

A Prospective Study of Family Engagement for Prevention of Central Line-associated Blood Stream Infections

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Introduction: We sought to determine if a family-centered care (FCC) handout intervention designed to encourage family engagement (FE) in the prevention of central line-associated bloodstream infections (CLABSIs) would alter parental perceptions of FCC and improve staff compliance with CLABSI bundle components. **Methods:** A prospective quasiexperimental study of 121 legal guardians of children with a central venous catheter (CVC) admitted to the pediatric intensive care unit (PICU). Baseline (n = 59) and intervention (n = 62) groups of parents completed an 18-question online survey assessing basic CLABSI care practices and FCC principles. The intervention group received an FE handout before completing the survey with information about CLABSI prevention practices designed to encourage active participation in their child's CVC care. **Results:** Independent sample *t*-tests found significant improvements in the intervention parents responses compared to the baseline group (no handout) on survey items assessing CLABSI knowledge ($P < 0.001$) and on parental perceptions of FCC in the domains of dignity and respect, information sharing, participation, and partnership (all with a $P < 0.001$). An improvement was observed in staff CLABSI maintenance bundle compliance in the postintervention period, increasing from 89% to 94%. **Conclusions:** Educating parents on CLABSI prevention strategies and encouraging family participation in CVC care was associated with improved parental perceptions of participation in their child's care, medical team's listening, attention, honesty, and explanation of treatment plans and was associated with an increase in staff compliance with CLABSI maintenance bundle practices. (*Pediatr Qual Saf* 2021;00:e467; doi: 10.1097/pq9.000000000000467; Published online 26 August, 2021.)

INTRODUCTION

An essential component of modern medical care, central venous catheters (CVCs) are also associated with the risk for developing central line-associated bloodstream infections (CLABSIs). Patients who develop CLABSIs have prolonged hospitalizations and increased morbidities, such as sepsis, renal failure, acute respiratory failure, and



death.¹⁻³ Each pediatric CLABSI is associated with an attributable cost of \$55,646 and an increase in the average hospital length of stay by 19 days.⁴ An estimated 65%–70% of CLABSIs may be preventable; well-conducted prospective trials demonstrate that introducing evidence-based guidelines for the insertion, maintenance, and prompt removal of unnecessary CVCs can substantially reduce CLABSIs in adult and pediatric populations.⁵⁻⁸ Data from the National

Healthcare Safety Network (NHSN) show that from 2007 to 2012, the CLABSI rate in the pediatric intensive care unit (PICU) of 173 US hospitals fell from 4.7 to 1.0 per 1,000 catheter days after the widespread adoption of CLABSI practice guidelines.⁹ Since then, further reductions in the CLABSI rate have proved to be more challenging over time. For example, using similar NHSN reporting data and adjusting for the number of PICU beds and children's hospital status, from 2013 to 2018, the PICU CLABSI rate remained unchanged with a mean of 1.39 per 1,000 catheter days.¹⁰ Miller et al⁵ suggested that continued reductions may be more challenging following the implementation of current standardized, evidence-based practices and additional novel methods are needed to effect further reductions.

Family-centered care (FCC), that is, putting patients and families in the center of care, is endorsed by the American Academy of Pediatrics and Society of Critical

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Care Medicine as an innovative and essential component of high-quality clinical healthcare delivery due to the emphasis on a mutually beneficial partnership among patients, families, and providers.^{11,12} Conceptually, both providers and families view patient and family engagement (FE) as beneficial to the health care experience, but placing families at the center of care as active partners can be challenging in the PICU due to patient complexity, illness severity, and life-supporting technological considerations. Using a family-centered approach of FE to promote healthcare quality and safety is cited by the National Academy of Medicine as an area to target to improve health care. We sought to use FCC principles to engage families through partnership and participation in basic CVC care and infection prevention strategies in the PICU to reduce patient harm due to CLABSIs.

MATERIALS AND METHODS

Study Design and Participants

We conducted a prospective quasiexperimental online survey study of parents in a 44-bed PICU at Children's Health—Children's Medical Center Dallas (CMCD) to assess FCC perceptions before (baseline group) and after (intervention group) a specially designed FE handout was administered to parents of children with a CVC. A single research investigator (T.C.) approached eligible participants that were English-speaking parents/guardians of children 0–18 years of age, admitted to the PICU with a CVC in place for at least 24 hours, either pre-existing or newly placed. An automated daily PICU CVC report identified potential candidates. Imminent death or CVC removal excluded eligibility. The University of Texas Southwestern Institutional Review Board approved the study as exempt with anonymous data collection requiring only verbal consent.

Study Intervention

After verbal consent by the parent, legal guardian, or representative (further referred to as parents), baseline and intervention groups of parents completed an 18-item survey questionnaire (**Supplemental Digital Content 1**, <http://links.lww.com/PQ9/A302>) on an iPad. The survey took 5–8 minutes to complete, and responses were directly imported into a secure REDcap database. The baseline group received no FE CLABSI education or handout. After completing baseline parental surveys, the PICU nursing staff received education during pre-shift huddles over 3 months on the FE handout content and instructions on encouraging family participation using the handout as a guide. Immediately following staff education, a physical copy of the FE handout along with face-to-face reinforcement by a PICU nurse or a CLABSI team member was provided to all parents of children with CVCs in the PICU. Parents were empowered to hold the staff and the medical team accountable by speaking up if they witnessed protocols not being performed. Parents were then approached and asked

to complete the same online survey. The CLABSI team comprised a group of PICU bedside nurses, team leaders, physicians, and clinical nurse specialists. During the baseline and intervention periods, parents were asked if they would be willing to complete an anonymous survey on their perceptions of care in the PICU and were unaware that the survey's purpose was part of a study to test the CLABSI handout. Although members of the bedside nursing staff were engaged as partners in the CLABSI handout process, they were not aware that a survey study was being performed to test its effect on parental perceptions.

FE CLABSI Handout Tool and Survey Questionnaire

We created a CLABSI handout entitled, "You Can Do It! Prevention of Bloodstream Infections" (**Supplemental Digital Content 2**, <http://links.lww.com/PQ9/A303>) adapted from the CDC Resources for Patients & Providers—Frequently Asked Questions about Catheters¹³ with input from the Patient and FCC Committee, consisting of PICU leaders, social work, and patient/family representatives. The handout outlined basic CLABSI prevention information and concrete steps on how parents could partner with the medical team to prevent a CLABSI from occurring. The online survey contained four CLABSI knowledge and prevention questions and 14 FCC questions using a combination of one multiple-choice, one true/false, and 16 four-point Likert scale items (1 = always, 2 = usually, 3 = sometimes, and 4 = never) where a lower score indicated a more favorable parental response. The survey questions were developed around core FCC principles' outlined by the Patient-centered Care and FCC Institute¹⁴ and grouped into the following domains for analysis (Table 1), central line care and patient safety (4 items), dignity and respect (3 items), information sharing (4 items), participation (4 items), and partnership (3 items).

CLABSI Maintenance Bundle Compliance

A single CLABSI infection could have significantly altered the infection rate; thus, the overall CLABSI rate was not used as an outcome variable. Alternatively, we focused on staff compliance with the CVC maintenance bundle practices to measure CLABSI quality improvement. Compliance with CLABSI maintenance bundle compliance was assessed via direct observational rounding by a CLABSI team member using an all or nothing (AON) methodology. The CLABSI maintenance bundle comprised 5 objective daily care practices: (1) discussion of CVC necessity during rounds; (2) a clean and occlusive CVC dressing site; (3) CVC dressing change on the correct day; (4) CVC cap and intravenous (IV) tubing change every 96 hours; and (5) protective coverings/securement of the CVC away from potential sites of contamination. To be compliant based on AON methodology, all 5 care practices must be met.

Table 1. Study Survey Knowledge and FCC Questions

Category	Questionnaire Subject Item
Central line care and patient safety	<ul style="list-style-type: none"> • Important steps for staff to do before using a central line • Time to complete “scrub the hub” for 15 s
Dignity and respect	<ul style="list-style-type: none"> • Perception of comfort with speaking up to ask staff to clean their hands when entering child’s room • Perception of staff efforts to prevent infections in the hospital • Perception of staff’s attention to the care of the child • Perception that team members treat child and family in a respectful manner
Information sharing	<ul style="list-style-type: none"> • Perception that staff listen to parental concerns • Perception that staff provide information about child’s illness • Parent’s understanding of treatment plan • Perception of knowledge about child’s progress
Participation	<ul style="list-style-type: none"> • Perception that the child’s plan of care is explained in a way that is understood by parent • Perception that parent is encouraged to provide input into child’s care • Perception that parent is encouraged to participate in child’s care • Perception that parent desires more participation in child’s care
Partnership	<ul style="list-style-type: none"> • Perception that parent is provided an opportunity to discuss child’s care with medical team • Perception that parent may stop staff if uncomfortable with actions • Perception that staff are receptive to feedback regarding their care • Perception that questions /concerns are answered honestly

Survey Validity and Reliability

To establish the survey’s face validity, the Patient Experience Officer at CMCD provided feedback to ensure the questionnaire content appropriately addressed FCC concepts. Survey reliability was assessed by testing the internal consistency of 1,062 baseline group responses via Cronbach’s alpha, where a value of >0.7 is generally considered acceptable.

Study Outcomes and Statistical Analysis

The primary study outcome was parental perceptions of dignity and respect, information sharing, participation and partnership, and knowledge of basic CLABSI practices in baseline and intervention groups. The secondary outcome measured the bedside PICU staff’s compliance rates with CLABSI prevention maintenance bundle practices during the baseline and intervention periods. Survey responses comparing baseline and intervention parent groups were analyzed individually and grouped by the FCC group variable domains. We present descriptive analyses of categorical data as frequencies, proportions, and means with SD. The Wilcoxon Rank Sum test compared individual question Likert scale variables between baseline and intervention group. A two-sample independent *t* test compared grouping variables between the baseline and intervention groups. A Chi-square test tested associations between true/false questions variables. Statistical analyses were performed using SAS (9.4, SAS Institute Inc.) and GraphPad Prism (8.4, GraphPad Software).

RESULTS

Questionnaire Reliability

The survey’s internal consistency overall was excellent (0.96). Internal consistency of the identified five domains was the following: CLABSI prevention and knowledge (0.71), dignity and respect (0.88), information sharing (0.87), participation (0.82), and partnership (0.88).

Survey Results

Of 127 eligible parents, 121 (95%) consented, 59 in the baseline group enrolled from March to September 2014, and 62 in the intervention group enrolled from January to March 2015. Six parents (5%) declined. All parents who verbally consented completed the survey and were included in the analysis. No patient or parental characteristics were collected. Not unexpectedly, correct responses improved to the four CLABSI knowledge and prevention items in the intervention group compared to baseline ($P < 0.001$) (Table 2). Intervention parents rated a more favorable Likert response to the medical staff’s infection prevention efforts and comfort when speaking up to ask providers to wash their hands (mean Likert scale [SD], 1.0 (0.18) vs 2.0 (0.73); $P < 0.001$). Somewhat unexpected, parental responses to the 14 FCC questions unrelated to CLABSI or infection prevention were also significantly lower. Likert scores between baseline and intervention groups differed by the Wilcoxon Rank Sum test for each of the 14 questions when analyzed individually (data not shown) and by domain grouping. Independent *t* test analyses of FCC variable domains showed significantly lower Likert scores (t-statistic value, degrees freedom (df) in each of the domains of dignity and respect, ($t = 25$, $df = 360$, $P < 0.001$); information sharing, ($t = 26$, $df = 482$, $P < 0.001$); participation ($t = 26$, $df = 482$, $P < 0.001$), and partnership ($t = 22$, $df = 361$, $P \leq 0.001$) (Table 2). Finally, parents in the baseline group scored a 1 on survey responses in 116/826 (14%) responses. In contrast, in the intervention group, 842/868 (97%) of responses scored 1 (Fig. 1).

CLABSI Bundle Measures

Audits were performed 5 days a week as part of our standard PICU practice on 5 core-bundle maintenance elements using an AON method described in the methods section. The central line utilization rate (number of central line days/number patient-days) was similar during

Table 2. Parent Control and Intervention Group Comparisons

Survey Questionnaire Categories	Control (n = 59)	Intervention (n = 62)	P	95% CI Difference
Central line care and patient safety				
Identify all line access steps, % correct	15	60	<0.001	
15 second scrub the hub time, % correct	67	100	<0.001	
CLABSI prevention, mean Likert score (SD), n = 2	2.0 (0.73)	1.0 (0.18)	<0.001	-1.19 to -0.93
FE/family-centered care principals, mean Likert score (SD)				
Dignity and respect, n = 3	2.0 (0.55)	1.0 (0.07)	<0.001	-1.12 to -0.96
Information sharing, n = 4	2.0 (0.58)	1.0 (0.09)	<0.001	-1.04 to -0.89
Participation, n = 4	2.2 (0.66)	1.0 (0.22)	<0.001	-1.25 to -1.07
Partnership, n = 3	2.2 (0.68)	1.1 (0.24)	<0.001	-1.25 to -1.05

Data presented are for the average Likert scale values and SDs for each FE principal grouping, n = number of questions in each respective group and 95% confidence interval (CI) of the difference between the means. Likert responses represent parental perceptions to FCC questions in each domain (1 = always, 2 = usually, 3 = sometimes, and 4 = never). Lower scores represented more favorable responses.

the baseline control period (0.49) and for the intervention period (0.46). Based on the AON methodology, CLABSI maintenance bundle compliance increased from 89% during the baseline to 94% in the intervention stage.

DISCUSSION

The Society of Critical Care Medicine FCC guidelines advocate for family presence in the ICU, family communication, and the use of specific family supportive consultations.¹² Broadly defined, FCC is the assurance of children and their families health and well-being through a respectful family-professional partnership encompassing the principles of mutual respect,

information sharing, communication, collaboration, and participation. Given this frame of reference, educating and empowering patients and families to partner with the healthcare team’s effort to improve quality and safety measures, such as with CLABSI prevention, works toward satisfying the intention of FCC. In this study, parents of children with CVCs in the PICU that received education on evidence-based CLABSI prevention practices and concrete steps of how to partner with the medical team to reduce CLABSIs demonstrated improvements in knowledge and prevention steps and self-reported more positive perceptions of FCC domains of dignity and respect, participation, information sharing, and communication.

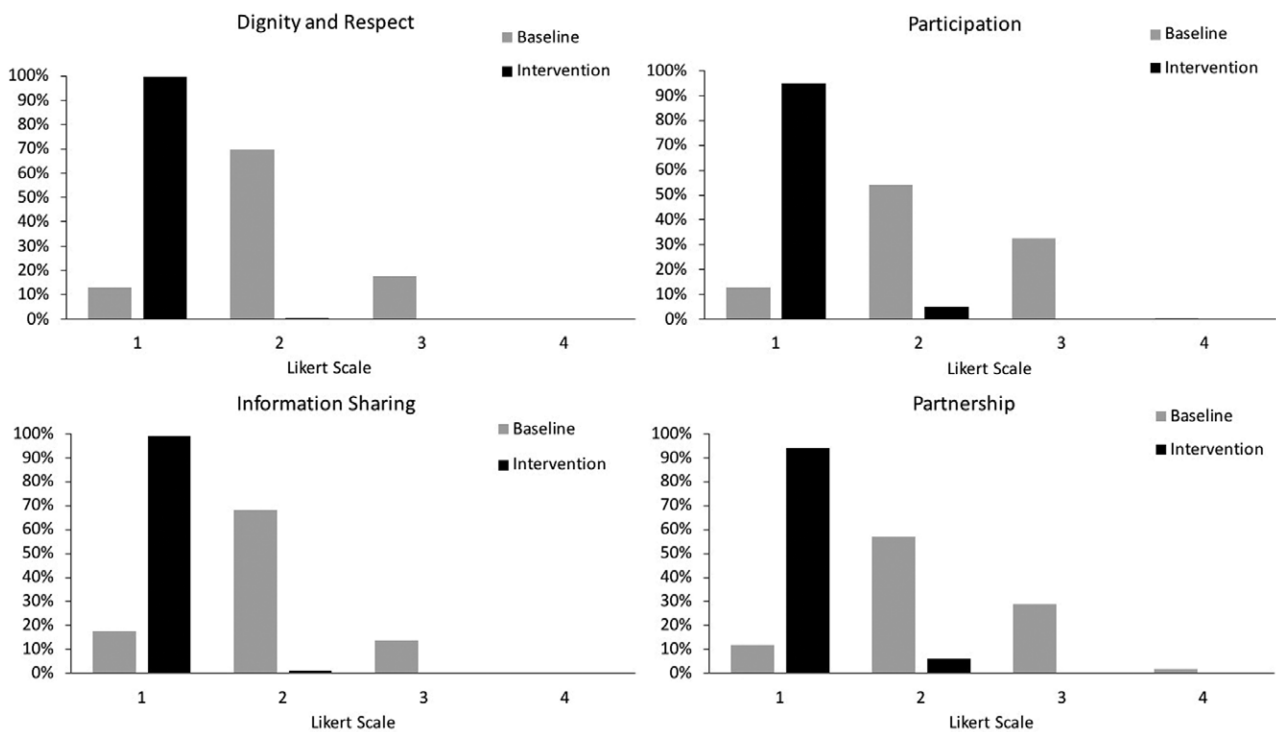


Fig. 1. Percentages of parental Likert Scale responses to 14 FCC survey questions grouped into 4 domains: dignity and respect, information sharing, participation, and partnership in baseline and after FE handout intervention. Likert responses represent parental perceptions to FCC questions in each domain (1 = always, 2 = usually, 3 = sometimes and 4 = never). Lower scores represent more favorable responses.

Previous studies have measured the impact of incorporating families on rounds in the PICU as a model of FCC.^{15–17} In general, results demonstrate a strong family desire to be present for rounds and a positive impact of family-centered rounds on family satisfaction scores.¹⁸ However, parents continue to identify collaboration, respect, and communication as areas for improvement despite the presence of family-focused rounding.¹⁶ The literature is less robust with pediatric studies using FCC and FE principles to reduce CLABSIs. In one study of neonatal ICUs implementing a multifaceted approach including team development, family partnership, and central line care reporting, CLABSI rates decreased by 71%.¹⁹ We found engaging families in active participation in their child's CVC care was associated with improved self-rated perceptions of respect, involvement, and information sharing, all of which are suggested cornerstones of the framework of parental satisfaction in the PICU.²⁰

Parents highly value a collaborative mutual partnership with healthcare providers, expect transparency from their care team, and report a strong desire to provide expert advice about their children.^{21,22} However, individual parents' willingness to participate in care may vary and depend on factors, such as the quality of communication, the nature of the information, and the staff's support and sensitivity to meeting the parent's needs.²³ Importantly, in our study design, parents took part in a face-to-face interaction with a PICU nurse or CLABSI team member who reviewed CLABSI prevention information and answered any questions that arose using the handout as a communication template. We did not encounter any adverse events related to FE in CLABSI efforts. Providing the material handout information was a necessary feature to help increase parental understanding of CLABSI prevention practices, but this alone may not be enough to change perceptions, and the direct parental–staff interaction may be a critical component of FE.²⁴

After participation in a national collaborative sponsored by the Children's Hospital Association collaborative in 2008, in agreement with NHSN data, we observed a significant reduction in the PICU CLABSI rate, which fell from 7.0 per 1,000 catheter days during 2005–2007 to 3.1 per 1,000 catheter days during 2009–2011. Since then, our PICU CLABSI rates have remained stable, ranging from 1.2 to 2.3 per 1,000 catheter days. Measuring the compliance with any prevention bundle practice is an essential part of a patient safety improvement strategy. Studies suggest that centers that can consistently and reliably perform CLABSI bundle practices at rates approaching 95% or higher will have lower CLABSI rates.²⁵ This is not easy to achieve or sustain and thus may require a multifaceted approach. We observed a modest but potentially relevant increase in compliance rates with CLABSI prevention bundle practices after introducing the handout. Future studies using FCC and FE as an approach for CLABSI prevention could examine longitudinal effects on CLABSI rates, its

impact on staff, and/or developing other novel methods to engage families in CLABSI prevention to increase bundle compliance.

The Agency for Healthcare Research and Quality posits that communication between the patient, family, and clinician is a critical component of high-quality, safe health-care—the foundation of partnerships between patients, families, and clinicians. Our study suggests that utilizing FE principles on common patient safety strategies, such as CLABSI prevention, can be successfully implemented in the PICU and may positively impact patient safety and parental–staff perception. Moreover, the CLABSI prevention handout is simple, inexpensive, and easy to implement. This study also incorporated several FCC hospital-level strategies outlined in the Agency for Healthcare Research and Quality's—*Guide to Patient and Family Engagement*.²⁶ It engaged families as participating members of their child's health care team, facilitated communication of CLABSI reduction efforts between staff and parents, increased parental knowledge, and supported the parents' ability to speak up for witnessed protocol deviations. Lastly, the intervention allowed parents to provide input into management and processes. This input may be an essential consideration, particularly in a PICU setting where parents may experience a sense of loss of control and feel overwhelmed with the acuity and severity of their child's critical illness.

STUDY LIMITATIONS

This study involved a single site and included only English-speaking subjects. It has several other limitations. Because of the study's short time frame, we did not include a direct measure of CLABSI infection rates. Unmeasured factors may have altered parental perceptions of PICU care during the baseline control and/or intervention periods, accounting for improved postintervention scores. The overall sample size was small and could be improved with more reliability testing of the FCC survey questions and a larger sample size. Parental perception of care is multifactorial, and patient and parental characteristics were not collected as part of the study. Thus, confounding patient or family variables were unaccounted. Also, we did not assess factors that may influence the PICU staff's compliance with CLABSI maintenance bundle practices, such as patient workload and patient acuity. The staff/patient ratio may have influenced the CLABSI compliance adherence. Finally, the survey used in the study was created by the investigators. We assessed validity using face validity, which is subjective, although the survey's internal consistency rating was high.

CONCLUSIONS

Providing parents with face-to-face education on how parents and staff may partner to prevent a CLABSI in the PICU was feasible. It was associated with improved parental CLABSI knowledge and feelings of

participation as well as improved perceptions of partnership and information sharing with the healthcare team. Family engagement also was associated with improved staff accountability and compliance as measured by observational auditing of CLABSI maintenance bundle practices.

DISCLOSURE

The authors have no financial interest to declare in relation to the content of this article.

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