Minding the gap in pediatric headache care

Can a focus on quality measures improve outcomes?

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Abstract

Background

The American Academy of Neurology Headache Quality Measures seek to improve care delivery and outcomes by addressing gaps in care. Our practice identified underperformance in 3 of the 7 measures that apply to children and adolescents. We expected that improved performance on these measures would lead to a reduction in emergency department (ED) visits and improvement in the average disability grade of established patients.

Methods

An interdisciplinary workgroup used the Institute for Healthcare Improvement's Model for Improvement. Quality improvement (QI) interventions focused on the use of Pediatric Migraine Disability Assessment (PedMIDAS), headache action plans (HAPs), nurse triage, and infusion center order sets.

Results

Provider use of PedMIDAS increased from 15% to 55% ($p < 0.0001$) of patient visits during the comparison period. Generation of HAP letters increased from 10% to 15% ($p < 0.0003$), but these gains were not sustained. ED visits for headache decreased by 32% ($p < 0.0001$). The average migraine disability grade remained unchanged.

Conclusions

QI efforts using team-based strategies and electronic medical record (EMR) integration can improve performance on headache quality measures, although it may be difficult to demonstrate improved patient outcomes. The project's time frame and disability assessment strategy were likely insufficient to detect a change in disability. Optimization of nurse triage and EMR workflows enabled more patients with status migrainosus to receive their treatment in the infusion center rather than the ED with a favorable revenue benefit for the hospital.

Nearly 60% of children worldwide experience recurrent headaches.¹ Approximately 12% of all adolescents and adults in the United States have migraine, and approximately 1% of them suffer from chronic daily headache.² Children with chronic headache experience considerable disability including decreased school attendance, parent work absences, poor quality of life, and high rates of anxiety and depression.³

Despite the availability of evidence-based care guidelines, treatment of pediatric headache often deviates from these recommendations. Fewer than 1 in 5 adolescents with chronic migraine takes a daily preventative medicine.⁴ Nearly 20% of migraine sufferers are prescribed

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opioids for acute headache treatment despite an associated risk of dependence and higher rates of anxiety and depression, disability, and emergency department (ED) utilization²

In 2014, the American Academy of Neurology (AAN) published a set of 10 Headache Quality Measures (HQM) targeting known problem areas: overuse of neuroimaging, underuse of preventive therapies, inappropriate use of acute treatments, and undertreatment of comorbidities.⁵ Seven of the 10 HQM apply to children or adolescents. We initiated a quality improvement (QI) project to appraise our providers' performance on these measures and devise a strategy to improve the quality of care provided to headache patients throughout our practice. Anticipating that improved performance would lead to better outcomes, we established a priori specific aims of a 30% reduction in ED visits for established patients and an improvement in disability by one-half grade level as measured on PedMIDAS' four-level grading scale.

Methods

The setting was a large academic pediatric neurology practice serving children across 5 states in the US Mountain-West. The practice sees over 300 patients with headache each month with approximately 12.5% seen by 1 of 3 headache subspecialists and 87.5% by 1 of 48 general neurology providers.

A doctor of nursing practice (DNP) student led the project as part of his Capstone requirement. An interdisciplinary team was formed that included physicians, advanced practice providers and nurses from neurology, a physician from the ED, a psychologist from behavioral health, and a charge nurse from the infusion center (IC). The Institute for Healthcare Improvement's Model for Improvement provided the framework for this project.⁶ The workgroup determined a priori that a baseline compliance rate of less than 75% would indicate inadequate performance on each measure (figure e-1, links.lww.com/CPJ/A81).

The target population was defined in an existing clinical care pathway as all children and adolescents aged 8–17 seen for a primary headache disorder including migraine and tension-type headache.⁷ “Active patients” were those who had been seen in the outpatient clinic between March 1, 2015, and February 29, 2016. Visits to a subspecialty clinic for

a primary complaint unrelated to headache and procedure-only visits (e.g., onabotulinum toxin or nerve blocks) were excluded from the denominator for process measures, as headache questionnaires are not typically completed at these visits.

A retrospective chart review from a sample of 10% of all patients with a primary headache diagnosis seen in the neurology clinic during a 1-month period ($n = 39$) showed that providers were performing adequately ($\geq 75\%$ adherence) on 4 of the HQMs and poorly ($< 75\%$ adherence) on 3 others. Measures identified for improvement included the following: (1) patients' headache-related quality of life measurements stayed the same or improved; (2) headache-related disability was assessed; and (3) a headache self-management plan was created. Of interest, all the headache subspecialty providers were meeting these standards at baseline, whereas the general providers were not. Workgroups targeted each of the 3 underperforming measures by selecting specific interventions and conducting a series of Plan-Do-Study-Act (PDSA) cycles to test, refine, implement, and disseminate changes across the practice.

Assessment of headache disability and quality of life

The Pediatric Migraine Disability Assessment (PedMIDAS) is a 6-item patient-completed survey assessing 3 domains of headache-related disability for children aged 4–18 years: school attendance, fulfillment of responsibilities at home, and participation in social and athletic activities. It is the only pediatric headache disability measure with established validity and reliability with an internal consistency of 0.78 and a test/retest reliability of 0.80.⁸ Patient disability is graded as “Little to none” (score 0–10), “Mild” (score 11–30), “Moderate” (score 31–50), or “Severe” (score > 50). According to the AAN Measurement Set, improvement in quality of life is inferred from a reduction in the PedMIDAS disability grade; therefore, PedMIDAS may be used to address both measures 8 and 9.⁵

Initial PDSA cycles targeted PedMIDAS distribution in the outpatient clinic with a registered nurse (RN) obtaining a preprinted form from the workroom and asking the patient to complete it while she gave report to the provider. The first cycle demonstrated that the PedMIDAS could be completed within 5 minutes; however, fewer than 50% of patients were given the form. A hyperlink was added to the RNs' electronic medical record (EMR) template, which prompted them to print and distribute PedMIDAS while still in the examination room. This improved the PedMIDAS distribution rate to $> 80\%$ through 2 follow-up cycles.

A second series of PDSA cycles focused on the collection and interpretation of disability scores. Providers were introduced to PedMIDAS at a faculty meeting. An EMR flow sheet was created to facilitate data entry, and a synopsis report allowed providers to view and graph changes in

disability scores over time. Provider education and EMR modifications did not improve PedMIDAS collection rates; however, when providers were given individual feedback on their performance relative to the group, PedMIDAS use increased from 15% at baseline to more than 55% within 3 months (figure 1).

Improvement in headache disability and quality of life

Research shows that clinicians often underestimate the burden of headaches on patients' lives⁹ and that knowledge of "the functional consequences of headache has been shown to positively affect physicians' perceptions and prescribing behavior... and may uncover the need for more aggressive and/or comprehensive treatment plans".¹⁰ Thus, the use of PedMIDAS was expected to not only measure headache disability but to encourage clinicians to treat headaches more aggressively when warranted. To reinforce this concept, our headache psychologist held a faculty seminar teaching providers additional strategies for improving patients' functional capacity as a means of decreasing their disability.¹¹ Providers were encouraged to recommend behavioral interventions that emphasized healthy behaviors (sleep, hydration, diet, and exercise), active coping skills, goal setting, pacing, normalization of routine, and clarification of parental roles (e.g., promote child self-efficacy and avoid pain-reinforcing behaviors) to improve patient functioning.

Provision of written action plans

For more than a decade, headache guidelines have recommended the use of customized action plans to promote patient self-management of recurrent headaches.^{7,12–14} In

2018, the American Headache Society published a Migraine Action Plan that included the patient's headache diagnosis, daily prevention strategies, acute home treatments, indications for emergency care, and an ED management plan that specified medications to avoid due to known proclivity to exacerbate migraines.¹⁵ Although evidence for the efficacy of headache action plans (HAPs) is lacking, written action plans for children with asthma (another acute-on-chronic condition) have been shown to reduce the number of ED visits and disability due to school absences.¹⁶

A PDSA series targeted the creation of HAP letters at each visit. Letters were chosen because they could be quickly located by triage nurses and easily tracked using EMR reports. Providers found letter production to be redundant and cumbersome, adding several minutes to each visit. Subsequent cycles incorporating a HAP script into the EMR visit template improved the inclusion of action steps in visit notes but did not increase the number of letters generated. A third cycle used electronic bookmarks to bracket the script within the visit note and copy it automatically into a letter template. Unfortunately, the resulting change in the letter's appearance disrupted the existing workflow and letter production decreased from 17% to 7% (figure 2).

Use of nurse triage and infusion center

The headache nurse coordinator developed and piloted a nurse telephone triage script that reinforced each step of the HAP and screened infusion candidates for signs of secondary headache. An EMR order set was created to streamline insurance authorization and scheduling. A second-order set

Figure 1 Percent of patients with PedMIDAS collected at visit, P chart

Control chart showing the percent of patients with headache who completed a PedMIDAS by month. Control charts use upper and lower control limits set at 3 SDs from the mean to determine when a process has departed from its historical pattern of variability. Avg = average; LCL = lower control limit; UCL = upper control limit.

Figure 2 Percent of patients receiving headache action plan letter at visit, P chart

Control chart showing the percent of clinic patients with a headache diagnosis who received an action plan letter at their visit by month. Avg = average; ED = emergency department; EMR = electronic medical record; LCL = lower control limit; UCL = upper control limit.

adapted from a standard infusion protocol facilitated provider order entry.¹⁷

Measures

For the primary outcome, a decrease in the number of patients visiting the ED for acute headache from a baseline level of 1.42% to a target of 0.90% or better, a sample size of 7532 was needed to achieve a power of 0.80 and $\alpha = 0.05$. This sample size was achieved by comparing 12 months of preintervention data to 12 months of postintervention data. A 2×2 contingency table was created to calculate differences between preintervention and postintervention groups. Chi-square analysis determined the probability that change was not due to random variation. An effect size was reported to show the magnitude of the change.

For the secondary outcome, change in PedMIDAS disability grade, an effect size of 0.5 required a sample of 64 patients in the pre- and post-intervention group analysis. This was achieved by comparing data from September 2014 to February 2015 (100 patients) with the corresponding data from September 2015 to February 2016 (104 patients). The Mann-Whitney *U*, a nonparametric statistical test was chosen to analyze the change in pre- and post-intervention groups.

Process measures included the percentage of patients with PedMIDAS collected and a HAP letter generated at their visit. The workgroup established a priori a target of 50% compliance for both measures as achievable within the project's time frame. All patients with a headache diagnosis were included in the denominator for each measure. Monthly EMR reports provided data for the control charts used to monitor process and outcome measures.

Standard protocol approvals, registrations, and patient consents

The protocol was approved by the College of Nursing's DNP Capstone Bridge Committee and determined to be human subjects exempt by the hospital's Organizational Research Risk & Quality Improvement Review Panel under the authority of the University's Multiple Institutional Review Board. The project was administratively supported and funded by the authors' institution.

Data availability

Anonymized data will be made available to any qualified investigator upon request.

Results

PedMIDAS collection rates increased from 15% to 55% during the comparison period (March 2014–February 2015 vs March 2015–February 2016). This exceeded the process goal of 50% (odds ratio [OR] = 0.49; 95% confidence interval [CI] [0.43–0.55], $p < 0.0001$; effect size: 0.25). The production of HAP letters also increased from 9% to 15% (OR = 0.77; 95% CI [0.68–0.88], $p < 0.0003$; effect size: 0.17), although this gain was not sustained after changes to the HAP letter template were made.

The percentage of established patients using the ED for acute treatment decreased from 0.83% to 0.54% (263–181 patients) during the 12-month comparison period (OR = 1.64; 95% CI [1.34–2.00]. $p < 0.0001$, effect size: 0.31) (figure 3). Comparison of the average disability grade between independent groups before and after the intervention yielded a *U* value of 11.5, well above the critical *U* value of 5 (at $p \leq 0.05$). The *Z*-score was 0.9608, and $p = 0.34$ indicating that the average PedMIDAS disability grade did not improve from baseline.

Our group was successful in focusing a large pediatric neurology practice toward the common goal of improved performance on national quality measures.

IC use increased from an average of 4 patients per month in 2014–2015 to 11 patients per month in 2015–2016, whereas the monthly number of ED visits decreased from 23 to 19 during the same period (figure 4).

Discussion

Our group was successful in focusing a large pediatric neurology practice toward the common goal of improved performance on national quality measures. Indeed, both process measures showed improvement with HAP use increasing by 50% ($p < 0.0003$) and PedMIDAS collection increasing 5-fold ($p < 0.0001$). Despite the small effect size, control charts (a measure of statistical process control) showed a deviation of more than 3 SDs, thereby confirming a change in both processes. Attempts to further improve our performance on HAP letters by automating this process backfired and its use returned to baseline levels. This experience illustrates how disrupting existing processes can sometimes worsen performance and underscores the value of using control charts to measure process variation in real time.

What remains unclear is whether any of the interventions aimed at improving our performance on the AAN's HQMs resulted in improved patient outcomes. Although there was

a sizable decrease in the number of established patients visiting the ED for acute migraine, it is unlikely that this can be attributed to the increased use of HAPs, given the low magnitude of this increase (5% above baseline and 15% of the total patients). Rather, we suspect that the reduction in the number of ED visits was due to changes in our nurse triage system and a streamlined infusion order entry and insurance verification process. Our triage and referral practices shifted away from sending established patients to the ED for migraine management in favor of the IC. The associated cost savings of treating a patient in the IC rather than the ED was estimated to be \$1,808.75 per visit (based on average ED vs IC charges for administering the same cocktail). A total of 358 patients received infusions between March 2015 and February 2016, 132 (37%) in the IC and 226 in the ED (63%). If the preintervention rate of IC use had persisted at 14%, we would have expected only 50 patients to have been treated in the IC. Therefore, 82 patients who would have received treatment in the ED were treated in the IC with an estimated cost savings of \$148,317.50.

We were also unable to show that administering PedMIDAS assessments and teaching providers how to address disability resulted in any improvement in disability grades. Although it was encouraging that functional disability assessments were performed more frequently, the lack of improvement in PedMIDAS grades suggests that a 1-time training of providers was insufficient to prepare them to adequately address functional disability. Ongoing training of medical providers and integration of clinical psychologists into medical teams might better address both the medical and behavioral health factors contributing to functional disability.

Detecting a change in disability was further hampered by our decision to measure a change in PedMIDAS grade rather than a change in score. This was done to modulate

Figure 3 Number of ED events per established patient, U chart

Control chart showing the number of ED visits (events) per established headache patient (unit) by month. Avg = average; ED = emergency department; EMR = electronic medical record; LCL = lower control limit; UCL = upper control limit.

Figure 4 Infusions for status migrainosus by location

the effect of very high (outlier) scores at baseline. Unfortunately, a change in grade can be harder to appreciate than a change in score. Disability grades are analogous to a school's "A–F" grading scale, which assigns an "A" to scores of 90% and above and an "F" to scores of 50% and below. Just as a student with an "A" can never hope to improve her letter grade, a patient with a PedMIDAS grade of "little to none" will not see a change in grade even if her score drops from 10 to zero. Similarly, patients with PedMIDAS scores over 100 could improve their score by more than 50 points and still be classified "severe" or "failing" despite experiencing a vast improvement in disability. Because our collection processes relied on the providers to enter PedMIDAS data, it is possible that providers were more likely to enter the data when disability was known to be an issue and less likely to enter it when little to no disability was identified. Collection methodology was much more rigorous in the baseline cohort of study patients.

Limitations

There were several limitations to the project. Although we suspect that PedMIDAS assessments improved providers' use of appropriate prevention and acute medications, this measure was not evaluated because of adequate performance at baseline. We were unable to obtain data on established patients seen at outside EDs for acute headache management because of EMR incompatibility with other health care systems. Adding a question about the patient's last ED visit to the EMR template could have remedied this. PedMIDAS' high weighting for school attendance and school functioning may limit providers' appreciation of headache disability during summer months.¹⁸ Disability assessments for non-English-speaking patients are limited by the lack of non-English PedMIDAS translations. Although no adverse events were reported, we did not specifically collect data on patient outcome or

satisfaction differences between the ED and IC. Unintended consequences included an increase in the overall number of infusions provided during the intervention period. The increased demand for infusions often exceeded IC capacity, which likely diminished the effect of this intervention on ED utilization. Informal feedback from the nursing staff indicated that the new telephone triage script added several minutes to each headache call.

This QI project sought to apply evidenced-based best practices within a local setting; however, some of these strategies may not be transferable to other settings. Having a 1:3 nurse-to-provider ratio facilitated PedMIDAS collection, permitted nurse triage of infusion candidates, and facilitated infusion scheduling. Capabilities of the EPIC EMR (Epic Systems Corporation, Verona, WI) including templates, hyperlinks, flow sheets, and synopsis reports facilitated the collection and reporting of PedMIDAS data over time. Strong institutional support for QI allowed the project leader and team members to attend quarterly meetings and facilitated interdepartmental cooperation within the institution.

Conclusion

Large-scale QI projects often require a considerable investment in time and resources from the sponsoring institution. Assembling the right interdisciplinary team and aligning the project with institutional priorities are critical to success. Control charts are essential for detecting process changes in real time, enabling team members to evaluate the effects of PDSA cycles, correct for worsened performance, and provide a visual progress report to all stakeholders involved.

Convincing highly autonomous individuals to behave differently is a challenge. Simply informing providers about the quality measures was insufficient to motivate compliance,

TAKE-HOME POINTS

- Large-scale QI projects often require a considerable investment of time and resources; aligning the project with institutional goals may enhance buy-in
- Control charts are essential for detecting and responding to process changes in real time
- Providers often struggle to assimilate change; embedding quality measures within EMR templates, automating processes, and providing feedback may facilitate implementation
- Further study is needed to determine whether better process performance produces better outcomes

but giving them individual feedback appeared to prompt robust change. In general, we found that changes that required more time and effort were poorly assimilated and those that facilitated “doing the right thing” were readily adopted. Giving providers adequate time and nursing support to address key quality indicators seems essential for improving performance. Incorporating HQMs into a practice’s documentation templates and automating the production of HAP letters may facilitate implementation and tracking of these measures.

Although we could not conclude that using PedMIDAS and generating HAPs improved our primary outcomes, our practice’s performance improved on key quality measures and our institution realized measurable cost savings. Implementing evidence-based practices consistent with the AAN HQMs has the potential to improve the quality of care in this challenging patient population, but further study is needed to determine whether better process performance produces better outcomes.

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Scott B. Turner, DNP	University of Alabama at Birmingham	Author	Conceptualized and designed the project; supervised all aspects of project; collected and analyzed the data; and drafted the manuscript
Amanda Foss, BSN	Children’s Hospital Colorado	Author	Major role in design and implementation of interventions; collected and analyzed the data; and revised the manuscript for intellectual content
Jessica Malmberg, PhD	University of Colorado	Author	Major role in design and implementation of interventions
Jennifer Disabato, DNP	University of Colorado	Author	Assisted with project design and implementation and revised the manuscript for intellectual content

References

1. Abu-Arafeh I, Razak S, Sivaraman B, Graham C. Prevalence of headache and migraine in children and adolescents: a systematic review of population-based studies. *Dev Med Child Neurol* 2010;52:1088–1097.
2. Buse D. Understanding Research: What is the American Migraine Prevalence and Prevention (AMPP) study and what have we learned from it? [Internet]. American Migraine Foundation; 2016. Available from: achenet.org/resources/ampp_study/pub/. Accessed February 22, 2015.
3. Rothner AD. Advancing Patient Care: Chronic Daily Headaches in Adolescents Are Major Medical, Family Problem. [Internet]. Cleveland Clinic Consult QD; 2014. Available from: consultqd.clevelandclinic.org/2014/12/chronic-daily-headaches-in-adolescents-are-major-medical-family-problem/. Accessed February 24, 2015.
4. Lipton RB, Manack A, Ricci JA, Chee E, Turkel CC, Winner P. Prevalence and burden of chronic migraine in adolescents: results of the chronic daily headache in adolescents study (C-dAS). *Headache* 2011;51:693–706.
5. American Academy of Neurology. Headache Quality Measurement Development Work Group. Headache Quality Measurement Set. Minneapolis: The Association; 2014:78.
6. Institute for Healthcare Improvement. The Breakthrough Series: IHI’s Collaborative Model for Achieving Breakthrough Improvement. IHI Innovation Series white paper. Available from: ihi.org/resources/Pages/IHIWhitePapers/TheBreakthroughSeriesIHI’sCollaborativeModelforAchievingBreakthroughImprovement.aspx. Accessed February 6, 2016.
7. Kedia S, Jorgensen J, Perry S, Pickard D. CHCO Clinical Care Guideline for the Outpatient Management of Primary Headache. [Internet]. 2013. Available from: childrenscolorado.org/File%20Library/Conditions-Programs/Neuroscience/Headache-Outpatient-Clinical-Care-Guidelines.pdf. Accessed February 6, 2016.
8. Hershey AD, Powers SW, Vockell AL, LeCates S, Kabbouche MA, Maynard MK. PedMIDAS: development of a questionnaire to assess disability of migraines in children. *Neurology* 2001;57:2034–2039.
9. Holmes WF, MacGregor EA, Sawyer JP, Lipton RB. Information about migraine disability influences physicians’ perceptions of illness severity and treatment needs. *Headache* 2001;41:343–350.
10. Buse DC, Rupnow MFT, Lipton RB. Assessing and managing all aspects of migraine: migraine attacks, migraine-related functional impairment, common comorbidities, and quality of life. *Mayo Clin Proc* 2009;84:422–435.
11. Lynch-Jordan AM, Sil S, Peugh J, Cunningham N, Kashikar-Zuck S, Goldschneider KR. Differential changes in functional disability and pain intensity over the course of psychological treatment for children with chronic pain. *Pain* 2014;155:1955–1961.
12. Beithon J, Gallenberg M, Johnson K, et al. Diagnosis and Treatment of Headache. Institute for Clinical Systems Improvement. Available from: icsi.org/_asset/qwrznq/Headache.pdf. Accessed February 6, 2016.
13. Gunner KB, Smith HD, Ferguson LE. Practice guideline for diagnosis and management of migraine headaches in children and adolescents: part two. *J Pediatr Health Care* 2008;22:52–59.
14. Papetti L, Spalice A, Nicita F, et al. Migraine treatment in developmental age: guidelines update. *J Headache Pain* 2010;11:267–276.
15. Peretz AM, Minen MT, Cowan R, Strauss LD. Introducing the migraine action plan. *Headache* 2018;58:195.
16. Ducharme FM, Bhogal SK. The role of written action plans in childhood asthma. *Curr Opin Allergy Clin Immunol* 2008;8:177–188.
17. Leung S, Bullock B, Yong C, Yonker M, Hostetler M. Effectiveness of standardized combination therapy for migraine treatment in the pediatric emergency department. *Headache* 2013;53:491–497.
18. Heyer GL, Merison K, Rose SC, Perkins SQ, Lee JM, Stewart WC. PedMIDAS-based scoring underestimates migraine disability on non-school days. *Headache* 2014;54:1048–1053.