An Initiative to Implement Quality Improvement Measures for Hemophilia

Natalie Duncan, MPH1, Christopher Roberson, JD, MPH1, Alice Lail, MPH2, Sharyne Donfield, PhD2, Amy Shapiro, MD1

1Indiana Hemophilia and Thrombosis Center, Inc. (Indianapolis, Indiana), 2Rho, Inc. (Chapel Hill, North Carolina)

BACKGROUND AND OBJECTIVES

Quality improvement (QI) consists of systematic and continuous actions that lead to measurable improvement in healthcare services and health status of targeted patient groups over time.1 To perform effective QI, key health measures must be identified and tracked. The U.S. Hemophilia Treatment Center (HTC) network is optimally organized to initiate a QI program. HTCs utilize a national database ensuring consistent reporting of data, and a National Hemophilia Program Coordinating Center, the American Thrombosis & Hemostasis Network (ATHN) is developing the reporting infrastructure to report quality measures for individual HTCs and the aggregate HTC network. The Indiana Hemophilia and Thrombosis Center, Inc. (IHTC) endeavored to determine what metrics are best suited to evaluate the effectiveness of a hemophilia program, with the secondary objective of proposing identified metrics to the broader HTC community.

METHODS

IHTC staff met with experts from the Centers for Disease Control & Prevention, National Institute for Health, Rho, Inc., and the American Thrombosis & Hemostasis Network (ATHN) to mind map potential measures. An extensive list of candidate measures were discussed and critiqued, resulting in an abridged list of approximately six measures. De-identified data were subsequently queried from the IHTC electronic medical record spanning 2008-2011. Extracted data included demographic/descriptive data, insurance status, contacts with IHTC staff, history of orthopedic procedures, and history of inhibitor contacts with IHTC staff. The IHTC database was queried to identify patients with severe hemophilia A or B. The dataset included all males with severe hemophilia utilizing prophylaxis.

RESULTS

Figure 1 identifies the percentage of patients with mild, moderate, and severe hemophilia who attended a comprehensive clinic from 2008-2011. IHTC encourages patients with severe hemophilia to attend comprehensive clinic annually, moderate patients every other year, and mild patients at least every three to five years. On average, approximately 35% of patients with mild deficiency, 50% of patients with moderate deficiency, and 75% of patients with severe deficiency attended a comprehensive clinic each year.

Figure 2 depicts the percentage of patients missing 0, 1-10, and over 10 days of work or school each year. From 2008-2011 approximately 82% of patients reported missing 0 days of work or school related to their bleeding disorder.

Figure 3 identifies the status of all patients with an inhibitor at the end of each calendar year (i.e., successful immune tolerance induction [ITI], transient inhibitor, patient indefinitely on a bypassing agent [generally resulting from a contraindication of ITI due to a past alloreactive reaction to clotting factor], or the patient remained on ITI). Each year, approximately 45% of patients with an inhibitor completed a successful regimen of ITI.

Finally, Figure 4 identifies the percentage of patients with severe hemophilia on prophylaxis separated by children and adults. On average, approximately 89% of pediatric and 55% of adult patients with severe hemophilia were utilizing prophylaxis.

CONCLUSIONS

Although implementing a QI initiative in the HTC network may create ambivalence amongst HTCs reluctant to share performance and outcome data, the benefits to the HTC community of a QI initiative may include ensuring continued funding from MCHB and the CDC, and most importantly, improving overall patient care. A comparable initiative was successfully undertaken by the Cystic Fibrosis Foundation (CFF) which now reports on four key health measures for each of its >110 accredited care centers.4 The CFF overcome these tensions by focusing their initiative on increasing, promoting, and sharing improvements in care; not on generating competition or criticism of poorer performing centers. An HTC QI program must similarly seek to promote information sharing in a manner that will enable all HTCs to improve outcomes and quantify the effectiveness of the HTC comprehensive care model.

Next steps include analyzing network-wide aggregate data to identify normative values, and establishing a forum to share best practices and to analyze the impact of various approaches to improve outcomes.

REFERENCES


