General

Title
Sickle cell disease (SCD): percentage of children younger than 18 years of age identified as having SCD presenting to an ED with severe pain who had a parenteral analgesic within 60 minutes following initial contact during the measurement year.

Source(s)

Measure Domain

Primary Measure Domain
Clinical Quality Measures: Process

Secondary Measure Domain
Does not apply to this measure

Brief Abstract

Description
This measure is used to assess the percentage of children younger than 18 years of age identified as having sickle cell disease (SCD) presenting to an emergency department (ED) with severe pain who had a parenteral analgesic within 60 minutes following initial contact during the measurement year. A higher proportion indicates better performance, as reflected by appropriate treatment.

Rationale
Approximately 2,000 infants are born with sickle cell disease (SCD) in the United States each year, a condition that occurs predominantly in people of African and Hispanic descent. SCD is a chronic hematologic disorder, characterized by the presence of hemoglobin S. From infancy onward, the presence of this hemoglobin variant can lead to an array of serious medical conditions, including the hallmark
clinical manifestation of SCD, the acute vaso-occlusive event or pain crisis. This unique type of pain can start as early as 6 months of age, recur unpredictably over a lifetime, and require treatment with opioids. Painful events are the most common cause of emergency department (ED) visits and hospitalization for children with SCD. For patients, families, and health care providers, the severity and unpredictability of pain, the lack of objective markers, and conflicting perceptions about intensity and treatment make pain management a particularly challenging aspect of SCD. In children, pain can be managed effectively in the ED with the aggressive use of currently available treatment approaches. This includes prompt provision of appropriate analgesics and timely assessment of pain following analgesic administration to determine efficacy of treatment. There are no existing quality measures for appropriate ED management of pain in children with SCD.

Evidence for Rationale


Primary Health Components

Sickle cell disease (SCD); pain management; parenteral analgesic; infants; children; adolescents

Denominator Description

The eligible population for the denominator is the number of children younger than 18 years of age with sickle cell disease (SCD) presenting to the emergency department (ED) with severe pain during the measurement year (January 1 to December 31) (see the related "Denominator Inclusions/Exclusions" field).

Numerator Description

The eligible population for the numerator is the number of children younger than 18 years of age with sickle cell disease (SCD) who presented to an emergency department (ED) with severe pain who had parenteral analgesic within 60 minutes following initial contact during the measurement year (January 1 to December 31) (see the related "Numerator Inclusions/Exclusions" field).

Evidence Supporting the Measure

Type of Evidence Supporting the Criterion of Quality for the Measure

A clinical practice guideline or other peer-reviewed synthesis of the clinical research evidence

A formal consensus procedure, involving experts in relevant clinical, methodological, public health and organizational sciences

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Additional Information Supporting Need for the Measure
Sickle Cell Disease Prevalence and Incidence
Sickle cell disease (SCD) is one of the most common genetic disorders in the United States (U.S.) (Kavanagh et al., 2011). The National Heart, Lung and Blood Institute (NHLBI) (2002) estimates that 2,000 infants are born with SCD in the U.S. each year. SCD affects 70,000 to 100,000 children and adults in the U.S., predominantly those of African and Hispanic descent (Hassell, 2010).

Sickle Cell Disease Pathology and Severity
Vaso-occlusion (the sudden blockage of a blood vessel caused by the sickle shape of abnormal blood cells) is responsible for most complications of SCD, including pain episodes, sepsis, stroke, acute chest syndrome, priapism, leg ulcers, osteonecrosis and renal insufficiency (Steinberg, 1999). In addition, SCD can have hemolytic and infectious complications that result in morbidity and mortality in children with the condition (Kavanagh et al., 2011).

Sickle Cell Disease Burden in Daily Life
The effect of SCD on children and families is significant; severe pain episodes and hospitalizations restrict daily activities and reflect negatively on school attendance and performance, as well as on sleep and social activities (Lemanek, Ranalli, & Lukens, 2009; Alvim et al., 2005). Although medical management of SCD continues to improve over time, 196 children in the United States died from SCD-related causes between 1999 and 2002 (Yanni et al., 2009).

Sickle Cell Disease Cost
In a study of health care utilization among low income children with SCD between 2004 and 2007, 27% of these children required inpatient hospitalization and 39% used emergency care during a year. Of these children, 63% averaged one well-child visit per year and 10% had at least one outpatient visit with a specialist (Raphael et al., 2009). Patients with SCD use many parts of the health care system, incurring significant costs. In 2009, mean hospital charges for children with SCD and a hospital stay were $23,000 for children with private insurance and $18,200 for children enrolled in Medicaid (HCUPnet, Healthcare Cost and Utilization Project, 2012). Kauf et al. (2009) estimate the lifetime cost of health care per patient with SCD to be approximately $460,000.

See the original measure documentation for additional evidence supporting the measure.

Evidence for Additional Information Supporting Need for the Measure

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Extent of Measure Testing

Reliability

Data and Methods. The testing data consisted of an audit of medical records from the three largest centers serving sickle cell disease (SCD) patients in Michigan during 2012: Children's Hospital of Michigan (CHM, Detroit), Hurley Medical Center (Hurley, Flint), and the University of Michigan Health System (UMHS, Ann Arbor). Combined, these sites treat the majority of children with SCD in Michigan. Medical records for all children with SCD meeting the measure specification criteria during the measurement year were abstracted at each site. Abstracting was conducted in two phases; during Phase 1, 435 records were abstracted among the three sites. In Phase 2, an additional 237 cases were abstracted at one site. In total, 672 unique records were reviewed for children with SCD to test this measure.

Reliability of medical record data was determined through re-abstraction of patient record data to calculate the inter-rater reliability (IRR) between abstractors. Broadly, IRR is the extent to which the abstracted information is collected in a consistent manner (Keyton et al., 2004). Low IRR may be a sign of poorly executed abstraction procedures, such as ambiguous wording in the data collection tool, inadequate abstractor training, or abstractor fatigue. For this measure, the medical record data collected by two nurse abstractors were compared.

Measuring IRR at the beginning of the abstraction is imperative to identify any misinterpretations early on. It is also important to assess IRR throughout the abstraction process to ensure that the collected data maintain high reliability standards. Therefore, the IRR was evaluated during Phase 1 at each site to address any reliability issues before beginning data abstraction at the next site.

IRR was determined by calculating both percent agreement and Kappa statistics. While abstraction was still being conducted at each site, IRR assessments were conducted for 5% of the total set of unique patient records that were abstracted during Phase 1 of data collection. Two abstractors reviewed the same medical records; findings from these abstractions were then compared, and a list of discrepancies was created.

Three separate IRR meetings were conducted, all of which included a review of multiple SCD measures that were being evaluated. Because of eligibility criteria, not all patients were eligible for all measures. Therefore, records for IRR were not chosen completely at random; rather, records were selected to maximize the number of measures assessed for IRR at each site.

Results. For this measure, 2 records were assessed for IRR among the cases eligible for the pain assessment numerator; 3 patient records were assessed among those eligible for the analgesic numerator. Additionally, in order for a record to be eligible for this measure, patients must meet a
specific medical criterion documenting that severe pain was present; consequently, IRR was also assessed for this eligibility criterion. For severe pain, 8 unique patient records were assessed for IRR across the three testing sites.

Table 7 of the original measure documentation shows the percent agreement and Kappa statistic for each numerator and the severe pain eligibility criterion of this measure for each site and across both sites. The overall agreement for the analgesic numerator was 100% and the Kappa was 1.00. The overall agreement for the pain assessment numerator was 50% and the Kappa was 0.00. The overall agreement for the severe pain eligibility criterion was 63% and the Kappa was 0.25. Note that the Kappa value is affected by the prevalence of the finding under consideration, similar to a positive predictive value being influenced by the prevalence of the condition. For rare findings, very low values of Kappa may not necessarily reflect low rates of overall agreement (Viera & Garrett, 2005).

Validity

**Face Validity.** The face validity of this measure was established by a national panel of experts and advocates for families of children with SCD convened by the Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). The Q-METRIC expert panel included nationally recognized experts in SCD, representing hematology, pediatrics, and SCD family advocacy. In addition, measure validity was considered by experts in state Medicaid program operations, health plan quality measurement, health informatics, and health care quality measurement. In total, the Q-METRIC SCD panel included 14 experts, providing a comprehensive perspective on SCD management and the measurement of quality metrics for states and health plans.

The Q-METRIC expert panel concluded that this measure has a high degree of face validity through a detailed review of concepts and metrics considered to be essential to effective SCD management and treatment. Concepts and draft measures were rated by this group for their relative importance. This measure was highly rated, receiving an average score of 8.1 (with 9 as the highest possible score).

**Validity of Abstracted Data.** This measure was tested using medical record data. This source is considered the gold standard for clinical information; our findings indicate that these data have a high degree of face validity. This measure was tested among a total of 101 children younger than 18 years of age with SCD (Table 8 of the original measure documentation). Overall, 18% of children with SCD (range: 17% to 20%) had parenteral analgesic within 60 minutes following initial contact in an ED; a pain assessment was conducted within 30 minutes following analgesic administration for 28% of children with SCD (range: 18% to 45%).

**Evidence for Extent of Measure Testing**


**State of Use of the Measure**

**State of Use**
Current routine use

Current Use
not defined yet

Application of the Measure in its Current Use

Measurement Setting
Emergency Department
Hospital Outpatient

Professionals Involved in Delivery of Health Services
not defined yet

Least Aggregated Level of Services Delivery Addressed
Single Health Care Delivery or Public Health Organizations

Statement of Acceptable Minimum Sample Size
Unspecified

Target Population Age
Age less than 18 years

Target Population Gender
Either male or female

National Strategy for Quality Improvement in Health Care

National Quality Strategy Aim
Better Care

National Quality Strategy Priority
Prevention and Treatment of Leading Causes of Mortality
Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need
Living with Illness

IOM Domain
Effectiveness
Timeliness

Data Collection for the Measure

Case Finding Period
The measurement year

Denominator Sampling Frame
Patients associated with provider

Denominator (Index) Event or Characteristic
Clinical Condition
Encounter
Patient/Individual (Consumer) Characteristic

Denominator Time Window
not defined yet

Denominator Inclusions/Exclusions

Inclusions
The eligible population for the denominator is the number of children younger than 18 years of age with sickle cell disease (SCD) presenting to the emergency department (ED) with severe pain during the measurement year (January 1 to December 31).

Note:
Eligible children are restricted to those with SCD variants identified in Table 1 of the original measure documentation, based on appropriate International Classification of Diseases, Ninth Revision (ICD-9) codes as documented in the medical record.

Intake Period: January 1 to December 31 of the measurement year.

Severe Pain: On a 3 point scale, a score of 3; on a 5 point scale, a score of 4 or 5; on a 10 point scale, a score of 6 or higher.

All ED visits for severe pain during the measurement year qualify, even for events such as a broken arm.

Exclusions

Inpatient stays, outpatient visits, urgent care visits, and acute care (evaluation and management)
visits with a primary care physician are excluded from the calculation. Children with a diagnosis in the sampled medical record indicating one of the SCD variants listed in Table 5 of the original measure documentation should not be included in the eligible population unless there is also a diagnosis for a sickle cell variant listed in Table 1.

Exclusions/Exceptions

not defined yet

Numerator Inclusions/Exclusions

Inclusions
The eligible population for the numerator is the number of children younger than 18 years of age with sickle cell disease (SCD) who presented to an emergency department (ED) with severe pain who had parenteral analgesic within 60 minutes following initial contact during the measurement year (January 1 to December 31).

Note:
Documentation in medical record must include, at a minimum, a note containing the time at which the parenteral analgesic was administered.

Parenteral Analgesic: International Classification of Diseases, Ninth Revision (ICD-9) codes to identify parenteral analgesics are listed in Table 2 of the original measure documentation.

Initial Contact: Child’s first presentation to ED staff. Use the earliest time stamp in the medical record.

Exclusions
Oral pain medications that were administered during the ED visit are excluded from the calculation.

Numerator Search Strategy

Encounter

Data Source
Electronic health/medical record

Type of Health State
Does not apply to this measure

Instruments Used and/or Associated with the Measure
Unspecified

Computation of the Measure

Measure Specifies Disaggregation
Does not apply to this measure

Scoring
Rate/Proportion

Interpretation of Score
Desired value is a higher score

Allowance for Patient or Population Factors
not defined yet

Standard of Comparison
not defined yet

Identifying Information

Original Title
Appropriate emergency department pain management for children with sickle cell disease.

Measure Collection Name
Sickle Cell Disease Measures

Submitter

Developer

Funding Source(s)
This work was funded by the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Medicare & Medicaid Services (CMS) under the CHIPRA Pediatric Quality Measures Program Centers of Excellence grant number U18 HS020516.

Composition of the Group that Developed the Measure
Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) Sickle Cell Disease Measure Developers:

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Financial Disclosures/Other Potential Conflicts of Interest
Unspecified

Adaptation
This measure was not adapted from another source.

Date of Most Current Version in NQMC
2014 Apr

Measure Maintenance
Unspecified

Date of Next Anticipated Revision
Unspecified

Measure Status
This is the current release of the measure.
The measure developer reaffirmed the currency of this measure in January 2016.

Measure Availability

For more information, contact Q-METRIC at 300 North Ingalls Street, Room 6C08, SPC 5456, Ann Arbor, MI 48109-5456; Phone: 734-232-0657; Fax: 734-764-2599.

NQMC Status

This NQMC summary was completed by ECRI Institute on January 23, 2015. This NQMC summary was verified by the measure developer on March 2, 2015.

The information was reaffirmed by the measure developer on January 7, 2016.

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Production

Source(s)


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