General

Title
Sickle cell disease (SCD): percentage of children younger than 18 years of age identified as having SCD presenting to an ED with an acute pain episode who had a pain assessment within 30 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 an acute pain episode who had a pain assessment within 30 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 hospitalizations for children. A majority of patients with SCD have at least one episode of pain per year, and a small minority will have almost constant pain. 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. Accurate, prompt, and insightful assessment of pain is essential, then, for developing an effective plan for treatment. There are no existing quality measures for appropriate ED assessment of pain in children with SCD.

Evidence for Rationale


Primary Health Components

Sickle cell disease (SCD); pain assessment; 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 an acute pain episode 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) presenting to the emergency department (ED) with an acute pain episode during the measurement year (January 1 to December 31) who had a pain assessment within 30 minutes following initial contact, as determined by a medical record review (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**


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 the measure numerator, 17 of 435 unique patient records (4%) from Phase 1 of the abstraction process were assessed for IRR across the three testing sites. Additionally, in order for a record to be abstracted for this measure, patients must meet a specific medical criterion (pain). Therefore, IRR was also assessed for this eligibility criterion. For pain, 25 of 435 unique patient records (6%) from Phase 1 of the abstraction process were assessed for IRR across the three testing sites.

Table 6 of the original measure documentation shows the percent agreement and Kappa statistic for the numerator and the pain eligibility criterion of this measure for each site and across all sites. The overall agreement for the numerator was 100% and the Kappa was 1.00, indicating a perfect IRR level was achieved. The overall agreement for the pain eligibility criterion was 84% and the Kappa was 0.57.

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 293 children younger than 18 years of age with SCD (Table 7 of the original measure documentation). Overall, a pain assessment was conducted within 30 minutes of initial contact in the ED for 90% of children with SCD (range among the three hospitals: 75% to 96%).

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
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 an acute pain episode during the measurement year (January 1 to December 31).
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.

**Acute Pain Episode**: Considered to have occurred if there is any documentation of a Numeric Pain Intensity Assessment (see Table 2 of the original measure documentation).

**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 sickle cell disease variants listed in Table 4 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) presenting to the emergency department (ED) with an acute pain episode during the measurement year (January 1 to December 31) who had a pain assessment within 30 minutes following initial contact, as determined by a medical record review.

**Note**:

- Documentation in medical record must include, at a minimum, a note containing the time at which the pain assessment was performed.
- Pain Assessment: A pain assessment was performed within 30 minutes following initial contact (see Table 2 of the original measure documentation). Assume that an institution uses the same pain scale over time.
- Initial Contact: Child's first presentation to emergency department staff. Use the earliest time stamp in the medical record.

**Exclusions**

Ineligible pain assessment procedure codes are listed in Table 3 of the original measure documentation.

**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 assessment for children with sickle cell disease.

**Measure Collection Name**

Sickle Cell Disease Measures

**Submitter**


**Developer**


**Funding Source(s)**

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**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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