COMMUNITY FOCUS

A descriptive study of United States bleeding disorders camps

Maria E. Santaella, Cynthia Nichols, Michelle Witkop

Background: Disease-specific camps present one means of helping children overcome the challenges associated with chronic conditions and improving clinical and psychosocial outcomes. For more than 50 years, bleeding disorders camps (BDCs) in the United States (US) have been promoting independence, self-care, and leadership skills in children with bleeding disorders, all while fostering camaraderie in a secure and safe environment. However, little is known about how BDCs are organised, administered, funded, staffed, or how staff are compensated. **Aim:** This article aims to describe the attributes of BDCs that service the US bleeding disorders community, and to compare and contrast these attributes to identify gaps in the BDC system and areas for improvement. **Methods:** The National Hemophilia Foundation (NHF), in collaboration with several members of its Nursing Working Group and Physical Therapy Working Group, developed a survey that was distributed to BDC administrators (CAs) and health care providers (HCPs). **Results:** A total of 101 HCPs and 20 CAs completed the survey. Findings indicated that BDCs are an informal extension of both the HTCs and NHF chapters, reaffirming that camps play a crucial role in the overall care of bleeding disorders. In general, diminishing financial resources threaten the existence of BDCs. Although there are BDC guidelines for formal staff training and specific interventions delivered to camp participants, adherence is variable. Other gaps included minimal self-infusion education follow-up with no documentation on effect or benefit of infusion education provided at camp. **Conclusion:** Addressing the gaps identified by this survey and documenting resultant data supporting the value of BDCs will facilitate their continued sustainability in light of increasingly limited funding.

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The first study of its kind to look at the service, education and care offered by bleeding disorder camps in the US establishes their key role in bleeding disorder care and identifies further opportunities for growth and improvement.

Keywords: *camping, blood coagulation disorders, haemophilia, staffing, children, adolescents*

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Medical advances have reduced childhood mortality and morbidity, resulting in more children with chronic illnesses living fuller lives [1]. However, despite improved prognosis, children with chronic conditions may experience biopsychosocial and developmental challenges [1,2]. Disease-specific camps (DSCs) help children overcome such challenges by providing a safe and enjoyable experience, offering community and friendship, improving self-concept, increasing disease knowledge and management, and contributing to their positive development [2]. The medical literature supports their value as part of a comprehensive approach to managing chronic disease and as having a positive impact on the health-related quality of life of children and adolescents living with cancer, diabetes, and juvenile arthritis [3,4]. Other health-related benefits of DSCs include improvements in social interaction, physical activity, and the mitigation of adverse childhood events [5-8].

In 1969, the first Bleeding Disorders Camp (BDC), Camp Bold Eagle, was formed in the state of Michigan [9]. Many BDCs have subsequently been created to promote independence and leadership skills while fostering camaraderie with others in a secure and safe environment [10]. Often organised by the National Hemophilia Foundation's (NHF) chapters, staffed by specialised haemophilia treatment centres (HTCs), health care providers (HCPs), and supported by the community, BDCs have an important role in broader HTC disease management initiatives. Self-reliance is encouraged and children learn to take ownership of their condition by participating in education that includes self-infusion classes. For unaffected individuals attending, BDCs provide valuable disease education, fostering awareness and encouragement to become advocates for the community [11].

Despite evidence supporting the value of DSCs and decades of described positive experiences, constraints on financial resources represent a threat to the existence of BDCs. Specifically, funding to cover camp and staff expenses has become problematic.

NHF's Nursing Working Group (NWG) guidelines, developed with assistance from the North American Camping Conference of Hemophilia Organizations and endorsed by NHF's Medical and Scientific Advisory Committee, provide a BDC operational framework [12]. However, little is known about how BDCs are organised, administered, funded, and staffed. Lack of information also exists about how BDCs deal with the use of medical marijuana, a therapeutic lacking evidence in the bleeding disorders (BD) population which, while legal in some capacity in most states, is illegal at the federal level and anecdotally seeing an increase in use.

Information is needed to identify best practices, cement BDCs' specific utility in the lifelong, comprehensive management of BDs and, in turn, ensure continued funding. With that in mind, NHF, in collaboration with several members of the NWG and Physical Therapy Working Group (PTWG), developed the Descriptive Study of United States Bleeding Disorders Camps with these specific aims:

a. Describe the attributes of BDCs that service the BD community
b. Compare and contrast the described attributes
c. Identify gaps in the BDC system and areas for improvement.

METHODS

This study was approved by the Munson Medical Center Institutional Review Board in Traverse City, Michigan. The research team and members of the NWG developed two surveys: one designed for camp administrators (CAs) and one for HCPs who staff camp.

BDCs were identified through several avenues, including the websites of NHF and the Hemophilia Federation of America. Each BDC was requested to identify appropriate potential participants. The provider survey was sent to every nurse listed in the Center for Disease Control and Prevention HTC staff directory [13].

Utilising the Qualtrics™ survey platform, surveys were sent out in January 2018, and then weekly for eight weeks until one of the following happened: the participant took the survey, opted out, or the survey ended (nine weeks total). A 'click to consent' informed consent was required before the survey was made available.

Survey results were exported in .csv format and then imported into Stata 15.1 (2017) for analysis. Only descriptive statistics are reported. Inferential statistics with significance testing to compare CAs and HCPs would lack generalisability due to the extremely uneven distribution of HCPs among the camps and the small number of camps in which at least one CA and one HCP responded. There were 73 survey items, with 24 common to both surveys, 29 unique to CAs, and 20 unique to HCPs. Responses varied due to survey logic.

RESULTS

1. Overall combined results (CA/HCP)

Survey responses

Surveys were emailed to 58 BDC CAs and 338 HCPs. Twenty-three addresses were undeliverable for a total of 373 delivered surveys. Seventeen declined consent and 235 did not respond to emails, leaving 121 respondents (101 HCPs and 20 CAs), and resulting in an overall 30.5% response rate. CAs from 18 US BDCs responded to the survey, but in two instances, two CAs responded for the same camp; the remaining 16 camps were each represented by one CA. On occasion, the two CAs who responded for the same camp did not agree. Unless otherwise stated, results were tabulated by number of CA responses rather than by camps. There were nine camps in which a combination of at least one HCP and one CA completed the survey.

Seventy-five (74.3%) HCPs had been a BDC volunteer in the past five years. Per protocol, logic excluded the remaining 26 HCPs (25.7%) from most of the survey items. Barriers to attending camp are listed in Table 1. Of the total 59 BDC camps in the US, 46 (78%) were represented in the study; 19 camps were represented by the 20 CA respondents; 37 camps were represented by the 75 HCPs who had participated in camp during the past five years. The number of HCPs per camp who completed the survey ranged from 1 to 12. Eighteen out of 73 (24.7%) HCPs reported participation in multiple camps (two did not answer this question).

Table 1. HCP barriers to attending camp (n=24)*

BARRIER	N	%
My HTC required I use personal/vacation time and I was not willing to do so	7	29.2
I did not have time to participate	4	16.7
The timing just hasn't been right	4	16.7
I am not licensed in the state in which camp is held	4	16.7
I can't leave my family for that length of time	3	12.5
My HTC would not allow for time off to participate	3	12.5
I don't like going to camp	2	8.3
I don't work with children, so I don't go to camp	1	4.2
It is too far to travel	1	4.2
I can't bring my family	1	4.2
Other	6	25.0

*Two HCPs did not answer these questions

Staffing expectations

When attending camp, 26/62 (41.9%) HCPs reported their HTC had an expectation that they work at the camp health centre (CHC), 17/62 (27.4%) reported this was a requirement, and 19/62 (30.7%) reported there was no requirement. One CA (5%) required that an HTC send staff and/or medical support, while 8 (40%) expressed only an expectation of HTC support.

Licensure and malpractice insurance

Most HCPs (65; 86.7%) worked in a camp that was in the same state as their primary employment and licensure. Table 2 summarises HCP employment outside camp and compensation. Only 4 of 20 CAs (20%) included staffing by out-of-state HCPs; three

Table 2. HCP employment outside of camp and compensation (n=75)

	N	%
Employment outside of camp		
HTC	65	86.7
Hospital (not HTC)	5	6.7
Neither hospital nor HTC	5	6.7
Employment status		
Full-time	66	88.0
Salaried	47	63.0
Hourly	28	37.0
20-35 hours/week	8	10.7
Less than 20 hours/week	1	1.3
Compensation while at camp		
Camp counted as work time	61	81.3
Compensation time given	8	10.6
Used vacation time	4	5.3
Combination of work time and compensation time	1	1.3
Breakdown of those who used work time to participate at camp (n=62)		
Allowed 8 hours/day	55	88.7
Allowed 12 hours/day	5	8.1
Allowed 24 hours/day	2	3.2
Breakdown of those who used compensation time to participate at camp (n=9)		
Allowed 8 hours/day	8	88.9
Allowed 24 hours/day	1	11.1
Breakdown of those who used vacation time to participate at camp (n=5)		
Allowed 8 hours/day	2	40.0
Allowed 24 hours/day	2	40.0
Allowed 12 hours/day	1	20.0

Table 3. Provision of factor, supplies, and medications during camp (n=20 CAs)
Survey respondents were able to select more than one option.

	CAMP		CAMPER		HTC		DONATION		CHAPTER	
	N	%	N	%	N	%	N	%	N	%
Over-the-counter medication	13	65	8	40	6	30	6	30	1	5
Supplies	9	45	9	45	7	35	9	45	1	5
Prescribed medication	2	10	19	95	2	10	2	10	0	0
Factor	0	0	19	95	0	0	1	5	1	5

Table 4. Guidelines/policy on storage and dispensing of medications at camp

	CAS (N=20)		HCPS (N=75)	
	N	%	N	%
Does your Camp Health Center have guidelines or policy on the storage of controlled substances (ADHD medications/opioids/benzodiazepines/etc.)?				
Yes	18	90.0	45	60.0
Don't know	2	10.0	26	34.7
No	0	0.0	4	5.3
Does your Camp Health Center have guidelines or policy on who can dispense medications?				
Yes	19	95.0	49	65.3
Don't know	1	5.0	23	30.7
No	0	0.0	3	4.0
Does your Camp Health Center have guidelines or policy on who can dispense controlled substances (opioids/benzodiazepines/etc.)?				
Yes	18	90.0	38	50.7
Don't know	2	10.0	31	41.3
No	0	0.0	6	8.0

reported camp, chapter, or provider paid for the out-of-state license, and one did not know who paid for it. Among the 10 (13.3%) HCPs who worked in a camp outside of their employment state, their second state license was provided via reciprocity (3; 30%), employer (3; 30%), camp (1; 10%), regional haemophilia association (1; 10%), a combination of the chapter and the employer (1; 10%), or self-paid (1; 10%).

Half of the CAs (10) reported requiring that HCPs maintain their own malpractice insurance, 6 (30%) did not, and 4 (20%) did not know. Twenty-seven (36%) HCPs did not know if the CHC required malpractice insurance, 27 (36%) indicated it was not required, and 21 (28%) indicated it was required. Of those HCPs who reported malpractice insurance was required (21), it was provided by their employer (18; 85.7%), personally (2; 9.5%), or by the camp (1; 4.7%).

Policies/procedures

Nineteen CAs (95%) indicated that CHC counsellor orientation was provided; 12 CAs (60%) reported an official HCP staff orientation compared to 21/75 HCPs (28%). Of those 12 CAs, 6 (50%) reported on-site HCP orientation; the others (6; 50%) reported orientation initiated online then completed on site. Of the remaining 8 CAs, 7 (35%) reported an unofficial orientation upon arrival, and one did not know if there was one. In comparison, 47 HCPs (62.7%) reported an unofficial orientation and 7 (9.3%) reported none. As to the 21 HCPs who reported an official orientation, it was either on site (11/52.4%), online (5/23.8%), or started online then completed on site (5/23.8%).

All CAs and most HCPs (72; 96%) indicated that the camp provided a separate space for campers to infuse their factor and store supplies (see Table 3 for source of medications and supplies). The majority of CAs reported having policies on the storage and dispensing of both medications and controlled substances; at least a third of the HCPs reported there was no policy/guideline or not knowing about them (Table 4).

Medical marijuana

At the time of the survey, the legal status of marijuana was correctly classified by 52/75 (69.3%) HCPs and 17 (85%) CAs. Nineteen (25.3%) HCPs and 2 (19%) CAs indicated that marijuana was not legal when it was legal, and 4 (5.3%) HCPs and 1 (15%) CA indicated that it was legal when it was not. Medical marijuana use was allowed in two camps located in states where it was legal.

HCP family involvement in camp

An equivalent representation of CAs (8/20; 40%) and HCPs (35/75; 46.7%) indicated that HCPs could bring their own children to camp regardless of a BD diagnosis, while 16 (21.3%) HCPs reported having brought their own children to camp. Those who brought their children to camp said they had no difficulty integrating into the camper groups and were

Figure 1. Infusion teaching follow-up after camp
Survey respondents were able to select more than one option.

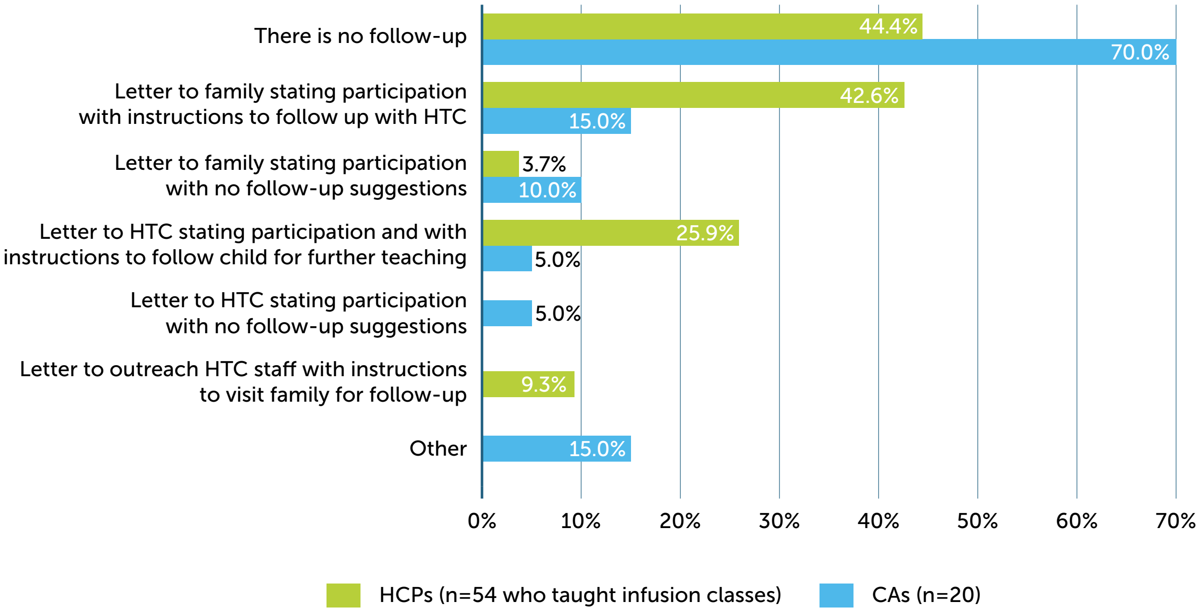
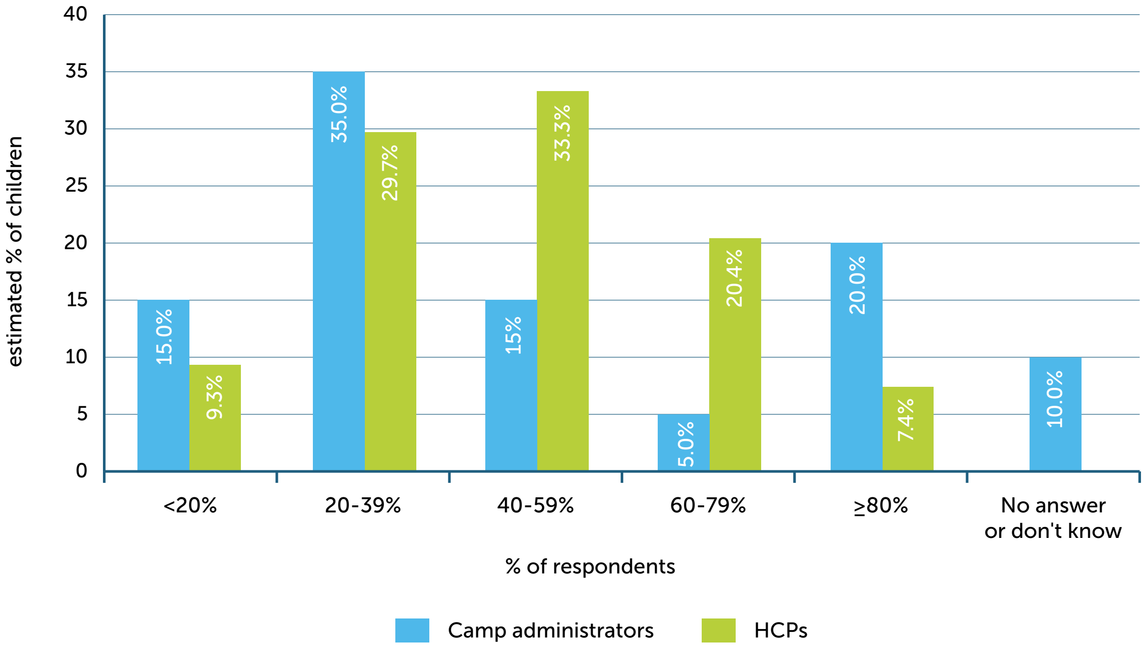


Figure 2. Respondents' estimate of the percentage of children who return to camp independent in self-infusion



not treated any differently: it was reported as a positive experience by 14 (87.5%), a negative experience by one (6.3%), and one was unsure as to how their child would define the experience (6.3%).

Education

Only 10 (50%) CAs required education specific to BDs including infusion classes, while 57 (76%) HCPs indicated a requirement for educational programming specific to campers' medical conditions. Of those CAs providing education, 7 (70%) also offered general health and wellness information. The CAs reported that most education was provided by camp nurses (8; 80%), advance practice providers (APPs) (6; 60%) and/or physicians (5; 50%), while HCPs reported multiple staff educators including CHC nurse (48; 84.2%), CHC APPs (30; 52.6%), CHC physician (33; 57.9%), non-health centre camp staff (20; 35.1%), and 'other' (4; 7%) (social workers, psychologists, physical therapists, dentists, specialty pharmacies, and home health staff). Of the 57 HCPs who reported they provided education, the majority (54; 94.7%) taught infusion classes, 49 (86%) taught about BD, and 25 (43.9%) provided other health/wellness education. Other health/wellness education topics included relaxation, exercise, diet and nutrition, first-aid, safety, joint health, oral health, hygiene and infection control, chronic disease management, family planning, genetics, social skills, self-advocacy, and mentoring others. One respondent reported that a prescription was required for the camper to participate in self-infusion classes. See Table 5 for details about infusion education while at camp, Figure 1 for follow-up after self-infusion classes, and Figure 2 for an estimation of how many children return to camp able to self-infuse independently.

2. Administrator-specific (CA) survey results

Employment, compensation, and funding

HTCs (6; 30%) and NHF chapters (5; 25%) were the most frequent employer of CAs. A combination of sources (10; 50%) provided camp funding including grants, private donations, chapters, HTCs, and industry, followed by single sources including chapters (4; 20%) and HTCs (2; 10%). Industry, grants, private donations, and self-funding comprised additional single-source funding (1; 5% each). Fifteen (83%) camps had a relationship with a federally funded HTC. Only 6 CAs (30%) received compensation; 5 (25%) counted their time at camp as work time by their employer: 3/5 (60%) counted 8 hours/day, 2/5 (40%) counted 24 hours/day as work time, and one (5%) received a stipend by the camp.

Camp composition

Most were all-gender camps (19; 95%) with only one reported as a girls-only camp. Enrolment included unaffected siblings and/or family (11; 55%) and children with other health problems (5; 25%); 3 (15%) limited enrolment to children with BDs. Camp length was reported as 1–5 days (12; 60%), 6–14 days (7; 35) and variable (1; 5%), with one session (16; 80%), two sessions (3; 15%), and three sessions (1; 5%). Session enrolment limitations ranged from <50 to >250, with the majority being <100 (15; 75%). Camp facilities were reported as rented (16; 80%), owned (3; 15%), or contracted for all services (1; 5%).

A majority of CAs (14; 70%) allow specialty pharmacy, homecare, or industry representatives to participate. Of those, 10/14 (71%) restricted participation to counsellor only or camp health centre staff only, and 4/14 (29%) allowed participation in any camp position. Six of the total 20 CAs (30%) excluded them entirely from their camps.

Table 5. Infusion education while at camp

WHO IS INFUSION EDUCATION OFFERED TO AT CAMP? (CHECK ALL THAT ARE APPROPRIATE)	CAMP ADMINISTRATORS (N=20)		HCPS (N=54 WHO TEACH INFUSION CLASSES)	
	N	%	N	%
Those diagnosed with hemophilia	9	45.0%	44	81.5%
Anyone on infusion therapy	9	45.0%	46	85.2%
Anyone interested in learning	8	40.0%	29	53.7%
Those diagnosed with von Willebrand's Disease	7	35.0%	34	63.0%
Those on prophylaxis	7	35.0%	40	74.1%
Carriers	6	30.0%	19	35.2%

WHO DETERMINES WHO IS TAUGHT SELF-INFUSION AT CAMP? (CHECK ALL THAT APPLY)	CAMP ADMINISTRATORS (N=20)		HCPS (N=54 WHO TEACH INFUSION CLASSES)	
	N	%	N	%
Parents	14	70.0%	35	64.8%
HTC	12	60.0%	46	85.2%
Camp nurse	12	60.0%	31	57.4%
Someone else	4	20.0%	7	13.0%
Camper	0	0.0%	8	14.8%

Figure 3. Camp's adherence to state and national guidelines, accreditation, and licensure requirements (n=20 CAs)

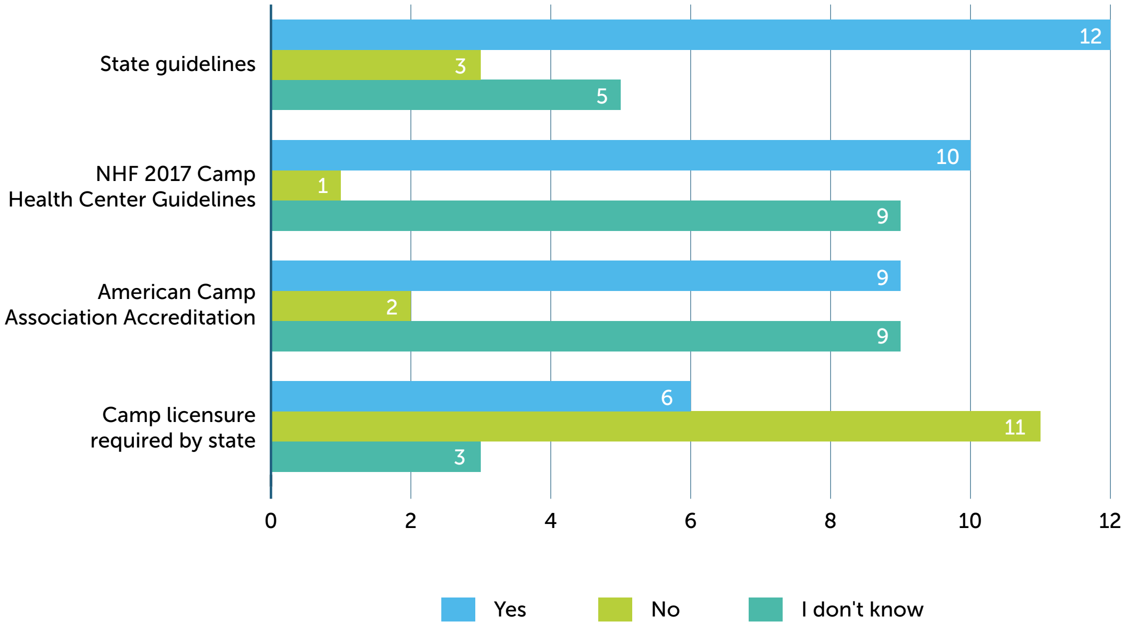


Figure 3 describes camps' adherence to state and national guidelines, accreditation, and licensure requirements.

Policies and procedures

Every CA required a medical form for each camper. Immunisation guidelines requiring immunisation for both campers and staff were reported by 13 (65%) CAs with 7 (35%) requiring campers only. Twelve CAs (60%) delegated decisions regarding pre-treatment for high-risk activities to the camp medical provider; 7 (35%) required pre-treatment, and one (5%) did not.

All CAs (100%) indicated that there was first-aid equipment close to camp activities. A majority of first aid kits only contained basic dressings (13; 65%), with only 7 (35%) including medications. CAs were equally split as to the camp's distance from the closest hospital that could offer specialised treatment (±30 minutes). Only one CA (5%) did not know if emergency air transport was available; the remainder of the CAs (19; 95%) reported availability.

Table 6. CHC staffing (n=101 HCPs)

Survey respondents were able to select more than one option.

	N	%
Medical HCPs from HTCs	86	85.1
Volunteers from HTCs and chapters	48	47.5
No affiliation with bleeding disorders community but PWBD are invited	9	8.9
Chapter personnel only	2	2.0
Other:	15	14.9
Other health care professionals	5	
Unknown/not sure	4	
Industry staff*	3	
Home care staff**	2	
Medical or nursing students/residents	2	
Specialty pharmacy staff***	1	

* Industry staff = Pharmaceutical company staff

** Home care staff = Persons who come to the home to help administer medications and treatments

*** Specialty pharmacy staff = Providers who supply bleeding disorder (clotting factor, etc.) medications to patients

3. HCP-specific survey results

Description of respondents

HCP respondents were registered nurses (78; 77.2%), APPs (21; 20.8%), one licensed practical nurse (0. 9%), and one social worker (0.9%). Table 6 describes CHC staffing.

Compensation for travel

Most HCPs (39/75; 52%) received no compensation for travel expenses, 25 (33.3%) received mileage only, and 4 (5.3%) received both travel time and mileage. Of the remaining respondents, one each received mileage, alternative travel mileage, and plane ticket; plane ticket only; rental car; travel time and rental car; or travel time only. One (1.3%) received travel time, mileage, and plane ticket. Employers compensated all 7 respondents who received travel time, and 25/32 (78.1%) of those who received mileage. Of the others who received mileage compensation, 2 (6.3%) were by the HTC, 2 (6.3%) by the chapter, and one each (total of 9.2%) by a grant, 340B money, or a state organisation. For the three who received a plane ticket, one plane ticket was provided by a chapter and 2 by the employer. Both HCPs who received alternative travel expenses were compensated by their employer.

DISCUSSION

This is the first survey of its kind to query US BDC staff. While there were many similarities between the CAs' and HCPs' responses, there were also differences in the way BDCs are organised and run.

Most HTCs either require or expect their staff to participate in BDCs, despite a lack of requirement from the camp or the CAs, demonstrating widespread support of the camping system from the provider community. Outside of the camp setting, most HCPs were primarily full-time, salaried HTC employees and received some sort of compensation to cover their camp hours, while the CAs were mostly employed by either an HTC or chapter and received no compensation. Chapters were involved in funding camp, staffing the CHC, teaching, providing funding for out-of-state HCPs' licenses, and reimbursing HCPs' travel expenses. These findings demonstrate that camps are an informal extension of both the HTCs and chapters and, as such, play a crucial role in the overall care of BDs.

In general, diminishing financial resources threaten the existence of BDCs. Fifty percent of the CAs identified a combination of funding sources, with chapters and HTCs holding a significant responsibility. All HCP respondents who participated in camp indicated some form of compensation. Those who did not participate in camp cited barriers associated with the use of personal time, employers not compensating or allowing time to participate, and not being licensed in the state where the BDC was held. This may explain why 70% of camps allow specialty pharmacy, specialty homecare, or industry representatives to serve as camp staff.

Despite the existence of state, national, NHF, and ACA guidelines, adherence is variable. Approximately half of the CAs reported following these guidelines. NHF's 2017 Health Center Guidelines for Camps Serving Persons with Bleeding Disorders indicate that all staff should receive education, which the authors interpret as at least an 'orientation' [12]. Despite this recommendation, many respondents reported no official orientation. The lack of an official orientation may explain why many HCPs did not know of the existence of important guidelines or policies on the storage and dispensing of medications and controlled substances.

CAs were more knowledgeable than HCPs about their individual state's medical marijuana laws; 25% of HCP incorrectly indicated that marijuana was not legal in their state. This is concerning since the community turns to HCPs for information and education on symptom management strategies, including novel options such as medical marijuana. HCPs should seek educational opportunities that can prepare them to address the growing interest being generated by medical marijuana.

Given that self-infusion instruction is anecdotally considered a mainstay of the camp experience, it was surprising to see little reported follow-up after children receive instruction or monitoring of success, such as documenting independence in subsequent years. NHF guidelines state "Infusion education documentation should be provided to the camper's HTC and primary caregivers," yet many (70% CAs, 44.4% HCPs) reported no follow-up. If any follow-up occurred, it was primarily via a certificate of participation or a note to the parents encouraging them to contact their HCP.

Implementation of a standardised quality improvement (QI) program is recommended to improve the effectiveness of the camp self-infusion education program. Suggestions include monitoring infusion independence in subsequent years, working with HTCs and parents to develop a follow-up program to reinforce the instruction that occurred in camp, and sending home a tip sheet on what parents can do to ensure continued success at home. A positive relationship between participating in camp and improved self-efficacy will help support the value of BDCs and thus encourage ongoing funding.

Limitations

Responses may have been limited due to firewalls blocking the survey's delivery. Additionally, while every attempt was made to include all BDCs, some camps may not have received a survey due to the absence of a prevailing camp directory. Inferential statistics comparing CAs and HCPs could not be performed due to the extremely uneven representations of CAs and HCPs from different camps.

CONCLUSION

This study, the first of its kind, surveyed US BDCs to understand gaps in service, education, and care. While camps have provided an opportunity for children to meet others like themselves and partake in experiences that may have been otherwise unattainable, this data identified opportunities for further improvement. Specific QI programs focusing on infusion education should be developed. Furthermore, CAs should become familiar with available guidelines and utilise them as a framework to organise and run BDCs. Implementation of an official orientation in all BDCs would improve understanding of policies and procedures. This is especially important when considering issues such as medication administration and storage, including controlled substances.

Anecdotally, the authors recognise challenges to establishing these recommendations including:

a. HTC staff turnover, which makes it difficult to establish/maintain a core group of experienced camp personnel
b. Lack of HCP interest/participation in camp, which makes it difficult to implement/follow up with education-specific camp components
c. Most respondents reported having a full-time job outside of camp, leaving the planning/implementation of camp to be performed on personal time, which leads to burnout for even the most passionate staff. Specific questions regarding how much time it takes to plan/implement camp were not asked but, anecdotally, it can take hundreds of hours.

While BDCs are known by reputation to be very successful, this survey demonstrates opportunities for continued growth and research. Future studies should focus on assessing the multiple benefits BDCs provide to those who attend them, not only to understand how camps can better serve the BD community in the future, but also to improve the experience of the camper addressing their increasing psychosocial and medical complexity.

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Informed consent has been obtained from the participants in the survey reported in this paper.

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