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Developing a Unit-Based Family Advocacy Board on a Pediatric Intensive Care Unit

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Abstract

Context: The pediatric intensive care unit (PICU) of Stony Brook University Hospital (Stony Brook, NY, USA) developed a family advocacy board to assist staff in providing patient- and family-centered care. The PICU Family Advocacy Board works in partnership with the medical center's leadership to promote and enhance family-centered pediatric care and services. The advocacy board is founded on the understanding that families play a vital role in ensuring the health and well-being of children.

Methods: Using the "Are Families Considered Visitors in Our Hospital or Unit?" self-assessment developed by the Institute for Family-Centered Care, we asked pediatric critical care staff to assess how well family presence and participation is supported on the unit. The data obtained from the assessment was used to help determine priorities for the advocacy board.

Results: The greatest improvement in the postimplementation assessment concerned questions related to patients and families as advisors. Answers for four questions in this category showed a statistically significant improvement ($p \leq 0.0001$) in the postimplementation data in comparison with the preimplementation data. Staff perception of the level of family involvement during anesthesia induction and after induction increased from 42% before implementation to 78% after implementation ($p = 0.0343$). The perception of inclusion of family members during resuscitation increased from 28% before implementation to 90% after implementation ($p \leq 0.0001$).

Conclusions: Patients' family members and unit staff have responded positively to the development of the parent advisory board and the deployment of board members' recommendations. Family members bring valuable experience and insight into the development of unit processes. Patients' and family members' ideas and participation in decision making should be embraced, not feared.

Introduction

Although patient- and family-centered care was a popular topic in many 2007 quality forums, very few hospitals at that time could truly claim to offer patient- and family-centered health care. Select members of our team had the opportunity to view a presentation made by a community hospital regarding the development of their patient and family advisory group at our Institute for Healthcare Improvement (IHI) Critical Care Learning Collaborative meeting in Texas in October 2007. Our members returned from the meeting eager to institute a similar program at Stony Brook University Medical Center.

Patient- and family-centered care is defined by the Institute for Family-Centered Care as "an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers."[1] Taking IHI's recommended approach of small tests of change,[2] our staff decided to create a small unit-based group of family members to act as advisors in the targeted unit's delivery of care. Because our pediatric intensive care unit (PICU) often had family members return to offer their gratitude and express their interest in helping other families, our PICU was identified as the pilot unit for this initiative.

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Development of the Advocacy Board

So that we could identify possible members for this group, a report was generated listing all patients discharged from the unit within the preceding 12 months. Unit staff were asked to identify families from the list whom they thought would be interested in participating in the advocacy board. Staff were instructed to identify those families whom they believed would offer feedback regardless of the outcome of their previous experiences on the unit.

Thirty-seven families were identified as potential PICU family advisors. Invitations to participate in the introductory meeting to discuss the advocacy board were sent to the identified families early in January 2008. Families were asked to attend an informational meeting to discuss what we hoped would be their participation with our performance-improvement team and the commitment associated with serving as family advisors. Of the 37 families who received the invitation, 8 responded positively to the request.

The first meeting of the PICU Family Advocacy Board (Table 1) occurred on February 14, 2008. We initially anticipated that some family members would withdraw from participation once they heard more about the program because of possible time-commitment issues. The time commitment for participation in this group was estimated to be between four and six hours each month. Surprisingly, all families attending the meeting expressed their desire to join our advocacy board.

Subsequent meetings have been held monthly, alternating between daytime and evening hours. Agendas are distributed to members for their review and input prior to each monthly meeting. Minutes are taken during meetings and reviewed at the following meeting to ensure accuracy and follow-through on outstanding issues.

For the group to work toward a tangible goal, a PICU family survival guide was developed by advocacy-board members. The guide provided helpful hints to assist families in navigating the hospital and surrounding area. It provided information regarding cafeteria hours, parent sleepover policy, parent participation during rounds, and so on. The same information was also formatted into a laminated poster and hung on the outside of each patient's bathroom door.

The first administrative actions executed by this group included the creation of a mission statement and objectives and the renaming of the group to *PICU Family Advocacy Board*. Next, the members identified a need to provide support services to family members of PICU patients. As the members believed they were able to meet the emotional needs of patients' family members, they expanded their scope of services to include participation in performance-improvement initiatives on the unit (Table 2).

Table 1. Members of the Pediatric Intensive Care Unit Family Advocacy Board

Name	Role
Thomas Archer	Parent advocate
Trevor and Mo Connolly	Patient advocates
Kathleen Culver, NP	PICU nurse practitioner
Barbara and Robert Mongillo	Parent advocates
Jeanne Morano	Parent advocate
Paul Murphy	Data analyst
Donna Panico, CNS	PICU clinical nurse specialist
Margaret Parker, MD	PICU medical director
Madeline Queck	Chaplaincy
Arlene and Thomas Reith	Parent advocates
Dawn Walsh	Parent advocate

PICU = pediatric intensive care unit.

Methods and Materials

Assessing Staff Perception of Unit's Patient- and Family-Centered Care Practices

In an effort to assess staff perception of the unit's commitment to patient- and family-centered care, pediatric critical-care staff were asked to complete a unit self-assessment prior to the formation of the PICU Family Advocacy Board.[3] Using the "Are Families Considered Visitors in Our Hospital or Unit?" self-assessment developed by the Institute for Family-Centered Care, medical, nursing, and clerical staff were asked to assess how well family presence and participation is supported on the unit. The data obtained from the assessment assisted to determine priorities for the advocacy board. The first assessment was done during the spring of 2008; 50 assessments were distributed and 14 assessments were completed and returned.

Staff generally believed that the unit was emotionally supportive to family members. Nevertheless, many key elements required to provide an infrastructure for family-centered care were identified as not provided or needing improvement. Shift-change reports, treatments and procedures, anesthesia induction and after induction, and resuscitation were identified as areas needing

… the *PICU Family Advocacy Board* identified a need to provide support services to family members of PICU patients—meeting their emotional needs … and … including them in performance-improvement initiatives …

improvement regarding inclusion of families. Lack of inclusion of patients and families as advisors in the developing, implementing, and evaluating of policies and quality improvement was also highlighted. Environmental factors such as adequate space for family members were recognized as needing improvement and a perceived priority for change.

Instituting Change

Rather than initially focusing on improving hospital facilities, the advocacy board chose to concentrate on process-related elements requiring improvement. Members believed process-related changes required minimal funding and were within the scope of the advocacy board's initial realm of influence. In response to the outcome of the assessment, several changes were implemented by the Family Advocacy Board in conjunction with PICU medical and nursing leadership. Members of the Family Advocacy Board were asked to join the unit's performance-improvement team charged with reducing complications due to infections and ICU mortality. The team meets twice a month to review performance data related to infections and high-risk processes and to offer recommendations to improve patient outcomes. Team members also provide oversight and measurement in the implementation of new processes to determine whether the improvement achieved the desired outcome.

In an effort to champion one of the National Patient Safety Goals of the Joint Commission (www.jointcommission.org/patientsafety/nationalpatientsafetygoals/), our hospital organized a medication retreat to identify potential patient safety issues related to adverse drug events and to suggest process improvements. Two of our family advocates were asked to participate in the medication retreat to offer their insight as to potential risks to medication safety. Participants provided their perceptions and concerns regarding communication in the prescribing and administering of medications to their family members.

Several family advocates also worked with our Corporate Education and Training Department to develop a module to educate staff regarding effective communication with patients and family members. Families were asked to identify real experiences (both positive and negative) for incorporation into the training program as learning opportunities for staff. Application of the educational modules led by our family advocates with members of our training department began April 2009. Unit staff expressed positive feedback regarding the content and delivery of the training program. Because of the success of the program, the scope of participants in the training session was expanded to include all pediatric (general pediatrics, pediatric hematology and oncology) medical, nursing, clerical, and ancillary staff.

One of our family advocates identified a concern in the delay of her son's admission from the Emergency Department (ED) to the PICU. Although she was instructed

Table 2. Improvements instituted by the PICU Family Advocacy Board and implementation dates

Date	Changes
May 2008	Designed and distributed a parent survival guide and informational poster in both English and Spanish for family members of newly admitted PICU patients
June 2008	Developed a mission statement and objectives for the PICU Family Advocacy Board
June 2008	Purchased and installed a table for the parent respite room
July 2008	Organized a "PICU coffee hour" on the unit for PICU family advocates to offer refreshments, emotional support, and assistance to family members of PICU patients
September 2008	Created voice mail hotline for PICU family members to leave messages in order to reach out for assistance from PICU family advocates
September 2008	Created PICU family advocate e-mail address for patients' families to contact family advisors and for advisors to communicate with one another
October 2008	Developed a protocol for offering one-to-one family advocacy services
October 2008	Participation of PICU family advocates on our PICU performance-improvement team
December 2008	Two PICU family advocates participated in our hospital-wide medication retreat to identify potential patient safety issues related to adverse drug events and to suggest process improvements
March 2008	Inclusion of families in nursing change-of-shift report
April 2009	Development and deployment of a "communication to family members" educational module for PICU staff
Spring 2009	Created performance-improvement team with family advocate representation to improve and accelerate the process of admission from the Emergency Department to the PICU
Fall 2009	Creation of a video on patient- and family-centered care by PICU Family Advocacy Board members
Winter 2009-2010 (anticipated)	Created end-of-life protocols with family advocate participation

PICU = pediatric intensive care unit.

by her physician to bring her son to the ED so that he could be admitted to the hospital's PICU, her son waited in the ED for more than four hours before he was moved to the PICU. As a result, the family advocate was asked to be part of a performance-improvement team to improve and accelerate admission process from ED to PICU. Team members believe that the parent's perspective of this difficult and sometimes overwhelming process is helpful in identifying and eliminating obstacles that cause unnecessary delays.

Results

A postimplementation survey was distributed and completed in March 2009,[3] nearly 12 months after baseline data were collected. Of the 50 assessments distributed to the PICU staff members, 11 were returned completed. Improvements were noted in several of the targeted family-centered care elements included in the assessment.

Questions related to patients and families as advisors noted the greatest improvement in the postimplementation assessment (Figure 1). Answers to all four questions in this category showed a statistically significant improvement ($p \leq 0.0001$) in the postimplementation data from the preimplementation data. Eighty-five percent of staff completing the preimplementation assessment believed that patients and families were *not* involved in developing, implementing, and evaluating hospital policies and practices. In the postimplementation assessment, 100% of the staff believed families *were* involved in these arenas.

Twenty-eight percent of the staff who completed the preimplementation assessment, as compared with 100% in the postimplementation assessment, believed that patients and families were involved in responding to and finding solutions to concerns and providing suggestions about family presence and participation. Twenty-eight percent of staff who completed the preimplementation assessment believed patients and family members were involved in developing, implementing, and evaluating quality-improvement initiatives, as compared with 98% in the postimplementation assessment. In the preimplementation assessment, 15% of staff believed that patients and families were involved in hospital or unit committees and workgroups, as compared with 100% in the postimplementation assessment.

Of the questions relating to patterns of care and collaboration in caregiving, five of the six elements showed an increase in positive responses (Figure 2). However, for only two of the five questions was there a statistically significant improvement in postimplementation data. The percentage of staff perceiving family involvement during anesthesia induction and after induction increased from 42% before implementation to 78% after implementation ($p = 0.0343$). The percentage of staff perceiving inclusion of family members during resuscitation increased from 28% before implementation to 90% after implementation ($p \leq 0.0001$).

The percentage of staff perceiving inclusion of family members during resuscitation increased from 28% to 90% …

The percentage of staff perceiving inclusion of patients and families in shift-change reports

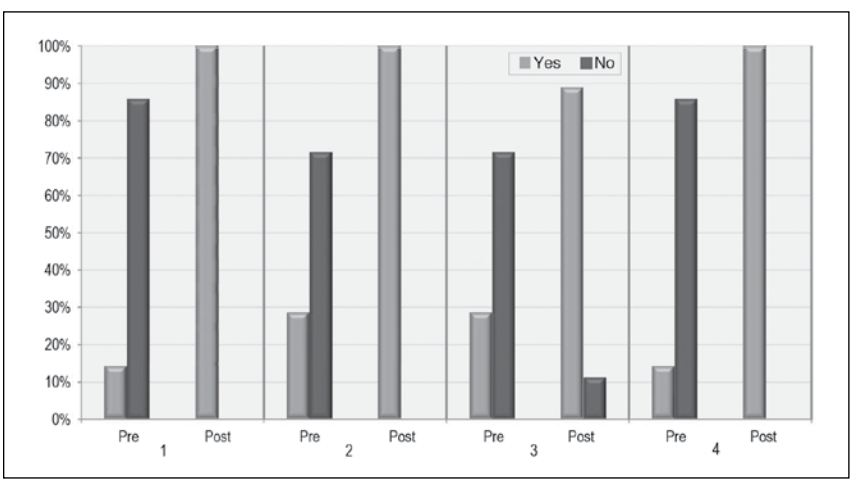

Figure 1. Staff responses before program implementation ("pre") and afterward ("post") to questions about whether patients and their family members were involved in:

1. Developing, implementing, and evaluating policies, programs, practices, and facility design relevant to family presence and participation shared by other families
2. Responding to and finding solutions for concerns and suggestions about family presence and participation shared by other families
3. Developing, implementing, and evaluating quality-improvement initiatives related to family presence and participation
4. Hospital/unit committees and work groups focused on issues related to the experience of care

Individual responses were kept confidential and were required to be collected and maintained pursuant to Public Health Law 2805, Sections j, k, l, and m, and Education Law Section 6527. Source of assessment questions: Ahmann E, Abraham MR, Johnson BH. Changing the concept of families as visitors: supporting family presence and participation. Bethesda, MD: Institute for Family-Centered Care; 2003.

increased from 28% before implementation to 50% afterward, but the increase was not deemed to be statistically significant because of the small response rate. Coincidentally, the unit is in the process of testing the inclusion of families in nursing shift-change reports. Family advocates were active in scripting and role playing as means of assisting staff in the preparation for inclusion of families during this process, one that traditionally excludes patients and families.

One area pertaining to patterns of care and collaboration in caregiving where the staff believed that unit staff were more inclusive of patients and families in the preimplementation assessment was treatments and procedures. Fifty percent of staff said that patients and families were included during treatment and procedures, as compared with 30% who said so after implementation. It is unclear why the staff believed the unit was more inclusive of families during the preimplementation period. This information is expected to be reviewed and addressed by the Family Advocacy Board members.

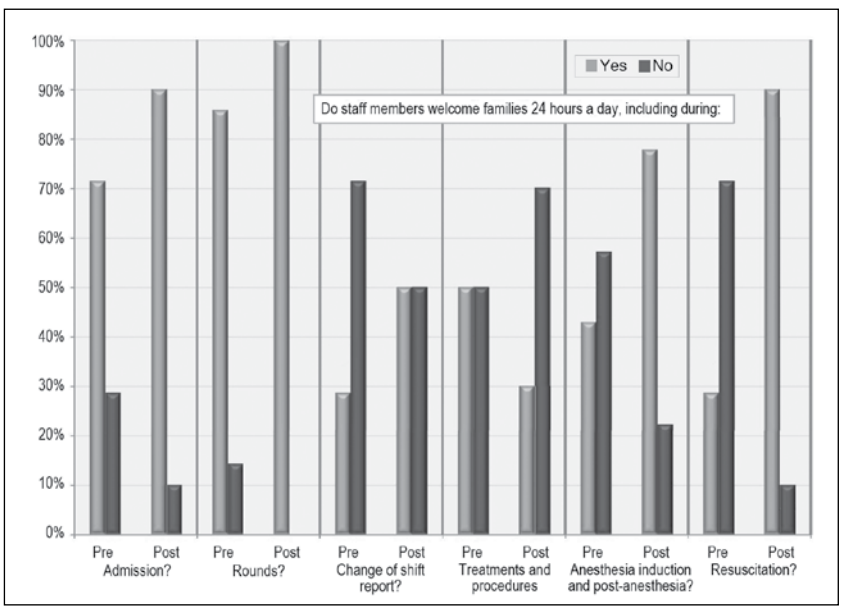

Figure 2. Family members' responses before program implementation ("pre") and afterward ("post") to questions about whether they were welcomed by staff, 24 hours a day, during:

1. Admission
2. Rounds
3. Shift-change reports
4. Treatments and procedures
5. Anesthesia induction and after induction
6. Resuscitation

Individual responses were kept confidential and were required to be collected and maintained pursuant to Public Health Law 2805, Sections j, k, l, and m, and Education Law Section 6527. Source of assessment questions: Ahmann E, Abraham MR, Johnson BH. Changing the concept of families as visitors: supporting family presence and participation. Bethesda, MD: Institute for Family-Centered Care; 2003.

Conclusions

Patients' family members and unit staff have responded positively to the development of the parent advocacy board and the implementation of board members' recommendations. Family members bring valuable experience and insight into the development of unit processes, and thus patients' and family members' ideas and participation in decision making should be embraced, not feared. Although staff were initially reluctant to incorporate patient and family input into the development or modification of unit-based processes, their reservations were alleviated once they observed the positive impact that such involvement had on patient care. ❖

Disclosure Statement

The author(s) have no conflicts of interest to disclose.

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