Parent Advocacy Group for Events of Resuscitation

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BACKGROUND  The presence of patients’ families during resuscitation has been an important practice issue. An American Association of Critical-Care Nurses (AACN) practice alert “Family Presence During Resuscitation and Invasive Procedures” supports family members of patients undergoing resuscitation being given the option of bedside presence. Parent Advocacy Group for Events of Resuscitation (PAGER) is an interdisciplinary collaborative in the pediatric intensive care unit.

OBJECTIVES  To ensure that patients’ families are provided the option of being with their child during cardiopulmonary resuscitation.

METHODS  Resuscitation data were collected for 12 months by using the AACN practice alert audit tool. The Family Nurse Caring Belief Scale was administered to 150 pediatric intensive care unit nurses. PAGER nurses received crisis education.

RESULTS  Pediatric intensive care unit nurses were supportive of providing the option of family presence during resuscitation. Family Nurse Caring Belief Scale data revealed areas for improvement in family caring practices. PAGER was implemented with positive outcomes for 2 families.

CONCLUSIONS  PAGER has improved the care of families whose children experience cardiopulmonary resuscitation and should be implemented in pediatric critical care units. PAGER nurses are prepared to serve as role models in providing family-sensitive care during crisis. (Critical Care Nurse. 2016;36[3]:58-64)

A young child is experiencing cardiopulmonary resuscitation in a pediatric intensive care unit. The parents are in a waiting room nearby. A nurse asks the care team, “May I bring the parents to the bedside?” No one from the care team replies. Again, the nurse asks, “Do you think it is time to bring the parents to the bedside?” No one from the care team replies. The family is not provided with the opportunity to be present with their child during 5 hours of resuscitation efforts, arriving at the bedside only minutes before their child dies.

This scenario contains details that are real and fictional.

The advantages and disadvantages of family presence during resuscitation have been argued since it was first proposed in 1987. The presence of patients’ families during resuscitation is a relevant practice issue, yet it remains somewhat controversial. The acute vulnerability of the family during resuscitation has been at the core of nurses’ concerns that witnessing such an event may be detrimental rather than helpful to patients’ families. For example, if their child dies, will the parents’ happy memories of their child be overshadowed by the final images of chest compressions? Will the
sight of providers’ intense actions and the sounds of frightening medical terms and equipment negatively affect grieving? Physicians and nurses have expressed concerns about patients’ families hearing inappropriate bedside conversations that can be spawned by stress (eg, medical jargon, profanity). Additionally, providers with various degrees of experience have feared that parental presence will impede the performance of invasive procedures and resuscitation, thereby affecting the outcome for the patient. In 2000, the American Heart Association endorsed recommendations for parents to be given the option of being present during their child’s resuscitation.6 And, despite providers’ differing opinions about parental presence during resuscitation and the practical implications of offering it, parents prefer to have a choice to be with and to support their children.7,8 Currently, major evidence-based international guidelines for resuscitation support families witnessing it.4 Perhaps most importantly, family presence during resuscitation may aid in parents’ understanding that everything possible has been done to save their child’s life and foster the start of healthy coping and bereavement when resuscitation fails.4,10

Background

Patient and family-centered care (PFCC) is “an approach to care that is respectful of and responsive to the preferences, needs, and values of individual patients and their families.”11 Innovation and mutually beneficial partnerships among patients, patients’ families, and health care providers are the foundation of pediatric PFCC policy.12 Indeed, a prominent PFCC focus in pediatric critical care research and practice has been family presence during invasive procedures and cardiopulmonary resuscitation (CPR). An American Association of Critical-Care Nurses (AACN) practice alert titled “Family Presence During Resuscitation and Invasive Procedures” supports family members of all patients undergoing resuscitation being given the option of presence at the bedside.13 Furthermore, the practice alert calls for patient care units to have guidelines that reinforce family presence as an option during pediatric resuscitation.13 Understanding health care providers’ perceptions of family presence during resuscitation combined with a staff education program, a dedicated core group of providers, and guidelines have improved family presence experiences.14,15 An appraisal of the status quo in one pediatric intensive care unit (PICU) revealed opportunity for improved fulfillment of the recommendations in the evidence specific to parental presence during CPR, inclusive of the recommendations in the AACN practice alert.

Project Aims

The Parent Advocacy Group for Events of Resuscitation (PAGER) is an interdisciplinary PFCC collaborative in the PICU at Children’s Hospital of Pittsburgh of University of Pittsburgh Medical Center. The primary aim of PAGER is to ensure that patients’ families are provided with the option of being with their child during CPR and are supported throughout the experience with skilled and sensitive care. Specifically, PAGER is intended to fulfill a need for critically ill children and their families during off-shifts and weekends and in situations when clinical social work resources are limited or exhausted (eg, multiple children requiring CPR during a shift with several parents in crisis). The collaborative is consistent with the hospital’s care delivery model and a critical care strategic goal to align priority initiatives with those of national nursing organizations.

Methods

Ethics

The critical care leadership team, the hospital’s evidence-based practice council, and the quality review board at Children’s Hospital of Pittsburgh approved PAGER. The critical care medicine division is apprised of the project at performance, quality, research, and safety or “PQRS” meetings.

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Setting and Preliminary CPR Data

The setting is a 36-bed PICU in a university-affiliated level I trauma center. CPR data were collected for 12 months during all shifts using the audit tool from the AACN practice alert on “Family Presence During Resuscitation and Invasive Procedures.” Data revealed a total of 8 events, all of which involved CPR. One event involved both CPR and an invasive procedure (ie, initiation of extracorporeal membrane oxygenation). Families were offered the option of being present for 6 CPR events. Six of the families who were offered the choice of being present during their child’s CPR accepted. Situations varied in that 1 mother chose to leave her child’s bedside during CPR, while another mother was present at the onset of CPR and chose to stay with her child for the duration.

The 6 families who were given the option to be present during CPR had at least 1 provider to facilitate the experience. Four families were supported by a clinical social worker; 1 family had a physician facilitator; a nurse supported 1 family and another family had a physician, care coordinator, and 2 nurses as cofacilitators. The family of the child receiving extracorporeal membrane oxygenation was not offered the option of being present because of the “sterile nature of the procedure.” Another child experienced 2 CPR events and the parent was present only during the second. Audits did not explain the details of the circumstances around the lack of parental presence for this child’s first CPR event.

Evaluation

The Family Nurse Caring Belief Scale (FNCBS) was developed to measure nurses’ attitudes toward providing family-sensitive care to families who are in crisis. The premise of the FNCBS study was that nurses’ attitudes and behaviors regarding family-sensitive care in a stressful setting such as a PICU may be influenced by experts serving as role models at the bedside with subsequent reflection on nursing practice. The authors of the FNCBS tested the specific construct of family-sensitive care that was defined as “a systems perspective of nursing that is sensitive to both the unique experiences of the family and interactions between nurse and family capable of reducing family stress in a health care crisis.”

We posited that FNCBS scores would guide meaningful PAGER curriculum development.

The FNCBS was pilot tested with a convenience sample of 60 PICU nurses to estimate initial content validity from a relevant population. The FNCBS is a 25-item Likert-type instrument. Respondents indicate the degree to which they agree or disagree with each of the statements on a scale of 1 to 5. An undecided response (score of 3) is useful as it demonstrates lack of support for family-sensitive care. The possible score range is 25 to 125 with lower scores reflective of nurses who are least family-sensitive care oriented. Completion of the FNCBS takes approximately 10 minutes. The FNCBS demonstrates sound psychometric properties with a child-rearing population. Cronbach α was estimated at 0.81, indicating that the FNCBS has acceptable internal consistency and reflects fine discriminations in family-sensitive care construct levels. The 163 participants in the FNCBS study were representative of neonatal intensive care unit and PICU nurses who were sampled by randomization from the AACN membership list population of PICU and neonatal intensive care unit nurses in 2003. Factor analysis revealed 4 factors: factor I (ethical caring practices), factor II (orientation to family), factor III (child advocacy), and factor IV (normalizing milieu). Some weaknesses in establishing concurrent validity related to the finding that nurses with advanced degrees in nursing had higher sum scores on the FNCBS than did nurses with a 2-year prelicensure education (P < .05), suggesting that nurses with higher degrees in nursing may have had more exposure to some of the complex concepts measured by the instrument.

Data Analysis

Permission to use the FNCBS was obtained from Sonja J. Meiers, RN, PhD. We sought to gain a rich understanding of the PICU nurses’ caring beliefs because the family-sensitive care construct may provide the foundation for how they think when caring for families in crisis. We posited that the evaluation of the PICU nurses’ FNCBS scores would reveal the current family caring culture and therefore guide meaningful PAGER curriculum development.

The FNCBS was administered electronically to 150 PICU staff nurses at Children’s Hospital of Pittsburgh. Nurse demographic data (eg, education level) were not collected. In the past, nurses have expressed skepticism that electronic survey data are anonymous, and we believed...
that omitting demographic data might eliminate that concern while enhancing participation. Also, we noted that Meiers and colleagues described nurses with advanced degrees as having higher FNCBS sum scores than nurses without advanced degrees when concurrent validity was established. Practically speaking, nurses with all degree types care for children who may require CPR, and the call to support a family of a child in cardiopulmonary arrest does not discriminate according to nurse education level. Forty-two percent (n = 63) of the staff nurses responded, and all 63 who responded answered all of the items. The PAGER leaders defined most oriented toward family-sensitive care as items with 90% or greater as the sum of “strongly agree and agree” or the sum of “strongly disagree and disagree” depending on whether a reverse scoring format was used for the items. Ten items (40%) had responses less than 90% as the sum of “undecided” and “strongly agree and agree” and “strongly disagree and disagree” depending on the scoring format and indicated least oriented toward family-sensitive care (Table 1).

A section at the end of the FNCBS provided for free-text comments. Qualitative data yielded the following comments from staff nurses:

We do a good job of supporting families . . . could do better with more resources and support . . . if someone could assist families with their well-being it would help everyone as a whole, including the patient.

The more the family is involved with care, the more input the family has and the more the family trusts the nurses.

**PAGER Education and Launch**

A clinical nurse leader and clinical nurse specialist serve as the PAGER innovators and leaders. They sent an electronic message to PICU staff nurses inviting those who are passionate about supporting parental presence and PFCC to participate. Those who responded formed the first PAGER (Table 2). Additionally, a critical care medicine physician who is an advocate for family presence during CPR serves as a liaison between PAGER and the critical care medicine division.

The PAGER leaders and a clinical social worker codeveloped the crisis education curriculum to prepare nurses for their role and to target the areas for improvement identified from the FNCBS data, specifically the items that revealed low scores regarding the provision of family-sensitive care (Table 3). For example, the FNCBS item “Explaining technology to the family will not increase their involvement in the child’s care” is discussed within the context of the PAGER nurse’s role. The PAGER nurse prepares the family for the sight of technology upon entering their child’s room, explains the equipment as it relates to supporting their child’s life, and assists the family with navigating the machines...
to get closer to their child to perhaps whisper “I love you” in a tiny ear. A father—an engineer by trade—who designs, tests, and calibrates technology everyday described brief explanations about equipment as “comforting.” The commonality with hospital technology and his field was something he could relate to and it was important for him to know his child was safe during CPR. Discussion of the scale item “I am not obligated to take care of the family” generates ideas about how PFCC aligns with CPR situations and how the role of the PAGER nurse supports the role of the bedside nurse. It will not be possible for PAGER nurses to serve in their role when they are the primary providers for patients receiving CPR, a key point of clarification that emerged during role-play exercises.

A hospital-wide self-defense course that is currently sponsored by the hospital police was the second part of the PAGER curriculum (Table 4). The PAGER leaders collaborated with the PICU self-scheduling committee for support with nurses’ attendance at the classes.

All of the nurses described the education as valuable. They reported feeling better prepared to offer families the option of being present during their child’s CPR and possessing a clear understanding of balancing the PAGER role and their usual responsibilities. Specifically, nurses appreciated a “fresh look into” or understanding of the family process during CPR events.

### Table 3

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<thead>
<tr>
<th>Category</th>
<th>Description</th>
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<tbody>
<tr>
<td>Objectives</td>
<td>The learner will:</td>
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<tr>
<td></td>
<td>1. Review the meaning of the data from the Family Nurse Caring Belief Scale</td>
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<td>2. Define the state of “crisis”</td>
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<td>3. List 1 characteristic of each of the 3 crisis stages;</td>
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<td>4. Describe 2 major tasks of crisis intervention theory;</td>
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<td>5. Model 1 style of communication for each task (cognitive, emotional, problem solving);</td>
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<td>6. Describe how a family’s coping style may be supported by using crisis intervention theory</td>
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<td>7. Describe individualization of families’ coping styles within the context of intervention</td>
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<tr>
<td>Didactic content</td>
<td>American Association of Critical-Care Nurses practice alert “Family Presence During Resuscitation and Invasive Procedures”</td>
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<tr>
<td></td>
<td>Crisis intervention theory</td>
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<td></td>
<td>Resource management</td>
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<tr>
<td>Role play</td>
<td>The clinical social worker creates scenarios; the learners enact roles of a parent and a PAGER nurse in a simulated family waiting area;</td>
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<td>The leaders and clinical social worker provide verbal feedback and lead discussion about how the roles felt for the learners;</td>
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<td></td>
<td>The learners identify positive aspects of role play and opportunities for improvement (eg, body language, communication style)</td>
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<td>Duration</td>
<td>2 h</td>
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### Table 4

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<th>Category</th>
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<tr>
<td>Objectives</td>
<td>The learner will:</td>
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<td></td>
<td>1. List 5 ways to promote the safety of individuals receiving and providing care</td>
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<td>2. Describe best practices to promote a healthy work environment</td>
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<td>3. Describe the impact of stress on the human system</td>
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<td>4. List 3 components of violence risk assessment</td>
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<td>5. List 5 common myths about suicide</td>
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<td>6. Define “trauma informed care”</td>
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<td>7. Describe components of a staff self-assessment</td>
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<td>8. Assimilate self-care behaviors with sources of/responses to traumatic stress</td>
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<td>9. Define “situational alliance”</td>
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<tr>
<td>Didactic content</td>
<td>Communication techniques</td>
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<td>Anxiety</td>
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<td>Verbal intervention goals</td>
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<td>Stress management resources for staff</td>
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<td>Role play</td>
<td>Defensive tactics instruction</td>
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<td>Duration</td>
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facilitating parental presence during CPR events that were prolonged and particularly tragic. The nurses each wrote and distributed an electronic summary of their respective experiences to the PICU staff, reflecting on challenges and emphasizing positive feedback from their peers and the affected families. Physician and nurse leaders responded to the electronic summaries with additional comments that contained themes of serving as role models, compassion, teamwork, and dedication. The consensus for both events was (1) family presence did not impede the workflow of the providers and (2) families appreciated the option of being present with their child.

We admitted a child who quickly decompensated. The family was present at the bedside and we facilitated them staying during their daughter’s 6 hour-long resuscitation. We included the family in her care. When chest compressions began, we brought the family in closely, helping them lie with their child until we stopped compressions and she died. I believe the family needed that moment . . . they appreciated the opportunity to say goodbye while their daughter was still alive and to see that everything possible was done for her.

Discussion

A staff nurse is responsible for specific PAGER work items, and they count toward the nurse’s professional advancement project. For example, the nurse developed the first evidence-based PICU guideline for family presence during CPR at Children’s Hospital of Pittsburgh. The guideline—an adaptation of one currently used in the hospital’s emergency department—is available on the PICU’s shared drive and in bedside reference binders. It includes (1) a brief review of the number of family members recommended in the child’s room during CPR, (2) the process for directing questions and concerns to the most appropriate provider, (3) the process for assessing the family’s coping, (4) the process for assessing family behaviors and how they may affect medical care of the child, and (5) elements recommended by Curley and colleagues9 regarding the responsibilities of PAGER members as parental presence facilitators.

The clinical nurse director of critical care has recommended an increased number of PAGER nurses in the PICU and the expansion of PAGER to the neonatal and cardiac intensive care units as goals. The PAGER leaders will share current evidence with the PAGER nurses and facilitate continuing education and research opportunities (eg, participation in relevant studies that are marketed in AACN publications such as Critical Care eNewsl ine). PAGER nurses’ responsibilities and compliance will be evaluated annually through 1-on-1 discussions with PAGER leaders and critical care medicine physicians, annual performance reviews, and audit data. The PAGER leaders may consider administering the FNCBS again with some periodicity to ensure that the culture of the PICU staff remains aligned with this vital PFCC care initiative.

Currently, there are sporadic debriefing sessions for PICU staff following the death of patients, but there is no process in place for debriefing that is specific to PAGER nurses and their role experiences—including situations wherein children survive CPR. We plan to seek input from the PAGER nurses as to whether debriefing about their role would be beneficial. If they believe it would, we will collaborate with them to provide the best way to accomplish PAGER role debriefing.

Based on the results of the FNCBS data and CPR audits, the culture of the PICU staff was generally supportive of providing the option of family presence during CPR, yet data revealed areas of nurse caring that could improve. Early implementation of the PAGER role has met with positive outcomes for families and staff. Currently, PAGER implementation is limited to when patients require CPR alone or in combination with invasive procedures. Efforts to improve parental presence during invasive procedures when CPR is not performed may be undertaken in the future.

Nurses typically learn about ethics- and culture-related topics via traditional education methods (eg, new employee
orientation classes, web-based tutorials). Although these are efficient and adequate venues to deliver required didactic content for large numbers of individuals, role modeling is a more powerful means to achieve and sustain culture change. Beyond facilitating family presence during resuscitation, PAGER nurses are uniquely positioned to model PFCC and care that is reflective of the factors born out of the FNCBS analysis during times of family crisis in a PICU: ethical caring, orientation to the family, child advocacy, and normalization of the environment. Supporting family presence during CPR preserves parental roles relative to the care they would normally provide to their child during times of wellness. If a family cannot get close to the bedside initially, simply holding a hand or stroking a foot and telling their child, “Mommy and Daddy are here” can be extremely important. Families may retain a sense of control when they would be deprived of it otherwise. Changing diapers, repositioning, wiping tears, and kissing a cheek are examples of nurturing behaviors that may help a family feel like they are still caring for their child during a terrifying and uncertain time when they believe they have nothing else to offer.

When a family is present at the bedside during CPR, the care team may gain a deeper appreciation for the meaning of the crisis and its impact on the family unit. Recommendations from the critical care medicine division are that a formal and deliberate effort be made by PAGER nurses to announce when the family has arrived to the bedside so sensitive care is enhanced and to create a culture shift from permission to a diligent expectation.

Conclusion

Technology in a PICU is overwhelming to families on a daily basis let alone during resuscitation events. PAGER nurses are prepared to explain complex technology to families who are stressed, thereby enabling them to feel comfortable being near their child during CPR and, if necessary, to be empowered to make difficult decisions about stopping lifesaving efforts. During times when CPR is futile, PAGER nurses may play a crucial role in a family’s grieving process that begins at the pivotal time when the family is united with their child—if that is their choice—and the child, the child’s family, and the care team experience the crisis of resuscitation together. CCN

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Financial Disclosures

None reported.

References
