Identification of Pica Behaviors in Youth With Sickle Cell Disease: A Quality Improvement (QI) Project

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This article describes a quality improvement (QI) initiative integrated into a pediatric psychology service that focused on improving the standardized assessment of pica behaviors in patients with sickle cell disease (SCD). Pica, the persistent mouthing or eating of nonnutritive substances, can result in serious health complications and is a known problem for patients with SCD. At the time of project initiation, pica behaviors were assessed, on average, in 36% of new consultations completed by psychology providers in patients with SCD across our hospital system. The primary goal for the current project was to increase documented screening for pica behaviors to at least 95% of patients with SCD newly referred for a pediatric psychology consultation. After QI project implementation, assessment of pica behaviors increased to 100% and was maintained at that level for the final 5 months of the 12-month project period. Systematic, standardized assessment of pica behaviors for patients with SCD was deemed feasible and acceptable based on initial uptake and maintenance of the change. Of note, incidence rates of pica behaviors for patients with SCD seen by psychology ranged from 21% to 34% across the hospital system, prompting an expansion of the original project scope to ensure that all patients with SCD with pica behaviors were identified as part of routine clinical care regardless of psychology referral. Our project suggests that quality improvement methods are an effective way to implement systemic changes in regular clinical practice across providers practicing in different settings at multiple hospitals.

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Pica, the persistent mouthing or eating of nonnutritive substances, is an eating behavior that occurs most commonly in young children, individuals with intellectual and developmental disabilities, and pregnant women (Corbett, Ryan, & Weinrich, 2003; Marchi & Cohen, 1990; Williams, Kirkpatrick-Sanchez, Enzinna, Dunn, & Borden-Karasack, 2009). Prevalence rates of pica in the general population are unclear, though estimates have ranged from 25% to 50% in high-risk groups (Lemanek et al., 2002). Ingestion of nonnutritive substances such as paper, foam, and powders can result in serious health complications, including abdominal pain, intestinal obstruction, lead poisoning and cognitive dysfunction, and gastric bezoars, which are solid masses of indigestible material that accumulate in the digestive tract (Chiu, Ciaccio, & West, 2005; Issaivanan, Ahmed, Sheker, Esernio-Jenssen, & Manwani, 2009; Stein-Wexler et al., 2006). Although the etiology of pica is not well understood, pica has been associated with iron, zinc, and other mineral and nutritional deficiencies (Federman, Kirsner, & Federman, 1997; Khan & Tisman, 2010), as well as anxiety and psychosocial stressors (Gundogar, Demir, & Eren, 2003; O’Callaghan & Gold, 2012).

Research indicates a high prevalence of pica among youth with sickle cell disease (SCD). Based on one medical chart review, about 34% of 395 children with SCD were found to have pica, with a higher prevalence (36%) among youth with greater disease severity (i.e., HbSS) (Ivascu et al., 2001). Lemanek and colleagues (2002) assessed 139 youth with SCD and noted that 51.8% of children demonstrated clinically significant levels of dysfunctional eating patterns that included pica. Several case reports further illustrate the health complications, such as surgical resection of gastric bezoars, that can arise from the ingestion of furniture fabric, hair, paper, and foam rubber among youth with SCD (Altepeter, Annes, & Meller, 2011; Hackworth & Williams, 2003; O’Callaghan & Gold, 2012; Stein-Wexler et al., 2006). Despite the prevalence of pica behaviors in SCD and the serious health complications that can result, to our knowledge, there are no evidence-based practice guidelines for the assessment or treatment of pica in youth with SCD (National Heart, Lung, and Blood Institute, 2014).

Our institution has undertaken an initiative to improve the quality of health care provided to patients through the implementation of quality improvement (QI) science. As part of this larger initiative, the Pica in SCD QI initiative was developed in 2013 to improve the standardized assessment of pica behaviors in patients with SCD. At the time of project initiation, patients with SCD were not routinely screened for pica behaviors during their consultations with pediatric psychologists or by medical providers. In fact, pica was typically identified as a problem in our comprehensive outpatient sickle cell clinics based on parents’ spontaneous report to medical providers, and likely represented only the most severe cases (e.g., destruction of furniture, mattresses, etc.). Severe symptoms of pica have been found in 4.4% of patients with SCD, whereas a majority (57.8%) demonstrated mild to moderate symptoms (Lemanek et al., 2002); therefore, reliance on spontaneous parental report of pica behaviors likely contributed to a gross underestimate of the incidence of pica among youth with SCD in our comprehensive clinic. The lack of systematic assessment of pica behaviors in patients with SCD was identified as a system wide performance gap based on clinical judgment. The need for a standardized assessment of pica in youth with SCD was identified as a key area of improvement to enhance the health care delivered to patients with SCD, and psychology providers were interested in taking this on as a QI initiative.

Our goal for the current project was to increase the documented screening for pica behaviors to at least 95% of patients with SCD newly referred for a pediatric psychology consultation within 1 year. This goal was adopted given its clinical relevance and congruence with institutional initiatives. Using improvement science methodology, PDSA (Plan-Do-Study-Act) cycles were conducted to evaluate documented rates of routine screening for pica. It was expected that the systematic implementation of a standardized screening protocol for pica behaviors would improve the identification and awareness of pica, as a necessary first step toward improved care for this population.
Method

Patient Population and Environment

The Aflac Cancer and Blood Disorders Center of Children’s Healthcare of Atlanta serves more than 1,700 children with SCD at three hospital locations across the Atlanta metro area and is the largest comprehensive pediatric SCD program in the country. All three hospital locations offer both inpatient and outpatient medical and psychological care for patients with SCD. Patients are referred to the Aflac Pediatric Psychology Consultation-Liaison service by a medical provider in both inpatient and outpatient clinic settings. During the time period of this project (April 1, 2013 to March 31, 2014), the consultation-liaison service comprised four clinical psychologists, three clinical psychology postdoctoral fellows, and one masters level provider across all hospital locations. Two of the three hospital locations used an electronic medical record for clinical documentation; one location continued to rely on paper charts.

During the project period, the psychology service conducted 425 new consults across the hematology/oncology service, 176 of which were for patients diagnosed with SCD. Patients diagnosed with SCD seen by pediatric psychology were primarily African American (98%) and on average 10.34 (SD = 4.97) years old.

Human Subjects Protection

This project was designed and implemented as a quality improvement project to improve on current clinical care. To determine the level of institutional oversight required, we contacted our Institutional Review Board (IRB) office. We were referred to our hospital’s written policy on distinguishing quality initiatives from research titled, “Institutional Review of Quality Initiative Studies and Non Human Subject Research Determinations.” This policy indicates that investigators are able to make determinations without an official IRB determination about whether a project is program evaluation, a quality project, or research requiring a full IRB submission for review. After reviewing this policy and discussing this project with our IRB representative, we determined that this project met the requirements of a quality project. Consequently, Institutional Review Board (IRB) submission and review were deemed unnecessary.

Outcome Measurement

The primary goal for the current project was to increase the screening of pica behaviors, the consumption of nonnutritive, nonfood substances, among patients with SCD. We defined our goal as documented screening in at least 95% of patients with SCD newly referred for a pediatric psychology consultation across our three-hospital system. The project described in this article was part of a larger project aimed at increasing identification of pica behaviors, in youth referred to the hematology/oncology psychology service, regardless of the referring problem. The primary outcome measure was the documentation of whether or not patients were screened for eating nonfood substances during an initial psychology consultation. Psychology providers asked the following question, “Does your child eat anything that is not food?” during each new consultation. This single question was adopted as a simple, easily understood but comprehensive screening item to be included in all new psychology consults. The adoption of this single question was deemed adequate as a screening item that would not burden providers or patients and could be feasibly documented and tracked. Psychology providers used clinical judgment to determine whether additional follow-up questions were needed. Provider adherence to including this question in new consults was manually tracked and recorded by each provider at the end of each workday in productivity logs that were already an established component of monitoring clinical productivity.

Quality Improvement Methodology and Implementation

PDSA (Plan, Do, Study, and Act) cycles were used throughout conceptualization and implementation of this project. Please see Schurman, Gayes, Slosky, Hunter, and Pino (2015) for a review of QI science as it relates to pediatric psychology and application of the PDSA cycle as a conceptualization for QI implementation.

Results

Data collection for this QI project occurred over 12 months and is presented in a run chart (see Figure 1), which was selected as a clear and simple depiction of process improvement over
time. A more complex control chart with an average and upper and lower control lines was considered but deemed unnecessary given the relative stability of our process that could be visually appreciated without control limit lines and the absolute ceiling provided by the outcome measure (i.e., rate of documented screening in patients with SCD) that we selected. During the 12-month QI project period, the psychology service conducted a total of 176 new consultations for patients diagnosed with SCD.

Baseline Assessment

Baseline data were not formally collected before the onset of the QI project, though the underidentification of pica behaviors was identified as a problem by psychology staff based on clinical experience. For the purposes of this article, a retrospective chart review was conducted to determine baseline levels of assessing pica behaviors for the 6-month period before QI project implementation. Across the 6-month baseline period, the psychology consultation-liaison service conducted 84 new consultations for patients diagnosed with SCD. The consumption of nonfood items was documented as having been assessed by the psychology provider on average 36% of the time, with rates ranging from 20% to 64% over the 6-month baseline period.

Outcome Measurement and Monitoring

PDSA 1. The initial PDSA cycle sought to trial the incorporation of pica screening for all patients newly referred for a psychology consultation across the three hospital system. The initial Plan stage began in January 2013 during an annual faculty retreat in response to a request from hospital administration that QI initiatives be implemented into each specialty service. Attending psychologists (Thompson, Griffin, & Johnson) identified the underidentification of the consumption of nonfood items, especially in patients with SCD, as a challenging clinical problem warranting additional attention. Institutional support and resources, including PDSA worksheets, from the manager of quality and project management guided the initial and subsequent PDSA cycles. The first intervention was rolled out in April 2013, when all psychology providers agreed to integrate the screening question about the consumption of nonfood
items into all new consultations. During the first PDSA cycle, the consumption of nonfood items was documented as assessed 100% of the time in patients with SCD, although rates were lower in the general Hematology/Oncology patient population. Feedback from psychology providers was collected during this 1-month cycle and reviewed during monthly faculty and staff meetings. Based on clinician feedback, the primary barrier to maintaining screening for pica was clinician forgetfulness to integrate the pica screening question into the assessment. Psychology staff also reported initial concerns that assessment of eating nonfood items was not necessarily feasible or acceptable for all referral concerns, such as brief consultations for long-term cancer survivors referred for neurocognitive difficulties.

**PDSA 2.** The second PDSA cycle began in May 2013 and sought to address the primary barrier of potentially forgetting to integrate the pica screening question during consultations. First, the question, “Does your child eat anything that is not food?” was incorporated into the standard psychology consultation form used during new consultations. Additionally, spreadsheets used to document psychology productivity were modified to track and monitor whether a clinical encounter was a new consultation, and if so, whether the screening question was completed. All psychology providers regularly used these tools, thus lending to the ease of integrating these primary solutions to address clinician forgetfulness. During the 3-month duration of PDSA cycle 2, an average of 98% of all patients with SCD newly referred to psychology were screened for pica. Over the course of this cycle, data regarding the implementation of pica behavior screening were reviewed regularly by examining the productivity spreadsheets. Data were presented to all psychology providers during monthly staff meetings. Psychology staff agreed that solutions imposed had reduced the potential for clinician forgetfulness but continued to express concern that the systematic assessment of the consumption of nonfood items was not necessarily indicated for all patients in the absence of warning signs. Analysis of the data collected across the first 5 months of the QI initiative revealed that the consumption of nonfood items had been identified in only one patient not diagnosed with SCD.

**PDSA 3.** In response to provider feedback, in August 2013 the third PDSA cycle was developed to focus assessment on those patients most at risk. The systematic assessment of pica behaviors for patients diagnosed with SCD was maintained. For all other medical diagnoses, psychology providers were to use clinician judgment to determine whether pica screening was necessary. During this 8-month cycle, an average of 98% of newly referred patients with SCD were documented as having been screened for pica. By month 8 of the 12-month QI project, psychology providers were consistently documenting assessment for pica behaviors in 100% of new consults for SCD. The QI project was continued for the planned 12-months to ensure sustainability, meet institutional expectations, and allow for the expansion of original goals.

During the project period, 49 patients endorsed either a history of or current consumption of nonfood items, resulting in an overall identification rate of 28%. Across the three hospital sites, pica behaviors were identified in 34% of patients (n = 79 consults), 21% of patients (n = 66 consults), and 25% of patients (n = 31 consults). Chi-square analyses indicated that the rates of pica behaviors did not statistically differ by hospital site, \( \chi^2 = 3.09, p = .21 \).

**QI Project Expansion**

Given rates of pica behaviors identified, system-wide changes were planned and implemented as an expansion of our original QI project’s goals. A Pica Working Group was formed in October 2013, consisting of specialty areas of psychology, nursing, and medicine. Membership in the Pica Working Group was based on provider interest. Psychology providers recruited members from the SCD teams at all three hospital campuses through word-of-mouth and emails sent to all SCD team members. Efforts were made to recruit members from different disciplines to ensure representation of viewpoints and all hospital campuses. This group met monthly starting in December 2013 with goals to promote awareness of pica behaviors within the hematology/oncology division and develop multidisciplinary treatment plans. Further, the working group sought to broaden the scope of screening for pica behaviors in...
patients with SCD, particularly because all patients with SCD are not referred to psychology and, thus, a significant subset of patients with pica behaviors may be missed. The working group evaluated the addition of the screening question to the review of systems, which was routinely conducted by nursing during every outpatient clinic visit for all patients with SCD. The electronic medical record was modified to include the screening question into the review of systems for ease of charting and documentation by nursing staff. Inclusion of the pica screening question into the electronic charting system ensured that all patients with SCD, including those not seen by psychology, would be assessed for pica behaviors. Working group members anticipated potential barriers to implementation from nursing, such as time constraints and limited buy-in. To address these barriers, working group members conducted in-service training for nursing staff on the purpose of assessment and the identified need based on data collected during PDSA cycles 1 through 3. Nurses did express initial concerns that the systematic assessment of pica behaviors would be a burden to their workflow. As nurses began having patients endorse pica behaviors and as nurses attended the Pica Working Group information sessions, however, buy-in grew and nurses were increasingly enthusiastic about incorporating the assessment of pica behaviors into their workflow.

Planning for Maintenance of Gains

Strategies for monitoring and maintaining the progress made through this QI project were implemented within the hospital system. These strategies were important for making the systematic assessment of pica behaviors part of providers’ workflow. In addition, we were anticipating the hire of new psychology providers along with regularly rotating trainees, so we wanted to ensure that all current providers were confident in the implementation of the project before new providers were added. As a first strategy to maintain gains, a process owner within psychology was identified (Thompson) to take responsibility for reviewing assessment data, to train incoming providers in the assessment and documentation protocols, and to provide regular feedback to all staff. Our process owner is also a member of the Pica Working Group and communicates regularly between the working group and all psychology providers. Second, psychology providers modified the regularly used consult template in the electronic medical record to include the patient’s response to the pica screening question and follow-up questions as necessary. Additions to the paper consult form and the productivity logs for documenting assessment were maintained, and all new providers and trainees are provided instruction on their use and taught to regularly assess for pica behaviors in patients with SCD.

Discussion

Implementing a systematic change in regular clinical practice across providers practicing in different settings at multiple hospitals is challenging, regardless of the perceived importance or seeming simplicity of the change. In this article, we describe the use of QI science to improve the standardized assessment of pica behaviors in patients with SCD across our 3-hospital system. It was clear from clinical and anecdotal experience that pica was an under-identified and undertreated problem. In less than a year, a team of 8 psychology providers across 3 sites increased the rate of systematically screening for pica behaviors in youth with SCD from 36% to 100%. In fact, providers not only consistently improved the rate of screening for pica behaviors, but also maintained a consistent 100% assessment rate for the five final months of the QI period. Notably, these improvements were not achieved without expected barriers. Including a prompt for the assessment of pica behaviors on the commonly used consultation form as well as modifying the psychology productivity logs to track and monitor provider adherence aided in addressing problems with forgetfulness and set the stage for future providers to systematically assess for pica behaviors.

Assessment results indicated that between 21% and 34% of patients with SCD seen by pediatric psychology endorsed a history of or current pica behaviors. Overall, incidence rates for this sample were consistent with past research on prevalence rates of pica behaviors in youth with SCD (Ivascu et al., 2001), and resulted in several systemic implementations within the hospital to better meet the needs of patients with pica behaviors. The formation of
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the Pica Working Group encouraged interdisciplinary collaboration on medical, behavioral, and social strategies for addressing pica behaviors and providing appropriate treatment. Through the working group, the electronic medical record was modified to include the assessment of pica behaviors during the nursing review of systems. This modification allowed for all patients with SCD, not only those seen by psychology, to be assessed for pica behaviors. Once pica behaviors are identified, providers can undergo further assessment from medical and psychology providers to inform collaborative treatment recommendations and facilitate outpatient referrals, as necessary.

Despite improvements in care achieved, this project has limitations that are important to address. A discussion of the challenges encountered throughout the QI process will hopefully be informative to readers embarking on new QI work. First, baseline screening data were not collected systematically before the onset of the QI project, as recommended in the conduct of QI work (Schurman et al., 2015). We addressed this limitation by conducting a retrospective chart review, though future QI initiatives will begin with baseline data. Second, we initially encountered varying levels of buy-in from psychology providers. Differences in perception of need were likely attributable to working in different settings (e.g., multidisciplinary specialty clinics, consultation-liaison) and with a variety of hematology/oncology diagnoses, some of which experience lower rates of pica behaviors. For providers accustomed to providing brief assessment and focused intervention around a specific referral question, pica behaviors were not necessarily considered as primary presenting concerns to be addressed. To increase consistent buy-in, project leaders balanced justification of systematic assessment with taking note of psychology providers’ concerns. Providers’ feedback was incorporated throughout the QI process, with systematic assessment of pica behaviors retained only for patients diagnosed with SCD in PDSA 3.

As providers saw their concerns impacting the QI process, buy-in and participation grew. Across the psychology service, the process of implementing a QI initiative generalized to other clinical problems. Providers described increased comfort with operationally defining the scope of clinical problems and integrating step-wise solutions to minimize provider burden. Once detection rates increased with regular assessment, the provision of appropriate treatment recommendations became paramount. Given the large geographical region served by our hospital system, this meant locating appropriate providers for the provision of behavioral therapy, which was oftentimes challenging. To address immediate treatment needs, members of the Pica Working Group developed a Pica Toolbox consisting of resources for patients and families. Resources included educational handouts describing pica and its prevalence in patients with SCD as well as behavioral strategies for addressing pica within the home (e.g., monitoring, reduced access, behavioral plans). Providers also worked to develop a shared referral list with providers across our geographic area, though adequate referrals, especially in rural areas accepting Medicaid, remain problematic.

Building on the success from this QI project, we intend to pursue future QI initiatives on the provision of interdisciplinary treatment for pica within established comprehensive SCD clinics. Future initiatives will occur within the context of ongoing monitoring of gains made through the current QI initiative with emphasis on maintaining regular screening for pica behaviors, especially as new providers join. Further, building on lessons learned from this project, our psychology providers have become increasingly interested in working with hospital administration to implement quality improvement with other populations and problems.

References


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