BRIEF REPORT

Effectiveness of Clinical Decision Support Based Intervention in the Improvement of Care for Adult Sickle Cell Disease Patients in Primary Care

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Introduction: **Although most patients with rare diseases like sickle cell disease (SCD) are treated in the primary care setting, primary care physicians may find it challenging to keep abreast of medication improvements and complications associated with treatment for rare and complex diseases. The purpose of this study was to evaluate the effectiveness of a clinical decision support (CDS) –based intervention system for transfusional iron overload in adults with SCD to improve management in primary care.**

Methods: **An electronic medical record based clinical decision support system for potential transfusional iron overload in SCD patients in primary care was evaluated. The intervention was implemented in 3 family medicine clinics with a control group of 3 general internal medicine clinics. Data were collected in the 6 months before the intervention and 6 months after the intervention. There were 47 patients in the family medicine group and 24 in the general internal medicine group.**

Results: **There was no management change in the control group while the intervention group improved primary care management from 0% to 44% ($P < .001$).**

Conclusion: **A CDS tool can improve management of SCD patients in primary care. (J Am Board Fam Med 2018;31:812–816.)**

Keywords: **Clinical Decision Support Systems, Control Groups, Electronic Health Records, Iron Overload, Primary Care Physicians, Rare Diseases, Sickle Cell Anemia**

Among patients with sickle cell disease (SCD), pediatric survival rates continue to improve.[1] Some recent evidence suggests a survival rate of approximately 95% for patients with SCD up to 18 years of age.[1] However, once SCD patients become adults, appropriate management is key to life expectancy.[2] Moreover, morbidity and corresponding health care utilization for hospitalizations and readmissions are high for young adults with SCD.[3,4]

Chronic exposure to repeated blood transfusions puts patients with SCD at increased risk of transfusion-related complications. Transfusional iron overload is a significant clinical issue in patients with SCD.[5–7] In 1 study, approximately one third of adults with SCD had iron overload at postmortem.[8] Elevated iron has been shown to have a detrimental effect on mortality as well as quality of life.[9–11] Transfusional iron overload can be successfully managed with chelation therapy.[5]

Although most patients with rare diseases like SCD are treated in the primary care setting, primary care physicians may find it challenging to keep abreast of medication improvements and complications associated with treatment for rare

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and complex diseases.[12] The ability to provide high-quality care often depends on having a sufficient volume of patients with a specific disease process, yet most individuals with SCD, particularly adults, do not use subspecialty or multidisciplinary care.[13] It is important that patients with SCD are appropriately managed in primary care because some patients may not have access to subspecialists. However, in a recent survey of more than 1000 academic family physicians, only 20% of respondents felt comfortable treating patients with SCD.[14] As such, primary care physicians need to be provided appropriate and up-to-date recommendations in a timely fashion, possibly through decision support at the point of care. Family physicians believe that clinical decision support (CDS) may help them in managing SCD complications.[14]

The purpose of this study was to evaluate the effectiveness of a CDS-based intervention system for transfusional iron overload in adults with SCD to improve management in primary care.

Methods

This study used a quasi-experimental design to compare the effectiveness of the CDS tool, which consisted of a best-practice alert (BPA) and provider education, in increasing the number of ferritin test orders to assess transfusional iron overload in adults with SCD. The intervention group consisted of 3 family medicine (FM) clinics (2 nonresidency and 1 residency) at the University of Florida where the CDS tool was implemented in the EPIC electronic health record (EHR) system and provider education was administered. The control group consisted of 3 general internal medicine (GIM) clinics (2 nonresidency and 1 residency) at the University of Florida that did not receive the CDS tool. Data for the study were collected during a 6-month preintervention (March 7, 2016 through September 6, 2016) and a 6-month intervention time period (September 7, 2016 through March 6, 2017).

The educational component of the CDS tool focused on transfusional iron overload as a complication of repeated blood transfusions among hemoglobinopathy patients. It included presentations to the faculty and clinic staff as well as slides that were available for review. The BPA was a notice to providers that appeared when the EHR was opened. The BPA text read, "This patient has Sickle Cell or Hemoglobinopathy documented on their Problem List. Please ask the patient if they have had a Red Blood Cell Transfusion in the past year. If so, consider ordering a Ferritin Level." The BPA also displayed the 5 most recent ferritin levels and dates, as well as buttons to Order/Do Not Order a ferritin test. The University of Florida's Institutional Review Board certified this study as a quality improvement project.

Although patients may have been receiving ferritin tests from a hematologist to check for iron overload, the purpose of the study was to have the patients managed in primary care rather than having fragmented care between primary care and specialist care in ongoing management of the SCD patient. The main outcome measure for the study was the proportion of adult patients with SCD seen in outpatient care during the evaluated timeframe who had an order placed by their primary care provider or primary care extender for a ferritin test to monitor for transfusional iron overload.

Demographics and Health-Related Characteristics

Demographic and health-related characteristics were collected from the EHRs of the adult patients with SCD. Gender was defined as male or female. Insurance status was categorized as private insurance, public insurance (Medicare or Medicaid), or self pay. All patients reported non-Hispanic ethnicity; thus, race was categorized as Black, White, and Other. Age was defined as the age at visit during the study period (either preintervention or intervention period); counts for office visits, emergency department (ED) visits, and inpatient visits were the total number of visits during the time period of March 7, 2014 to March 6, 2017. Age, arrived office visits, ED visits, and hospital inpatient visits were not normally distributed, and were transformed into categorical variables. Age was categorized as 18 to 28, 29 to 44, and 45+ years. Arrived office visits were categorized as 1 to 4, 5 to 10, and 11+ visits. ED visits and hospital inpatient visits were categorized as 0, 1 to 3, and 4+ visits. The patient problem count was the total number of problems listed on the patient's problem list from the EHR. Problem count was categorized as 1 to 8, 9 to 14, and 15+ problems.

Analysis

A difference in proportions test was computed to test the difference in ferritin test orders placed

Table 1. Demographic Characteristics of Active Patient Population of Adult Sickle Cell Disease (SCD) Patients in the Intervention (FM) Group and the Control (GIM) Group (N = 71)

	Intervention (FM) (Patient N = 47), %	Control (GIM) (Patient N = 24), %	*P*-Value
Gender			
Male	40.4	33.3	.56
Age (years)			
18 to 28	31.9	29.2	.94
29 to 44	42.5	41.7	
45+	25.5	29.2	
Insurance Status			
Private	32.6	34.8	.85
Public	67.4	65.2	
Race			
Black	100	95.8	.34
White	0	4.2	
Other	0		
Ethnicity			
Non-Hispanic	100	100	1.0
Arrived Office Visits			
1 to 4 visits	44.7	20.8	.07
5 to 10 visits	29.8	29.2	
11 + visits	25.5	50	
Emergency Department Visits			
0 visits	36.1	50	.31
1 to 3 visits	38.3	20.8	
4 + visits	25.5	29.2	
Hospital Inpatient Visits			
0 visits	53.2	58.3	.43
1 to 3 visits	34	20.8	
4 + visits	12.8	20.8	
Problem Count			
1 to 8 problems	36.2	33.3	.44
9 to 14 problems	36.2	25	
15 + problems	27.7	41.7	

FM, family medicine; GIM, general internal medicine.

between the intervention (FM) and control (GIM) groups. Differences between the practices were examined using χ^2 tests. One patient in the FM group and 1 patient in the GIM group were categorized as self pay and were excluded from the insurance status bivariate calculation.

Results and Discussion

The total number of adult patients with SCD with clinic visits during the preintervention and intervention periods in the FM group was 47 and in the GIM group was 24. Table 1 shows the characteristics of each group. There were no statistically significant differences between the FM and GIM patient groups in either the patient demographics or clinical care characteristics. In the preintervention period, the proportion of SCD patients with an order of a ferritin test placed by the primary care physician was 0% (0 out of 20 patients) in the FM group and 0% (0 out of 12 patients) in the GIM group. During the 6-month intervention period, there was an increase in the proportion of SCD patients with an order of a ferritin test placed by the primary care provider to 44% in the FM group (11 orders placed for 25 patients). In contrast, there was no change in the proportion of patients with a ferritin test order in the GIM group which remained stable at 0% (0 orders for 12 patients). The

difference in these proportions was statistically significant ($P < .001$). The BPA appeared 379 times during the 6-month intervention period in the FM group.

This study showed that a CDS-based intervention using both an EHR BPA and provider education was particularly effective in helping primary care physicians begin to address an often unrecognized but important quality of care issue in adult patients with SCD, transfusional iron overload. Although this project was paid for by an external funder, the costs are small and are limited to the programmer time required to include a BPA into the EHR. Faculty development and creation of BPAs are part of the ongoing management of the department. This trial provides evidence that decision support may be a useful strategy to help primary care physicians better manage patients with rare diseases such as SCD, thereby reducing the need for management by specialists. The American Board of Family Medicine and department Chairs in Family Medicine encourage a broad scope of care for family physicians, and these results point to the viability of managing patients with rare diseases when assistance is provided.[15]

There are several limitations to this study. First, all the patients were within the same health system. The same health system could have a similar culture of practice across primary care disciplines and there could be some movement of the patients across departments. Further, the results showed that if there was a common culture in the University of Florida health system that the decision support tool changed practice. Second, the intervention was not a randomized trial, thus the results could have been affected by known or unknown differences between the groups. This was a quasi-experimental trial for which the physicians and patients in the GIM group were unaware of the intervention, and the patient populations were similar. It is possible that there are differences that we did not control for between GIM and FM. Further, our denominator in all analyses was all hemoglobinopathy patients not just patients at risk of transfusional iron overload. Therefore, there may have been differences in the number of transfused patients between the 2 groups. This may also have increased the possibility of clinician fatigue with regard to the BPA, as the appearance of the alert was not limited to only the patients at risk of transfusional iron overload. Further, additional sessions of provider education helped to supplement the BPA and explain to the providers the background and need to investigate possible iron overload in their SCD patients. Finally, the intervention consisted of both the BPA and provider education, so the effect of either of these activities on their own could not be measured.

In conclusion, management of SCD patients in primary care can be improved with the use of CDS-based intervention. However, checking for transfusional iron overload is only the first step of what needs to be implemented. Managing iron overload with chelation therapy is the next step that will be incorporated into this CDS-based system. Future research will focus on enhancing the current decision support system and evaluating its adoption and effectiveness for both process outcomes as well as patient outcomes.

To see this article online, please go to: http://jabfm.org/content/31/5/812.full.

References

1. Quinn CT, Rogers ZR, McCavit TL, et al. Improved survival of children and adolescents with sickle cell disease. Blood 2010;115:3447–52.
2. Paulukonis ST, Eckman JR, Snyder AB, et al. Defining sickle cell disease mortality using a population-based surveillance system, 2004 through 2008. Public Health Rep 2016;131:367–75.
3. Brousseau DC, Owens PL, Mosso AL, et al. Acute care utilization and rehospitalizations for sickle cell disease. JAMA 2010;303:1288–94.
4. Hunt SE, Sharma N. Transition from pediatric to adult care for patients with sickle cell disease. JAMA 2010;304:408–9; author reply 409.
5. Yawn BP, Buchanan GR, Afenyi-Annan AN, et al. Management of sickle cell disease: summary of the 2014 evidence-based report by expert panel members. JAMA 2014;312:1033–48.
6. Blinder MA, Vekeman F, Sasane M, et al. Age-related treatment patterns in sickle cell disease patients and the associated sickle cell complications and healthcare costs. Pediatr Blood Cancer 2013;60:828–35.
7. Puliyel M, Mainous AG 3rd, Berdoukas V, et al. Iron toxicity and its possible association with treatment of Cancer: Lessons from hemoglobinopathies and rare, transfusion-dependent anemias. Free Radic Biol Med 2015;79:343–51.
8. Darbari DS, Kple-Faget P, Kwagyan J, et al. Circumstances of death in adult sickle cell disease patients. Am J Hematol 2006;81:858–63.
9. Mainous AG 3rd, Gill JM, Carek PJ. Elevated serum transferrin saturation and mortality. Ann Fam Med 2004;2:133–8.

10. Ward R. An update on disordered iron metabolism and iron overload. Hematology 2010;15:31131–7.
11. Mainous AG 3rd, Wright RU, Hulihan MM, et al. Elevated transferrin saturation, health-related quality of life and telomere length. Biometals 2014;27:135–41.
12. Mehta SR, Afenyi-Annan A, Byrns PJ, et al. Opportunities to improve outcomes in sickle cell disease. Am Fam Physician 2006;74:303–10.
13. Sobota A, Neufeld EJ, Sprinz P, et al. Transition from pediatric to adult care for sickle cell disease: Results of a survey of pediatric providers. Am J Hematol 2011;86:512–5.
14. Mainous AG 3rd, Tanner RJ, Harle CA, et al. Attitudes toward management of sickle cell disease and its complications: A national survey of academic family physicians. Anemia 2015;2015:853835.
15. Peterson LE, Blackburn B, Phillips RL Jr, et al. Family medicine department chairs' opinions regarding scope of practice. Academic Med 2015;90: 1691–7.