Documents for the American Society of Addiction Medicine (ASAM)
prepared by the Bleeding Disorders Substance Use and Mental Health Access Coalition
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Background on the Barrier to Addiction Treatment Faced by the Bleeding Disorders Community

Inherited bleeding disorders are lifelong, genetic conditions with no known cure. Recent medical advances and the development of effective medications have enabled patients with bleeding disorders to lead full and active lives. However, because of their bleeding disorder (BD) and the use of their life-changing medications, many individuals with BDs are being denied access to the addiction treatment they need.

In late 2021, a 20-year-old individual from New England with a BD requested that his hemophilia treatment center (HTC) assist him in finding a residential treatment facility for his significant substance use disorder. Although the HTC nurse called many local residential addiction treatment facilities, none of them would take a patient with a BD who required intravenous (IV) infusion medications during their stay. Without access to appropriate treatment, the patient overdosed and died.

Unfortunately, this tragedy is not unique to New England. In a recent national survey of HTC social workers, 72% of those that had attempted to secure placement for their BD patient at an addiction treatment facility or at a mental health facility failed. Other BD patients have also died as a result of their inability to access necessary addiction treatment.

The New England Hemophilia Association (NEHA) has partnered with the Hemophilia Federation of American (HFA), the National Hemophilia Foundation (NHF), HTC providers, and BD community members to establish the Bleeding Disorders Substance Use and Mental Health Access Coalition (the Coalition) to address this critical access issue for the bleeding disorders community. The mission of the Coalition is to advocate for access to appropriate substance use and mental health treatment facilities for all individuals with bleeding disorders.

In surveying the landscape, the Coalition found that BD patients generally have access to both acute, hospital-based, inpatient treatment programs (Level 4) and various outpatient programs (Level 2). Therefore, the focus of the Coalition is on securing access to residential addiction treatment facilities (Level 3). The Coalition recognizes that some states use the terms “inpatient” and “residential” interchangeably when describing longer, live-in treatment facilities that may not have medical staff or medical oversight. For these documents, the Coalition will use the term “residential” to describe Level 3 programs, so as not to confuse them with Level 4 acute, hospital-based detoxification programs.

Assessing the Stability of a Bleeding Disorder Patient

The American Society of Addiction Medicine (ASAM) requested that the Coalition provide a definition of “stability” in the context of hemophilia and other bleeding disorders. The goal was that ASAM could provide addiction treatment facilities with an independent standard to determine whether BD patients are healthy enough for admission to residential facilities that do not have medical staff or oversight available. However, after consulting with providers from HTC’s–federally funded treatment centers with specific expertise in bleeding disorders–from across the country, the Coalition declined to develop a specific standard for stability.

Assigning a concrete definition to the word “stable” in a person with a bleeding disorder can be challenging considering that the concept of stability can be fluctuating and unpredictable for anyone. Merriam-Webster defines “stable” as firmly established, not changing, and steady in purpose. This is not a one size fits all concept, therefore we decided to focus on assessing a person’s baseline level of functioning (i.e., maintaining activities of daily living), which is typically easier to measure.

Unlike diabetes and hypertension, in which the stability of the patient can be assessed by reviewing glucose or A1C levels, or blood pressure readings, bleeding disorders do not have specific labs that can be used as markers of stability. Instead, the Coalition proposes to ASAM that they provide residential facilities with specific assessment questions that could be asked to a prospective patient’s hematologist to assess whether the patient is appropriate for admission to a facility that does not have medical staff or provide medical oversight. If the residential facility requires further assurances of the appropriateness of the placement from a BD perspective, we encourage the facility to contact the patient’s hematologist, who can share additional details regarding the patient’s condition. The Coalition has drafted a sample letter that a hematologist could share with an addiction treatment facility to provide assurance that the patient is appropriate for admission to a residential facility.

Assessment Questions that an Addiction Treatment Facility Could Use to Assess the Appropriateness of Prospective Patients with Bleeding Disorders for Admission

1. Does the patient have any active bleeds or other bleeding-related issues that require medical supervision while at the facility? YES NO

   If yes, please describe.

2. Are there any bleeding disorder-related activity restrictions for this patient at the treatment facility? YES NO

   If yes, please explain.

3. Does the patient self-administer their bleeding disorders medication? YES NO

   If no, please describe how the patient will receive medication while at the treatment facility.

4. Does the patient have a current treatment plan and access to medication?

   YES NO

Draft Letter from the HTC to the Addiction Treatment Facility Regarding the Stability of a Bleeding Disorder Patient

Patient Name: [*insert patient name*]

This patient has [*insert diagnosis*]

Maintained on [*insert medication*]

Inherited bleeding disorders are lifelong genetic conditions with no known cure. Recent medical advances and the development of medications to treat bleeding disorders have allowed providers to make strides in the care of patients. These medications can be used prophylactically to prevent bleeding or to treat bleeding. We believe that the current medications that [*insert patient name*] is taking, significantly decreases their risk of spontaneous bleeding and bleeding related to routine activities of daily living.

There are no restrictions for activities except participation in activities that could result in significant physical injury (ex: football, wrestling, hockey, contact martial arts, etc.)

The patient does not require any medical supervision at your facility but may need to self-administer their bleeding disorder medication while there. This medication is routinely self-administered either subcutaneously or intravenously. [*insert patient name*] is fully competent to self-administer their medication.

[ ] With access to medication in the stable environment that your facility provides, we are confident that the patient's bleeding disorder will be sufficiently controlled for admission to [i*nsert facility name*]. We are available and will assist with the patient's bleeding disorder management plan while they receive treatment at [*insert facility name*].

Thank you for your time and collaboration,

Signature of Provider

Date

Clinic/Day Phone

Emergency/ On Call Phone

Bleeding Disorder Basics for Residential Addiction Treatment Facility Staff

About Bleeding Disorders:

Bleeding disorders are life-long, genetic conditions that make it harder for a person's blood to clot. Bleeding can occur under the skin, and into muscles, joints, or elsewhere. People with bleeding disorders work with their medical teams and are trained to recognize the early signs of bleeding, which are often not visible. It is important to listen when someone with a bleeding disorder says that they are having a bleed - whether or not you see any visible signs of a problem.

Medications:

Many people with bleeding disorders take medicine intravenously or by injection to prevent bleeding, or to control acute bleeding that may occur despite preventive treatment. Treating with these medications requires the use of needles or some other form of intravenous access, such as a peripherally inserted central venous catheter (PICC line). Some individuals with milder bleeding disorders may use oral medication (such as aminocaproic acid (Amicar) or tranexamic acid (Lysteda)) or nasal sprays for treatment of bleeding episodes. Lysteda, in particular, is frequently used to treat heavy menstrual bleeding. In most situations, the individual with a bleeding disorder is able to self-administer their medication. Most medications for bleeding disorders cannot be dispensed by a retail pharmacy and require the use of a specialty pharmacy. Most patients have pre-existing relationships with specialty pharmacies that can provide access to their bleeding disorder medications.

Internal bleeding causes pain. Clotting medication is not a pain reliever but is taken to stop the bleeding and allow the blood to clot. Treating bleeds early avoids complications and long-term disability and gets people back to their regular activities. People with bleeding disorders do not require laboratory work on a consistent basis.

Manufacturers typically recommend storing products in the refrigerator, although many are stable at room temperature for a limited time. Products should never be frozen. Medications requiring refrigeration should be kept in a refrigerator in the same area where other medications are stored. Do not let a refrigerated product come to room temperature and then refrigerate it again.

Key Points to Remember:

1. **Most bleeds are not emergencies:** Most accidents, even without visible injury, should be addressed with first aid, rest and ice. Consult the patient's emergency plan and call the hematology team if you need help.
2. **You have time to figure it out:** People with bleeding disorders do not bleed faster than others, just longer. You have time to check the treatment plan, or call the hematology team, if necessary.
3. **Trust the patient's self-assessment:** When a person says that they are in pain or have a bleed, trust them. People with bleeding disorders are experts in their condition. Ask the individual if they need to get a dose of their medication.
4. **Use acetaminophen to treat pain.** Never give someone with a bleeding disorder aspirin, ibuprofen, or naproxen (Advil, Aleve, Motrin). These medications make the bleeding worse. Only use acetaminophen (Tempra, Tylenol). When acetaminophen is inadequate, the selective COX-2 inhibitor celecoxib (Celebrex) may be another option for pain control, provided that it is prescribed for the patient by a healthcare provider.

5. **Emergencies:** Some bleeds require prompt, emergency care; emergency treatment recommendations may be sent with a patient to the treatment facility. Call the patient's hematology team and 911 immediately, if the person injures their:
    - Head
    - Throat
    - Abdomen
    - Eyes

Draft Policies and Procedures Document

Storage of bleeding disorder medication and needles,

1. Storage of bleeding disorder medications:
   a) Medication should be temperature controlled based on the product's specific requirements. Follow the instructions on the product label. Some products may need to be refrigerated; other products may be able to be stored at room temperature.
2. Container for safe and secure storage of injectable/intravenous medications, needles, and supplies:
   a) Facilities shall provide containers for safe storage of injectable or intravenous medications, needles, and supplies and proper disposal of sharps.
   b) All drugs, biologicals, needles and supplies shall be stored in locked rooms or compartments, separate from food and laboratory specimens, and under proper temperature control in accordance with United States Pharmacopeia standards.

Policies regarding infusions/ injections

1. Provide a private space for infusions/injections: Infusion/injectable medications may not be provided to any resident if other residents are in the storage or office area used for infusions/injections.
2. Provide a clean space for infusions/injections: Facilities must provide residents with a clean and well-lighted workspace (tabletop) area for the infusion/injection.
3. Self-administration of infusion/injection medications: An individual may self-administer infusion or injectable medications with the written permission of the patient's hematologist.
4. Infusions/injections by qualified health care professionals: Qualified health care professionals employed by the licensee or provided by a visiting nurse may administer bleeding disorder products to residents who are unable to administer their own medication.
5. Infusions/injections for children under 18 residing with their parent or guardian: For children under 18 residing with their parents, medication may be administered by the child's parent or guardian.
6. Observed infusions/injections: Staff shall observe the resident infusing/injecting the prescribed dose to ensure that the infusion/injection is consistent with the resident's recovery.

Sharps Disposal

1. Discarded sharps shall be placed directly into leak resistant, rigid, puncture resistant containers, without clipping or breaking.
2. Containers shall be taped closed or tightly lidded to preclude loss or leakage of contents and stored in a locked compartment.

Addendum to emergency plan regarding bleeds

1. The emergency care plan for a person with a bleeding disorder shall include:
   a) Patient's diagnosis
   b) Patient's baseline factor level
   c) Name of the patient's bleeding disorder medication(s)
   d) Patient's weight
   e) Emergency contact information for the patient's hematologist
   f) The patient's hematologist's recommendations for medication and dosing in the event of:

i) Minor Injuries/Bleeding
ii) Major Injuries/Bleeding
iii) Prolonged nose or mouth bleeding
iv) Head injury

g) A warning that the use of aspirin and ibuprofen or other NSAIDs is contraindicated due to their anti-platelet effects.
h) Per the patient's hematologist' recommendation, other relevant advisory statements regarding patient's care in the event of an injury such as:
   i) [*In the event of soft tissue trauma, muscle bleeding, or major injury, intravenous infusion of Recombinant Factor VIII (rFVIII) will be required IMMEDIATELY.]*
   ii) *[If significant injury or internal bleeding is suspected, any required diagnostic imaging should be obtained AFTER the bleeding disorder medication is given.]*
   iii) *[The patient currently receives prophylactic intravenous infusions [insert schedule] to prevent bleeding. Additional doses will be required to treat significant injury or bleeding.]*
   iv) *[The patient is trained to self-administer bleeding disorder medication.]*

About The Bleeding Disorders Substance Use and Mental Health Access Coalition (The Coalition)

Mission Statement: The mission of the coalition is to advocate for access to appropriate substance use and mental health treatment facilities for all individuals with bleeding disorders.

Coalition Members:

- Kate Bazinsky: Board Member, New England Hemophilia Association (NEHA); Chair, Bleeding Disorders Substance Use and Mental Health Access Coalition
- Jacqueline Bottacari: Licensed Clinical Social Worker, Yale Hemophilia Treatment Center
- Marla Feinstein: Senior Policy and Healthcare Analyst, National Hemophilia Foundation
- Jen Feldman: Nurse Coordinator, University of Massachusetts Memorial Hemophilia Treatment Center
- Miriam Goldstein: Director of Policy, Hemophilia Federation of America
- Mark Hobraczk: Senior Manager for Policy, Hemophilia Federation of America
- Ziva Mann: Massachusetts State Lead, the New England Bleeding Disorders Advocacy Coalition; Board Member, National Hemophilia Foundation
- Nick McRae: Board Member of Hemophilia Alliance of Maine, Maine State Lead with the New England Bleeding Disorders Advocacy Coalition
- Ann Marie Minichiello: Massachusetts State Lead, New England Bleeding Disorders Advocacy Coalition
- Lucy Ramirez: Social Worker, Rush University Medical Center Hemophilia Treatment Center
- Gillian Schultz: Director of Programs, Bleeding Disorders Foundation of North Carolina
- Joanne Fadale Wagner: Social Work Care Manager, Dartmouth Health Hemophilia Treatment Center
- Joe Zamboni: Advocacy Coordinator, New England Bleeding Disorders Advocacy Coalition