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Clinical paper

Trauma-informed and family-centered paediatric resuscitation: Defining domains and practices



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Abstract

Aim: For paediatric patients and families, resuscitation can be an extremely stressful experience with significant medical and psychological consequences. Psychological sequelae may be reduced when healthcare teams apply patient- and family-centered care and trauma-informed care, yet there are few specific instructions for effective family-centered or trauma-informed behaviours that are observable and teachable. We aimed to develop a framework and tools to address this gap.

Methods: We reviewed relevant policy statements, guidelines, and research to define core domains of family-centered and trauma-informed care, and identified observable evidence-based practices in each domain. We refined this list of practices via review of provider/team behaviours in simulated paediatric resuscitation scenarios, then developed and piloted an observational checklist.

Results: Six domains were identified: (1) Sharing information with patient and family; (2) Promoting family involvement in care and decisions; (3) Addressing family needs and distress; (4) Addressing child distress; (5) Promoting effective emotional support for child; (6) Practicing developmental and cultural competence. A 71-item observational checklist assessing these domains was feasible for use during video review of paediatric resuscitation.

Conclusion: This framework can guide future research and provide tools for training and implementation efforts to improve patient outcomes through patient- and family-centered and trauma-informed care.

Keywords: Paediatric resuscitation, Psychological sequelae, Family-centered care, Trauma-informed care

Introduction

For children and their families, invasive procedures such as resuscitation can be extremely stressful experiences with potential for significant short- and long-term medical and psychological consequences, including symptoms of posttraumatic stress disorder (PTSD). Approximately 20% of acutely ill or injured children go on to develop clinically significant PTSD symptoms¹; parents/caregivers show similar rates of distress.^{2,3} Persistent PTSD symptoms can impact quality of life and functional outcomes, including family relationships and school performance.⁴

Psychological sequelae of resuscitation may be reduced when healthcare teams apply principles of both patient- and family-centered care (PFCC) and trauma-informed care (TIC). PFCC is

care that emphasizes respect for patient and family perspectives and encourages patient and family participation in care and decision-making.^{5,6} TIC refers to providing healthcare in a way that minimizes the potential for psychological traumatization or PTSD symptoms related to illness, injury, or treatment experiences.^{7,8} PFCC and TIC are complementary, distinct but overlapping, concepts⁹; each is associated with improved health outcomes and better patient and family experience.^{6,9,10} This project addresses implementation of PFCC and TIC in the context of resuscitation in the emergency department (ED). Our working definition of resuscitation is providing care quickly with a multidisciplinary medical team for a patient with a time-sensitive, emergency-care-responsive problem.¹¹

While PFCC and TIC in the resuscitation context encompass multiple aspects of healthcare team-patient-family interactions, the

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most visible and widely known aspect is providing the option for parents or caregivers to be present during resuscitation. There is a well-established body of evidence demonstrating the positive impact of family presence for patient safety, patient/family satisfaction, and emotional health,^{5,10,12} and showing that family presence does not negatively impact the quality of care, i.e. does not lead to interference in the care process nor delays in time-critical interventions.^{13–15} Joint guidelines from the American Academy of Pediatrics (AAP), American College of Emergency Physicians (ACEP), and the Emergency Nurses Association (ENA) recommend allowing the option of family presence during paediatric resuscitation.¹⁰

Beyond support for family presence, most family-centered care policies and guidelines have not described specific practices by the healthcare team; i.e., as they interact with each other in the presence of the family, with the child (when awake/aware), or with family members (whether present in the resuscitation room or waiting elsewhere). A noteworthy exception is Farah et al.'s¹⁶ description of specific practices for implementing family presence from the time of the family's arrival at the ED, throughout the resuscitation event, and after resuscitation is over. Several publications have noted that the lack of specific guidelines may be impeding optimal delivery of PFCC and TIC in paediatric acute care.^{9,10,17}

In this project we aimed to translate broad PFCC and TIC practice guidelines from professional organizations, as well as existing research evidence from diverse fields, to (1) define a set of core PFCC and TIC domains; (2) identify granular, evidence-based PFCC and TIC practices; and (3) develop practical methods to assess these behaviours during paediatric resuscitation in the ED. Our overarching objective is to provide a framework useful for clinically relevant research and for training and implementation efforts to improve patient outcomes through PFCC/TIC.

Methods

Our multidisciplinary, multi-institutional project team included experts in relevant fields with a shared interest in addressing knowledge gaps related to best practices for PFCC and TIC in paediatric resuscitation. Our team included expertise in paediatric emergency medicine, paediatric emergency nursing, paediatric critical care medicine, behavioural science, paediatric traumatic stress, and paediatric psychology. To identify concrete, feasible behaviours that make up PFCC and TIC during paediatric resuscitation, and develop a practical means of assessing these practices, we followed a structured step-wise process, consistent with established frameworks for developing observational checklists.¹⁸ Each stage refined and built on prior stages: (1) Narrative review of guidelines and research literature, (2) Define domains and specific observable practices, (3) Observe team behaviours to refine list of practices, (4) Create a practical observational measure and provide an initial assessment of inter-rater agreement.

Step 1 – Narrative review of guidelines and research literature

We reviewed expert consensus documents, policy statements, and practice guidelines from major academic committees and professional/scientific organizations to extract PFCC/TIC domains and evidence-based PFCC/TIC behaviours, and to help identify relevant research literature. We then searched PubMed, PsycInfo, and CINAHL to identify additional review articles and meta-analyses

addressing effective practices for promoting family involvement and reducing child and parental distress in paediatric emergency care.^{10,19–22}

Step 2 – Define domains and specific observable practices

Based on literature reviewed in Step 1, our interdisciplinary group defined a number of broad PFCC/TIC domains. We drafted an initial list of evidence-based behaviours and practices, as well as potentially harmful behaviours and practices, drawn from the literature and the team's relevant experience in clinical care. We prioritized for inclusion those behaviours with the strongest evidence for their association with improved outcomes, and those identified as practices to avoid because of their association with poorer outcomes.

Step 3 – Observe healthcare team behaviours to refine list

We reviewed videos of in-situ simulated paediatric resuscitations and catalogued interactions between the care team, 'patient', and scripted parent-actors. Videos had been previously collected as part of the ImPACTS project, approved by the Yale IRB (Protocol #1211011074).²³ Videos were reviewed (by a medical student team member) using the Event-Sequential Continuous Recording method²⁴ in which observed behaviours were listed in order of occurrence. We included all observed provider-parent and provider-patient interactions (utterances and physical gestures), plus other behaviours with potential psychological effects for patient or parent (e.g. using insensitive language to discuss patient condition in front of parent). We cross-checked the resulting list of unique behaviours with the evidence review from Step 2, and categorized new items into PFCC/TIC domains.

Step 4 – Create practical observational measure

We aimed to create a tool that can be used in research, training, and quality improvement efforts to assess delivery of PFCC/TIC by a healthcare team during paediatric resuscitation. Starting with the refined list from Step 3, we added descriptive examples for specific behaviours where possible. After formatting the tool for ease of use, we piloted and refined items for clarity and feasibility of observation, and developed anchors and definitions for global ratings. We then assessed inter-rater agreement (defined as concordance of two independent raters within one point on the 1–10 scale) for overall and domain-specific global ratings of care delivered by healthcare teams responding to simulated resuscitation scenarios, as part of a larger project approved by the Children's Hospital of Philadelphia IRB (Protocol #17-014752).

Results

Step 1 – Narrative review of guidelines and research literature

In Step 1, we identified key professional organizations in pediatrics, emergency medicine and nursing, resuscitation care, trauma care, and psychology, and their statements and guidelines related to PFCC or TIC. We examined seven expert consensus documents, policy statements, or practice guidelines from organizations such as the American Academy of Pediatrics, Emergency Nurses Association, American College of Emergency Physicians, American College of Critical Care Medicine, American Hospital Association, Institute for Patient- and Family-Centered Care, The Joint Commission, and the Medical Traumatic Stress Working Group of the

National Child Traumatic Stress Network.^{5,20,25–29} We also identified six systematic or narrative research reviews, from the reference lists of the organizational statements plus additional searches using keywords such as patient-centered, family-centered, or trauma-informed, along with pediatric, emergency care, or resuscitation.^{19,30–34}

This narrative review of the literature found widespread agreement regarding the importance of PFCC/TIC in paediatric resuscitation and the need for policies to support the option of family presence. Though we identified several guidelines for the logistics of PFCC/TIC program implementation, we noted a paucity of specific instructions for effective behaviours by healthcare teams. We identified one instrument assessing departmental-level PFCC/TIC systems,³⁵ one paper describing suggested healthcare team practices,¹⁶ and self-report measures of healthcare professionals' comfort and confidence implementing practices associated with family presence,³⁶ but we were unable to find any assessment instruments specifically designed to assess provider or team behaviours for educational, quality improvement, or research purposes.

Step 2 – Define domains and specific observable practices

In Step 2, by extracting concepts and domains described in guidelines and research reviews, we identified six comprehensive PFCC/TIC domains (i.e., overarching aims that represent distinct aspects of PFCC/TIC) in the paediatric emergency/resuscitation setting. These domains were: (1) Sharing information with the patient and family; (2) Promoting family involvement in care and decisions; (3) Addressing family needs and family distress; (4) Addressing child distress (pain and emotional distress); (5) Promoting effective emotional support for the child; (6) Practicing developmental and cultural competence. In order to better describe specific evidence-based practices, we conducted targeted reviews of the literature and examined selected original research articles, many identified in the review and consensus documents noted above, that delineated and evaluated relevant practices. For example, the traumatic stress literature notes the importance of early pain management in reducing PTSD symptoms.^{20,37} The paediatric psychology and paediatric anesthesiology literatures identify the benefits of distraction in reducing child distress during painful or invasive procedures, and the counterintuitive adverse impact of emotionally reassuring statements which can inadvertently worsen child emotional distress.^{21,38,39} We extracted an initial list of 29 PFCC/TIC behaviours by the healthcare team, across these six domains.

Table 1 presents the six domains, with a brief rationale for each domain's relevance to PFCC/TIC drawn from the literature review (Step 1), selected observable behaviours for each domain (Steps 2 and 3), and illustrative examples from video review (Step 3). The term "parent" here refers to anyone in a parent/caregiver role present when a child requires resuscitation.

Step 3 – Observe healthcare team behaviours to refine list

In Step 3, we observed healthcare teams in order to refine the list of behaviours informed by care as it is currently practiced in the ED. We reviewed 26 videos of in-situ simulated paediatric resuscitations conducted with emergency department teams in their usual site of practice, featuring cases of infants with a foreign body airway obstruction, hypoglycemic seizure, or septic shock and a child in cardiac arrest (non-responsive). To capture a broad sample of care environments, we reviewed resuscitation footage from actual teams of ED profes-

sionals across eight states in both low paediatric volume community EDs (caring for less than five children per day), as well as higher volume community EDs and academic paediatric EDs (caring for over one hundred children per day). This initial video review yielded a list of 38 unique team/health professional behaviours. One author (LB) categorized these behaviours into the six domains, and the categorized behaviours were reviewed and discussed by authors with expertise in behavioural science and paediatric emergency medicine (NKA and MA) to reach consensus regarding their relevance to each domain and connection to the evidence-base and best practice recommendations.

Step 4 – Create practical observational measure

In Step 4, we created an observational checklist. Iterative refinement of the initial list of behaviours and those identified during video review resulted in a list of 71 unique items (observable behaviours) across six domains. As one example, several direct observations helped us refine items related to communication with parents/caregivers, e.g.: "Team member shares parent's HPI with team aloud: 'Dad's saying the child has had a fever for a few days and has had decreased urine output.'" and "Team members repeatedly ask family same question -- parent was asked 3 times for weight of child in a 15 minute period." These observations were categorized in Domain 2 (Family involvement in care/decisions) informing item 2.3 (involving parent in reporting on child's medical history/history of present illness), but also helped us refine items 1.12 and 1.13 regarding designating a primary family liaison and avoiding having multiple team members interacting with family within a short period of time.

We piloted an initial version of the checklist during real-time and post-session video observation of several additional simulated resuscitation scenarios, and then further refined and formatted to improve usability; i.e., ensuring that behaviours were well-defined and reliably observable, and providing behavioural examples for many items. To enable the tool's use in more formal research or quality improvement efforts (in addition to informal team self-review) we clarified operational definitions and anchoring guidelines for overall and domain-level global ratings. In each domain we defined which team behaviours were 'crucial' (e.g., item 1.2: explaining primary assessment and plan to family at some point), and which were 'always possible' in a paediatric resuscitation - thus denoting missed opportunities when not observed (e.g., item 1.7 or 1.8: providing spontaneous or prompted updates on patient status to the family). To facilitate reliable domain scoring on a 1–10 scale, we defined anchors for global ratings of 1 (poor), 5 (satisfactory), and 10 (excellent). For example, a domain global rating of 5 denotes that the team actively addressed the goal of the domain, exhibited all or nearly all behaviours defined as crucial, and no or few potentially detrimental behaviours, but may have missed some opportunities to enact desired PFCC/TIC behaviours. Using these guidelines to rate team behaviours during 11 video-recorded simulated paediatric resuscitation scenarios, we found 91% inter-rater agreement for overall PFCC/TIC global rating and 86% inter-rater agreement for domain global ratings. Inter-rater differences on the 1–10 scale were generally small (mean difference = 0.59) and easily resolved via discussion. The current version of the Pediatric Resuscitation Observation Checklist for Patient/Family-Centered and Trauma-Informed Care with behavioural examples and detailed rating and scoring guidelines is freely available here: <https://www.healthcaretoolbox.org/observation-checklist-pediatric-resuscitation>.

Table 1 – Domains of patient- and family-centered care and trauma-informed care relevant to paediatric resuscitation, with brief rationale and selected examples.**Domain 1. Sharing information with patient and family**^{5,26,29,50}**Rationale: Evidence that information-sharing promotes patient safety and patient/family satisfaction with care and may reduce emotional distress.**

Team member explains primary assessment/plan of action

“We’re going to look over him head to toe to find out what’s going on”

Team member explains status/procedure using language appropriate for parent’s health literacy

“We’re going to have to put a breathing tube in her throat to help her breathe”

Domain 2. Promoting family involvement in care and decisions^{5,26,29,50}**Rationale: Evidence that family involvement promotes patient safety and patient/family satisfaction with care.**

Team member asks parent about child’s medical history or history of present illness.

“So, [parent name], tell me about what happened today. . . does [child] have any other medical problems?”

Team member asks parent if they want to be with child during acute care/procedure.

“You are welcome to be here while we take care of [child]. Whatever you choose, we will keep you informed.”

Domain 3. Addressing family needs and family distress^{19,28}**Rationale: Evidence that family presence is appreciated by parents but can be stressful.**

Team member offers comfort items to family member

“Can we get you anything? A chair? Cup of water?”

Team member explicitly checks parent /coping

“How are you doing? It can be hard to see this happening with your child.”

Behaviour that may increase distress: Team member verbally expresses lack of clarity about treatment plan/procedural details*

“Does anyone know which ET tube size we need?”

Domain 4. Addressing child distress (pain and emotional distress)^{19–21,28}**Rationale: Evidence for association of acute pain and acute emotional distress with persistent posttraumatic stress in children.**

Team member observes behavioural indicators of child emotional distress, and probes to assess further

“You look like you might be feeling worried”

Behaviour that may increase distress: Team member apologizes to child for past or future action*

“I’m sorry sweetie, I know that hurt you.” Or “I’m sorry, I have to press there again.”

Domain 5. Promoting effective emotional support for child^{19,21,28,38}**Rationale: Evidence that specific provider and parent behaviours have an impact on immediate child distress.**

Team member actively engages child in a distracting activity or conversation just before/during a potentially painful or distressing procedure

“What’s your favorite movie?” or “Let’s look over here [away from active procedure site] and count the number of X’s you see”

Team member makes specific suggestion for parent action to support child during procedure

“[Parent’s name], why don’t you come over here and hold his hand while we do this?”

Domain 6. Practicing developmental and cultural competence²⁹**Rationale: Evidence of developmental impact on children’s understanding of medical procedures and information, and of cultural variation in interactions with healthcare teams.**

Team member explains specific procedure to child and checks child’s understanding

“I just told you a lot of things. Can you explain it back to me in your own words?”

Team member asks about child’s and family’s religious/spiritual background

Chaplain asks, “Does your family have any religious or spiritual affiliation of any sort?”

* Note: Some behaviours (such as apologies) by team members are associated with greater child or family distress and are thus potentially detrimental.

Discussion

This project identified domains and specific behaviours that represent key facets of PFCC and TIC in paediatric resuscitation, and that can be leveraged for training and quality improvement efforts. This lays the groundwork for defining discipline- and role-specific core competencies related to PFCC and TIC in future training and skill assessment projects.⁴⁰ With burgeoning awareness of the need for family-centered and trauma-informed care and greater acceptance of family presence, it is time to move beyond general policies supporting family presence and to assess and improve specific practices within the resuscitation room. A 2016 *JAMA Pediatrics* review of TIC points to unclear best-practice guidelines as a barrier to implementation of effective TIC.⁹ The American Association of Pediatrics Technical Report on PFCC for children in the ED called for the “development of a compendium of best practices” as a much needed area of research.¹⁰ To our knowledge, this project is the first to explicitly delineate specific observable behavioural metrics for the

delivery of PFCC and TIC during paediatric resuscitation, and to provide practical assessment tools to support training, quality improvement, and research regarding these elements of care.

Awareness and acceptance of PFCC has grown remarkably over the past decade; half of general EDs and 75% of paediatric EDs in the United States currently have family-centered care policies for children.⁴¹ Healthcare professionals also convey enthusiasm for optimizing PFCC and TIC - two international surveys of emergency healthcare staff found high levels of interest in education related to PFCC and TIC, but few reported any formal skill training in this area.^{42,43} Without clearly defined practices or assessment metrics, it is difficult to teach trainees how to provide optimal PFCC and TIC in the paediatric resuscitation setting, or to expect them to apply these skills in practice. This lack of clarity can lead to significant variability across teams and individual professionals. As Baren pointed out over 20 years ago, it is unfair to expect healthcare professionals to change their behaviour with regard to PFCC in the ED without providing a methodology to do so.¹⁷

This project suggests several directions for future work regarding equitable and ethical care,⁴⁴ well-being of the healthcare team, and development of a specific evidence base for family-centered and trauma-informed paediatric resuscitation. Regarding equity in care, a granular observational tool for specific practices can allow examination of potential variations in delivery of PFCC and TIC based on patient and family race/ethnicity or marginalized status.^{45,46} Understanding disparities in specific practices and child-family-team interactions would point the way to interventions and training to mitigate biases in care delivery and allow teams to measure change in these processes over time.

All members of the healthcare team may experience secondary traumatic stress from repeated exposure to emotionally challenging paediatric resuscitations and emergent care.^{47–49} To prepare healthcare teams to optimally deliver PFCC/TIC during paediatric resuscitation, we need evidence-based, accessible supports for healthcare providers' well-being. Future research might examine changes in implementation of PFCC/TIC across teams with and without emotional support programs for team members.

Research from related fields and settings has been instrumental in highlighting the importance of PFCC and TIC in paediatric acute care and laying the foundation for practice recommendations. Much of the data related to PFCC and TIC has come from other clinical settings, extrapolated for use in acute resuscitative and emergency care. Future research and quality improvement efforts should continue to delineate and evaluate PFCC and TIC practices specific to (and practical for) paediatric and general emergency departments and other acute care settings.

Several limitations of the current project should be noted. We did not conduct formal systematic literature reviews; future work to refine the measure could include a series of systematic reviews of the evidence for specific team behaviors within each domain. This project did not gather family member perspectives regarding practices included in the observational tool; this would be a key step for future research. It would also be useful to assess the tool's usability and reliability amongst a wider range of healthcare professionals engaged in quality improvement efforts, and explore creating a briefer version for real-time use during paediatric resuscitation events.

Conclusion

Heeding the calls from leading professional organizations for more family-centered and trauma-informed paediatric acute care requires that we move beyond broad policies to delineate specific practices. This project represents a key first step toward defining healthcare team behaviours that can be readily understood and reliably observed, and has created a practical observational tool feasible for use in video review of real or simulated paediatric resuscitation. This may provide a useful framework to advance quality improvement and research in emergency and acute care settings, as well as training and continuing education for healthcare professionals.

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CRedit authorship contribution statement

Nancy Kassam-Adams: Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft. **Lucas Butler:** Conceptualization, Methodology, Investigation, Writing – review & editing. **Julia Price:** Conceptualization, Methodology, Writing – review & editing. **Marcie Gawel:** Conceptualization, Investigation, Writing – review & editing. **Leila Graham:** Methodology, Investigation, Data curation, Writing – review & editing. **Sage Myers:** Conceptualization, Writing – review & editing. **Marc Auerbach:** Conceptualization, Methodology, Supervision, Writing – review & editing.

Declaration of Interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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