FAMILY PRESENCE DURING RESUSCITATION AND INVASIVE PROCEDURES IN PEDIATRIC CRITICAL CARE: A SYSTEMATIC REVIEW

By Sarah Smith McAlvin, RN, MSN, CPNP, CCRN, CPEN, and Aimee Carew-Lyons, RN, MSN, CPNP, CCRN, NEBC, CPHQ

Background In pediatric critical care, family-centered care is a central theme that ensures holistic care of the patient and the patient’s family. Parents expect and are encouraged to be involved in the care of their child throughout all phases of the child’s illness. Family presence is generally accepted when the child’s condition is stable; however, there is less consensus about family presence when the child becomes critically ill and requires resuscitation and/or invasive procedures.

Methods The PRISMA model guided this systematic literature search of CINAHL, MEDLINE, Ovid, and PubMed for articles published between 1995 and 2012. Specific search terms used included pediatric intensive care, parent presence, family presence, pediatrics, invasive procedures, and resuscitation.

Results This literature search yielded 117 articles. Ninety-five abstracts were evaluated for relevance. Six articles met criteria and were included in this review. The findings indicate that parents want to be present during invasive procedures and resuscitation, would choose to be present again, recommend being present to others, and would not have changed anything about the presence experience. Parents who were present had better coping and better adjustment to the child’s death. Parents who were not present reported more distress.

Conclusions These studies support the suggestion that family presence during resuscitation and invasive procedures increases parents’ satisfaction and coping. However, the generalizability of these findings is limited by small sample sizes and inconsistent evaluation of confounding variables. Further research is needed to determine the benefits of family presence and prevent barriers to true implementation. (American Journal of Critical Care. 2014;23:477-485)
In pediatric critical care, family-centered care is a key theme that ensures holistic care of the patient and the patient’s family. Parent presence is an important component of family-centered care. Parents expect and are encouraged to be involved in the care of their child throughout all aspects of the child’s illness. Family presence is defined as the attendance of family member(s) in a location that affords visual or physical contact with the patient during resuscitation or an invasive procedure. This presence is generally accepted when the child is in stable condition; however, there is less consensus about family presence when the child’s condition becomes unstable, requiring invasive procedures and/or resuscitation. Many hospitals do not have formal protocols or guidelines about family presence in these situations. Furthermore, providers often create barriers to parent presence, specifically regarding invasive procedures and resuscitation. This systematic review is focused on family presence during resuscitation and invasive procedures in pediatric critical care.

Family presence during resuscitation and invasive procedures is endorsed by many health care organizations. The American Association of Critical-Care Nurses, the Emergency Nurses Association, and the American Academy of Pediatrics Committee on Pediatric Emergency Medicine have released position statements in favor of family presence during resuscitation. In 2000, the American Heart Association endorsed family presence in its cardiopulmonary resuscitation guidelines. Although family presence is endorsed by many medical and nursing organizations with published guidelines, variation in practice and opinion persists among health care providers, specifically with regard to resuscitation and invasive procedures. Often, providers are reticent to encourage parent presence.

Some health care providers have stated that they are afraid of family members critiquing performance, increasing staff stress, causing distractions, and impairing care. Providers also fear that witnessing resuscitation adversely affects family members and promotes litigation. Nurses have been noted to oppose parent presence to a lesser extent than their physician colleagues.

Family members experience a great deal of stress and anxiety while their child is hospitalized in critical condition. Signs and symptoms of acute stress disorder are prevalent in parents of children who are hospitalized in the intensive care unit and are strong predictors of future symptoms of posttraumatic stress disorder. Parents commonly report that being separated from their hospitalized child is a major stressor and they have a particular interest in being present during procedures as well as participating in their child’s care.

With family-centered care becoming more commonplace in pediatric critical care, it is important for nurses and other health care providers to understand how the concept of family presence, when implemented during resuscitation and invasive procedures, may help parents cope and promote increased satisfaction with care. A number of reports documenting the perspective of health care providers have been published; however, few studies explore parents’ coping and satisfaction when present. The purpose of this systematic review is to evaluate the experiences of patients’ family members when present during resuscitation and invasive procedures in pediatric critical care settings, specifically looking at satisfaction with care and ability to cope.

Methods

The PRISMA model guided this systematic literature search and article selection (see figure). Studies

Providers often create barriers to parent presence during invasive procedures and resuscitation.

About the Authors

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published between 1995 and 2012 were reviewed by using 4 electronic databases: CINAHL, MEDLINE, Ovid, and PubMed. Bibliographic searching also was done. The population studied was parents and caregivers of children undergoing resuscitation and/or invasive procedures in the critical care setting. Keywords entered into the electronic search were pediatric intensive care, ICU, PICU, parent, parent presence, family, family presence, pediatrics, family-centered care, critical care, pediatric critical care, invasive procedures, and resuscitation. Inclusion criteria entailed full-text articles written in English with search terms found in the title or as keywords. Exclusion criteria for full-text articles included literature reviews, articles unrelated to the pediatric critical care setting, mixed adult/pediatric studies, case reviews, articles with a focus on provider attitudes and perspectives, opinion pieces, articles not focused on resuscitation or invasive procedures, and resource manuals. Each study was evaluated for rigor of study design, sample, and analysis. The evidence was leveled in accordance with the Johns Hopkins Nursing Evidence-Based Practice Research Appraisal Guidelines.13 In order to obtain a holistic view of this concept, quantitative, qualitative, and mixed-methods research articles were reviewed. Both authors reviewed each of the articles individually and then collaboratively.

Results

The systematic literature search yielded 113 articles through database searching and 4 through bibliographic searching. After duplicate articles were removed, 95 remained, each of which was evaluated for relevance. The abstracts were screened for eligibility, and 49 were excluded because they did not meet inclusion criteria. Forty-six full-text articles were assessed, 6 of which were included in this review. Of the included studies, 1 was quantitative, 1 was qualitative, and the remaining 4 were of mixed-methods design. The studies were conducted in the United States or Australia. Table 1 characterizes the studies included in this systematic review.

A thematic analysis of study findings revealed 3 main themes: being present, satisfaction with care, and coping (Table 2).

Being Present

Parents in all studies9,14-18 expressed their desire to be present during invasive procedures and/or resuscitation of their child. Respondents discussed an inherent need to make the decision for themselves as to whether or not they chose to be present.9,15 In 5 of the 6 studies,9,14-17 researchers noted that parents felt that their presence was helpful to their child. Parents also commented that being present was beneficial for them,14,15,17 specifically noting that physical contact with their child was valuable.9,16,17 Additionally, 81% of parents felt that their presence was beneficial to the medical staff.14

Fifty-five percent of those who were not present wished that they had been present for cardiopulmonary resuscitation, and 60% thought that their presence would have been a comfort to their child.16 Parents who had not been present felt as though they had failed in their role as the child’s protector.15 Support for parents during and after resuscitation was noted to be crucial, and it was apparent that support was best left to experienced staff, most often nurses.15 Parent presence gave parents a new positive perspective of the nurses’ role.15 Family members reported that they served as the link between the child and the rest of the family and indicated that if they thought their presence would be detrimental to their child, they would leave the bedside.9

Satisfaction

If given the option, 94% of parents would choose to be present again for invasive procedures9 and 100% would choose to be present again for resuscitation.17 Parents would also recommend presence to others.9,16 Seventy-six percent of those present would not change anything about their experience compared with only 25% in the nonpresent group.16

Figure

PRISMA diagram of study selection.
# Table 1
Summary of study findings

<table>
<thead>
<tr>
<th>Reference, year; evidence level</th>
<th>Study aim</th>
<th>Study design and intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Powers and Rubenstein,14 1999; level I</td>
<td>Determine if allowing 1 or both parents to be present during invasive procedures reduces parents’ anxiety in the PICU Evaluate if parents’ presence was helpful to the child and parent</td>
<td>Prospective, cross-sectional study using Likert scale surveys completed within 24 hours after procedure Intervention group: parents present during invasive procedures Control group: parents not present during the same procedures</td>
</tr>
<tr>
<td>Maxton,15 2008; level III</td>
<td>Provide an in-depth understanding of the meaning for parents who were present or absent during a resuscitation attempt on their child in the PICU</td>
<td>Qualitative, descriptive design based on van Manen’s interpretative hermeneutic phenomenological approach using in-depth unstructured interviews Contact with patients’ families made 1 week after successful resuscitation or after 3 months if the child died</td>
</tr>
<tr>
<td>Tinsley et al,16 2008; level III</td>
<td>Determine parents’ perceptions of the effects of their presence during resuscitation in the PICU and whether they recommend the experience to other families</td>
<td>Mixed methods, retrospective, descriptive design using a questionnaire and interviews Comparison of families present with those not present during CPR All children died at least 6 months before interview</td>
</tr>
<tr>
<td>McGahey-Oakland et al,9 2007; level III</td>
<td>Describe family experiences of children undergoing resuscitation in the ED Identify information to improve circumstances for future families Assess mental and health functioning of families</td>
<td>Mixed-methods, retrospective, descriptive design using the Parkland Family Presence During Resuscitation/Invasive Procedures Unabridged Family Survey and investigator-generated questions in semistructured interviews Mental and health functioning assessed with Brief Symptom Inventory, Short Form Health Survey Version 2, and Posttraumatic Stress Disorder Scale</td>
</tr>
<tr>
<td>Mangurten et al,17 2006; level III</td>
<td>Determine the effectiveness of a family presence protocol in facilitating uninterrupted care and describe parents’ and providers’ experiences in the ED</td>
<td>Mixed-methods, retrospective, descriptive design using the Pediatric Family Presence Survey to interview parents via phone The survey contained the Pediatric Family Presence Attitude Scale adapted for parents Parents surveyed 3 months later by a psychiatric consult liaison nurse during an audiotaped phone interview</td>
</tr>
<tr>
<td>Boie et al,18 1999; level III</td>
<td>Determine if parents want to be present during invasive procedures</td>
<td>Mixed-methods, descriptive design using a self-administered written survey with 5 scenarios of increasing procedural invasiveness and resuscitation Parents answered if they wanted to be present Descriptions of scenarios provided on survey</td>
</tr>
</tbody>
</table>

Abbreviations: CPR, cardiopulmonary resuscitation; ED, emergency department; PICU, pediatric intensive care unit.
### Quantitative studies

| Intervention group: 16 parents of 16 children undergoing 1 or more procedures in a PICU | Mann-Whitney and Wilcoxon rank-sum tests | Parent presence during procedures decreases parental procedure-related anxiety compared with parents who were not present. Parents thought presence was helpful to the child, themselves, and medical staff. Parents would repeat the choice to be present again. |
| Control group: 7 parents of 7 children undergoing 1 or more procedures in a PICU | Purposeful, consecutive sampling used |

### Qualitative studies

| 14 parents of critically ill children whose child survived or died after resuscitation in a PICU | Construction of thematic statements and 4 themes Hermeneutic phenomenological interpretation provided understanding for what it is to “be” a parent in this situation | There is an inherent need for the choice to be present. Parents did not report additional trauma by being present. Memories of resuscitation were not long-lasting. Support for parents during and after resuscitation was crucial. Parents who did not witness the resuscitation were more distressed. Not being present made coping more difficult. Managing coping was more effective for some if they were able to leave and return. |
| Purposive sampling used |

### Mixed-methods studies

| Parents/guardians of children who underwent CPR and died | Thematic content analysis Descriptive statistics of results Groups compared via $\chi^2$ analysis | All families of previously healthy children wished they had been present. Of those not present, most wished they had been present and believed that their presence would have been a comfort to the child and would have helped in coping with the child’s death. The resuscitation was not traumatic. Parents would recommend being present to others. 76% of those present would not change anything compared with only 25% who were not present. |
| 115 families met inclusion criteria | 41 interviews done: 21 present, 20 not present during CPR in a PICU | Purposive sampling used |

| Family members identified through a performance improvement activity of the CPR committee | Standard qualitative data analysis done for open-ended questions Identified emerging themes by using independent thematic categorizing Descriptive statistics for demographic and survey results Quality-metric software used to score Short Form Health Survey Version 2 | All families expressed the importance of the option to be present. Presence provided strength to the child and gave family the opportunity to give the child permission to die. Physical connections facilitated healing for family members. Presence reassured families that all possible options were exhausted, doubts were dispelled, and closure was provided. If not present, parents wondered if outcomes could have been different. Family members began the process of accepting the child’s death while present for the resuscitation. |
| 25 charts met criteria | 10 family members included: 7 present, 3 not present | All children underwent CPR in a children’s hospital ED and subsequently died | Purposive sampling used |

| 22 parents who chose to be at the bedside during resuscitation or an invasive procedure in a pediatric ED | Mean attitude scores calculated Resuscitation vs invasive procedure groups compared via $\chi^2$ analysis or analysis of variance Mann-Whitney U test used to calculate differences in family members’ attitude scores Constant comparative technique for content analysis used | All parents said it was important to be at the bedside and believed their presence was helpful to the child. 95% felt that being present helped them personally and assisted them in understanding their child’s condition. 86% believed they had a right to be there, and 82% did not think their presence made a difference in the providers’ care. All would be present again. All agreed or strongly agreed that presence gave them peace of mind, was the right thing to do, gave them the chance to let their child know that they loved him/her, and helped them know everything possible was done for their child. |
| Purposive sampling used |

| Parents or grandparents in an ED waiting room | Descriptive statistics of results $\chi^2$ analysis used to compare results | Most parents want to be present during invasive procedures. With increasing invasiveness of procedure, parental desire to be present decreased. 65% wanted to be present for all scenarios. For major resuscitation scenarios, 71% (unconscious resuscitation) and 81% (conscious resuscitation) wanted to be present. 83% wished to be present if their child were likely to die. Only 0.8% did not want to be present for any procedures. |
| 407 met criteria | 400 included in study | Purposive, convenience sampling used |
A parental lack of understanding occurred if parents were not present.\textsuperscript{15} Presence enabled them to comprehend the severity of their child’s illness.\textsuperscript{9,15,17} Being present during resuscitation allowed them to see that everything had been done for their child\textsuperscript{9,15,17} and doubts were dispelled.\textsuperscript{9}

Furthermore, parents noted that they were able to participate in decision making and advocate for their child, including requesting the cessation of futile efforts.\textsuperscript{15} Parents were also able to ask questions and provide timely health information about their child.\textsuperscript{17} Being present gave them a sense of control, fear of the unknown was eased, and all reported that being present gave them peace of mind.\textsuperscript{17} Eighty-two percent of parents did not think their presence made a difference in the care their child received.\textsuperscript{17}

**Coping**

Being present for resuscitation reportedly helped parents make sense of the situation.\textsuperscript{15} Those who were not present reported that imagining the scene was worse and led to distress, chaos, and uncertainty.\textsuperscript{15} Specifically, restriction to the waiting room caused anxiety of the unknown,\textsuperscript{9} whereas parent presence reduced anxiety related to invasive procedures.\textsuperscript{14} When not present, parents wondered if the outcome for their child would have been different.\textsuperscript{9} They felt as though they had failed their child and displayed signs of guilt.\textsuperscript{15}

Parents reported no additional trauma caused by being present during resuscitation, as they reported that their focus was on the child, not the resuscitation.\textsuperscript{9,15} No long-lasting memories of the resuscitation were generated.\textsuperscript{15} Parents who did not witness the resuscitation were more distressed than those who did and also noted that coping was more difficult.\textsuperscript{15} Coping was more effective for some if they were able to leave and return during the resuscitation.\textsuperscript{15}

Eighty-three percent of parents wanted to be present if they thought their child might die.\textsuperscript{18} Saying goodbye was regarded as important.\textsuperscript{13} The physical connection offered healing for family members and provided closure.\textsuperscript{9} Presence also allowed the parent to give the child permission to die.\textsuperscript{9} Sixty-seven percent of those present thought it helped them cope with the child’s death.\textsuperscript{15} Fifty percent of parents who were not present thought that being present would have helped them cope with the death of their child.\textsuperscript{16} In addition, family members began the process of accepting the child’s death while present for the resuscitation.\textsuperscript{9}

**Discussion**

This systematic review describes the benefits of family presence from the parental perspective. Although these studies have some limitations, the findings suggest that family presence during resuscitation and invasive procedures is beneficial to parents, increases satisfaction with care, and aids in coping. Parent respondents expressed their desire to be at the bedside and emphasized their inherent need to make the decision whether or not to be present.\textsuperscript{9,15} Presence was acknowledged as being beneficial to parents, patients, and health care providers.\textsuperscript{9,14,17} Many parents who were not present wished to be, or at least wished to be given the option.\textsuperscript{9,15,16} Parents were more satisfied with care if they were present with their child. They expressed desires to repeat their choice to be present and would recommend being present to others, also suggesting satisfaction.\textsuperscript{9,14,16,17} Of note, significantly more parents who were present would not have changed anything about the presence experience compared with parents who were not present.\textsuperscript{15} In addition, coping was noted to be much better when parents were present, especially if the child died.

The hospitalization of a child is not an occasion that most parents anticipate, especially when a previously healthy child becomes ill. A critically ill child

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**Table 2**

<table>
<thead>
<tr>
<th>Being present</th>
<th>Satisfactory</th>
<th>Coping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents desired to be present or at least be</td>
<td>Want to be present again</td>
<td>Parents who were not present displayed</td>
</tr>
<tr>
<td>given the option</td>
<td>Would recommend being present to others</td>
<td>more distress and were more disturbed</td>
</tr>
<tr>
<td>Helpful to the child</td>
<td>Reassured all options were exhausted</td>
<td>Coping was more difficult when not present</td>
</tr>
<tr>
<td>Helpful to the parent</td>
<td>Eased parents’ sense of fear</td>
<td>Coping was more effective when parents</td>
</tr>
<tr>
<td>Helpful to medical staff</td>
<td>Would not change anything about the situation</td>
<td>could leave the room and return</td>
</tr>
<tr>
<td>Brought comfort to the child</td>
<td>when present compared with those who were not</td>
<td>Better coping and better adjustment to death of</td>
</tr>
<tr>
<td>Decreased parent’s anxiety related to the</td>
<td>present</td>
<td>child if present</td>
</tr>
<tr>
<td>procedure</td>
<td>Gained information about the child’s condition</td>
<td>Gave parents peace of mind, dispelled doubts,</td>
</tr>
<tr>
<td>No additional trauma was incurred because</td>
<td>Felt a sense of control</td>
<td>and provided closure</td>
</tr>
<tr>
<td>parent’s presence</td>
<td></td>
<td>Physical connection promoted healing</td>
</tr>
<tr>
<td>Focus was on the child, not the resuscitation</td>
<td></td>
<td>Began process of accepting the child’s</td>
</tr>
<tr>
<td>No long-lasting memories of resuscitation</td>
<td></td>
<td>death while present</td>
</tr>
</tbody>
</table>

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**Three themes were revealed:**

- being present
- satisfaction with care
- and coping.

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imposes significant distress on families. Family presence may be a simple, cost-effective way to reduce stress and minimize parental distress. By prohibiting family member presence, health care providers most likely compound the stress of parents.

Family-centered care is associated with increases in patient safety, patient, family, and staff satisfaction, as well as high-quality outcomes for patients. Family presence enables parents to be advocates for their children and comfort them while collaboratively working with the health care team. Communication is enhanced by family presence allowing parents to share pertinent medical information with providers as well as receive progress reports as events occur. Presence also permits parents to participate in real-time decision making including the cessation of futile efforts.

Many provider concerns that serve as barriers to parent presence were unsubstantiated. Parents reported that they were not traumatized by the resuscitation efforts as their focus was on their child and they had no lasting memories of the resuscitation. Parents also stated that their ability to cope began while they were present during resuscitation.

Providers have reported concerns that parent presence may change the management of the child; yet, researchers in 1 study found no clinically relevant difference in resuscitation time in pediatric trauma patients when parents were present. Additionally, clinicians have stated that parent presence did not affect their performance technically and did not alter their ability to make therapeutic decisions or teach.

Education is necessary to prepare health care providers to serve as resources to parents during resuscitation and invasive procedures. Support for the patient’s family during and after resuscitation is essential and is often provided by experienced staff nurses. However, various hospital personnel have been cited as appropriate family presence facilitators including nurses, physicians, psychologists, chaplains, social workers, and child life specialists. Specialized training to prepare for this role is warranted in order to educate the presence facilitator on preparing the family for presence, explaining medical care, and supporting parents during the procedure or resuscitation. Implementation of parent presence is more likely to occur if facilitators are properly trained. Training may be accomplished in a number of ways. Researchers in 1 study recommended workshops with high-fidelity simulation, educational videos, and self-learning packets. Clinicians who attended a training session for parent presence facilitators and practiced skills reported higher levels of comfort with parent presence and a greater ability to prepare parents, support them during procedures, and assist those who were unable to tolerate the events.

In order to incorporate family presence in pediatric critical care settings, all disciplines must be amenable to implementation and educated about the benefits. Clinicians report that they are more likely to institute family presence during invasive procedures and resuscitation when policies and/or guidelines exist. Successful generation and application of family presence policies may be limited by the opinions and attitudes of health care providers. It has been noted that as procedures become more invasive, both physicians and nurses are less likely to allow parent presence. Fewer than half of nurses and physicians support parent presence during resuscitation; however, nurses were more likely to support parent presence than were physicians. Education of the health care team may help providers to understand the benefits of family presence as well as the detrimental effects to parents if they are not present. In a survey done after the implementation of a presence policy, clinicians reported greater comfort with providing the option for parents to be present during invasive procedures and resuscitation.

Limitations

These studies have some limitations. All studies but one were limited by small sample sizes. In addition, all of the studies are single institution experiences in either the United States or Australia, making it difficult to generalize the results. Nonetheless, the conclusions were similar in each study. In addition, most studies were retrospective and involvement of participants was voluntary, which may introduce selection bias. Confounding variables that could alter the generalizability of results such as ages of the children and parents, marital status, education, race, ethnicity, religion, sex, socioeconomic status, child’s diagnosis, and previous health status were not consistently accounted for.

Conclusion

Until parent presence policies and guidelines are widely implemented in pediatric critical care, various evidence-based practices should be considered to ensure that parent presence is implemented without harm to the clinicians, parents, or patients. Presence should be encouraged with the most experienced and trained health care provider.
Parents should be allowed to leave and return as necessary 16

Family should be removed from the clinical area if behavior becomes disruptive or obstructive 21

Facilitators should provide no direct patient care 21

All health care providers should be aware that the patient’s family is present during the procedure and/or resuscitation 21

Parents should be clearly informed as to what to expect, interventions, and the patient’s status 21

Continual assessment of parents and provision of support are important 21

Parents should be allowed to leave and return as necessary 14

assuming the role of the liaison between the patient’s family and the health care team. This facilitator should be established before the patient’s arrival, provide no direct patient care, and remain exclusively with the patient’s family during the entire procedure or resuscitation. 21 All health care providers should be aware that the patient’s family is present. Continued assessment of the patient’s family is crucial, and parents should be removed from the treatment area if their behavior becomes disruptive or obstructive. 21 Family members should be clearly informed about what to expect, the interventions performed, and the status of the patient. 21 Parents should be allowed to leave the bedside without being scrutinized, as coping was more effective when parents were allowed to leave and return as needed. 15

In conclusion, many articles exist in which parent presence is discussed, but few researchers have examined how family presence influences a parent’s ability to cope and satisfaction with care. More research is warranted with a focus on these areas. Prospective, multicenter studies with larger sample sizes may yield more rigorous results. The results of future studies could be used as educational tools for providers to assist in promoting family presence, generating guidelines and protocols, as well as dispelling doubts.

FINANCIAL DISCLOSURES

None reported.

eLetters

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REFERENCES