

A Review of Best Practices for Monitoring and Improving Inpatient Pediatric Patient Experiences

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ABSTRACT

CONTEXT: Achieving high-quality patient-centered care requires assessing patient and family experiences to identify opportunities for improvement. With the Child Hospital Consumer Assessment of Healthcare Providers and Systems Survey, hospitals can assess performance and make national comparisons of inpatient pediatric experiences. However, using patient and family experience data to improve care remains a challenge.

OBJECTIVE: We reviewed the literature on best practices for monitoring performance and undertaking activities aimed at improving pediatric patient and family experiences of inpatient care.

DATA SOURCES: We searched PubMed, Cumulative Index to Nursing and Allied Health Literature, and PsychINFO.

STUDY SELECTION: We included (1) English-language peer-reviewed articles published from January 2000 to April 2019; (2) articles based in the United States, United Kingdom, or Canada; (3) articles focused on pediatric inpatient care; (4) articles describing pediatric patient and family experiences; and (5) articles including content on activities aimed at improving patient and family experiences. Our review included 25 articles.

DATA EXTRACTION: Two researchers reviewed the full article and abstracted specific information: country, study aims, setting, design, methods, results, Quality Improvement (QI) initiatives performed, internal reporting description, best practices, lessons learned, barriers, facilitators and study implications for clinical practice, patient-experience data collection, and QI activities. We noted themes across samples and care settings.

RESULTS: We identified 10 themes of best practice. The 4 most common were (1) use evidence-based approaches, (2) maintain an internal system that communicates information and performance on patient and family experiences to staff and hospital leadership, (3) use experience survey data to initiate and/or evaluate QI interventions, and (4) identify optimal times (eg, discharge) and modes (eg, print) for obtaining patient and family feedback. These correspond to adult inpatient best practices.

CONCLUSIONS: Both pediatric and adult inpatient best practices rely on common principles of culture change (such as evidence-based clinical practice), collaborative learning, multidisciplinary teamwork, and building and/or supporting a QI infrastructure that requires time, money, collaboration, data tracking, and monitoring. QI best practices in both pediatric and adult inpatient settings commonly rely on identifying drivers of overall ratings of care, rewarding staff for successful implementation, and creating easy-to-use and easy-to-access planning and QI tools for staff.

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Patient-centeredness is critical for high-quality health care¹⁻⁵ and is associated with positive health outcomes such as treatment adherence, receipt of preventive care, improved clinical outcomes, and lower health care use.⁶⁻⁸ Although less work has been done in pediatrics, patient- and family-centered pediatric care is associated with positive clinical outcomes, including reduced nonurgent emergency department visits, improved receipt of anticipatory guidance, and reduced unmet needs.^{5,9} Transformation from the traditional provider-centric model to a patient-centered model that is holistic, individualized, and relationship based is challenging. It requires changes in culture, resource allocation, staffing, training, collaborative teamwork, and a robust data collection and monitoring system.¹⁰⁻¹⁷

Collecting, monitoring, and using patient experience data is a common means of improving quality of care. Quality improvement (QI) activities are used to examine whether a program or practice meets implementation objectives such as improving the patient and family experience.¹⁸ QI efforts are aimed at determining evidence-based best practices or better practices on the basis of local context that can be incorporated into clinical decision-making processes. Effective QI requires incremental changes guided by measurement, monitoring, and performance feedback.¹⁹ Organizations can use patient experience data to assess current performance and evaluate progress in making improvements.

Assessments of the adult patient experience have demonstrated variation in performance across hospitals, health plans, and providers.^{20,21} Adult Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) studies have shown that scores can be improved^{22,23} and that positive characteristics of hospitals and providers, such as greater cultural competency, collaborative cultures,

and higher physician engagement, are associated with better scores.²⁴⁻²⁷ HCAHPS measures the patient experience in the adult inpatient setting, and there are no questions about pediatric inpatient care, such as communication of doctors and nurses with the parent or age appropriateness of care. The Child HCAHPS survey was developed to assess specific aspects of inpatient pediatric care. Child HCAHPS measures the pediatric inpatient experience by asking parents or guardians of patients aged <18 years with at least 1 overnight stay at a hospital to report on provider communication, attention to patient safety and comfort, and hospital environment.²⁸ It has 62 items: 39 patient experience items, 10 screening questions, 12 demographic and/or descriptive items, and 1 open-ended item. Child and Adult HCAHPS both have measures addressing communication with nurses, communication with doctors, responsiveness of hospital staff, the hospital environment, an overall rating of the hospital, and willingness to recommend the hospital. Even when composites address the same topic, their component items in some cases vary between the child and adult surveys (eg, Child HCAHPS responsiveness of hospital staff measure does not include such Adult HCAHPS items as help getting to the bathroom or using a bedpan). Child HCAHPS contains 3 domains not included in Adult HCAHPS: privacy, patient safety, and age appropriateness of care.

Importantly, Child HCAHPS enables hospitals with pediatric patients to assess their performance on patient and family experiences and make national comparisons of inpatient pediatric care. Child HCAHPS illuminates potential QI areas specific to pediatric inpatient experiences.^{28,29}

Given the increasing number of hospitals using Child HCAHPS, there is a need to understand best practices and lessons learned surrounding its use for QI. We review research on QI aimed at improving pediatric inpatient experiences

and identify lessons learned, barriers, facilitators, and implications for clinical practice.

METHODS

We reviewed how QI practices relate to improvements in pediatric inpatient experience. We adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines for quantitative studies, the Enhancing Transparency in Reporting the Synthesis of Qualitative Research approach for qualitative studies, and the Assessment of Multiple Systematic Reviews tool for literature reviews.³⁰⁻³²

Eligibility Criteria

We included (1) English-language peer-reviewed journal articles published from January 2000 to April 2019; (2) articles based in the United States, the United Kingdom, or Canada; (3) articles focused on pediatric inpatient hospital settings; (4) articles in which pediatric patient and family experiences were described; and (5) articles that included content on QI activities.

Information Sources and Search Strategy

We searched PubMed (Medline), the Cumulative Index to Nursing and Allied Health Literature, and PsychINFO (American Psychological Association) using the search terms noted in Table 1 in the title and abstract fields.

Data Collection Process and Data Items

Two researchers reviewed the full article and abstracted specific information: country, study aims, setting, design, methods, results, QI initiative performed, internal reporting description, best practices, lessons learned, barriers, facilitators and study implications for clinical practice, patient experience data collection, and QI activities. We noted themes across samples and care settings. Best practices were defined as a set of interrelated work activities repeatedly used by individuals or

TABLE 1 Search Strategy

Concept	MeSH	Search Terms	Syntax
Study setting	Hospitals, neonatal intensive care	Hospitals, pediatric, neonatal intensive care, pediatric unit, pediatric intensive care	((((English[Language])AND ("2000"[Date - Publication]: "3000"[Date - Publication])))AND ((Feedback OR "Feedback loop" "R "Internal report" OR "internal reporting" OR Monitor OR benchmark OR benchmarking OR Compare OR Trend OR "Information sharing" OR "personalized feedback" OR "Quarterly report" OR "Monthly report" OR "Executive committee" OR "Staff meeting" OR Dashboard OR "Self service reporting" OR transparency)))AND ("Quality improvement" OR "Performance improvement" OR "Process improvement Performance" OR CQI OR "Continuous quality improvement" OR "Plan do study act" OR "root cause analysis" OR Lean OR "Six sigma" OR "Learning collaborative" OR "Best practices"))AND ("patient experience" OR "patient experiences" OR "patients' experience" OR "patients experiences" OR "patient centered care" OR patient satisfaction [MeSH] OR "patient satisfaction" OR "customer satisfaction"))AND ("Hospitals, Pediatric"[Mesh] OR NICU OR "Neonatal Intensive Care" OR "Pediatric unit" OR PICU OR "pediatric intensive care")
QI	QI, root cause analysis, total quality management, practice guidelines	QI, performance improvement, process improvement, plan do study act, root cause analysis, Lean Six Sigma, learning collaborative, best practices	
Internal reporting	Feedback, benchmarking, information dissemination	Feedback, feedback loop, internal reporting, monitor, benchmark, compare, trend, information sharing, personalized feedback, quarterly report, monthly report, executive committee, staff meeting, dashboard, self-service reporting, transparency	
Patient experience	Child, patient-centered care, patient satisfaction, patient experience	Children, patient experience, patient-centered care, patient satisfaction	

MeSH, medical subject heading.

groups that a body of knowledge demonstrates will yield optimal results (ie, good patient outcomes). Lessons learned were defined as experiences and reflections discerned from a project

that should be considered in future similar projects. We reconciled differences through team discussion. The 10 identified themes are outlined in Table 2.

Synthesis of Results

We conducted a descriptive and thematic synthesis of included studies. We did not conduct a meta-analysis because of an inadequate number of randomized

TABLE 2 Summary of Thematic Synthesis

Theme	Articles ^a	Definition	Child HCAHPS Survey Composite
Designing, implementing, and evaluating QI efforts	16	Evidence-based approaches in designing, implementing, and evaluating QI efforts	N/A
Internal reporting	16	Internal system of communication of patient data to staff and hospital leadership	N/A
Role of patient experience data in QI	16	Patient experience survey instruments and how data were used to initiate and/or evaluate QI interventions	N/A
Patient and family feedback	5	Optimal times (eg, real time, at discharge, post discharge) and modes (eg, print versus e-mail versus text message) for patient engagement in providing feedback about their care and experiences	N/A
Staff training	4	Areas that require more and sustained staff training	N/A
Communication	4	Communication between parents or guardians and providers	Communication about your child's medicines; how well nurses communicate with your child; communication between you and your child's nurses; communication between you and your child's doctors; keeping you informed about your child's care
Patient safety	3	Tools and organizational features that empower patients and providers to focus on patient safety	Preventing mistakes and helping you report concerns
NICU	3	Care delivery in NICUs	N/A
Patient comfort	1	Steps taken to improve nursing pain knowledge and parental satisfaction with child comfort	Helping your child feel comfortable
Clinic environment	1	Approach to family-centered clinic design that can be assessed by patient and family experience of care	N/A

N/A, not applicable.

^a Articles do not add up to 25 because some articles covered multiple themes.

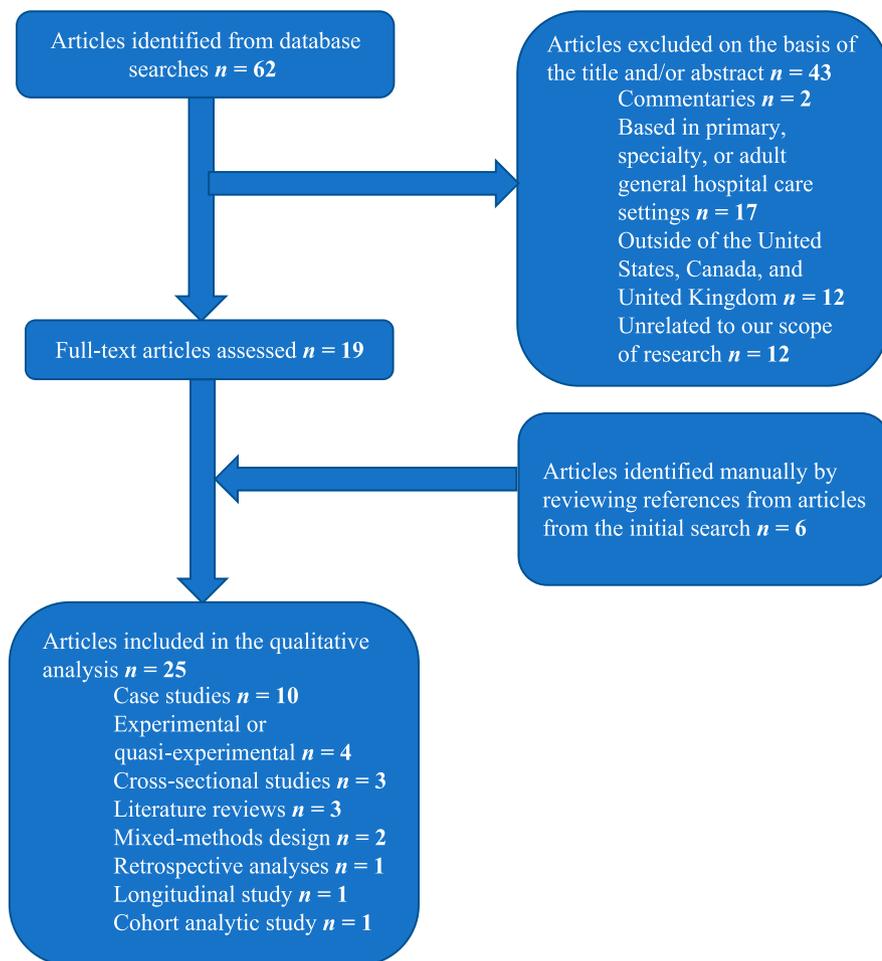


FIGURE 1 Summary of the search strategy.

control trials and heterogeneity of designs.

RESULTS

Study Selection

We identified 62 unique articles. The criteria used to identify 19 of these 62 for further review are shown in Fig 1. We manually identified 6 more articles by reviewing references of the articles. We included a total of 25 articles for analysis and abstraction of best practices and lessons learned for QI efforts aimed at improving inpatient pediatric patient and family experiences.

Study Characteristics

Of the 25 articles included, 19 (76%) were in the United States, 4 (16%) were in the United Kingdom, and 2 (8%) were in Canada. This included (see Fig 1) case studies, cohort studies, and experimental

interventions. In Supplemental Table 3, the 4 (16%) interventional studies are detailed; in Supplemental Table 4, the 8 (32%) noninterventional studies are shown; in Supplemental Table 5, the 10 (40%) qualitative studies are described; and in Supplemental Table 6, 3 (12%) literature reviews are summarized.

Risk of Bias Within Studies

Qualitative approaches were used in 10 (40%) articles, quantitative methods were used in 12 (48%) articles, and narrative reviews were employed in 3 (12%) articles. Of the 12 quantitative studies, 4 (33%) were interventional and used quasi-experimental designs.^{33–36} Reporting of outcome data was inadequate because none of the interventional studies included effect sizes, and they all employed uncontrolled before-after designs^{33–36} (with patient populations

that might have changed over time^{33–35}), which might have had practice changes not related to the intervention,³⁶ leading to possible overestimation of the effects of interventions.

Eight (67%) of 12 quantitative studies used noninterventional designs; of these, 3 (38%) used cross-sectional data,^{28,37,38} 2 (25%) used retrospective data,^{39,40} 1 (12%) used longitudinal data,⁴¹ 1 (12%) used cohort analyses,^{42,43} and 1 (12%) used mixed methods.⁴⁵ In these studies, the authors proposed care models or described processes (eg, patient engagement or hospital redesign). Their limitations included nonrandom sampling, different sample populations before and after (ie, provider data before and patient data after), use of survey tools with unknown psychometric properties, low survey response rates, and inability to draw causal inference.

Themes of Best Practices for Inpatient Pediatric Experiences of Care

We identified 10 themes of best practices (shown in Table 2 in order of frequency). We describe each below.

Designing, Implementing, and Evaluating QI Efforts

Sixteen (64%) studies included best practice recommendations on designing, implementing, and evaluating QI efforts in the pediatric setting. At the QI design stage, study authors highlight the importance of using evidence-based approaches, of early stakeholder involvement, and of ensuring leadership support throughout the QI effort.^{44,45} Several articles underline the need for institutional infrastructure to foster collaborative learning, team-based work, and pediatric staff communication.³⁴

Best practices for evaluating QI activities centered around ensuring meticulous tracking of data, use of pediatric-only indicators, and establishing national benchmarks.^{28,29,44–47} Organizational structure and culture were identified as key facilitators of QI for inpatient pediatric care. For example, when pediatric physicians are directly accountable to senior leadership they are more likely to engage in QI initiatives and use patient experience data

in their QI efforts.⁴⁸ Organizations that appoint specific pediatric leadership groups or QI champions are better positioned to conduct a staged approach to QI that includes setting goals, sharing data, motivating a culture of change, and negotiating complex issues.^{36,49,50}

Culture change included relying on evidence-based clinical practice, collaborative learning, and multidisciplinary teamwork.^{36,41} Regular management and committee and staff-level meetings, in which pediatric hospital staff feel safe to review existing evidence and performance, experiment, and raise issues about knowledge and practice deficiencies, are perceived as crucial to effective QI.^{36,41,51}

Barriers exist primarily around workforce and institutional capacity. Inadequate funding for pediatric patient experience improvement efforts, particularly when leadership is not fully committed to QI, makes it difficult to prioritize improvements in patient and family experiences among competing needs.⁴⁹ Such funding is needed for resources, staff time and software,⁴⁹ and QI consultants and coaches.^{36,50} Workforce-level barriers include staff shortages, insufficient QI knowledge and data analysis, low motivation, and workforce aversion to QI and collaborative learning. Staff-provided reasons for these barriers include perception of QI efforts as an opportunity to fail, particularly in the absence of institutional support and resources.

Internal Reporting of Performance Data

QI is facilitated by internal reporting of data. Whether the feedback is provided through regular team meetings or 1-to-1 in coaching sessions, ensuring that staff know and understand data trends and findings enables early identification of implementation issues and areas of need.^{45,48} Team huddles were identified as useful for clarifying patient care objectives, improving workforce morale, and consolidating multiple information sources.

Factors that undermined internal reporting of patient experience performance data included lack of physician involvement in and commitment to using data⁴⁸; lack of

understanding or expertise in data analysis and statistics among physicians, nurses, and administration; lack of resources to collect, analyze, or act on data⁴⁹; and limited electronic health record functionality.

Internal reporting of patient experience performance data is facilitated by having an organizational culture supportive of QI and performance improvement.⁵¹ The function of internal reporting is accentuated when organizations use benchmarking as a QI tool to identify opportunities.⁴⁷

Role of Patient Experience Survey Data in QI

Nine (75%) of the 12 quantitative articles included pediatric patient experience surveys. The resulting survey data were used for identifying and targeting new QI initiatives (eg, aiming to improve customer service, staff courtesy, discharge workflow, physician-family communication, patient education, or patient engagement)^{28,33,34,36–39,42} and motivating cultural change (eg, setting expectations and educating staff on discipline-specific best practice and standards of care).³⁶ The authors of 1 study noted that although pediatric patient experience data allow organizations to prioritize improvements, they yield limited tactical insights on how to effect change.⁴⁹ Such data need to be supplemented with observational data from trained staff to help the organization choose patient- and family-centered solutions.⁴⁹

Institutional policy recommendations for promoting the use of patient experience surveys include fostering an organizational culture that supports evidence-based change and QI, clearly allocating responsibility among units and departments, and ensuring that patient feedback is accurately attributed to the service level.^{34,44}

Patient and Family Feedback

In 5 (20%) articles, authors described best practices for maximizing patient and family engagement in providing feedback about their care and experiences. These included systematic administration of patient and family surveys,³⁹ survey administration to the parents and/or family at the point of discharge,⁵² discharge surveys

supplemented with real-time feedback on services,⁵³ and meaningful patient and family involvement in service and care provision redesign (ie, codesign).^{49,53}

Staff Training

Workforce development and staff expertise in various aspects of QI are essential to QI success.^{35,54} Data analysis empowers staff to adapt broader QI principles to their specific local context, identify local problems, and find solutions that can benefit a broader range of patients.^{33,35,37,38,41,48,54} In particular, training should be focused on exploring and understanding the context of care provision, on cross-cultural communication,⁵⁵ and on fostering autonomous learning by care providers.⁴¹ Cultural and multilingual competence of staff is especially important for patients and families with different ethnic backgrounds or with conditions such as autism spectrum disorders.^{35,48,54}

Communication

In 4 (16%) studies, the authors discussed best practices in communication between patients and families and the care team. These included nurse bedside communication with the child and parents or guardians³³; acknowledgment of the patient and parent or guardian as part of the care team, especially when symptom assessment rested primarily on parent or guardian report^{37,38}; and parents or guardians making staff aware about optimal ways to communicate with their child.⁵⁴

Limited Best Practices Specific to Neonatal care, Patient Safety, Patient comfort and Clinic Design

A limited number of studies included best practices related to NICUs, patient safety, patient comfort, and the design of the clinic environment.

NICU

In 3 (12%) studies, authors highlighted theoretical and practical evidence for patient-centered care models for NICUs, including family-integrated care (FIC)^{42,55} and FIC delivery.⁵⁰ Because infants in the NICU are physically separated from their parents or guardians, which often has an impact on the physical, psychological, and emotional

health of both parents or guardians and child, FIC is an approach to planning an delivering care that encourages greater parent or guardian involvement in their child's care. FIC consists of providing physical and educational support, emotional support, and opportunities for patients to role play caregiving skills to promote parent-child interactions, and build parent and guardian confidence.⁴² O'Brien et al⁴² found that the FIC model decreased parental stress between enrollment and discharge, whereas Lalani⁵⁵ argued that FIC encourages meaningful parent or guardian involvement in the child's care and enhances parent or guardian education and caregiving abilities.

Patient Safety

In 3 (12%) studies, authors discussed patient safety, including such practices as extending an error-prevention toolkit to patients and families to reduce preventable harm,⁴⁸ creating internal mechanisms for staff to report medical errors,⁵¹ and educating parents or guardians about cobedding practices (ie, child sleeping with parents or guardians or multiples sharing beds).⁴⁰ Coleman and Pon⁵¹ argue that a functional team that manages handoffs and communication at all phases of care can significantly affect patient and family experiences in PICUs. Kirby et al⁴⁸ and Polizzi et al⁴⁰ identified educational support through continuous feedback and review processes as an opportunity to empower parents or guardians to speak up when they feel they should, thereby increasing infant safety and improving patient and family experiences.

Clinic Environment

In 1 (4%) study, authors evaluated the process of family-centered hospital redesign with input from architects, care providers, and families.⁴³ Some lessons learned included the need to approach design through the eyes of the child (and parent or guardian) and consider patient privacy, space flexibility, daily noise, walking burden, and provider sight lines.

Child Comfort

In 1 (4%) study, authors evaluated the impact of a QI initiative related to the use of topical anesthetics, nursing pain knowledge,

and parent- or guardian-reported experience with child comfort.⁵⁶ The steps included a needs assessment, self-identified champions, data transparency, and a train-the-peer-trainer approach. Although no effect sizes were reported from the quasi-experimental design, authors documented increases in use of anesthesia (10%–36.5%), nursing pain knowledge (7% increase), and parent- or guardian-reported experience with child comfort (83%–88%). Success of the intervention was only anecdotal (ie, understood in the context of those involved with QI implementation and unit professionals who championed the initiative).

DISCUSSION

The literature reviewed here is consistent with findings from the adult inpatient setting. For example, results from 3 interventional studies align with the QI processes and communication themes we identified for pediatric hospital care. Brener et al⁵⁶ informed best practice communication between patients and the care team to improve patient experience by providing photographs of the care team on admission. Fleisher et al⁵⁷ and Gormley et al⁵⁸ underscore the need for early involvement of multidisciplinary teams and stakeholders. Evidence on the importance of staff training on survey methods and using faculty role modeling, peer mentoring, and peer observation supports our findings on the need for more and sustained staff training.^{59–61} Likewise, adult and pediatric QI approaches converge on the notion of creating a culture of improvement through measuring and incorporating patient experience data in QI processes.^{62–67}

Our review suggests that there are 2 gaps in the QI and patient experience literature. First, there has been insufficient evaluation of the relationship between quality measures and patient-reported health outcomes,²⁹ except in studies such as the one by Kahn et al⁶⁸, who found a significant relationship between ambulatory process of care and health-related quality of life. Second, more rigorous or multisite studies are needed to identify the specific barriers and facilitators perceived by staff in using patient experience data. Current evidence is

based primarily on case studies.^{10,69} Our review also identified another gap: empirical evidence of implementation success in pediatric care is limited; this gap is also evident in other care settings.

Overall our review revealed that parent- and/or family-reported patient experience data are vital to experiences of care in a pediatric inpatient setting. Such data help care teams identify and target areas of care that need improvement. Of the 10 emerging themes that identify best practices within inpatient pediatric care, most relate to the institution's structural organization of caring for children and families. Three of the 10 are related to specific domains of experience included in Child HCAHPS: communication, patient safety, and patient comfort.

Regarding specific QI strategies, we found evidence in the inpatient pediatric setting that leadership support is vital. Leadership is crucial because successful QI efforts require time, collaborative work, and financial investment in systems of data tracking and monitoring and in staff development. Internal reporting mechanisms are generally part of broader accountability structures, but to be successful in the inpatient pediatric setting, they require physician involvement, data expertise, and good team-based communication. QI best practices rely on data to identify areas of improvement, monitor progress, and reward staff for successful implementation. QI efforts and internal reporting of performance should be conducted as a complementary, unified effort. Finally, a change in culture toward embracing the use of data in decision-making occurs when QI and internal reporting rely on evidence-based clinical practice, collaborative learning, and multidisciplinary teamwork.

All 4 interventional studies and all 3 literature reviews were based in the United States. One of the noninterventional studies (in the United Kingdom) was focused on using patient-reported outcome tools, and in another (in Canada), the FIC model was proposed. Of the 10 qualitative studies, 3 were based in the United Kingdom (2 were focused on national benchmark

development, and 1 was focused on using narrative or participatory feedback in QI) and 1 was based in Canada (on merits of FIC). The small amount of work and the absence of more rigorous designs to study QI and internal reporting in pediatric inpatient settings indicate that scientific evidence is in the early stages of development.

Our study is limited because of the heterogeneity of the articles we reviewed. External validity is a limitation for the 10 (40%) case studies that were focused on a single organization or system. Inferences to the United States from the 6 (24%) articles based in Canada or the United Kingdom are limited because of the differences in health systems. Several articles had unrepresentative samples ($n = 10$ articles, 40%), self-selected respondents ($n = 4$, 16%), small sample sizes due to low patient response rates ($n = 3$, 12%) or low physician response rates ($n = 1$, 4%), absence of patient-reported outcomes ($n = 3$, 12%), or high staff turnover ($n = 1$, 4%).

CONCLUSIONS

Although research on best practices for internal reporting and QI of inpatient pediatric patient experiences is in its early stages, studies to date offer several lessons. Existing research highlights the importance of leadership, information flow, and internal reporting of patient experience performance data. Organizations that appoint specific leadership groups or QI champions are better positioned to set goals, share data across departments, motivate a culture of change, and negotiate complex issues.

Previous research underscores 2 points on patient and family involvement. First, the inclusion of patients and families is crucial in all QI planning stages, especially in the earliest stages. Parents or guardians often find this involvement empowering and rewarding, whereas providers gain the unique perspective of patients and families, thereby aligning QI with patient and family priorities.

Second, it highlights the importance of administering, monitoring, and using data from patient experience surveys, such as

Child HCAHPS, that have pediatric-specific measures about the child's or the parent or guardian's experiences of care. Such data can be most effective in QI when they are circulated widely and frequently with providers in easily understandable formats to identify targets for improvement and compare or benchmark performance. Hospitals with pediatric patients can also assess their performance on patient and family experiences against national benchmarks. As organizations seek to implement QI initiatives to improve the pediatric inpatient experience, they need to understand how to best report performance data internally and how to incorporate these data into meaningful improvements of inpatient pediatric patient experiences.

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