



# The Annenberg Academy for Team-Based Care

## Interprofessional Care of Patients with Hemophilia

### MANAGING PATIENTS WITH HEMOPHILIA: KEY CONCEPTS

The management of patients with hemophilia continues to involve with the introduction of several classes of medications for acute and prophylactic treatment of patients with hemophilia A or B and with or without inhibitors. Beyond clotting factor concentrates and improved recombinant factor, new classes of medications include factor VIII mimetics, rebalancing agents, and gene therapies. Key concepts to keep in mind when managing patients with hemophilia are:

- The Medical and Scientific Advisory Council and World Federation of Hemophilia recommend that prophylaxis should be:<sup>1</sup>
  - Initiated at an early age, ideally before age 3 years and prior to the second joint bleed.
  - Individualized and sufficient to prevent all bleeds at all times.
- The treatment of patients with hemophilia is a balancing act comprised of safety, efficacy, and patient adherence to treatment, requiring support of the interprofessional care team.<sup>1,2</sup>
- The optimal therapy may vary among individuals with hemophilia, thus shared decision making is essential to understand the patient's values, goals, and concerns.<sup>2</sup>
- Beyond clotting factor concentrates, several classes of novel therapies are available to treat persons with hemophilia.
  - All are very effective in reducing bleeding compared to clotting factor concentrates.
  - Key characteristics include:
    - Factor VIII mimetics (emicizumab and Mim8\*)<sup>3-8</sup>
      - Administered subcutaneously.
      - Thrombotic complications: emicizumab (infrequent), Mim8 (none reported).
    - Rebalancing agents (concizumab, fitusiran, marstacimab)<sup>9-15</sup>
      - Administered subcutaneously.
      - Thrombotic complications: concizumab (infrequent), fitusiran (low incidence), marstacimab (none reported).
    - Gene therapies (etranacogene dezaparvovec, fidanacogene elaparvovec, valoctocogene roxaparvovec)<sup>16-21</sup>
      - Phenotypic improvement in bleeding rate.

\*Not approved by the US Food and Drug Administration for hemophilia

### INTERPROFESSIONAL COLLABORATION PRINCIPLES

For the evolution in treatment to be of optimal benefit to patients, comprehensive strategies for choosing, delivering, monitoring, and modifying therapy have become especially important. As a consequence, care is typically provided by an interprofessional, multidisciplinary care team that extends beyond physicians to include nurses, nurse practitioners, pharmacists, physician associates, social workers, and others, often involving collaboration between providers in community and academic settings.

To that end, the following reflects a conversation among 3 healthcare professionals about interprofessional care and how collaborative practices and teams can strengthen our health systems.

**Christopher Flores, MD:** In medical school, I was taught that the patient-doctor relationship was the most critical and important dynamic in healthcare. But after 30-plus years in clinical care, I can attest that healthcare is a team sport and we deliver care in teams of individuals with different training, different skills, different talents. And we teach each other, we learn from each other, we brainstorm and solve problems to meet the needs of the patient.

I want to make a point that interprofessional refers to clinicians in different professions, such as nurses, nurse practitioners, pharmacists, physicians, and physician associates. Multidisciplinary refers to clinicians in different specialties or sub-specialties, such as cardiology, dermatology, and oncology. LaTosha, do you want to talk about interprofessional collaboration?

**LaTosha Mollette, DNP:** The World Health Organization defines interprofessional collaboration as when multiple healthcare workers from various backgrounds work together with patients, families, and communities to provide the best healthcare possible.<sup>22</sup> This is exactly what teamwork should look like, but it is important to remember that healthcare teams can vary from patient to patient.

I work in a rural setting, working together with various healthcare professionals to improve access to needed healthcare services, which helps to prevent unnecessary delays in care and treatment. Ultimately, working together as a team helps to meet the needs of others to improve health outcomes, patient care, and safety.



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**Christopher Flores, MD:** I think all of us in healthcare are trying to figure out how to do things better, make life easier for ourselves, and make everybody happier, patients, our staff, and ourselves, to make things more sustainable. Interprofessional collaboration can accomplish this. There's a growing body of literature that shows that interprofessional collaboration can improve patient outcomes, acceptance of treatment, and satisfaction.<sup>23-26</sup> It can decrease costs, improve efficiency, reduce disparities, improve health equity, and make things more sustainable for providers.<sup>23,27-34</sup>

The Interprofessional Education Collaborative has identified 4 behavioral competencies for effective interprofessional collaboration: 1) roles and responsibilities; 2) values and ethics; 3) communication; and 4) teams and teamwork.<sup>35</sup> Michael, do you want to talk a little bit about the roles and responsibilities?

**Michael Smith, PharmD:** Certainly, it's one of these things that we don't often think about, but it's important for 2 reasons. One, understanding our own responsibility and roles that we have within our team and what our teammates can expect from us in terms of what we can deliver to them and deliver to patients.<sup>35</sup> The other is understanding what your team can do for you as well, so that you understand their educational background and you can help them practice at the top of their license by utilizing their skillset to the fullest extent.

It is increasingly common for clinicians, even those within a profession, to take different educational and practice paths leading to clinical practice. As an example, there are various differences in training a pharmacist. Nowadays, all pharmacists graduate with a Doctor of Pharmacy degree (PharmD), but some of us have done 1 or 2 years of residency training or postdoc fellowships. So, getting to know your teammates and what you can expect from them and what they can expect from you can really help your team function at a high level.

**Christopher Flores, MD:** We talk about values and ethics as well.<sup>35</sup> In medicine, we're constantly required to make very difficult and complicated treatment decisions for our patients. We really are missing a great opportunity if we don't involve the opinions of all the members of our team. What does the nurse think about this plan or what does the social worker who has talked to the family members think about this plan? Or what does the physical therapist think, who has

been working with the patient for the last 3 days? LaTosha, what do you think about communication?

**LaTosha Mollette, DNP:** Communication is essential in everything we do, and it's how we're able to effectively achieve goals, as well as improve relationships and interactions with others.<sup>35</sup> The healthcare system is often described as being fragmented with little communication and collaboration, but when healthcare professionals communicate responsibly and respectfully, this allows them to overcome differences and work together to accomplish a shared goal, including learning from each other, to better improve patient outcomes and safety.<sup>28,36-38</sup>

**Christopher Flores, MD:** We're talking a lot about teams and teamwork. Michael, do you have any other points you want to make about teamwork?

**Michael Smith, PharmD:** Most of us are members of various teams during the course of a typical day. Think about the team members that you work with to take care of patients, but also think about a team from a networking standpoint. Do you have a network of like colleagues? As an example, other pharmacists in our healthcare system may reach out to me for advice about a patient with pain, whether or not I'm actually seeing the patient. We can make our team small, we can make them big, but we should be making our teams in ways that everybody's functioning at a high level and putting the patient at the center of the team.

**Christopher Flores, MD:** Michael, LaTosha talked about the fragmented healthcare system and how interprofessional collaboration can help with that. Do you have any examples from your experience?

**Michael Smith, PharmD:** Think about the patient's experience through our healthcare system. Even if a patient receives all of their healthcare within 1 system, they often have to travel to many different places just to access care. From a primary care clinic to a hospital, to a specialty clinic, to a pharmacy. We can fill these gaps by using our interprofessional framework, our education, and allowing our collaborative practice teammates to step in and fill that.

**Christopher Flores, MD:** In conclusion, I just want to summarize that medicine is a team sport and that there is a growing body of evidence that supports the various benefits of interprofessional collaboration. LaTosha, Michael, do you have any final thoughts?



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**LaTosha Mollette, DNP:** I think just being willing to change is crucial. I think sometimes we have become complacent in clinical practice, but our healthcare system is ever evolving. So, learning how to be a team player always benefits everyone involved.

**Michael Smith, PharmD:** I've learned a great deal from my interprofessional colleagues, and I hope that I've helped them learn as well, with the ultimate goal of really improving patient care.

### INTERPROFESSIONAL CARE OF PATIENTS WITH HEMOPHILIA

Advances in the treatment of persons with hemophilia have extended the life expectancy from less than 20 years in the 1960s to a near-normal lifespan of a person without hemophilia today.<sup>39</sup> For the survival and other benefits resulting from advances in treatment to be realized, changes in the healthcare delivery system were needed. Over the past 4 decades, hemophilia treatment centers (HTCs) have emerged to provide the physical, psychosocial, and emotional support needed by persons with hemophilia, as well as other congenital coagulation disorders.<sup>40</sup> To optimize patient outcomes, HTCs provide care based on a team-based, interprofessional, multidisciplinary, shared decision-making model.

Widespread adoption of this care model was recommended more than a decade ago by the National Hemophilia Foundation in collaboration with McMaster University.<sup>41</sup> The provision of comprehensive care through this core team also become a requirement for classification as a federally qualified hemophilia treatment center.<sup>42</sup>

Composition of the interprofessional, multidisciplinary hemophilia care team has often been described somewhat differently; a hematologist, specialized hemophilia nurse, physical therapist, and social worker are at the core.<sup>40</sup> As the complexities of care have expanded, physicians in other specialties, as well as other healthcare professionals such as dietitian, genetic counselor, and pharmacist, are often considered part of the interprofessional care team.<sup>40</sup> Nonetheless, survey data demonstrate that patients with hemophilia highly value care provided by an interprofessional, multidisciplinary care team.<sup>43,44</sup> A nationally uniform survey of patients who obtained care from 133 of 138 US HTCs in 2014 showed high levels (>90%) of patient satisfaction with how the core interprofessional team work together.<sup>43</sup>

A systematic review of 27 non-randomized studies was undertaken to assess the effects of the integrated care model on persons with hemophilia.<sup>45</sup> Although the quality of evidence was generally low, the integrated care model, in comparison to other models of care, was found to reduce mortality, hospitalizations, and emergency department visits. An association was also found for fewer missed days of school and work and increased knowledge seeking among patients.

Despite the benefits of the integrated model of care provided by an interprofessional, multidisciplinary team, opportunities for improvement among the team have been identified. A recent international panel of healthcare professionals, patients, and caregivers of patients with hemophilia strongly emphasized the need to improve interprofessional collaboration among healthcare professionals working in different organizations and with different backgrounds.

Social workers, for example, appear to be underutilized as demonstrated by an online survey of clinicians at HTCs conducted by the National Hemophilia Foundation (NHF) (now National Bleeding Disorders Foundation).<sup>46</sup> While hemophilia clinicians value the role played by social workers, they identified time, limited resources, and confusion about the role of the social worker as barriers to utilizing social worker services. Many of these same issues were identified by a survey of social workers at US HTCs.<sup>47</sup> Specifically, social workers identified that they spent the majority of their time on case management, with limited involvement in providing counseling and psychosocial support to patients and caregivers. Barriers included lack of social worker input, insufficient budgeted time, and inadequate training. These findings suggest that education about the roles and responsibilities of the interprofessional hemophilia care team, including social workers, as identified by the Interprofessional Education Collaborative, is needed.<sup>35</sup>

Among persons with hemophilia, the care provided to adolescents needs improvement. A working group of the Factor Think Tank recently considered specific issues relating to the management of adolescents with hemophilia, recognizing that there are unique challenges faced by this group of patients with hemophilia.<sup>48</sup> Among other recommendations, the group affirmed the importance of care provided by an interprofessional, multidisciplinary care team. Communication between the care team and patient were deemed to be especially important to better help



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adolescents develop self-management skills as they navigate the transitions of care into adulthood. While digital means for communicating with adolescents with hemophilia were felt to be preferred, face-to-face meetings should be offered as a complement since digital communication can contribute to feelings of loneliness and isolation.

The interprofessional, multidisciplinary care team, including the patient with hemophilia, has been and continues to be at the center of the evolution in patient management.

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