



NATIONAL HEMOPHILIA PROGRAM COORDINATING CENTER

Hemophilia Treatment Center Services Provided

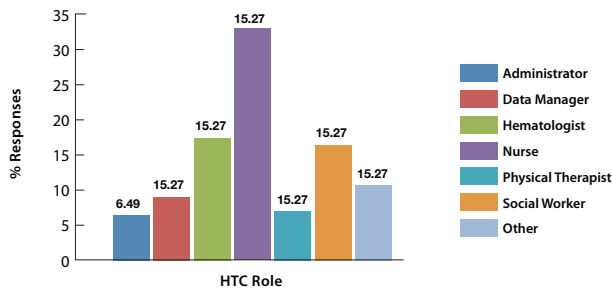
The national hemophilia treatment center network (HTCs) provides comprehensive multidisciplinary services to over 30,000 persons with inherited bleeding disorders. In 2012, the Health Resources and Services Administration (HRSA) funded the American Thrombosis and Hemostasis Network to establish a National Hemophilia Program Coordinating Center (NHPCC) to collaborate with the eight regional HRSA regions to develop a more cohesive national network.

As an initial step, the NHPCC performed an evaluation of the resource needs of the staff to improve quality of care, access to care and availability of services to persons with bleeding disorders. The NHPCC contracted with the South Carolina Rural Health Research Center to conduct a survey of staff at the HTCs. The survey asked the respondent's primary role at the HTC and what services are offered at the HTC. HTC staff from 140 treatment centers (97.90% HTC response rate) completed a total of 524 surveys.

Key Findings

Center Staff (Figure 1)

PRIMARY HTC ROLE OR POSITION (N=524)

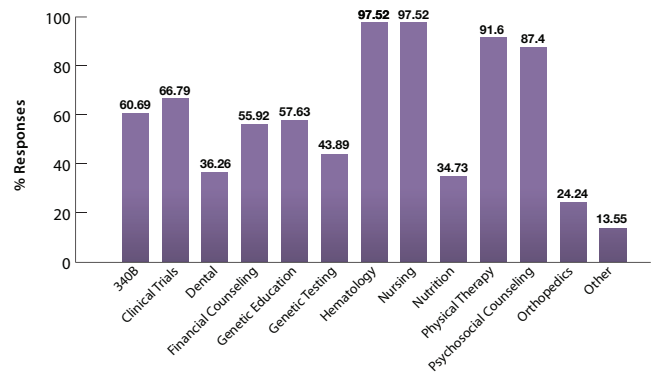


- The primary HTC role or position of the respondents was examined to understand the context of their work in caring for patients with hemophilia and blood disorders.
- Nurses including RNs, LPNs and NPs (n=173; 33.02%), hematologists (n=91; 17.37%) and social workers (n=86; 16.41%) were the top three survey respondents. The distribution was similar across regions except for the Great Plains, which had data managers (19.30%) represented as the third most common role or position.

Services Offered

- Services were offered by core team members, including hematologists, nurses, physical therapists and social workers; and supportive team members, including orthopedists, mental health professionals, dentists, nutritionists and genetic counselors.
- Nursing (n=511) and hematology (n=506) were the most common services offered during comprehensive care clinic. Other core comprehensive care services such as physical therapy (n=480) and psychosocial counseling (n=458) were reported by most, but not all respondents. Referral to clinical trials (n=350) were reported by two thirds of the respondents.
- Survey respondents were also asked to provide information about treatment specialties or services provided at their parent institution. The most common services reported were coagulation lab (n=319; 66.88%), physical therapy (n=317; 60.50%), and orthopedics and psychosocial counseling (n=313; 59.73% each).

SERVICES OFFERED AT COMPREHENSIVE CARE CLINICS (N=524)



About the NHPCC

In June 2012, the Maternal and Child Health Bureau (MCHB) in the Health Resources and Services Administration (HRSA) funded the American Thrombosis and Hemostasis Network (ATHN) to establish the first National Hemophilia Program Coordinating Center. The NHPCC serves as a bridge between the regional hemophilia treatment center networks, helping to create value on a national scale. The NHPCC is partnering with regional leadership, over 130 ATHN Affiliate HTCs, NHF, HFA and other patient advocacy groups, government partners, 340B pharmacy programs, the genetics and newborn screening collaborative, payers and thought leaders to guarantee a community-wide perspective.



To learn more about the NHPCC, visit www.athn.org.