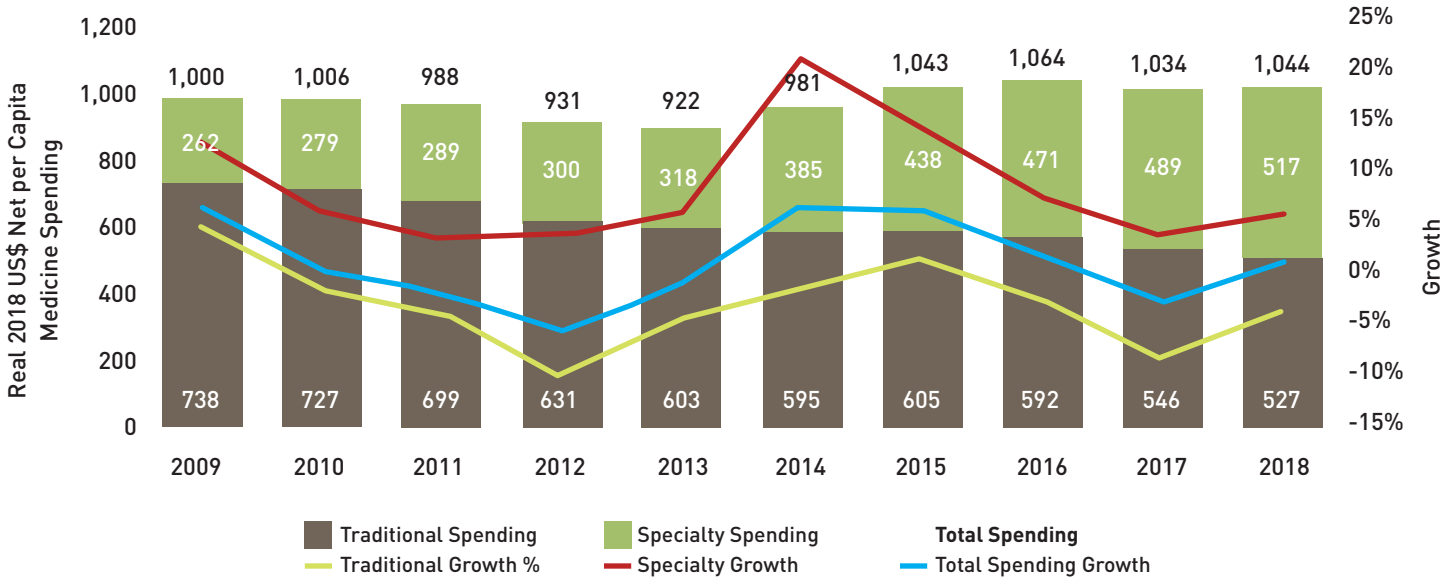
CCSC
Comprehensive Care Sustainability Collaborative
NATIONAL HEMOPHILIA FOUNDATION

Managing Costs and Outcomes among Beneficiaries with Rare, High-Cost Diseases: The Employer Vantage Point on Hemophilia and Other Bleeding Disorders

In 2018, specialty drug spending grew →5% for the second consecutive year, doubling that of traditional pharmaceuticals. Although these medications only accounted for 2.2% of total prescription volume, they accounted for 49.5% of net spending in 2018, up from 26.2% in 2009. These trends are expected to continue into the foreseeable future, driven partly by innovation and increased utilization among high-cost, chronic diseases.[1] In an effort to best mitigate risk, purchasers of healthcare have begun focusing their drug management strategies on the specialty drug sector.

Patients who develop an inhibitory antibody to clotting factor replacement (known as an inhibitor) average $722,000 in specialty drug claim costs, often easily surpassing the $1M mark in annual claims.[8]

2018 US Net per Capita Medicines Spending and Growth by Drug Type.[1]



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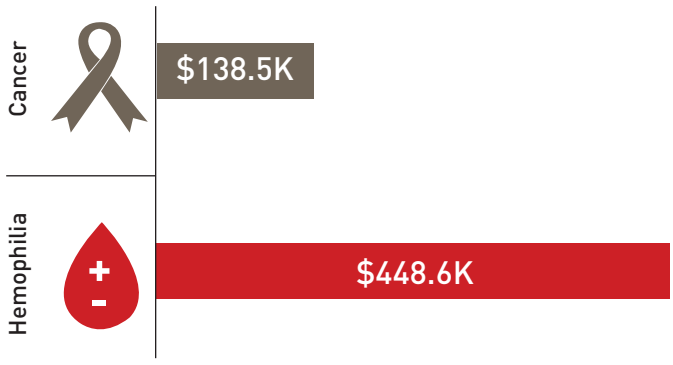
In 2000, the World Health Organization (WHO) recommended that countries move from passive purchasing to strategic purchasing. Passive purchasing implies following a predetermined budget or simply paying bills when presented. In contrast, strategic purchasing involves a continuous search for the best ways to maximize health system performance.[2] In 2001 the US Institute of Medicine called on purchasers to use their market power to promote quality and better outcomes.[3] Self-Funded employer purchasers are in a unique position, to collaborate with providers to identify value based contracting opportunities. Employer benefit managers are charged with being stewards of health care dollars for both the beneficiaries and their company's healthcare spending. As part of this increased involvement, employers, employer coalitions, and individual benefit managers are exacting increased focus on overall specialty drug classes and specific high-cost, chronic conditions.

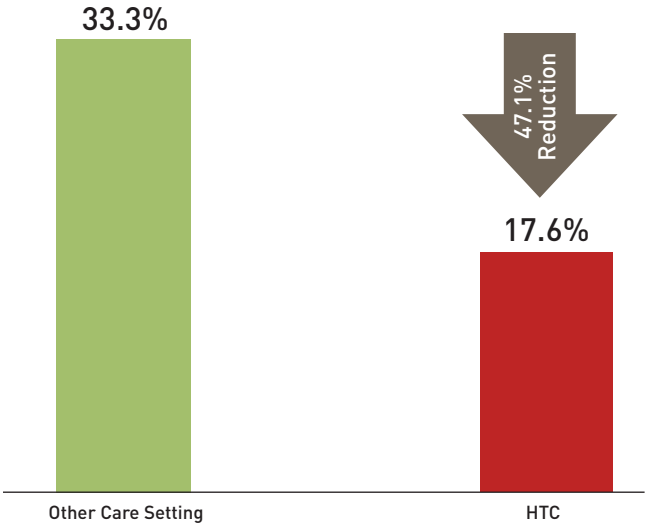
Although hemophilia only affects approximately 20,000 Americans, it ranks amongst the highest cost claimants. The disease necessitates a lifetime of intensive disease management and care intervention strategies, best delivered by an expert interdisciplinary team that sub-specializes in rare bleeding and clotting disorders to achieve optimal outcomes at the lowest total cost of care.[4,5] The average annual cost of hemophilia is $250,000, approximately 90% of which is attributed to the specialty drug treatment costs.[6,7,8] These costs vary greatly depending on disease severity, treatment strategy, clinical complications, and comorbidities. Patients who develop an inhibitory antibody to clotting factor replacement (known as an inhibitor) average $722,000 in specialty drug claim costs, often easily surpassing the $1M mark in annual claims.[8] Overall, clotting factor costs for children and adults with inhibitors are 3x to 6x higher than among those without inhibitors. Similarly, comorbidities can result in increased expenditures, such as 1.4x higher clotting factor costs observed among adults with HIV or HCV than among those without infection.[7,8] And while hemophilia consistently ranks among the top-10 high-cost claims conditions in the US, health care purchasers have very limited knowledge and experience with hemophilia or any bleeding disorders in general.[9] By comparison, cancer is the #1 high-cost claim condition based on frequency and cost of cancer claims; however, the average treatment cost for hemophilia is →3x higher than the average cost to manager cancer, despite affecting a significantly smaller proportion of beneficiaries.[9]

Average Annual per Patient Claims Cost Comparison: Cancer vs. Hemophilia[9]

Considering that hemophilia is a rare disorder requiring expert hematologic and multidisciplinary services, a network of hemophilia treatment centers (HTCs) were formed →40 years ago as federally designated centers of excellence. HTCs deliver integrated, multidisciplinary care and ancillary services necessary for delivering optimal outcomes. The HTC model of care represents family-centered, comprehensive management delivered by an integrated on-site multidisciplinary team that is dedicated and knowledgeable in bleeding disorders. In addition to clinical acumen, the HTC care team understands how best to interact with the patient and their family to impact behavior and ultimately achieve optimal outcomes. Care delivered in an HTC setting has been cited in published literature as resulting in ↗40% reductions in mortality, hospitalization, and emergency department (ED) utilization.[4,5,10] In addition to improved outcomes, HTCs are often able provide clotting factor concentrate and related specialty drug products at reduce pricing negotiated via participation in the federal drug 340B discount pricing program. Where applicable, the ability to access these resources, helps HTCs to offer this medical home model of care which includes 24/7/365 provider access & care coordination point with all providers. Another element of cost containment—assay management—requires rigorous oversight and reporting, which should be expected from any dispensing specialty pharmacy.



Reduction in ED Utilization among Patients Seen in an HTC Setting[10]



Contracting with HTCs as in-network providers for beneficiaries with bleeding disorders is one means by which employers can improve patient outcomes and manage health care costs. Conversely, employers may actually be contributing to fragmented care and discouraging HTC use, when HTCs are not in the health plan network and by carving out specialty pharmacy services to an exclusive provider, which can contribute to higher total cost of care.

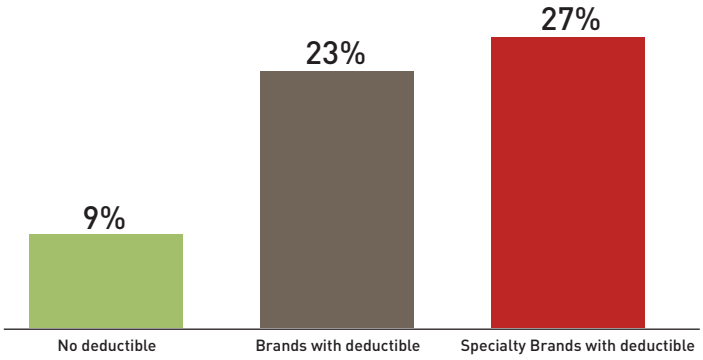
Improving adherence to chronic disease management and treatment plans is a critical facet to improving outcomes for hemophilia patients and lowering the total cost of care.

In terms of benefit design then, employers should give careful consideration before implementing any cost shifting strategies as a one size fits all option. For hemophilia patients, medication adherence is critical, so offering consumer directed health plans (CDHP's) as an only option with high deductibles, copays and annual out of pocket expenditures, will likely only result in barriers to adherence, and increasing costs for the employer. If a hemophilia patient can't afford their monthly specialty medications, they are left to treat bleeds (reactively) instead of preventing them (proactively) and seeking their infusions in the ER setting and/or hospital, which is the highest cost site of care.

Implementing copay accumulator adjustment programs without making some exception for hemophilia patients has the same risk of unintended consequences.

One consideration would be to place hemophilia products on the preventative drug list, which many large employers are implementing.

Prescription Abandonment by Drug Type and Level of Beneficiary Cost-Share[11]



To effectively manage the total cost of care for beneficiaries with bleeding disorders, employers should first determine if the patient's care is being delivered by a federally designated Hemophilia Treatment Center of Excellence. Employers should also further investigate the channel(s) through which the patient receives his/her clotting factor replacement specialty medications (e.g., through an HTC integrated specialty pharmacy, a PBM/specialty pharmacy or home care company). Next employers should seek to identify what the contracted pricing per unit paid is, and how well the pharmacy is managing adherence, dosing and target to dispense assay management. An employer Communication Response Pathway is available at CCSCHemo.com to guide health care purchasers through the process of managing beneficiaries with bleeding disorders.

Similar to the management of any chronic disease, collaboration among multiple health care stakeholders is necessary to achieve optimal outcomes and mitigate rising health care expenditures. In response, the National Hemophilia Foundation (NHF) established the Comprehensive Care Sustainability Collaborative (CCSC), in 2014 as a quality improvement and cost management initiative. The aim of CCSC is facilitate dialogue between payers and providers to identify the HTCs as the gold standard in caring for patients with bleeding disorders and to help payers develop strategies to best mitigate cost risk and population health outcomes. The initiative is responsible for

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disseminating standards of quality care, cost management interventions, and information regarding the benefits of interdisciplinary medical management for bleeding disorders. CCSC also provides outreach, education, and data collection tools to drive transparency, key to managing the total cost of care.

Employers should not give away the management of high cost diseases to those who might be conflicted, such as a PBM that also owns the specialty pharmacy recommended as the exclusive contracted provider; at least without, gaining knowledge of the 3 cost centers that drive hemophilia spend, and understanding which data should be expected for transparency and specialty pharmacy performance.

Employers can and should connect with CCSC to gain this insight and use of data transparency tools, as well as an opportunity to connect with key supply chain partners such as HTC providers, health plans and other employers, to further mitigate cost risks and identify value based contracting opportunities to lower the total cost of care. For more information regarding the initiative and opportunities for employer participation, please visit CCSChemo.com.

Have questions or want to find out how to participate?

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The National Hemophilia Foundation (NHF) is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy, and research.

Impact Education, LLC's, mission is to develop education that improves patient outcomes in combination with increased health care efficiency and cost-effectiveness.