Sickle Cell Disease Quality Metrics and Health Outcomes: Kaiser Permanente Mid-Atlantic – Johns Hopkins Medicine Collaboration

Sophie Lanzkron (JHM) and Michael Horberg and Monica Ter-Minassian (KP)

Progress Report May 2018
Manuscript accepted to the *Journal of the National Medical Association*, waiting for copy-edited proof.

Lay-person article with a description of research and implications for clinical practice posted in December 2017 to MAPMG My Doctor Online external website
https://mydoctor.kaiserpermanente.org/mas/mapmg/news/blog/sickle_cell.html

Progress Report August 2017
Abstract presented at FSCDR in May 2017
Lanzkron S, Ter-Minassian M, Derus A, Brown E, Horberg M, "Sickle Cell Disease Quality Metrics and Health Outcomes: Kaiser Permanente Mid-Atlantic – Johns Hopkins University Collaboration," FSCDR, Miami, Florida, May, 2017

BACKGROUND: To date, there are no standardized, well-accepted, quality metrics that guide care for adults with sickle cell disease (SCD). The primary objective of this study was to evaluate metrics that are in use at the Adult Sickle Cell Disease Program at Johns Hopkins Hospital (JHH) and to determine if these metrics can be applied at Kaiser Permanente Mid-Atlantic States (KPMAS), a developing adult sickle cell disease program within an integrated healthcare system.

METHODS: We performed a retrospective cohort study of 148 KPMAS and 324 JHH patients from January 1, 2014 – December 31, 2015. Demographics, genotype and data on 3 quality metrics (yearly screening labs, vaccinations and hydroxyurea prescriptions written) were collected from electronic health records (EHR).

RESULTS: Patients at JHH were younger than those as KPMAS (median age 34 and 44 respectively) and more likely to have hemoglobin SS disease (65% and 28% respectively). Yearly lab performance is shown in the figure. Given that only vaccinations administered within our institutions are included, 80% of KPMAS patients received pneumococcal and 75% received flu vaccinations compared to 80% and 48% at JHH. 26 of 62 (42%) of patients at KPMAS and 115 of 261 (44%) at JHH with hemoglobin SS or S-thal were written a hydroxyurea prescription over the study period. This data includes all patients with those genotypes and not necessarily those who meet the eligibility criteria in the NHLBI guidelines. Only 65% of KPMAS and 53% of JHH patients written a prescription for hydroxyurea were provided scripts to cover at least 6 months over the two-year study period.

CONCLUSIONS: Using the number of prescriptions written for hydroxyurea (and not more stringent hydroxyurea refill data), it is clear that interventions to improve adherence to hydroxyurea should be a focus. Developing dashboards to monitor adherence to guideline based care for those with SCD has limitations but there is an opportunity to use the EHR to refine and implement this to improve access to high quality care for those with SCD. One limitation that will have to be addressed is data recording, including vaccinations that happen outside our institutions.

Manuscript: First draft being written now. Targeted journal TBD.

System Implementation: KPMAS—Now a targeted area of quality outreach by Pediatric and Adult Hematology-Oncology with best practice alerts in KPMAS Epic ("HealthConnect") and outreach to patients by MAPMG Quality Team. Further, provider reports to Heme-Onc providers specifically noting where there are deficiencies based on the quality metrics defined by this study. JHM—Best practice alert has been implemented and renewed emphasis on hydroxyurea medication adherence.