The Value of Family Advisors as Coleaders in Pediatric Quality Improvement Efforts: A Qualitative Theme Analysis

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Abstract

Engaging family advisors in pediatric quality improvement (QI) efforts is well-studied in intensive care but less understood in other settings. The purpose of this study was to assess the perceived impact of including a family advisor as a colead on a QI initiative that successfully improved the family-centered timing of routine morning blood tests performed on pediatric inpatients. Five structured written reflections from core QI team members were analyzed using inductive thematic analysis and 3 major themes were identified. The first found that a family advisor's presence from the beginning of a QI initiative helps inform project design. The second determined that family partners working with residents fostered a better shared understanding of the role of trainees and caregivers in improving the quality of care. The third found that a family partner is an effective change agent to enact practice improvement, support professional development, and enhance resident education. Our qualitative analysis showed that engaging a family advisor as a colead influenced the design, implementation, and post-intervention impact of the initiative and improved family-centered outcomes.

Keywords

family advisors, family-centered interventions, qualitative theme analysis, patient and family experience

Introduction

The inclusion of patient and family advisors on quality improvement (QI) teams provides a myriad of positive benefits. These include better health care outcomes for patients, reduced medical errors, and perspective into adverse events, as well as increased patient and employee satisfaction (1–4). Patient advisors are individuals who have previously received health care within an organization, whereas family advisors are caregivers of patients. Both offer unique insights so organizations can better meet the needs of their clients (5).

The use of patient and family advisors in QI work is evolving. In one of the earliest descriptions of this role, Harrison led a group of family advisors in 1993 to author *The Principles for Family-Centered Neonatal Care*. This defined the need to build partnerships between parents and the health care team, laying the foundation for the role of family advisors in neonatal intensive care unit (NICU) QI work (6). Macdonell et al further described the value of partnering with NICU parents as key stakeholders, encouraging QI efforts to include parents as primary team members at the beginning of a project to apply principles of translational science to put an idea into practice (7). Czulada et al stipulated that including a family advisor as an equal member of the QI team was essential to inform project design and outcomes (8).

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Table I. The Institute for Patient- and Family-Centered Care (IPFCC)'s Framework for Family Involvement in QI and Classification.

Level I	Families complete surveys or engage in other evaluative activities as respondents (eg, focus groups).
Level II	Family advisory councils serve as a resource to the quality improvement team (eg, review projects, documents).
Level III	Families participate as occasional reviewers and consultants during an improvement project.
Level IV	Families participate as active members of improvement teams and/or may serve on unit-based task forces and committees and faculty for staff and clinician education.
Level V	Families are coleaders of improvement initiatives: They are fully integrated as critical members of the QI team at all levels. They codesign and lead tests of change for staff education.

Several industry leaders have published guidelines endorsing the use of family advisors in QI work. The Institute for Patient- and Family-Centered Care (IPFCC) proposed 6 key recommendations for creating partnerships within QI organizations, 3 of which focus on the necessary inclusion of patient and family advisors throughout the design, implementation, and evaluation phases of QI projects to optimize outcomes (9). Additionally, the Agency for Healthcare Research and Quality (AHRQ) has published an implementation handbook designed for patients, families, and health care professionals as a guide for incorporating the perspectives that patients and families lend to QI projects (1). Both the IPFCC and the AHRQ recommend inclusion of family advisors on activities such as quality committees, improvement and safety initiatives, and processes for reviewing data related to OI initiatives (1,9).

The IPFCC has proposed a framework for classifying the level of family involvement in the QI process, stratifying this into 5 levels: participants (I), advisory board or council members (II), occasional reviewers and consultants (III), ongoing advisors and consultants (IV), and at the highest level (V), coleaders (Table 1) (10). Health care organizations should strive to establish level V family advisor involvement in their QI initiatives (11).

Role of Family Advisors at Our Institution

Patient- and family-centered care has been a core value at our institution and a larger health care system for over a decade (12). Recent efforts have sought to engage family advisors in QI initiatives to enhance patient- and familycentered care and optimize outcomes (13). Standardized practices and specific mechanisms are not yet in place to support universal inclusion of family partners on improvement efforts. Furthermore, family advisors do not generally operate as coleaders (level V). The aim of this study was to assess the perceived impact of including a family advisor as a colead on a QI initiative to improve the family-centered timing of routine morning lab work performed on pediatric inpatients through a qualitative theme analysis.

Methods

Background: The QI Effort

The QI effort was conducted on the Pediatric Hospital Medicine service at a single-site urban medium-sized children's hospital in the Northeastern United States from March 2018 to September 2019. The multidisciplinary QI team included 12 hospitalists, a resident physician, 3 nurse practitioners, 2 nurses, a QI coach, an administrative assistant, and a family advisor who was the mother of a long-term patient cared for at the children's hospital. The effort aimed to ensure that 4 key aspects of medical care were consistently reviewed daily on rounds: intravenous Lines, Expiring orders, Antimicrobial therapy, and Diagnostic testing including bloodwork and imaging. To promote and standardize discussions, the LEAD mnemonic and rounding checklist were developed by coauthor M.S.L. with input from other QI team members.

With insight and guidance from the family advisor colead, a key intent of the Diagnostic testing domain was to address the psychosocial stress of overnight blood draws to improve the delivery of family-centered care. As a result, the percentage of lab tests ordered to be drawn after 7 AM was the primary outcome measure and utilization of the LEAD checklist was the process measure. The balancing measure included the percentage of labs obtained after 11 AM due to the potential for delays in care and discharges. To assess the impact of interventions, we applied the model for improvement framework and 5 Plan-Do-Study-Act (PDSA) cycles were implemented.

The QI effort successfully improved the primary outcome: the frequency of blood work ordered to be drawn after 7 AM increased from a baseline median of 24% to 65% postintervention and demonstrated a statistically significant shift. The QI effort supported patients and families being awake for lab draws, facilitated Child Life interventions to support coping, and improved the delivery of familycentered care.

Data Collection

To evaluate the perceived impact of including a family advisor as a colead on a QI initiative, 5 core team members from the larger multidisciplinary group were surveyed and written reflections to structured prompts regarding their experiences were obtained (prompts in Table 2). These included reflections from 2 hospitalist attendings, family advisor, QI coach, and resident physician. Members of the larger multidisciplinary QI team participated at varying levels but did not collaborate with the family advisor as deeply as the 5 core members. The core team consistently attended monthly meetings, codesigned PDSA cycles, educated staff, and were critically involved in the implementation and evaluation of the longitudinal QI effort. The institutional review board of our institution at the University of Rochester deemed the study exempt (STUDY00004219), and a waiver of consent was obtained from participants.

Qualitative Data Analysis

Reflections were analyzed for patterns of meaning and areas of interest, representative of each participant's personal reflection and overall experience. A qualitative theme analysis was conducted using the thematic analysis of Braun and Clarke as a guide (14). Two members of the larger multidisciplinary QI team examined reflections and identified similar responses that were coded as discrete ideas. Inductive coding methods were used to organize codes and quotations from each member's personal reflections into overarching themes and subthemes representing common perspectives and shared insights; these were collectively analyzed, reviewed, and refined to achieve consensus (15,16).

Table 2. Prompts for Written Reflection From Core TeamMembers.

- 1. What makes a high performing QI team in your perspective?
- 2. As a medical professional, do you incorporate experiences from your family life into your practice? If so, how?
- 3. Why is it important to have a family partner on QI teams?
- 4. How did the relationship between resident and family advisor partnership evolve in this project? What was the context that fostered this?
- 5. How did the LEAD project affect your definition of a team?
- 6. What experience from participating with the LEAD team will you incorporate in your long-term professional development?

Results

Three major themes were identified, each reflecting the value of including a family advisor on a QI effort and the positive impact study participants expressed (Table 3) (16). Selected quotations from participants relevant to the identified themes are listed below.

Theme 1: Building a QI Team Representative of Key Stakeholders

Crucial to the success of the QI initiative—titled "LEAD the Way"—was the focus on a model of improvement that aimed to engage patients and families in hospital-wide QI efforts. To achieve this, the team assembled representatives from various health care professions.

Assembling the multidisciplinary QI team. The team felt strongly that the inclusion of multidisciplinary members was essential to aligning goals and creating a shared agenda dedicated to improving the patient and family experience of care. The attending physician lead explained:

Ideally, a team should be multidisciplinary because different perspectives and skillsets allows a team to implement a QI project with success. QI is intended to improve a complicated system with many stakeholders, so the team needs to have representatives from varied levels of the healthcare system to be able to disseminate and conduct PDSA cycles.

The family advisor similarly commented:

A high performing QI team has team members that come from different backgrounds. This is important for team members to bring different ideas and perspectives...

With a shared vision and common goals among members from different professional backgrounds and skills, the team was able to develop a culture based on mutual trust and respect. A collegial atmosphere was formed where everyone's ideas and participation were deemed meaningful and valued.

Them	es	Subthemes	Code examples
Ι.	Building a QI Team Representative of Key Stakeholders	 Assembling the multidisciplinary QI team The necessity of including a family advisor as a coleader Family advisors in informing project design 	 Mutual trust and respect Meaningful participation Equal roles
2.	Resident Physicians and Families as Partners	 Understanding each other's roles on the healthcare team Working together to lead change 	PartnershipShared understanding
3.	Family Advisors as Change Agents	 Forming lasting impressions about family advisors on QI teams Impact on the future 	 Collaboration Professional development

Table 3. Inductive Thematic Analysis and Code Examples.

The necessity of including a family advisor as a coleader. From the beginning, the team recognized the importance of partnering with patients and families at an individual and institutional level to improve patient and family-centered care. The family advisor's role was fundamental. The QI coach explained:

The presence of patients and families on our QI teams ensures system design and changes are patient and family-friendly.

By engaging a family advisor as a colead, the team recognized the value that patients and families bring to their own care. Partnering with a family advisor and infusing the family voice helped foster the project's design and implementation. The resident physician explained:

We often talk about patients and families as intangibles; however, by having a family member as a colead on a QI project, they offer their own perspective and experiences to help shape medical care because they are the ultimate recipients.

The attending physician and pediatric residency associate program director explained:

In each QI project, the patient and family are the ultimate key stakeholders. Despite well-intentioned efforts, those in administration, those at the bedside, and those guiding research do not possess the perspective of a patient or family. There needs to be involvement from a family advisor.

Family advisors in informing project design. The family advisor brought a critical and unique perspective to the team by sharing her experiences as a mother of a long-term patient cared for at the children's hospital. She explained:

A family partner has personal experience to bring to the team to help others understand how an idea for improvement may affect future patients and families. They help the team understand exactly what a patient and family may be going through.

The family advisor's perspective and leadership motivated the team to identify improving the familycenteredness of routine bloodwork as the primary aim of the QI initiative. As a result, the team shifted their view from "doing for" patients and families to "doing with."

Theme 2: Resident Physicians and Families as Partners

Having a family advisor share her personal experience with the QI team and with resident physicians enabled health care personnel to better understand and empathize with the parent perspective.

Understanding each other's roles in the health care team. Knowledge gaps can exist between resident physicians and families due to confusion about the roles and responsibilities involved in caring for a child in the inpatient setting. By listening to and recognizing family needs, residents and families can work together to improve care. The resident physician stated:

"By having a family advisor share their perspective, residents can see how patient-family experiences might be improved in the hospital."

The attending physician and pediatric residency associate program director added:

"The resident and family partnership continued to grow as just that, a partnership with each contributing to the project based on their experiences and perspectives. This project can be used to show involvement of residents and to help those in training understand by experiencing different ways of working with families..."

Working together to lead change. To improve outcomes, the QI committee enacted several PDSA cycles, one of which involved the family advisor educating residents at 2 noon conferences about the QI effort and its focus on enhancing the patient and family experience in the hospital. This example demonstrated the importance of resident–family collaboration to improve patient care. The family advisor stated:

This speaking opportunity helped residents identify with the family perspective and gave them a better sense of how to approach patient-families in the hospital setting and build the families' trust. It also helped residents understand what a family may be going through.

The QI coach shared her perspective:

I think the context that fostered such strong resident and family advisor collaboration in this initiative was the support of team leaders, the open and supportive personality of our resident and family advisor, and the evidence that supports family involvement in QI...

As members of the improvement team, both the resident and family advisor recognized the value of shared learning to influence one another positively and foster purposeful collaboration to support and enact change within the hospital. By engaging residents and families as a team, their partnership seemed to advance beyond an "us-them" model to foster mutual understanding and improve patient care.

Theme 3: Family Advisors as Change Agents

By partnering with a family advisor as a colead, our QI team better understood the value of incorporating the beliefs and preferences of patients and families into improvement efforts. Our family advisor's voice helped define the goal and purpose of the initiative. Her role also influenced the professional development of the team both individually and as a whole.

Forming lasting impressions about family advisors on QI teams. The resident physician described her experience as follows:

Our family advisor influenced me to listen to the patient-family story and to incorporate the family voice into my own future practice.

For the family advisor on the QI committee, the experience of being an integral member of the team influenced her decision to expand her involvement in hospital-wide QI efforts and cemented her passion for health care. She stated:

As a family advisor, I was able to see what goes on "behind the scenes" of a hospital. This solidified my decision to return to school so I can use my experience to help focus on patient safety and improve the patient experience.

Impact on the future. Having a family advisor on the QI initiative inspired members of the team to partner with families for future hospital-wide QI projects and expand their individual career goals. The QI coach stated:

The next stage of my professional development is to create programs that support family involvement in QI efforts and on high performing teams.

The attending physician lead described the impact as follows:

I will continue to advocate for and include family advisors in future QI efforts, recognizing that they bring the same value to other efforts such as research.

The attending physician and pediatric residency associate program director added:

A next step in my career development may be to have a patient/ family mentor to help improve my clinical skills, education, and work within the community.

The family advisor summarized her experience:

Something I will take with me into my future career from being on the QI team is the understanding that it does not matter where you come from or the title you have. Everyone has an important place in improving the quality of care.

Discussion

There is increasing evidence that involving patients and families in QI is essential to enhancing outcomes and enacting sustainable change (9,17). A growing number of institutions have followed the IPFCC's recommendations to engage patients and families in the QI process at various levels (10,11).Example initiatives include work by Taff et al utilizing family advisor surveys to elicit feedback and gather perspectives from patients and families primarily in an ambulatory setting to improve health care experiences (18). Members at Stony Brook University Hospital developed a family advisory board to assist in providing more comprehensive patient- and family-centered care in the pediatric intensive care unit (19). Atwood et al described a family advisor's involvement to improve the family experience during newborn hospitalization for neonatal abstinence syndrome (20). A study by Rosenberg et al incorporated a family advisor to assess the provider-family dynamic as it applies to the safety of pediatric inpatients (21). While these studies highlight the value of family advisors as key stakeholders in QI efforts, none engaged family advisors as level V participants.

Our QI team implemented a novel approach by establishing a family advisor as a level V coleader on an improvement initiative. From the beginning, our family advisor was fully integrated as part of the QI effort, and team members viewed her personal experience and unique perspective as critical to the QI effort's codesign and patient- and family-centered aim. Across the core team, her inclusion was perceived as essential to its success.

Strengths and Limitations

As a colead, our family advisor contributed to the design, development, and evaluation of our initiative and contributed to a cultural shift within the residency program and hospital system that improved patient- and family-centered care. Our team identified opportunities for improvement in hospital practice from a parent perspective and enacted change because of this insight (22).

This analysis revealed that the relationship that developed between family advisor and residents seemed to impact both parties positively. The team structure of engaging family partners on a QI initiative demonstrated the value of families and residents as partners to initiate change within the health care system. The model of coleadership for a quality and safety effort with family advisors and resident physicians showed promise for advancing improvement science and project management.

This study has several limitations. First, the small sample size of 5 study participants may have resulted in minimal variation and may not have allowed for saturation. However, these team individuals had the most experience as core members of the QI effort and were from multiple disciplines, providing the most detailed accounts. Future studies should consider increasing the sample size and surveying individuals in the QI effort with varying level of involvement to evaluate whether findings remain consistent. Second, the intervention was conducted at a single-site medium-sized university hospital in an urban setting within 1 QI team. The transferability of these data to other institutions in different settings is uncertain. Lastly, researcher bias may have influenced the results, as themes were chosen subjectively based on common ideas and overarching themes, though attempts were made to mitigate this with group review and independent analysis. For future studies, computer-aided qualitative data analysis software should be considered, as well as theme identification by noncore team members and open reflection as opposed to structured questions.

Conclusions and Recommendations

Our qualitative theme analysis suggests that the inclusion of a family advisor as a coleader on an improvement effort is critical to ensuring efforts are patient- and family-centered and optimizing outcomes. We urge improvement teams to fully embrace family advisors as level V coleaders to transform health care delivery.

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