NATIONAL HEMOPHILIA PROGRAM
COORDINATING CENTER

NHPCC CASE STUDY

Transition of Care for Hemophilia Patients:

A National Hemophilia Program Coordinating Center Quality Improvement Case Study.

Introduction

Hemophilia is a bleeding disorder that prevents the blood from clotting normally. It affects approximately 20,000 people in the United States and impacts all ages, races, and socioeconomic groups. Left untreated, hemophilia can lead to chronic joint disease, pain, and other important bleeding-related negative outcomes.[1] However, when patients and families understand the disease and receive care from the integrated, multidisciplinary comprehensive care teams at hemophilia treatment centers (HTCs), they can successfully manage this chronic condition.

In 2012, the National Hemophilia Program Coordinating Center[2] (NHPCC) was established to identify gaps in services, standardize and improve access to care, and share best practices within the U.S. HTC network to improve care for people living with hemophilia. The NHPCC is a Health Resources and Services Administration (HRSA)-funded project awarded to and administered by the American Thrombosis and Hemostasis Network (ATHN). As one of the NHPCC priorities, HRSA has identified the need for quality improvement (QI) in the transition from pediatric to adult care.

This case study outlines the important work that one HTC, Western New York BloodCare (formerly Hemophilia Center of Western New York) conducted to meaningfully engage patients and families in their efforts to improve the transition from pediatric to adult care as part of the NHPCC's QI pilot program. By focusing on patient and family engagement and including these important perspectives in their work, Western New York BloodCare has built a model that may inform future practice.

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[1] https://www.cdc.gov/ncbddd/hemophilia/facts.html

[2] The NHPCC project is funded through the Health Resources and Services Administration grant #UC8MC24079.

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Background

Western New York BloodCare provides care to individuals with hemophilia and other genetic bleeding disorders in a comprehensive care setting. Since its inception in 1969, Western New York BloodCare has evolved to provide state-of-the art care to patients in eight counties in western New York. It is a separate, not-for-profit, New York state-licensed diagnostic and treatment center offering a variety of specialized diagnostic and health maintenance services for persons with bleeding disorders that require lifelong medical management. Through its clinical services, advocacy, education, and research initiatives, the center's mission is to improve the quality of life for those affected by hemophilia and other genetic bleeding disorders. The center staff strives to create an atmosphere in which families can learn from and support each other, easing the burden of living with a chronic bleeding disorder.

The NHPCC partners with over 135 ATHN-affiliated HTCs like Western New York BloodCare, working with the U.S. Hemophilia Treatment Center Network (USHTCN) across the country. Its work involves aligning strategic efforts within the network to increase the national capacity to deliver a continuum of high-quality, evidence-based, and culturally sensitive services and support. As a federally supported HTC within the New England regional network, Western New York BloodCare has been a successful participant in the NHPCC's efforts to build QI capacity.

NHPCC Quality Improvement Program

In August 2015, the NHPCC launched a national quality improvement program to embed the principles of QI within HTCs. Participating HTCs were strongly encouraged to include parents and families in their QI work. Through their participation, Western New York BloodCare wanted to improve their patients' process of transitioning from pediatric to adult care. This process began with an assessment of the patient's readiness for transition and ended with the patient being fully integrated to adult care and functioning independently. By working on this process, Western New York BloodCare sought to improve patient and staff satisfaction with the transition experience and to empower patients to take control of their health.

An Element of Success: Engaging a Consumer Advisory Committee

Thanks to a strong interdisciplinary team and leadership support for their work, Western New York BloodCare quickly became a leader among the participating HTCs in the QI program, and succeeded in building local expertise in QI methodology. This work helped them to understand the impact that patient and family feedback had on their ability to improve the care offered at the center, and the important role that these experts could play in the improvement of care. Western New York BloodCare also benefitted from having a well-established Consumer Advisory Committee, which predated the QI program. As the QI team assessed the impact of this committee, they identified it as an under-utilized resource with low patient participation. To address this issue, the QI team created a series of tests to understand how they could improve patient and family participation and the overall outcomes associated with the committee. Based on their findings, they moved the location of meetings to an on-site meeting room, developed meeting agendas that allowed time to ask specific questions of the participants, and built in time at the end of each meeting for open feedback from participants.

As a result of these seemingly simple changes, patients began participating routinely and involvement began to grow. The QI team received valuable feedback and creative ideas that they were able to use to improve both processes and outcomes for patients for the QI program and in general.

A Case Study in Family Involvement

Building off the success of their reinvigorated Consumer Advisory Committee, Western New York BloodCare invited two individuals to join the QI team: one patient and one family member. The patient representative was not able to continue with the work, but Mary, the family member, remained with the team throughout the project and continues to be an active team member.

Mary is a mother of children with bleeding disorders and she was excited to share with the QI committee her family's experience with hemophilia and her own experience as a caregiver. Mary was involved in ongoing discussions about improving patient care and processes, particularly the process of transitioning a pediatric patient into adult care. This transition is a critical time for young adults with bleeding disorders who are assuming greater personal responsibility for their care.

Mary's children are now 27, 25, 23, and 19 and have completed the transition process. She has been able to provide the QI team with practical feedback about what worked and did not work for her children, what transition is like for parents, and how her adult children are now managing their hemophilia. Having Mary's practical experience as a part of the QI team has resulted in the creation of a more patient-centered experience for those who attend Western New York BloodCare.

Conclusion

As a result of participating in the NHPCC's QI program, Western New York BloodCare was able to systematically test and improve its process of engaging patients and families in the design and provision of care, particularly in the transition from pediatric to adult care. By re-energizing their Consumer Advisory Committee and including a parent representative in their quality improvement team, Western New York BloodCare provides a successful example of how to meaningfully improve the quality of care, including the important process of transitioning from pediatric to adult care.

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