

## PHYSICAL THERAPY MANAGEMENT OF PEOPLE WITH BLEEDING DISORDERS AND CHRONIC PAIN

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### Executive Summary

The Pain Initiative Taskforce (PITF) of the National Bleeding Disorder Foundation's (NBDF) Medical and Scientific Advisory Council (MASAC) convened an expert panel of physical therapists to develop recommendations for the physical therapy specific assessment and treatment of chronic pain in people with bleeding disorders (PWBD). The recommendations are based on a systematic review of the published medical literature, professional experiences of the panel experts, and external multistakeholder reviews.

### Recommendations

#### A) Assessment

1. Physical therapists evaluating people with a bleeding disorder and chronic pain should utilize a combination of patient and clinician reported measures of health-related quality of life (HRQOL) and functional outcomes to best identify a plan of care focusing on patient-specific impairments and goals.

#### B) **Treatment:** All PWBD experiencing chronic pain should:

2. receive education on pain.
3. receive education on musculoskeletal anatomy, biomechanics, and joint health.
4. receive education on the safety and efficacy of exercise.
5. receive education on prevention and treatment of bleeding episodes.
6. be offered aquatic intervention as part of their physical therapy plan of care.

7. receive an individualized therapeutic exercise program.
8. participate in a pain management program with psychosocial support to reduce pain's impact and support skilled therapeutic exercise programs.
9. be offered manual therapy interventions as part of an individualized treatment program.

## **INTRODUCTION**

### **Background**

Chronic pain is one of the most common chronic conditions in the United States (US),<sup>1</sup> with annualized prevalence among of 20.4%. The diagnosis of chronic pain is widely used to describe an innumerable number of clinical presentations. It is multifactorial, associated with actual and or potential tissue damage, and is defined as pain that lasts longer than three months extending past normal healing time.<sup>2</sup> Research in people with hemophilia (PWH) shows a high prevalence of chronic pain with 34-58% living with chronic pain,<sup>3</sup> 39% describing poorly managed pain,<sup>4</sup> and pain that affects general activity (74%), walking ability (70%), normal work (71%) and relations with other people 56%.<sup>5</sup> While the prevalence of chronic pain in PWH is documented in the literature, improving the clinical treatment of chronic pain represents a critical need and priority for PWBD.

The impact of chronic pain on function and quality of life (QOL) is individual, specific, multifaceted, and dynamic. In PWBD, recurrent bleeding episodes cause progressive musculoskeletal (MSK) changes that impact bone, cartilage, and muscle. The pain experience in PWBD depends on many factors including MSK tissue damage, previously available treatment methods, medical experience and trauma, and one's personal family history involving bleeding disorders<sup>6</sup>. Pain intensity and pain interference varies among PWBD even those with similar clinical presentations.<sup>7, 8</sup> The biopsychosocial model of healthcare allows consideration of many factors which contribute to the experience of chronic pain. This model can identify and explain differences between individuals and establish a foundation for the interdisciplinary, multimodal management of pain.

### **Rationale**

This document provides practical guidance to physical therapists who care for PWBD experiencing chronic pain. It serves as a companion to the document "Management of Chronic Pain in Persons with Bleeding Disorders: Guidance for Practical Application of The Centers for Disease Control's Opioid Prescribing Guidelines",<sup>9</sup> which was published by MASAC in 2020. This also is a companion document to the document "MASAC Recommendations Regarding Physical Therapy Management for the Care of Persons with Bleeding Disorders".<sup>10</sup>

### **Scope and Audience**

The recommendations provided in this document are intended for physical therapists working with PWBD experiencing chronic pain. Chronic pain in PWBD is often due to the sequelae of joint bleeding and damage; however, the described practices can be applied to PWBD experiencing chronic musculoskeletal pain regardless of location.

## **Methods and Process**

The interdisciplinary PITF was formed by the NBDF MASAC leadership to address the issue of chronic pain in the inherited bleeding disorders community. The PITF is an expert panel of clinicians and community members working in the bleeding disorder community and includes clinicians in medicine, social work, psychology, physical therapy, nursing, and community members. The physical therapy subcommittee of this taskforce led the development of the physical therapy-specific recommendations for the assessment and treatment of chronic pain in PWBD.

The subcommittee conducted a systematic review of available evidence through July 2022 to guide the development of the recommendations presented in this document. PubMed was used to identify current literature regarding chronic pain assessment and management in PWBD. Only full-text articles were included, with no restriction on date of publication, age of participants, or original language of article. There were forty-three articles reviewed and after thorough screening of abstracts, twenty-five articles were identified as addressing PWBD, chronic pain, and physical therapy interventions. They were then evaluated using components of the GRADE process. Thirteen additional articles were identified through the review process and included.

The strength and quality of evidence in the literature and expert opinion of assessment and treatment of chronic pain were considered in these recommendations. Draft recommendations were reviewed and revised by all members of the MASAC PITF and made available for external review by the NBDF's Physical Therapy Working Group. Pertinent comments were integrated and addressed in the final version of this document.

The final recommendations were organized into 2 domains based on the research studies identified in the literature: (1) Assessment and (2) Treatment. Treatment was further subdivided into 5 categories: (1) Education, (2) Aquatic Therapy, (3) Therapeutic Exercise, (4) Therapeutic Modalities, and (5) Manual Therapy.

## **RECOMMENDATIONS**

Physical therapy stands as a pivotal cornerstone in chronic pain management. Navigating chronic pain demands a comprehensive perspective, delving into the biopsychosocial intricacies of the pain experience.<sup>9</sup> The imperative lies in tailoring the treatment strategies to the distinct requirements of every individual. Skilled physical therapists can utilize the recommendations below to curate a chronic pain care plan for PWBD.

A physical therapist's close collaboration with the hematology team is necessary to ensure appropriate medical management, factor levels, referrals to other care providers, and to reduce barriers to care. Common medications prescribed to maintain hemostasis prophylactically or on demand include but not limited to factor replacement, bispecific antibodies, antifibrinolytics, and desmopressin. Medication management for chronic pain may require ongoing monitoring by prescribing medical providers. Analgesic medication use prior to or after exercising, if required, should be directed by the medical provider, and requires continual re-evaluation so that medications can be titrated to effect or stopped when no longer necessary.<sup>9</sup>

Patient involvement and adherence to the plan of care is paramount and increases the likelihood of optimal outcomes.

## A) ASSESSMENT

Rationale: A well-rounded, holistic assessment is essential to evaluate health status, guide treatment, and assess the effects of treatment in PWBD who experience chronic pain. There are several outcome measures identified as valid and reliable for use in PWBD.<sup>5, 11, 12</sup> However, a combination of assessment tools can best address the complex nature of pain as understood within the framework of the biopsychosocial model.<sup>7</sup> By utilizing disease-specific functional assessment tools in combination with pain and HRQOL measures, physical therapists can promote patient engagement, target functional impairments, establish a plan of care, and assess outcomes of pain management interventions for PWBD. Chronic pain requires a interdisciplinary, multimodal approach with pain assessments across multiple domains (Table 1). Use of a Numeric Rating Scale (NRS) or Visual Analog Scale (VAS) alone for assessing chronic pain is inadequate.

- 1. Physical therapists evaluating people with a bleeding disorder and chronic pain should utilize a combination of patient and clinician reported measures of HRQOL and functional outcomes to best identify a plan of care focusing on patient-specific impairments and goals. (Table 1)**

Practice implications: Bleeding disorder-specific assessment tools evaluate joint and muscle health, self-reports of pain and function, and HRQOL. An individual's specific impairment and participation goals will guide the choice of assessment tools and outcome measures. Multiple tools are required to fully evaluate pain, target interventions, guide the physical therapy plan of care and track outcomes. Pain assessment should not be limited to NRS and VAS scales alone.<sup>12</sup> [Table 1] Clinicians are encouraged to choose a core set of outcomes measures to follow in all patients with pain and use additional measures as guided by each patient's clinical needs and goals.

Special considerations: Given the biopsychosocial nature of pain, it is recommended a psychosocial clinician (i.e., a specialist in behavioral and mental health assessment and intervention) be incorporated into an individualized pain management program.<sup>13, 14</sup>

## B) TREATMENT

### **Education**

Rationale: Patient education is an individualized, collaborative process between health care providers and patients to foster the integration of knowledge, skills, and attitudes to achieve optimal health outcomes.<sup>15</sup> Education, including the neurophysiology and neurobiology of pain, can positively affect perceived pain intensity, level of catastrophizing, kinesiophobia, and impact of pain on daily functioning.<sup>15, 16</sup> Additional education on musculoskeletal anatomy,

biomechanics, joint health, safety and efficacy of exercise, and prevention and treatment of bleeding episodes support PWBD to reach their goals.<sup>17</sup>

**2. All PWBD experiencing chronic pain should receive pain education.**

Practice implication: Pain education should be integrated into routine clinical practice for managing pain in PWBD to align beliefs and knowledge with current evidence-based pain science. The utilization of pain science assessment tools (e.g. COPI, rNPQ) is highly encouraged to identify the knowledge gaps and misconceptions, target education, and evaluate the effectiveness of pain education.<sup>16, 18-20</sup>

Special consideration: It is essential to acknowledge the tissue damage, tissue alterations, and resultant biomechanical changes in PWBD with hemophilic arthropathy.<sup>6</sup>

**3. All PWBD experiencing chronic pain should receive education on musculoskeletal anatomy, biomechanics, and joint health.**

Practice implication: Education on musculoskeletal anatomy, biomechanics, and joint health should be integrated into routine clinical practice for managing pain in PWBD to enhance understanding of body functions and impairments. It is essential to consider the clinical presentation in addition to the diagnosis to tailor the education to the patient's needs.<sup>18, 19</sup>

**4. All PWBD experiencing chronic pain should receive education on the safety and efficacy of exercise.**

Practice implication: Education on the safety and efficacy of exercise should be integrated into routine clinical practice for managing pain in PWBD to encourage regular physical activity and decrease kinesiophobia. Treatment interventions (i.e., guided, skilled therapeutic exercises, aquatic therapy, and aerobic conditioning) have been shown to be safe and effective in the management of chronic pain in PWBD.<sup>18, 20, 21</sup>

**5. All PWBD experiencing chronic pain should receive education on prevention and treatment of bleeding episodes.**

Practice implication: Education on prevention and treatment of bleeding episodes should be integrated into routine physical therapy clinical care for managing pain in PWBD to enhance patient independence and competence. Competent self-management in the prevention and treatment of bleeding episodes will enable and broaden options of activity participation for PWBD experiencing chronic pain.<sup>6, 18</sup>

## **Aquatic Exercise**

Rationale: Aquatic Exercise has many different names (hydrotherapy, aquatherapy, hydro kinesiotherapy, aquatic therapy, training in pool). It is performed in warm water and is one of the oldest therapeutic interventions. The properties of water, including hydrostatic pressure, buoyancy, and temperature (33-34 Deg C) impact an individual's physiology by improving

circulation, increasing parasympathetic response, and decreasing weight bearing. Skillful utilization of these properties during aquatic exercise reduces pain, improves functional capacity, allows for movement in all planes, and improves strength.<sup>22</sup>

**6. All PWBD experiencing chronic pain should be offered aquatic intervention as part of their physical therapy plan of care.**

Practice Implication: Aquatic exercise can improve joint range of motion, strength, aerobic function, and pain intensity in PWBD. Buoyancy decreases compressive and gravitational forces on joints during immersion which promotes active participation in therapy. Aquatic exercise is shown to be an effective intervention for pain relief.<sup>21, 23, 24</sup>

Special consideration: Access to an aquatic environment may be limited by several external factors (i.e., insurance, culture, location, entrance/exit to pool). Additionally, medical clearance is required for individuals who have immune deficiency, central venous catheters, skin conditions, cardiovascular disease, chronic kidney disease, pregnancy, and thermoregulation difficulties.

## **Therapeutic Exercise**

Rationale: PWBD who experience soft tissue, joint, and muscle bleeds may present with decreased range of motion and impaired muscle activation that can negatively impact participation, activities of daily living, and hobbies.<sup>25</sup> Therapeutic exercise is a broad category of physical therapy interventions used to address impairments and maximize function and participation.

**7. All PWBD experiencing chronic pain should receive an individualized therapeutic exercise program.**

Practice Implications: A combination of therapeutic exercise types (i.e., strengthening, stretching, aerobic exercise, and functional activities) is used to individualize a program to meet the needs of the patient.<sup>18, 20, 23, 24, 26-29</sup> Therapeutic exercise programs with variable duration, frequency, and intensity have shown to be safe in PWBD and effective in decreasing the experience of chronic pain.

Special Consideration: The research available reinforces the importance of bleed prevention strategies when engaging in therapeutic exercise. Prior to initiation of plan of care, use of medications to prevent bleeding before or after exercise should be discussed with the treating hematologist.<sup>27, 29</sup>

**8. All PWBD experiencing chronic pain should participate in a pain management program with psychosocial support to reduce pain's impact and support skilled therapeutic exercise programs.**

Practice Implication: Skilled therapeutic exercise and cognitive-behavioral therapy support the biopsychosocial treatment model for chronic pain. Used in combination,

improvements in self-efficacy, QOL and emotional status, while reducing pain and kinesiophobia are shown when compared to therapeutic exercise alone.<sup>19</sup>

Special Consideration: Mental health service access and an individual's receptiveness to intervention may vary.

## **Therapeutic Modalities**

Rationale: Therapeutic modalities are part of a larger biophysical agent category, including electromagnetic, thermal, and mechanical tools, utilized by physical therapists to relieve pain and reduce inflammation. These are often combined with other skilled PT interventions in a comprehensive pain management plan of care.<sup>28</sup>

### **9. PWBD experiencing chronic pain should be offered therapeutic modalities as part of a multimodal treatment approach for chronic pain.**

#### Practice Implications:

- a. Electrotherapy modalities (Transcutaneous Electrical Nerve Stimulation (TENS), electromagnetic field, high intensity laser therapy) are insufficiently studied in PWBD with chronic pain; however, they can be considered as part of an individualized plan of care.<sup>24, 30</sup>
- b. Cryotherapy and heat therapy: Although the use of cryotherapy has been studied in this population for treatment during acute bleeding events, the use of cryotherapy has not been fully examined for chronic pain. The use of heat as a modality exists in many forms, for example therapeutic ultrasound, hot packs, and diathermy. As with many existing therapeutic modalities, research investigating the efficacy and safety of these modalities in PWBD with chronic pain is extremely limited.<sup>24, 30</sup>

Special Consideration: Due to lack of high-level evidence, using therapeutic modalities with PWBD should be considered carefully and monitored over time. Other modalities, such as dry needling, acupressure, cupping, blood flow restriction, and instrument assisted soft tissue mobilization have not been studied in the PWBD population and chronic pain, and therefore should be used with caution and in coordination with the hematology health care provider due to their mechanism of action and potentially increased risk for bleeding.

## **Manual Therapy**

Rationale: Manual therapy involves the mobilization of soft tissues through joint traction, muscle stretching, joint mobilization, and proprioceptive neuromuscular facilitation to improve mobility, functionality, and reduce pain. PWBD may present with altered limb alignment, contractures, loss of soft tissue and bony structure integrity, weakness, altered proprioception and kinesiophobia that result in chronic pain and impact HRQOL, functional mobility, and ADLs.

Manual therapy is utilized to address the soft tissue restrictions that result from recurrent bleeding events.

**10. PWBD experiencing chronic pain should be offered manual therapy interventions as part of an individualized treatment program.**

Practice implications: Manual therapy (grades 1 and 2 joint mobilizations) has been studied in PWBD. These investigations suggest that manual therapy is safe and did not cause bleeding events.<sup>20, 31-35</sup> It was shown to be effective in improving range of motion by mobilizing soft tissues, such as the joint capsule, muscle, and fascia.<sup>20, 31-35</sup> Further benefits in pain perception,<sup>20, 31, 32, 34, 35</sup> functional mobility,<sup>34</sup> proprioception,<sup>20</sup> muscle strength,<sup>20, 35</sup> QOL,<sup>20</sup> and perception of disease<sup>20</sup> can occur.<sup>20, 34, 35</sup>

Special Considerations: Due to potential risk of injury and bleeding complications, grade 4 mobilizations and grade 5 manipulations are not recommended.



**Recommended Physical Therapy Assessment Tools for the Evaluation of Chronic Pain (Table 1)**

ICF Categories	Assessment tools utilized in research		Additional assessment tools
Health condition	HJHS <sup>12, 24, 27-29, 31-34, 40 *</sup>		
Body Function and Structure	Postural assessment <sup>27</sup> HJHS <sup>24, 27-29, 31-34 *</sup> Timed up and go <sup>26, 29*</sup> 6 MWT <sup>24, 28 *</sup> Timed sit to stand <sup>23, 28</sup> GaitRite <sup>20, 24</sup> VAS <sup>12, 18, 19, 21, 22, 24, 26-28, 31-39</sup>	Strength <sup>20, 23, 24, 26, 28, 29, 35, 39, 41</sup> Goniometer (ROM) <sup>22, 29, 31-35, 39</sup> MCTSIB <sup>26</sup> Romberg <sup>24, 33</sup> Step test <sup>26</sup>	NPRRS <sup>53, 54</sup> 3MWT <sup>55, 56</sup>
Activity	BPI <sup>36</sup> SF-36 <sup>12</sup> A 36 Hem QoL <sup>18-20, 24</sup> HAL <sup>12*</sup> Functional independence score in hemophilia (FISH) <sup>12, 27*</sup>	FADI <sup>47</sup> ODI <sup>48</sup> NDI <sup>49</sup> HOOS <sup>50</sup> KOOS <sup>51</sup> PREE <sup>52</sup>	LEFS <sup>57</sup> PROMIS-29 <sup>44, 45</sup> UEFT <sup>58</sup> DASH <sup>46</sup>
Participation	BPI <sup>36*</sup> Tampa Scale of Kinesiophobia <sup>19, 28, 29</sup> SF-36 <sup>12</sup> A 36 Hem QoL <sup>18-20, 24*</sup>	Concept of Pain Inventory (COP) <sup>42</sup> PROMIS-29 <sup>44, 45</sup> DASH <sup>46</sup>	
Environmental - access to assessment	SF-36 <sup>12</sup> A 36 Hem QoL <sup>18-20, 24</sup>	PROMIS-29 <sup>44, 45</sup>	
Personal Factors	Tampa Scale of Kinesiophobia <sup>19, 28, 29*</sup> Patient Global Impression of Change (PGIC) <sup>29</sup> SF-36 <sup>12</sup> A 36 Hem QoL <sup>18-20, 24</sup>	COP1 <sup>42</sup> rNPQ <sup>43</sup>	

**\* Indicates recommended tool. Table 1 provides evidenced based assessment tools available for the clinician to utilize based on their clinical judgement. The recommended assessment tools represent a quick reference guide for each area of impairment.**

### Glossary of Terms

<b>Abbreviation</b>	<b>Assessment Name</b>
3 MWT	Three Minute Walk Test
36 Hem QoL	Hemophilia-Specific health-related quality of life questionnaire
6 MWT	Six Minute Walk Test
BPI	Brief Pain Inventory
COPI	Concept of Pain Inventory
DASH	Disabilities of the Arm, Shoulder, and Hand
DGI	Dynamic Gait Index
FADI	Foot and Ankle Disability Index
FISH	Functional Independence Score in Hemophilia
HAL	Hemophilia Activities List
HJHS	Hemophilia Joint Health Score
HOOS	Hip Disability and Osteoarthritis Score
KOOS	Knee Disability and Osteoarthritis Score
LEFS	Lower Extremity Functional Scale
MCTSIB	Modified Clinical Test of Sensory Interaction in Balance
MMT	Manual Muscle Testing
NDI	Neck Disability Index
NPRS	Numeric Pain Rating Scale
ODI	Oswestry Disability Index
PGIC	Patient Global Impression of Change
PREE	Patient-Rated Elbow Evaluation
PROMIS-29	Patient-Reported Outcome Measurement Information System 29 profile
rNPQ	Revised Neurophysiology of Pain Questionnaire
SF-36	36- Item Short Form Survey
TSK	Tampa Scale of Kinesiophobia
TUG	Timed Up and GO
UEFI	Upper Extremity Functional Scale
VAS	Visual Analog Scale

### Conclusion

More research is needed to specifically address pediatric chronic pain, the addition of complementary and alternative medicine in combination with physical therapy treatments, and the impact of chronic pain on all PWBD. These recommendations do not represent the extensive

skill set that physical therapists bring to the treatment of chronic pain but summarize the research that is currently published. Using available research and expert opinion, these recommendations will improve the function, QOL, and pain intensity of PWBD.

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