

Physical therapy within US HTC: A multicentre survey of utilization, practice patterns and pain management approaches

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Abstract

Introduction: Practice patterns and utilization of physical therapists (PTs) affiliated with Hemophilia Treatment Centers (HTCs) in the United States (US) are not well known.

Aims: Describe utilization, role responsibilities and practice patterns of US HTC PTs. Identify practice patterns specifically focusing on assessment and treatment of pain. Recognize gaps in utilization and role responsibilities of PTs as part of the multidisciplinary team and suggest guidelines for PT involvement within the HTC.

Methods: Respondents were a subset of a convenience sample of healthcare providers who responded to a non-validated survey developed by a multi-disciplinary panel of haemophilia experts.

Results: A 33.0% response-rate ($n = 59$) representing all regions of US HTCs was achieved. Those working ≥ 10 hours per week were more likely to provide nutrition education ($P = .026$) and surgical options education ($P < .001$). Those who billed insurance for their services during comprehensive visits were more likely to provide education regarding surgical options ($P = .046$). The majority of PTs (95.0%) evaluated pain regardless of time spent in clinic and felt comfortable treating pain. Fifty-eight percent used a formal pain measurement tool and more likely to use a formal pain measurement tool if billing insurance ($P = .004$). Top five non-pharmacologic treatments recommended for pain management included splints/braces (84.8%), aquatic therapy (74.6%), orthotics (71.2%), surgical options (47.5%) and yoga (32.2%).

Conclusions: This study demonstrated PT utilization across HTC centres varies widely. Gaps in care may be addressed through salary support, funded education, greater regional/national collaboration of PTs specializing in bleeding disorders and advocacy for insurance coverage for appropriate services.

KEYWORDS

haemophilia, insurance coverage, pain, Patient Care Team, physical therapist

1 | INTRODUCTION

Care for people with bleeding disorders (PWBD) has included physical therapists (PTs) since the establishment of comprehensive haemophilia clinics in 1975 within the United States (US).¹ As rehabilitation and habilitation experts, PTs are core members of the haemophilia treatment centre (HTC) team providing musculoskeletal evaluation, treatment and education.² The World Federation of Hemophilia (WFH) Guidelines for the Management of Hemophilia recommend annual comprehensive clinic evaluations that, at minimum, include a haematologist, nurse, social worker and PT.²

The Centers for Disease Control and Prevention (CDC) and Maternal and Child Health Bureau (MCHB) grants and surveillance studies historically supported PT involvement in the HTC, but as grant distribution and funding change, financial support for PT salaries is variable and presents a challenge for US HTCs. The status of funding for PTs within US HTCs is currently unknown.

Haemophilia is a rare, inheritable bleeding disorder characterized by musculoskeletal bleeding, including intra-articular bleeding, resulting in joint and soft tissue pain. Recurrent bleeding leads to haemophilic arthropathy, chronic and debilitating pain, and significant functional limitations.²⁻⁴ Pain is prevalent in adults with haemophilia. Pain interference is reported as high as 89% in the last 4 weeks,⁵ acute/intermittent pain is more common than chronic/persistent pain across all haemophilia severities (29% vs 13%),⁶ chronic pain becomes more prevalent with age,⁷ with the most common reported sites of joint pain as the ankles (37.4%), knees (23.7%) and elbows (18.9%).⁸ As part of the HTC team, PTs are uniquely skilled to evaluate and develop treatment plans addressing functional limitations and pain associated with haemophilic arthropathy.^{2,9}

PTs are well versed in the management of musculoskeletal conditions related to bleeding disorders that result in pain, and thus, can be integral in pain management. Progressive strength training demonstrated improved muscle strength, functional capacity and reduction in pain with an improvement in self-rated health status.¹⁰ PTs provide a variety of interventions, including strengthening, range of motion, proprioception and coordination training, functional training and orthotics/shoe adaptations; all of which assist with pain management.¹¹⁻¹³ As a component of multimodal pain management, physical medicine and rehabilitation plays an important role in prevention and treatment of chronic haemophilic arthropathy and associated pain. In collaboration with other disciplines, physical medicine thus contributes to improving or maintaining functionality of PWBD.¹⁴

The National Hemophilia Foundation (NHF) Medical and Scientific Advisory Council (MASAC) formed the Pain Initiative Taskforce to address gaps in current pain management practices within US HTCs. This multidisciplinary taskforce developed a survey to explore team members' roles and practice patterns within HTCs. The published results¹⁵ addressed survey themes common to multiple disciplines but did not report discipline-specific details. The following PT-specific aims reported here are:

1. Describe utilization, role responsibilities and practice patterns of US HTC PTs.
2. Identify PT practice patterns addressing assessment and treatment of pain.
3. Recognize gaps in utilization and role responsibilities of PTs within the interdisciplinary team and suggest guidelines for their involvement within the HTC.

2 | METHODS

The survey used for this study was developed by NHF's MASAC Pain Initiative Multidisciplinary Sub-committee consisting of physicians (3); nurse practitioners (2); doctor of nursing practice (1); registered nurse (1); social workers (2); psychologists (2); physical therapists (3); patients (2); and a statistician (1). The overall goal of the survey was to better understand HTC multidisciplinary providers' pain management practices, incorporating the CDC Pain Guidelines.¹⁶ The survey was not formally validated or previously tested. For the PT-specific survey (Appendix 1), 16 items were common to all three disciplines; one was common to PTs and social workers; nine were PT-specific. Items explored the following themes: (1) Practice Patterns and Role responsibilities in the HTC; (2) Billing Practices; and (3) Pain Management Practices. The study was approved by the Institutional Review Board at Munson Medical Center in Traverse City, Michigan. Only PT-specific data not published in the multidisciplinary article are reported here.

PTs working in federally funded HTCs across all US regions were eligible to participate and identified from the publicly available CDC HTC Staff Directory.¹⁷ Additional eligible PTs, not listed within the directory, were identified by NHF's PT Working Group (PTWG) members and subsequently invited to participate.

Qualtrics™, a secure server, was utilized as the survey platform. Surveys were sent with an introductory email to every provider weekly for 9 weeks beginning on 7 May 2018, until one of the following occurred (a) the participant completed the survey, (b) the participant opted-out, (c) the 9-week survey timeframe ended. A 'click to consent' was presented prior to survey completion.¹⁵ Due to an error in survey logic in the initial version of the survey, one insurance billing question was subsequently resent to all 59 PT respondents with 45 (76.3%) responses. Data were analysed using Stata 15.1.¹⁸ A descriptive data summary was submitted to the PT members of the multidisciplinary team, who then recommended specific post-hoc inferential exploratory analyses based on the descriptive summary. Frequency count data were analysed using the Pearson Chi-square test when cell counts were ≥ 10 , and the Fisher's exact test was used when cell counts were < 10 . None of the data reported here were normally distributed, therefore the Wilcoxon rank-sum test was used for two-group comparisons. The Kruskal-Wallis test with Benjamini-Yekutieli adjustment was used for rank-ordered data and non-normally distributed data. Spearman's Rho with Kendall tau for tied ranks was used for correlational analyses.¹⁸ All *P* values were

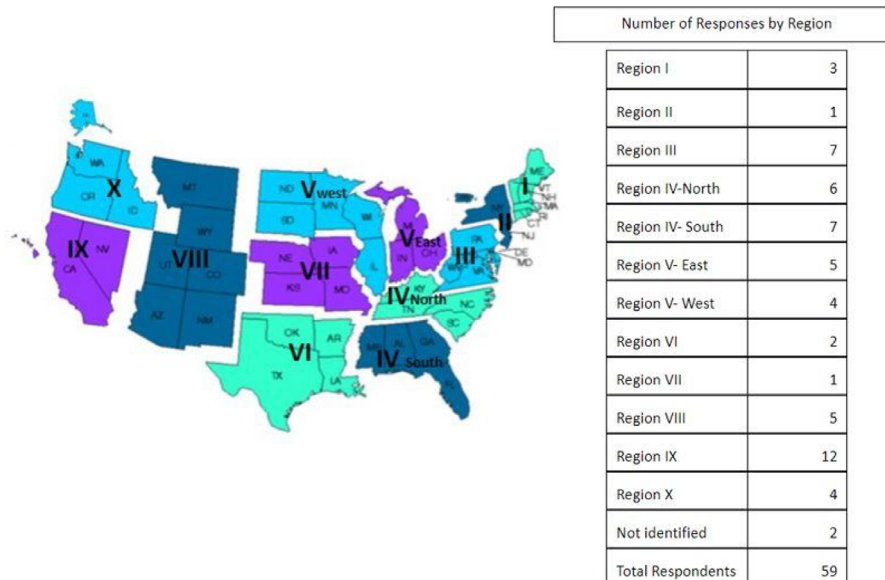


FIGURE 1 PT respondents by CDC HTC region

based on two-tailed tests. Inferential statistical analyses assumed the null hypothesis for any evaluation of relationships between variables.

3 | RESULTS

Of the 189 surveys sent to PTs, 10 were undeliverable; 59 responded (33.0% response rate) (See Figure 1). Seven (11%) respondents were from small HTC (< 100 patients); 22 (37.3%) from medium size HTCs (100-250 patients); 28 (47.5%) from large HTCs (> 250 patients), and two (3.4%) subjects did not specify their HTC. When compared to 2017 National Patient Satisfaction Survey Data Set, there was no significant difference in the ratio of small, medium and large centres in our sample of HTCs ($P = .093$ Kruskal-Wallis test).¹⁹

3.1 | Physical therapy role responsibilities and practice patterns

Most respondents cared for both adults and children ($n = 36$; 61.0%); children only ($n = 12$; 20.3%); and adults only ($n = 11$; 18.6%). Forty-two (71%) respondents worked in the HTC < 20 hours/week with 20 (34.0%) working as few as 4–12 hours/month. Full time HTC employment was less common with only 9 (15.0%) reporting > 32 hours/week (Figure 2). There was no relationship between hours worked per week and time spent in the annual comprehensive evaluation ($P = .348$), however, those treating both adults and children spent more time during comprehensive clinic and worked more hours in the HTC than those who saw either adults or children only ($P = .022$ and $P = .023$, respectively, Kruskal-Wallis test).

PTs perform comprehensive evaluations of PWBD as part of the HTC team.^{2,9} Thirty-three (55.9%) reported > 30 minutes to do their evaluations, 12 respondents have 21–30 minutes (20.3%) and 13 (22.0%) have 11–20 minutes. One respondent was not involved in comprehensive clinic visits. The majority ($n = 35$, 59.3%) were available for individualized PT follow-up visits which did not differ between those seeing only children, only adults or both ($P = .295$). Of those who were not available for follow-up ($n = 24$, 40.1%), multi-select options for follow-up included: (1) recommended/assisted with a prescription to acquire services ($n = 19$, 32.2%), (2) referred to providers outside their institution ($n = 16$, 27.1%), (3) referred patients to their institutional rehabilitation department ($n = 15$, 25.4%) and/or (4) suggested other types of follow-ups outside of their HTC ($n = 3$, 5.1%).

PTs provided direct treatment > with > 80% addressing education, chronic sequelae and acute bleeding (Table 1). There was no relationship between the availability to provide treatment and time spent performing the annual comprehensive evaluation or hours/week in the HTC. Time allotted for annual comprehensive evaluation was unrelated to PT-specific treatment services provided, including (1) treatment of acute bleeds, (2) treatment of chronic sequelae, (3) treatment of other musculoskeletal conditions, (4) durable medical equipment (DME) orders and (5) education (See Table 2). Within the category of education, however, as comprehensive clinic evaluation time increased, a greater percentage of PTs provided education regarding pain ($P = .01$) and surgical options ($P = .001$) (See Table 3).

Among PTs who provide education, those who worked > 10 hours/week in the HTC were more likely to provide nutrition education ($n = 11$; 55.0%; $P = .026$) and surgical options education ($n = 16$, 53.3%; $P < .001$) than those who worked < / = 10 hours per week (Fisher's exact test). There was no difference in hours worked per week and other types of education provided (exercise, joint health, sports, pain, safety, transition, vocational). PTs who provided treatment

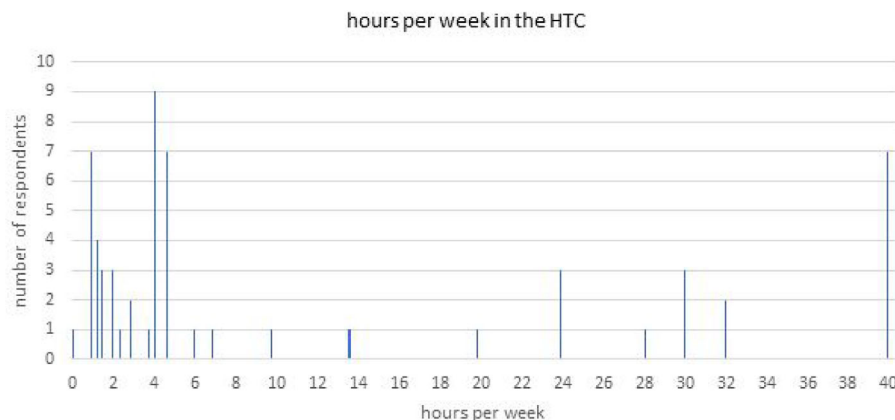


FIGURE 2 Reported hours per week by HTC physical therapists

TABLE 1 Services and education provided by physical therapists at their HTC

Education provided	n (%)
Exercise Education	57 (100)
Joint Health Education	56 (98.25)
Nutrition Education	20 (35.09)
Pain Education	51 (89.47)
Sports Education	52 (91.23)
Surgical Options Education	29 (50.88)
Safety Education	56 (98.25)
Transitional Education	34 (59.65)
Vocational Education	25 (43.86)
Other education ^a	11 (19.30)

^aOther includes gait biomechanics, preventative education, orthotics recommendations, general haemophilia information from a PT perspective, equipment, mindfulness, helping to problem solve various related issues, occasionally vocational related, equipment, bracing, funding options (HFA), muscle bleeds, general health & wellness, bleed recognition, management & recovery, school accommodations, physical education classes, lifting, assistive devices.

for both children and adults were more likely to provide education in nutrition ($n = 17$; 47.2%; $P = .036$), sports ($n = 34$, 94.4%; $P = .032$) and surgical options ($n = 24$, 66.7%; $P = .001$, Fisher's exact test).

3.2 | Billing practices

The 45 PTs (76.3%) who responded to the resent billing question due to survey logic error, 12 (26.7%) reported billing insurance for direct patient care during comprehensive clinic visits, while 33 (73.3%) did not. Among the 35 available for follow-up care in the HTC, 20 (57.2%) billed insurance and 15 (42.9%) utilized grant funding. There was no relationship between billing insurance for the comprehensive clinic visit and PT availability to provide follow-up. Among the 31 who responded to both questions about billing insurance for comprehen-

sive clinic and billing for follow-up, those who billed insurance for the comprehensive clinic evaluation were significantly more likely to bill insurance for follow-up visits ($n = 9$, 56.3%) than those who did not bill insurance for comprehensive clinic evaluation ($n = 1$, 6.7%; $P = .006$) (see Table 4).

There was no relationship between billing for PT follow-up visits and providing any of the five PT services: treatment of acute bleeds, treatment of chronic sequelae, treatment of other musculoskeletal conditions, DME orders and education. However, those who billed insurance for their services within the comprehensive visit ($n = 12$) were more likely to provide education regarding surgical options ($n = 10$, 83.3%) versus not billing insurance ($n = 2$, 16.7%; $P = .046$; Fisher's exact test).

3.3 | Pain management practice patterns

Most PTs (94.9%) evaluated pain regardless of time spent during annual comprehensive evaluation. Level of comfort in providing physical therapy to PWBD with chronic pain did not differ between those who saw children, adults or both children and adults. When asked how their HTC manages pain (slightly well to extremely well on a 1–4 Likert scale), those working with children only ($n = 12$) ranked pain management higher than those who work with adults only ($n = 11$, $P = .028$; Wilcoxon test). There was no relationship between hours worked per week and level of comfort in providing PT treatment for PWBD and chronic pain. PT's comfort level of treating pain was unrelated to availability for follow-up treatment, opinion about how well the HTC is managing pain, time spent for the annual comprehensive evaluation or hours worked per week in the HTC.

As reported previously,¹⁵ 33 (58.9%) of the 56 PTs who evaluate pain in PWBD used a formal pain measurement tool. Billing insurance for comprehensive evaluation was not associated with the use of a formal pain measurement tool. However, those who billed for follow-up treatment were more likely to use a formal measurement tool ($n = 34$, $P = .004$; Chi-square test). More time spent in the comprehensive clinic evaluation was not associated with more frequent use of a formal pain measurement tool. There was no difference

TABLE 2 Treatment activities of PTs in comparison to time spent in comprehensive clinic

Time spent in Annual Comprehensive Evaluation	Treatment of Acute Bleeds	Treatment of Chronic Sequelae	Treatment of other Musculoskeletal conditions	DME Orders	Education
n (%) ^a					
11-20 minutes	10 (76.92)	12 (92.31)	9 (69.23)	8 (61.54)	12 (92.31)
21-30 minutes	10 (83.33)	11 (91.67)	6 (50)	11 (91.67)	12 (100)
>30 minutes	29 (87.88)	29 (87.88)	19 (57.58)	26 (78.79)	33 (100)
p value (Fisher's exact test), excluding the person not involved in comp clinic	.622	1.000	.626	.177	.431

^an = 58; excludes 1 PT who is not involved in comprehensive clinic.

TABLE 3 Education provided by PTs based on time spent in comprehensive clinic

Time for Annual Comprehensive Evaluation	Exercise Education	Joint Health Education	Nutrition Education	Pain Education	Sports Education	Surgical Options Education	Safety Education	Transition Education	Vocational Education	Other Education
n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
11-20 minutes (n = 13)	12 (100)	12 (100)	5 (41.67)	8 (66.67)	12 (100)	3 (25)	12 (100)	7 (58.33)	5 (41.67)	4 (33.33)
21-30 minutes (n = 12)	12 (100)	11 (91.67)	2 (16.67)	11 (97.67)	9 (75)	4 (33.33)	12 (100)	6 (50)	3 (25)	2 (16.67)
>30 minutes (n = 33)	33 (100)	33 (100)	13 (39.39)	32 (96.96)	31 (93.94)	22 (66.67)	32 (96.97)	21 (63.64)	17 (51.52)	7 (21.21)
P value (Fisher's exact test)	n/a	.421	.382	.016	.115	.019	1.000	.713	.311	.56
P value (Wilcoxon Rank-sum)	n/a	.472	.672	.01	.812	.001	.411	.564	.277	.39

*n = 57; 1 did not provide education, 1 was not involved in comprehensive clinic.

between patient age groups with regards to which pain assessment tool was used most often. Among the 33 PTs who used a tool, the 0–10 Numeric Pain Rating Scale was used most often (n = 21, 63.5%), with no difference between patient age groups. In contrast, all six PTs who used the Brief Pain Inventory (BPI) spent ≥30 minutes in the annual comprehensive evaluation (6/19, 31.6%); none of those who spent ≤30 minutes used the BPI (0/14, P = .033; Fisher's exact test).

The top five recommended non-pharmacologic complementary treatments for pain management were splints and braces (n = 50, 84.8%), aquatic therapy (n = 44, 74.6%), orthotics (n = 42, 71.2%), surgery (n = 28, 47.5%) and yoga (n = 19, 32.2%). There was no relationship between hours worked per week and the likelihood of recommending any specific non-pharmacologic treatments (all P values > .05). More time spent in annual comprehensive clinic evaluation increased the likelihood of including psychology (P = .006) and Transcutaneous Electrical Nerve Stimulation (TENS) (P = .004) in the top five recommended non-pharmacologic treatments. There was no association between the PTs level of comfort providing pain management and the top five non-pharmacologic treatments recommended except for herbal remedies/vitamins, most frequently recommended by those PTs only somewhat comfortable versus those with higher levels of comfort in managing pain with PWBD (See Table 5).

4 | DISCUSSION

4.1 | Physical therapy role responsibilities and practice patterns

The survey results describe, for the first time, the role and utilization of PTs within US HTC and their pain management practices. Represented HTCs varied in size, population ages and utilization of PT services. Within their scope of practice, PTs engaged in pain evaluation, follow-up treatment, education and management recommendations for PWBD. Although there was significant variability in HTC hours worked per week, PTs were comfortable caring for patients with pain related to their bleeding disorder. Those who worked more hours/week or spent more time in the annual comprehensive evaluation provided a greater variety of PT-related education.

Education empowers PWBD to optimize activity throughout the lifespan as described throughout the WFH guidelines.² PTs provide education for PWBD at birth with parents and with patients at age-appropriate intervals focusing on bleed recognition, bleed recovery and sport/activity participation.^{20,21} Transitioning to adulthood includes education specific to exercise and strengthening, adaptive equipment, orthotics, workplace interests and adaptations, and activity modifications. As PWBD age, additional topics include

TABLE 4 Billing practices for follow-up PT comprehensive clinic

How do you provide follow up PT treatment: (n = 31)	Bill insurance for PT comprehensive clinic evaluation? N = 1		P value (Fisher's exact test)
	no (n = 21)	yes (n = 10)	
Within the HTC billing insurance (n = 16)	7 (43.75%)	9 (56.25%)	.006
Within the HTC without billing insurance- covered under our grant (n = 15)	14 (93.33%)	1 (6.67%)	

balance, falls, assistive devices, home modifications and surgical planning. The HERO study highlighted how health-related quality of life (HRQoL) can be negatively affected by pain and decreased mobility such that 51% of PWBD reported constant daily pain that interfered with life and almost 90% indicated pain interrupted their lives in the last 4 weeks.¹⁰ Supporting time and access to a skilled HTC PT to provide education can potentially improve HRQoL and disease management.

4.2 | Billing practices

Insurance billing for a PT evaluation incorporates the degree of complexity as directed by clinical findings, social considerations, overall physical function and health status.⁹ According to the Center for Medicare and Medicaid Services, low complexity evaluations average 20 minutes and high complexity evaluations average 45 minutes.⁹ The HTC PT's evaluation incorporates all the elements of the International Classification of Functioning, Disability and Health (ICF) model.²² At a minimum, the NHF PTWG recommends including assessments of pain, posture, joint integrity, muscle strength, balance, gait and activity participation.⁹ Given that 43% of respondents report they have ≤ 30 minutes allotted to complete this extensive evaluation during the annual comprehensive evaluation, this implies that a large percentage of assessments are of low complexity and/or do not include assessment of all these crucial elements for all patients.

Financial support of the HTC PT was not directly evaluated in this survey. Grants or other funding such as 340b pharmacy programmes, contracts with the institution's rehabilitation department or a combination of both are common. Stability of reimbursement and funding is required to ensure PT specialized evaluation and treatment, both during comprehensive clinic and individualized follow-up. Variability in insurance billing suggests the need for further investigation in this area given that funding sources may decrease over time. If this occurs, direct insurance billing by PTs may become necessary. Standardizing billing practices may reduce a gap between capability and utilization of the PT and address potential access barriers to services.

4.3 | Pain management practice patterns

Worsening pain and loss of participation present as a continuum of functional impairments that a skilled HTC PT addresses with multiple treatment strategies. Survey respondents identified a moderate to high degree of comfort working with PWBD who have pain, primarily focusing on non-pharmacologic interventions within their scope of practice. Pain assessment and management remains a key component of a musculoskeletal evaluation per the WFH guidelines.^{2,9}

The Pain, Functional Impairment and Quality of Life study addressed the validity of a variety of pain assessment tools for PWBDs.²³ Our findings suggest variability in pain assessment methods used by PTs, ranging from no formal pain assessment to utilization of the BPI by 58% of PTs who had 30 minutes in comprehensive evaluation. This represents a gap in care that increased time for evaluations and PT education can address.

Bleeding disorder-specific care is not commonly included in US PT education programmes. Opportunities for specialized training are necessary to build expertise and ensure evidence-based treatment. Ways to develop expertise and improve knowledge can include the following:

1. Connect HTC PTs to the network of trained professionals who mentor one another through regional, national and international conferences.
2. Participate in disease-specific professional groups such as the NHF PTWG and the newly formed US Hemophilia Treatment Center Physical Therapy Collaborative.
3. Support/encourage participation in educational programs such as Partners PRN in Indianapolis, IN,²⁴ virtually or in-person, to advance PT specific training in PWBDs care.

5 | LIMITATIONS

This survey was descriptive; post-hoc inferential analyses were exploratory and without any a priori hypotheses. While responses represented all US HTC regions and HTC sizes, the CDC directory does not likely include all PTs who are affiliated with HTCs. As a result, it is unclear if an adequate cross section of HTC PT practice was obtained. PTs formal training or supervised experience in care of PWBD was not assessed and could explain some results. Reasons for variability in PT time allocation within the HTC were not explored. This may be an administrative decision, a reflection of the size of the HTC or based upon budgetary constraints. The reduced number of respondents resulting from the survey logic error limited a complete analysis of billing practices. Respondents were not asked if specific services were provided at the time of the comprehensive clinic or at time of follow-up, which could potentially explain the lack of significant associations between time allotted, services provided and recommended treatment. Adjusting the selection process to "select all that you recommend" rather than "top 5 choices" may have yielded a broader view

TABLE 5 Comfort level of PTs with respect to non-pharmacological treatments offered

(Select one to up to five options)	Somewhat Comfortable (n = 3) n (%)	Neither Comfortable or Uncomfortable (n = 4) n (%)	Moderately Comfortable (n = 24) n (%)	Very Comfortable (n = 28) n (%)	P (Fisher's exact test)
acupressure	0	0	0	1(3.57)	1
acupuncture	0	0	0	3 (10.71)	.483
aquatic therapy	2 (66.67)	3 (75)	17 (70.83)	22 (78.57)	.829
biofeedback	0	0	1 (4.17)	4 (14.29)	.667
CBT	0	0	0	3 (10.71)	.483
distraction	0	0	4 (16.67)	2 (7.14)	.727
imagery	0	0	2 (8.33)	0	.386
herbal remedies or vitamins	2 (66.67)	0	3 (12.5)	1(3.57)	.041
therapeutic touch	0	0	0	2 (7.14)	.607
humour	1 (33.33)	0	0	2 (7.14)	.129
surgery	2 (66.67)	2 (50)	10 (41.67)	14 (50)	.877
joint injections	1 (33.33)	2 (50)	5 (20.83)	4 (14.29)	.286
massage	1 (33.33)	2 (50)	5 (20.83)	7 (7)	.573
mindfulness	0	0	6 (25)	4 (14.29)	.649
music or art therapy	0	0	0	1(3.57)	1
orthotics	2 (66.67)	3 (75)	18 (75)	19 (67.86)	.953
psychology	0	0	1 (4.17)	3 (10.71)	.771
splints or braces	3 (100)	4 (100)	23 (95.83)	20 (71.43)	.075
TENS	0	1 (25)	3 (12.5)	4 (14.29)	.812
Yoga	1 (33.33)	2 (50)	6 (25)	10 (35.71)	.744

of nonpharmacological pain management utilized by PTs. Accessibility of recommended pain treatment options was not queried.

6 | CONCLUSION

This study demonstrated a wide variety of PT utilization, practice patterns, billing and pain management practices within US HTC. Increased time in comprehensive clinic allowed for specific PT education regarding pain and surgical options. However, evaluating the benefits of education on patient outcomes was beyond the scope of this study and warrants further research. The majority of PTs (57/59) provided diagnosis-specific education during comprehensive clinic visits. When PTs had increased time in annual comprehensive clinics, they were more likely to include education around lifestyle choices such as sports, nutrition and surgical interventions and more likely to use a standardized assessment tool. Additional time in comprehensive clinic may provide opportunities to further explore and educate on nonpharmacological options. Gaps in care may be addressed by ensuring PT presence through salary support, funded education, greater regional and national specialty collaboration, and advocacy for insurance coverage for appropriate services. When PTs are accessible and utilized fully at the HTC, they can provide individualized services to optimize care and pain management for PWBD.

As such, we offer the following recommendations:

1. Ensure uniquely trained and skilled HTC PTs are utilized as core members of the HTC treatment team by:
 - a. Securing HTC PT salary support through existing funding sources,
 - b. Enhancing billing practices to maximize financial support,
 - c. Providing sufficient time for patient evaluation, PT-specific education and follow-up PT treatment.
2. Supporting PT access to specialized educational opportunities to advance expertise in the care of PWBD. Including PTs within the interdisciplinary HTC management of pain.

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CONFLICTS OF INTEREST

The authors have no competing interests. KJB has acted as a paid consultant for Sanofi Genzyme; CN is a paid consultant for the National Hemophilia Foundation; and Tyler Buckner has worked as a paid consultant for uniQure, BioMarin and Tremeau Pharmaceuticals. He has served as an advisory board member and received honoraria from uniQure, BioMarin, Tremeau Pharmaceuticals, Novo Nordisk, CSL Bearing, Genentech, Spark, Sanofi, Pfizer and Takeda.

AUTHOR CONTRIBUTIONS

JN and ND contributed to study project and design, coordination, data analysis and drafted manuscript. KB, AYL and CDN participated in data analysis and drafted manuscript. MW initiated the project, contributed to study design, coordination and edited manuscript. MS contributed to study project and design, coordination and edited manuscript. TWB contributed to study project and design, and edited manuscript. Final submission was approved by all authors.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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