Nurses' Perceptions of a Novel Rooming-in Program for Infants With Critical Congenital Heart Disease

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Background The transition to home for infants who require complex care can be overwhelming for caregivers. Infants with critical congenital heart disease (CCHD) require advanced care management, so their caregivers must acquire extensive training before the infants are discharged home. Rooming-in programs have improved patient outcomes in other settings, such as the postpartum period. However, little research has examined a rooming-in program in a pediatric cardiac acute care setting.

Objective To describe nurses' perceptions of a novel rooming-in program implemented in a pediatric cardiac acute care unit.

Methods A qualitative descriptive research design was used to describe nurses' perceptions of the rooming-in program for infants with CCHD. Three focus groups were conducted with a convenience sample of 13 registered nurses who cared for infants with CCHD during the rooming-in program. Four trained independent coders performed qualitative thematic analysis.

Results Nurses provided critical insight into the rooming-in program. Three themes were identified: improved nursing and family outcomes, leading the way through collaboration, and room for improvement.

Conclusions Infants with CCHD have complex needs, and caregivers must acquire advanced skills to adequately care for these infants. This study is the first to explore nurses' perceptions of a rooming-in program for infants with CCHD. The findings could improve rooming-in programs in the pediatric acute care setting, which can translate to better patient outcomes. (*American Journal of Critical Care.* 2023;32:54-61)

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In the United States, congenital heart defects occur in approximately 8 of every 1000 infants born each year and are the most common congenital defects.[1] Congenital heart defects can range in complexity from mild to severe. Infants with severe congenital heart defects, known as critical congenital heart disease (CCHD), require surgery, close monitoring, and complex medical management. Following surgery, caregivers of infants with CCHD need extensive training on advanced medical care for their child to support their safe transition from hospital to home.

Caregivers of infants with CCHD encounter extensive amounts of complex medical education and skills training and are expected to absorb large quantities of material in a short time before discharge home.[2] Included in the complex education and skills training are safe medication administration, feeding regimens, monitoring nutritional progress and weight, wound care, respiratory management, recognizing early signs and symptoms of cardiac deterioration, and coordination of follow-up appointments.[2,3]

The transition to home for infants with CCHD can be overwhelming for caregivers and presents significant challenges.[4,5] Caregivers of infants with CCHD have described the transition to home as challenging and stressful.[6] Research suggests that caregivers of children with CCHD experience higher levels of distress than do parents of healthy children.[7,8] These caregivers have said they felt physically, emotionally, and educationally unprepared for discharge.[4,9] Feelings included mixed emotions, fear, and worry about knowledge and preparedness for discharge home after surgery.[4] To better support families during the transition to home, inpatient mother-baby, postpartum, and neonatal intensive care units have implemented rooming-in programs before discharge.[10,11] The World Health Organization defines rooming-in as allowing an infant and mother to remain together 24 hours a day during the postpartum period,[12] providing caregivers with the opportunity to learn, practice, and achieve necessary skills to care for their infant before being discharged home.[2,11] Implementation of rooming-in programs has been associated with enhanced child and parent outcomes. For neonates, rooming-in has resulted in various physical health benefits including a reduced need for medications, shorter hospital stays, and a lower incidence of moderate to severe neurodevelopmental impairments.[13,14] Research suggests that the benefits of rooming-in extend beyond physical health to also include improvement in the psychological well-being of parents and infants[14,15] and promotion of family-centered care.[16]

Although positive outcomes have been noted for parents and infants participating in rooming-in during the postpartum period[17] and in the neonatal intensive care unit,[10] we know of no research that has explored a rooming-in program for infants with CCHD. Because nurses work directly with family caregivers during the discharge process, understanding nurses' and caregivers' perceptions of the benefits and barriers of implementing rooming-in for infants with CCHD before the discharge process is important. Therefore, the purpose of this study was to describe nurses' perceptions of a novel rooming-in program evaluated with guidance from the reach, effectiveness, adoption, implementation, and maintenance (RE-AIM) framework in a pediatric cardiac acute care unit (CACU).

> Transition to home for caregivers of infants with complex illnesses can be challenging and stressful.

Methods

Setting and Program Overview

This study took place in a pediatric CACU within a pediatric inpatient hospital in a large metropolitan area in the southeastern United States. A novel rooming-in program was originally developed and implemented in the CACU in 2019 as the result of a nursing evidence-based practice project to address gaps in caregiver knowledge and better involve caregivers in their child's care. Rooming-in was initiated

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Table 1
Characteristics of nurses

Characteristic	No. of participants
Sex	
Female	13
Male	0
Race	
White, non-Hispanic	11
Black or African American	2
Age range, y	24-61
Years worked as a registered nurse	
<1	0
1-5	6
6-10	1
11-15	4
>15	2

Table 2
Nursing focus group questions

1. Tell us your thoughts on the rooming-in process.
2. What are the strengths of the rooming-in process?
3. What are the weaknesses of the rooming-in process?
4. What situations have made the rooming-in process difficult for the nursing staff?
5. How would you describe your level of confidence in documenting a parent's rooming-in experience?
6. Are the expectations clear regarding what is considered a pass or fail?
   a. If no, what needs to happen to make these expectations clear?
      i. How could we improve this process moving forward?
   b. For parents who "fail" the rooming-in process, what can be done to reduce this possibility? What can help them to not "fail"?
7. What (if any) impact does the rooming-in process have on the parents' level of confidence?

24 hours before discharge and included demonstration of caregivers' mastery in their child's care through a series of skills gained. Nurses checked off these important skills on a rooming-in checklist. The checklist included assessing the patient (eg, monitoring vital signs), performing wound care, obtaining the patient's weight, administering medications on time and at the right dose, and demonstrating feeding techniques.

Thirteen nurses with experience providing care to children with critical congenital heart disease participated in focus groups.

For this study, we examined nurses' perceptions of implementing the novel rooming-in program to identify benefits and barriers. A study examining discharge readiness and outcomes of implementing rooming-in in the CACU is currently in progress.

Study Design

This study incorporated a qualitative descriptive research design to describe the rooming-in program from the perspective of nurses providing care to children with CCHD and their caregivers in a pediatric CACU. The goal of this study design is to provide a summary of events in the language of the people experiencing the events, requiring minimal abstract data interpretation.[18] We used qualitative focus groups for data collection because focus groups provide a flexible and stimulating environment that enhances the collection of rich data from participants.[19]

Setting and Participant Selection

Thirteen participants were included in 3 focus groups. The participants were a convenience sample of nurses providing care to infants with CCHD and their caregivers who were participating in the rooming-in program in a pediatric CACU. Eligibility criteria for nurses participating in the study were the ability to read and speak English, current practice as a registered nurse, and history of working at least 3 months as a registered nurse in the CACU. Nurses were recruited from day and night shifts to provide a variety of perceptions of rooming-in. Focus groups were held in person in a private room adjacent to the CACU.

Data Collection and Analysis

University and hospital institutional review board approvals were obtained. Participants provided verbal informed consent. Participants' demographic data were collected at the time they provided consent (Table 1). Participant incentives included food and beverages. We used an institutional review board–approved semistructured interview guide consisting of open-ended questions (Table 2).[20] Focus group sessions were led by a trained moderator and lasted approximately 60 minutes. The focus group moderator recorded any nonverbal language and noted insights about participants' responses by using field notes. Focus groups were audio recorded, transcribed verbatim, and analyzed independently by 4 trained qualitative coders. Audit trails and peer debriefing were completed to enhance rigor and achieve trustworthiness.[21,22] Thematic analysis was conducted using qualitative software (NVivo, QSR International) to organize themes using an inductive approach. This type of approach connects the research objectives to the data during the analysis process.[23] The RE-AIM framework was used to guide the qualitative data analysis and organize key thematic concepts to inform future implementation of

the rooming-in program.[24] The 5 components of the RE-AIM framework are reach, effectiveness, adoption, implementation, and maintenance.[25]

Results

Participants were eager to share insight into the rooming-in program, which added to the richness of the qualitative data. Participants shared important perspectives of nurses engaged in the rooming-in program, potentially enhancing the program. We identified 3 overarching themes during data analysis: improved nursing and family outcomes, leading the way through collaboration, and room for improvement.

Improved Nursing and Family Outcomes

Nurses perceived that nursing outcomes improved as a result of the rooming-in program. Nurses spoke about the impact that rooming-in had on their ability to prepare caregivers for discharge:

> Rooming-in is really an opportunity for us [nurses] as well to see just how well we do when we teach our parents. So it is good when you can see that they [caregivers] really have succeeded.

These feelings of increased confidence in caregivers translated to feelings of greater nurse satisfaction:

> On the nursing side of it [rooming-in], it gives us more confidence…it gives us a sense of peace of mind, satisfaction to know that "OK, I feel good about that child going home; that mom really gets it!"

Nurses also reported greater satisfaction in ensuring that caregivers were prepared to care for their infant with CCHD at the time of discharge. Improved patient and family outcomes were represented by nurses' recognition of more confidence and competence among caregivers of infants with CCHD, as reflected in the following quote:

> I think it [rooming-in] builds their [caregivers'] confidence; it also helps us [nurses] to know that we're not sending babies home into unsafe environments.

Caregivers appeared better prepared with skills necessary to safely care for their infant at home. One nurse shared a story about a parent being able to place a nasogastric tube confidently and correctly. Using teach-back methods over the duration of the rooming-in program led nurses to express more confidence in knowing they effectively taught caregivers vital skills before discharge:

> I think it [rooming-in] will essentially. . . cut down on the readmissions because some readmissions are . . . "I brought my kid in because the NG [nasogastric] tube came out" . . . [or] "Well, we roomed-in and we put it [the nasogastric tube] in, we took it out. . . . You watch the comfortability level of your kid with this tube, so you know the signs and symptoms if something were to go wrong."

Nurses shared that rooming-in allowed caregivers to learn from nurses and then apply what they learned to ensure comprehension. This way of teaching allowed nurses to recognize areas for further instruction. Being able to practice skills with mentorship and guidance was a success of rooming-in, from the nurses' perspective:

> Parents have a chance to truly room-in with education that's needed. The process tends to work really well. Parents feel ready and feel comfortable and just have this opportunity to practice with support.

Overall, nurses reported the rooming-in program allowed caregivers to acquire and demonstrate skills to care for their infant and opportunities for nurses to provide additional education and support, if needed. The nurses all agreed that improvement in families' ability to care for infants was a direct result of rooming-in and led to improved outcomes. Nurses discussed how teaching caregivers the skills for discharge and observing caregivers to ensure effective learning were paramount for the child's safety. These concepts are reflected in the RE-AIM model as the reach and effectiveness components. Reach represents the people who benefited from and participated in the intervention, which in this program were pediatric patients with CCHD, caregivers, and nurses.[26] Effectiveness represents the possible benefits, such as reducing readmission for replacement of nasogastric tubes.[26]

Leading the Way Through Collaboration

Nurses detailed how rooming-in improved organization in the discharge process and led the way to better care coordination. An unexpected result of rooming-in was improved collaboration between nurses and the discharge coordinator. This benefit was evident in the following quote:

> I like that it [rooming-in] is organized and I think communication between nurses and the discharge coordinator has been excellent for it.

Communication between discharge coordinators and physicians also improved. The following quote from one of the nurses illustrates this result:

> I do think that our discharge coordinators and our cardiologists do a very good job making sure people are prepared.

Effective collaboration between nurses, discharge coordinators, clinicians, and caregivers promoted the success of rooming-in. Building partnerships between caregivers and the larger health care staff was critical to ensure that a collaborative and cohesive relationship formed during rooming-in and led the way to a smooth transition home for caregivers of infants with CCHD.

> I've been in a room when it is presented appropriately by the discharge coordinator. We want to make sure that you feel comfortable to go home, and that's the whole point of this [rooming-in].

Nurses discussed being transparent with caregivers about the goal of ensuring caregivers' confidence with the necessary skills for discharge. Incorporating discharge coordinators throughout rooming-in encouraged collaboration and communication among caregivers during the discharge process, which led the way toward successful discharge. This theme is supported by the adoption and implementation components of the RE-AIM framework: all staff members were invested in the implementation of the program and received details about where and how rooming-in was delivered.[26]

Nurses perceived improved outcomes for nurses, patients, and caregivers due to rooming-in.

Room for Improvement

Although nurses described many benefits to patients, nurses, and families, they noted areas of improvement for the rooming-in program. One area for improvement was the language used by health care staff during rooming-in. Caregivers were deemed to "pass" or "fail" on a rooming-in checklist according to their ability to carry out necessary skills. This conversation became important as nurses described the impact of using negative language, such as "failing" rooming-in. A nurse described the impact of negative language on caregivers:

> And I think people are smarter than we give them credit for . . . they feel offended by this so now they're not even receptive to what we're trying to teach or what we're trying to make sure they know . . . it's like they don't want to do it at that point.

Nurses thought that the idea of passing or failing was subjective. Although a rooming-in checklist with tasks and skills to complete was used to determine discharge readiness, nurses suggested developing a way to better measure passing or failing for specific caregiver needs:

> I don't think we have actually made the attempt to adjust to how a pass or fail looks like for different people.

Another nurse discussed the need to reevaluate which part of rooming-in was challenging and unsuccessful for each specific caregiver. The need to adjust the delivery of education to caregivers was evident in the following quote:

> I just think sometimes, like with the ones who may not do it as well as others, that there should be some type of discussion about it . . . well, why did they fail? What happens when they fail? Do we go back and say, "OK, let's sit down and talk about what you did for the last 24 hours and let's see what we could do differently" to help them be more successful?

Individualizing the rooming-in program was identified as an area for improvement to ensure that each caregiver receives training that matches their learning needs. This change would ensure that information is delivered in the most effective way for discharge readiness. Nurses said that caregivers have a range of learning needs and a one-size-fits-all approach does not work:

> People are all different so I think that's what makes it so difficult. . . . [We need to] individualize each rooming-in plan for each family.

Overall, the rooming-in program had many successes, from the nurses' perspective. However, the program has room for improvement, with the potential to further enhance patient, nursing, and family outcomes. This theme is supported by the maintenance component of the RE-AIM framework, in which the program's improvement and maintenance rely on identifying individual and setting factors to enhance sustainability.

Discussion

Rooming-in programs are frequently cited as an approach to care that supports the caregiver role in

Table 3
Components of the RE-AIM framework applied to the rooming-in program[a]

Component	Definition	Example	Theme
Reach	Who benefited and participated in the intervention?	Pediatric patients with critical congenital heart disease, caregivers, and nurses	Improved nursing and family outcomes
Effectiveness	What were the most important benefits?	Reduced readmission for replacement of nasogastric tube, enhanced nursing satisfaction, and increased parental confidence	Improved nursing and family outcomes
Adoption	Where was the program applied and who applied it?	Nursing staff in the cardiac acute care unit of a pediatric hospital	Leading the way through collaboration
Implementation	How consistently was the program delivered, how will it be adapted, how much did it cost, and why did the results come about?	Sharing of details on how the rooming-in program was adapted and delivered, including use of checklists for parents to demonstrate mastery of skills	Leading the way through collaboration
Maintenance	When did the initiative become operational, how long was it sustained (setting level), and how long were the results sustained (individual level)?	Identification of individual- and setting-level factors to enhance sustainability	Room for improvement

Abbreviation: RE-AIM, reach, effectiveness, adoption, implementation, maintenance.

[a] Based on information from Glasgow and Estabrooks.[20]

successful discharge. To our knowledge, this qualitative study is the first to examine nurses' perceptions of a rooming-in program for infants with CCHD in the acute care setting.[27] Nurses emphasized how the rooming-in program in the CACU contributed to improved outcomes, a result that is consistent with findings of published studies. Rooming-in programs and discharge readiness have improved neonatal outcomes.[28] In contrast, caregivers of infants in a neonatal intensive care unit who did not participate in a rooming-in program before discharge to home expressed increased anxiety and decreased confidence in their ability to care for their infant.[10] Additionally, discharge unreadiness and inadequate preparation have been associated with higher readmission rates.[29] As highlighted in this study, nurses play a critical role in the successful implementation of rooming-in programs and improved outcomes.

Although many successes were identified during rooming-in, nurses described room for improvement, such as ensuring discharge readiness of caregivers. A review of the literature revealed the importance of assessing caregiver readiness to receive discharge education before initiating a rooming-in program.[30] In a study of patients with medically complex conditions, caregivers reported feeling less stress and anxiety if they had received medical information and training that prepared them for discharge,[31] a finding that was supported in our study.

In this study, we learned that rooming-in lacked consistency among advanced practice providers and that nurses strongly felt a need for more consistency in deciding which caregivers passed the rooming-in assessment. Nurses suggested that identifying discharge readiness for high-risk families early in the admission process was important. Research indicates that poor discharge coordination contributes to higher readmission rates for newborns.[29] Hospital readmission is not only stressful for caregivers and patients but also poses an economic burden; therefore, proper discharge education and readiness may alleviate emotional burden and health care costs. The nurses in this study suggested adaptations to education and training to reduce unreadiness to rooming-in. The incorporation of discharge coordinators along with strong collaborations with nurses may improve care coordination and outcomes during rooming-in.

The quality of discharge education is one of the strongest predictors of discharge readiness.[31] Nurses must feel confident and competent in providing education and training to caregivers. Engaging caregivers during rooming-in ensures that learning is taking place.[32] Therefore, nurses should feel confident in their ability to provide training and education to caregivers of patients with medically complex conditions.

This study of a novel rooming-in program for caregivers of infants with CCHD has the potential to generate future research to evaluate outcomes and ways to improve rooming-in. Although the purpose of this study was to describe nurses' perceptions of a novel rooming-in program in a pediatric CACU, the use of the RE-AIM framework to organize findings has greater implications. Table 3 outlines the components of RE-AIM and how they were applied to the analysis of this novel rooming-in program. The RE-AIM framework is an effective way to translate

research to practice and help improve a program's ability to work in real-life settings.[25]

Limitations

This study had several limitations. The study was conducted in one hospital's CACU. The sample in this study was relatively small and homogeneous. Because most participants were White, future research should include a larger and more racially diverse sample. This study did not include the perspectives of the family caregivers.

Conclusions

Infants with CCHD have complex needs, and caregivers must be prepared to care for these infants after discharge to home. Although research has been conducted on rooming-in programs in other settings and populations, little is known regarding rooming-in for caregivers of infants with CCHD. This study is the first to explore nurses' perceptions of a rooming-in program for infants with CCHD. Nurses worked directly with caregivers of infants with CCHD during rooming-in and provided critical insights into ways to enhance the program.

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FINANCIAL DISCLOSURES
None reported.

SEE ALSO

For more about preparing family caregivers for their infant's discharge, visit the *Critical Care Nurse* website, **www.ccnonline.org**, and read the article by Davidson et al, "'Baby Steps to Discharge': An Interprofessional, Developmental Milestone–Based Checklist for the Neonatal Intensive Care Unit" (October 2020).

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