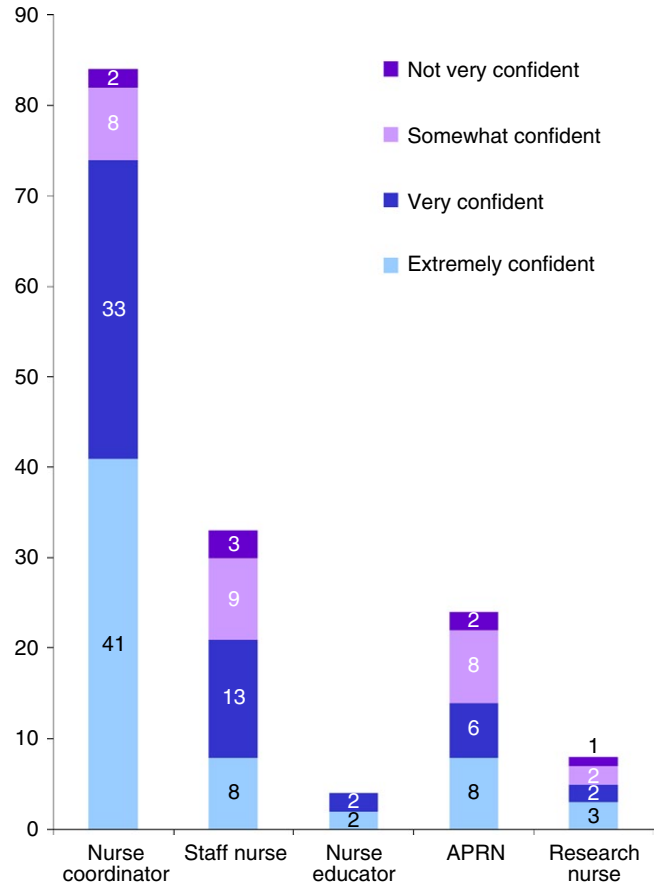
**TABLE 1** Study participants demographic characteristics

	Frequency	%
<b>Gender</b>		
Female	144	92.3
Male	9	5.8
Missing data	3	1.9
<b>Education*</b>		
LPN	1	0.6
Diploma in nursing	7	4.5
ADN	21	13.5
BSN	79	50.6
MSN	45	28.8
Doctorate (PhD, DNP)	2	1.3
Missing data	1	0.6
<b>Current position</b>		
Staff nurse	34	21.8
Advanced practice registered nurse	24	15.4
Nurse educator	4	2.6
Research nurse	8	5.1
Nurse coordinator	85	54.5
Missing data	1	0.6
<b>Patient population</b>		
Pediatric	47	30.5
Adults	16	10.4
Both	91	59.1
Missing data	2	1.3
<b>Federal Region of HTC</b>		
New England	18	11.5
Mid-Atlantic	14	9.0
Southeast	29	18.6
Great Lakes	46	29.5
Northern States	3	1.9
Great Plains	11	7.1
Mountain States	16	10.3
Western States	19	12.2
<b>HTC associated with</b>		
Academic center	96	61.5
Private clinic or hospital	17	10.9
Community/public clinic or hospital	31	19.9
Independent, self-standing HTC	11	7.1
Missing data	1	0.6

n=156

\*In order from lowest to highest level of education

working at a HTC ( $\chi^2=22.32, P = .001$ ); and current position ( $\chi^2=17.91, P = .011$ ) on the confidence level in teaching HI. Nurses' confidence level in teaching HI increased with the number of years worked as a



**FIGURE 2** Confidence in teaching home infusion by position

nurse and at a HTC. Nurse educators and nurse coordinators were more confident in teaching HI. No statistically significant relationship was found between confidence in teaching HI with either patient population served or the use of a formal curriculum.

The most common methods of learning how to teach HI was observing another nurse (58.3%), trial and error (37.2%), attending a workshop (17.9%), personal experience as a nurse (9.1%), and CDs provided by pharmaceutical companies (8.3%). When the respondents were asked to give only one answer, the primary method of teaching was one-on-one (63.5%). However, when a follow-up question was posed where the respondents could select multiple options, as well as select "other" and free-text their answer, 46.8% of respondents reported teaching at camp, 26.3% at group workshops, 22.4% in patient educational meetings, and 3.6% during home nursing visits.

Data demonstrated that 80.1% of patients attend more than one training session, with a mean of 4.6 sessions (SD=2.5, range 1-15) and the mode 3 (Figure 3). The hemophilia nurse coordinator was the most common person to follow up with the patient and families on HI teaching (57.7%). Others identified as being responsible were: a home health nurse (42.9%), parent (41.7%), another HTC nurse (19.2%), and a clinical APRN (11.5%).

The nurses (20.5%) who reported not being responsible for teaching HI indicated it was because: someone else in the center was responsible for this task (11.5%), they relied on home nurses (7.0%), there were no expectations to teach HI (3.7%), an inability to perform

**TABLE 2** Confidence in teaching chi-square test analysis

Characteristic	Confidence level			Value	P
	Extremely confident	Very confident	Less confident		
Years as a nurse					
0-10	1 (3.8)	14 (53.8)	11 (42.3)	24.167 <sup>a</sup>	.002*
11-20	11 (34.4)	11 (34.4)	10 (31.3)		
21-30	23 (50.0)	17 (37.0)	6 (13.0)		
31-40	23 (56.1)	11 (26.8)	7 (17.1)		
41-50	4 (57.1)	2 (28.6)	1 (14.3)		
Years at HTC					
0-10	24 (26.7)	39 (43.3)	27 (30.0)	22.324	.001*
11-20	14 (45.2)	13 (41.9)	4 (12.9)		
21-30	13 (72.2)	3 (16.7)	2 (11.1)		
31-40	8 (66.7)	1 (8.3)	3 (25.0)		
41-50	1 (100.0)	0 (0.0)	0 (0.0)		
Current position					
Staff nurse	8 (24.2)	13 (39.4)	12 (36.4)	17.908	.011*
Nurse practitioner	8 (33.3)	6 (25.0)	10 (41.7)		
Nurse educator	2 (50.0)	2 (50.0)	0 (0.0)		
Research nurse	3 (37.5)	2 (25.0)	3 (37.5)		
Nurse coordinator	41 (48.8)	33 (39.3)	10 (11.9)		
Population served					
Pediatric	20 (42.6)	11 (23.4)	16 (34.0)	8.561 <sup>b</sup>	.068
Adult	4 (25.0)	9 (56.3)	3 (18.8)		
Both	38 (42.7)	35 (39.3)	16 (18.0)		
Use of formal curriculum					
Yes	25 (53.2)	19 (40.4)	3 (6.4)	5.037 <sup>b</sup>	.076
No	29 (38.7)	31 (41.3)	15 (20.0)		

Less confident level includes: Somewhat confident, Not very confident, and not at all confident responses.

<sup>a</sup>Pearson Chi-Square value

<sup>b</sup>Fisher's Exact Test value

\*P<.05

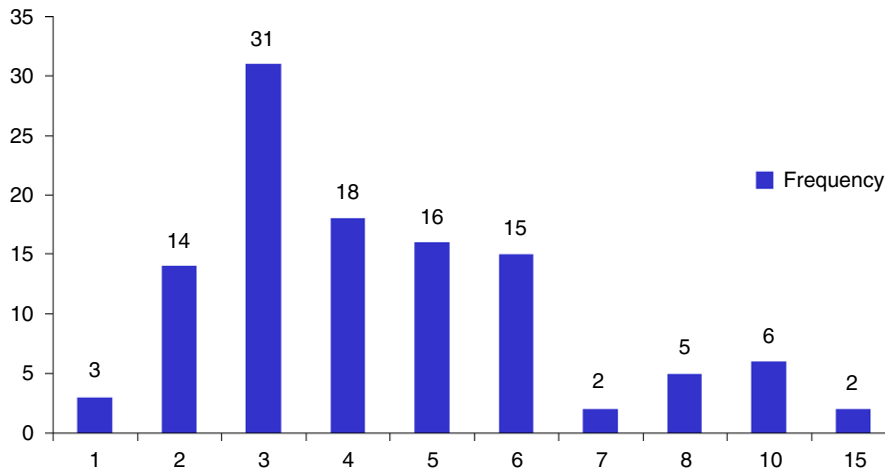
venipunctures proficiently (1.3%), or a lack of confidence in teaching the skill (0.6%).

It was found that 30.1% of HTC nurses utilize a formal written curriculum to guide each infusion workshop while 48.1% do not. Of those who utilize a formal curriculum, 27.7% had created the curriculum themselves, 36.2% used a curriculum developed by a nurse in their center, 4.3% used one developed by a nurse in their region, and 4.3% used one developed by a nurse in another HTC. Twenty-eight percent (27.7%) used a combination of the resources and curricula available. Most HTC nurses (67.9%) used various tools and resources to teach HI to patients and families. These are summarized in Table 3. When asked if there is a need for additional tools and resources, 51.3% replied yes while 46.8% replied no. The majority who responded yes identified a need for standardized written materials and videos. Other needs identified through free-form text responses included updated puppets,

rubber arms, written materials with pictures, demonstration kits and technologic aids such as vein finders. Data also showed that 59% of participants were allowed to utilize tools and resources with industry logos on them, 30.8% were not allowed, and 9% did not know if these were permitted by their institutions.

### 3.3 | Venipuncture practice

Of the participants, 84% indicated they perform venipunctures, with 91.2% of them having 5 or more years of experience in performing the skill. A significant number (41.7%) were not taught to perform venipunctures in nursing school and 32.1% reported learning on the job. Half (50%) of participants had job orientation or competency training that included venipunctures. The majority of participants (84%) reported their employers had a policy and procedure in place for



**FIGURE 3** Number of sessions to learn how to self-infuse

**TABLE 3** Participants tools and resources used

	f	%
Teaching tool made by self	30	19.2
Teaching tool made by another RN at HTC	25	16.0
Teaching tool made at another HTC	19	12.2
Chester Chest™	33	21.2
Rubber arm	65	41.7
Bay-cuff™ by Bayer	67	42.9
Bob puppet™ by Pfizer	22	14.1
Infusion booklet® by Baxalta	34	21.8
Infusion video from pharmaceutical companies	13	8.3
Hand/Self Infusion Training Kit by Pfizer	13	8.3%
Hemophilia of Georgia Handbook	2	1.2%
Demonstration kits from manufacturer	2	1.2%

n=156

Bayer: Whippany, NJ, USA

Pfizer: New York, NY, USA

Baxalta: Lexington, MA, USA

performing venipunctures, 67.3% confirmed they had reviewed it. When performing venipunctures, almost all of the participants (96.8%) used both palpation and visualization; 57.7% used alcohol and 34.6% used alcohol/chlorhexidine to clean the skin (Figure 4).

## 4 | DISCUSSION

Teaching HI to hemophilia patients and their caregivers has become a standard practice in the USA as it has been proven to be safe and beneficial.<sup>1-3,5,8</sup> The Medical and Scientific Advisory Council (MASAC) of the National Hemophilia Foundation recommends that hemophilia nurses have training in infusion skills and patient/family education, so

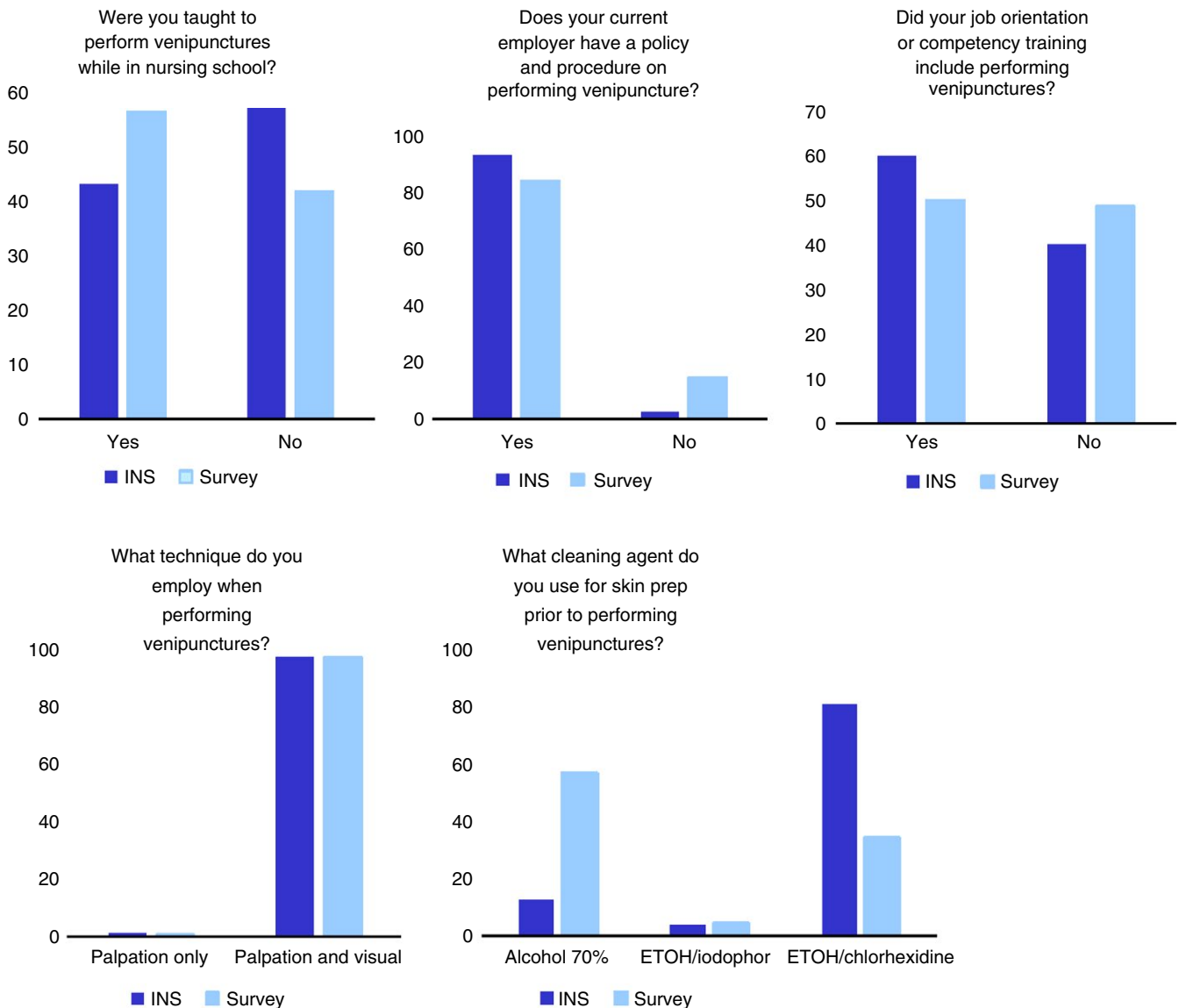
that education and training in home and self-infusion be provided to all eligible patients and their caregivers.<sup>1</sup> There are, however, no national guidelines or standardized curricula to assist nurses teaching HI.

While nurses are responsible for teaching HI, both the literature and this survey suggest that many have not received formal education in venipuncture; most report learning the skill on the job.<sup>11-13</sup> The survey revealed that many HTC nurses learn how to teach venipuncture by either observation or trial and error. This confirms the notion that even though nurses are expected to teach venipuncture many have not received proper training to master or teach the skill.

The participants in this study identified themselves as a group of highly educated nurses, most with college and postgraduate degrees, possessing many years of nursing experience; although 38.5% had worked in a HTC for less than 5 years. The majority of nurses responsible for teaching HI felt extremely confident or very confident teaching the skill. However, a surprising 23% felt somewhat confident or not very confident despite having anywhere from 8 to 41 years of nursing experience. The level of confidence in teaching HI was significantly influenced by a nurse's years of experience, as well as, the number of years working at a HTC. Nurse coordinators, who most frequently teach HI, reported a higher confidence level in teaching HI when compared to other positions. The lack in confidence experienced by almost a quarter of nurses may affect their effectiveness as teachers and negatively impact patient outcomes.<sup>10</sup> This demonstrates the need for additional resources to support nurses who are responsible for teaching HI.

Results demonstrated that patients required a mean of 4.6 sessions to learn to infuse and that these sessions were performed in different settings (including group workshops, camp, and one-on-one) utilizing non-standardized tools. HTCs from all regions have developed both curricula and tools to teach HI, or utilize those already available in the community (Table 3). Although participants from all regions responded as having formal curricula, results confirmed that not everyone utilizes them. This could be due to a lack of awareness or to these curricula not meeting the centers' educational needs. One would have expected that HTC nurses are primarily responsible for teaching home infusion, but the results confirmed that many HTCs sometimes rely on home health nurses to teach and reinforce teaching.





**FIGURE 4** Infusion Nurses Society (INS) vs survey results

Nurses were given the chance to identify additional potential tools and resources. There was a uniform need identified for standardized written materials and videos. Other needs included updated puppets, rubber arms, written materials with pictures, demonstration kits, and technologic aids such as vein finders. A significant number of nurses (59%) were allowed to utilize tools and resources with industry logos, affording them many options when teaching HI. However, over 30% of nurses could not use branded educational materials which limits their selection of resources available. This may result in the development of individual tools and resources that could potentially differ from current standards of practice and underscores the need to create uniform, non-branded materials to be used at all centers.

Participants had the opportunity to submit tools and resources used at their HTC. A total of 4 tools were submitted. One consisted of a detailed competency table to keep track of education provided and skills taught, demonstrated, and performed under supervision and eventually independently. Another included a summary of the

venipuncture procedure, and infusion of AHF, as well as how to identify allergic reactions and when to contact the HTC. The third center created videos showing step-by-step guides on how to mix, according to the different manufacturers, and infuse AHF. The fourth center submitted a comprehensive curriculum which was divided into 5 modules with corresponding tests covering: hemophilia, recognition and treatment of bleeds, AHF replacement therapy, an orthopedic overview, and dental, nutritional, safety, and psychosocial issues. Although all tools were different in style and complexity, most confirmed the importance of teaching the skill as well as providing additional medical information to assist non-medical individuals make medical decisions.

Some countries have developed educational manuals and curricula to assist nurses in teaching HI.<sup>7,8,14-16</sup> In 2002, the Dutch Network of Haemophilia Nurses developed a comprehensive training manual which covers basics of hemophilia, home treatment, types of AHF and dosing, potential complications, and techniques for infusing

peripherally and via implanted central venous access devices. The training is completed after the patient or caregiver pass an exam.<sup>5,16</sup> The USA does not have a standardized national curriculum.

Finally, this study results were compared to the INS's 2013 survey. The results were consistent with both the survey and current literature supporting the findings that the majority of nurses do not receive formal education in venipuncture while in school, with most reporting learning the skill on-the-job. Results also confirmed that the vast majority of the HTC's venipuncture practices fall within the INS's recommended standards. For example, INS standards recommend the use of visualization and palpation when finding a vein, and the use of alcohol/chlorhexidine as the preferred cleaning agent before performing venipunctures, although alcohol/iodophor and alcohol 70% are still acceptable (Figure 4).<sup>13,20</sup> Therefore, even when nurses have the knowledge, they may not feel confident to teach it.

This study confirms the authors' position that our community would greatly benefit from national guidelines and a standard curriculum to assist nurses in teaching HI because these would:

1. Include evidence-based and current information, improving the quality of patient/family training
2. Offer guidance to all nurses teaching HI, especially those who are new or not confident with venipuncture or teaching
3. Provide a uniform, comprehensive, and standard curriculum for all nurses to follow ensuring that all patients receive consistent information

#### 4.1 | Limitations

Study limitations were identified. The study descriptive correlational design, which addressed survey responses from strictly HTC nurses in the USA, does not allow for generalization of results to the larger international HTC nursing population. This was a self-directed survey and individuals who responded were already willing to participate. Self-reported responses may lead to study participant response biases. These biases include social desirability where participants may give answers they believe will present them in a favorable light.

The study response rate of 27.2% resulted in a small sample size with the limitations of self-selection.<sup>21</sup> The response rate was impacted by the inaccuracy of the panel list obtained from the CDC's HTC directory and verified with other sources. It was discovered that this directory is not routinely updated and that multiple email addresses belonged to nurses who no longer worked at a HTC. Furthermore, it is possible that even though some centers employ several nurses, all of whom were included in the survey, only those responsible for teaching HI responded. These factors may have contributed to a lower response rate resulting in non-statistically significant results despite providing interesting insight.

In addition to the low response, there was also a greater response rate in some regions compared to others resulting in uneven data distribution. There was no statistical significance found when variables were compared between regions.

## 5 | CONCLUSION

HI teaching is one of the primary responsibilities of the HTC nurse, however, many nurses lack the knowledge and confidence to teach HI to patients and their families. Regrettably, there are currently no guidelines or standards in the USA to support the practice and, although curricula exist, they are not uniform in content or use, even within the same region. This suggests that not all patients are learning the same information in the same manner.

The study supports standardization of the process by creating national guidelines and curricula to provide guidance to nurses employed at HTCs and the community to ensure that the information used is evidence-based and current. This presents an opportunity for HTC nurses in the USA to come together to develop, and subsequently implement, such guidelines and curricula in all centers across the nation.

Future research with a focus on evaluating the patients' perspectives on learning HI is recommended. This could help identify potential patient/family issues and additional areas of unmet needs.

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#### RELATIONSHIP DISCLOSURES

The authors stated that they had no interests which might be perceived as posing conflict or bias.

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