



# INDIVIDUALIZED FAMILY-CENTERED DEVELOPMENTAL CARE FOR INFANTS WITH CONGENITAL HEART DISEASE IN THE INTENSIVE CARE UNIT

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**Background** Individualized family-centered developmental care (IFDC) is considered the standard of care for premature/medically fragile newborns and their families in intensive care units (ICUs). Such care for infants with congenital heart disease (CHD) varies.

**Objective** The Consortium for Congenital Cardiac Care–Measurement of Nursing Practice (C4-MNP) was surveyed to determine the state of IFDC for infants younger than 6 months with CHD in ICUs.

**Methods** An electronic survey was disseminated to 1 nurse at each participating center. The survey included questions on IFDC-related nursing practice, organized in 4 sections: demographics, nursing practice, interdisciplinary practice, and parent support. Data were summarized by using descriptive statistics. Differences in IFDC practices and IFDC-related education were assessed, and practices were compared across 3 clinical scenarios of varying infant acuity by using the  $\chi^2$  test.

**Results** The response rate was 66% (25 centers). Most respondents (72%) did not have IFDC guidelines; 63% incorporated IFDC interventions and 67% documented IFDC practices. Only 29% reported that their ICU had a neurodevelopmental team. Significant differences were reported across the 3 clinical scenarios for 11 of 14 IFDC practices. Skin-to-skin holding was provided least often across all levels of acuity. Nurse education related to IFDC was associated with more use of IFDC ( $P < .05$ ).

**Conclusion** Practices related to IFDC vary among ICUs. Opportunities exist to develop IFDC guidelines for infants with CHD to inform clinical practice and nurse education. Next steps include convening a C4-MNP group to develop guidelines and implement IFDC initiatives for collaborative evaluation. (*American Journal of Critical Care*. 2022;31:e10-e19)

**C**ongenital heart disease (CHD) occurs in approximately 1% of all live-born infants worldwide.<sup>1-3</sup> A subset of infants with complex CHD require hospitalization in the intensive care setting immediately after delivery. Length of stay can vary depending on the severity of illness and the need for medical or surgical intervention. Although most of these infants will survive into adulthood, research has demonstrated that they are at increased risk for neurodevelopmental abnormalities (eg, cognitive disabilities) and behavioral and mental health problems (eg, attention-deficit/hyperactivity disorder, autism, anxiety, and gross motor deficits).<sup>4</sup>

Interestingly, alterations in brain development that have been documented in infants with CHD are strikingly similar to those found in infants born prematurely.<sup>5</sup> Postnatal exposure to the intensive care unit (ICU) environment and life-sustaining interventions poses further risk to this vulnerable population.<sup>6,7</sup> The focus of care for infants with CHD in ICUs often centers on hemodynamic monitoring, postoperative management, and other medical priorities.<sup>6,8,9</sup> The invasive and stressful nature of critical care places infants in an often unpredictable, painful, and overstimulating environment.<sup>10-16</sup> Infants are exposed to stressors including invasive procedures, catheters and tubes, sedation, and positioning that can alter normal development.<sup>7,8</sup> Infant acuity often prevents parents from bonding and participating in caregiving.<sup>8,17-20</sup> Together, these factors may contribute to these infants' risk for cognitive, behavioral, and physical alterations during development.<sup>8</sup>

Individualized family-centered developmental care (IFDC) is a model of care that is regarded as standard practice for premature and medically fragile newborns who are being cared for in an ICU.<sup>8,21</sup> Als et al<sup>22-26</sup> originally and then other researchers<sup>27-30</sup> described developmentally supportive care in the Newborn Individualized Developmental Care and

Assessment Program, which demonstrated neurodevelopmental benefits and is a foundation for similar models such as the Universe of Developmental Care.<sup>31</sup> The IFDC model includes interventions that incorporate cue-based assessment and care, provide a supportive environment, and engage parents and encourage their participation in care.<sup>7,8,29</sup> Despite increasing calls in the literature for the inclusion of IFDC practices in pediatric ICUs that care for infants with CHD, wide practice variation has been documented.<sup>8,9,20,29,32-34</sup> Nurses, as a consistent presence

at the bedside, arguably have a key role in ensuring that IFDC interventions are implemented at the point of care, yet few studies to date have specifically examined IFDC-related bedside

nursing practice in pediatric ICUs caring for infants with CHD. The purpose of this project was to assess the current state of IFDC-related nursing practice in ICUs where infants with CHD are receiving care. A secondary purpose was to determine whether IFDC practice varies because of known barriers including infant acuity and available IFDC education.<sup>8,20,29,35</sup>

**Nurses have a key role in ensuring that IFDC interventions are implemented at the point of care.**

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## Methods

### Survey Population

The Consortium for Congenital Cardiac Care—Measurement of Nursing Practice (C4-MNP) is an international collaborative of 45 cardiovascular programs in pediatric hospitals across the United States, Canada, and the Middle East; the collaborative's overall aim is to identify nursing care actions for measurement in the highly complex pediatric cardiovascular patient environment.<sup>36</sup> A core activity of the C4-MNP is to establish the current state of specific pediatric cardiovascular nursing practices, identify variation, and develop recommendations to standardize practice across participating programs.<sup>37</sup> Established in 2011, the consortium includes nurses, advanced practice nurses, administrators, and scientists.<sup>36,38</sup>

**Table 1**  
Demographic characteristics of 25 participants/centers

Characteristic	No. (%)
Intensive care unit type	
Pediatric	1 (4)
Cardiac	21 (84)
Combination	3 (12)
Job title	
Staff nurse	20 (80)
Clinical nurse specialist	1 (4)
Nurse educator	3 (12)
Nursing administrator	1 (4)
Years of experience in position	
<1	1 (4)
1-4	9 (36)
5-9	8 (32)
10-14	4 (16)
>15	3 (12)
Years of experience providing care to newborns/infants	
<1	0 (0)
1-4	7 (28)
5-9	9 (36)
10-14	6 (24)
≥15	3 (12)

### Survey Development and Administration

An electronic survey of 55 multiple-choice questions was developed by using the available literature and content experts, which contributed to the survey's face validity. Questions assessed how ICU nurses incorporate IFDC into their nursing practice and were grouped into 4 sections: respondent demographics, nursing practice, interdisciplinary practice, and parent education and support. Respondents were asked to rate their perceived competence with and frequency of participation in core IFDC nursing practices, including cue-based care and provision of a supportive environment. Participants rated perceived competency on a Likert scale: "not competent," "a little competent," "very competent," and "fully competent." Definitions for specific IFDC interventions were provided for each category. Developmentally appropriate light was defined as providing low ambient light during the day and darkness at night, and using an eye shield on the infant when light was necessary for bedside procedures. Developmentally appropriate sound was defined as sound levels equivalent to library-level conversation. Developmentally appropriate positioning was defined as positioning the infant midline, with flexed extremities, hands close to face, and with containment. Because patient acuity has been repeatedly cited in the literature as a barrier for integrating IFDC into the care of infants with CHD, the survey was designed so that nurses could report on their practice in 3 clinical scenarios; patient acuity differed in each scenario<sup>8,20,34,35</sup>: (1) an

intubated infant who is receiving continuous sedation and chemical paralytic agents and with various catheters and tubes (high acuity), (2) an intubated infant who is not sedated or chemically paralyzed but requires various catheters and tubes (moderate acuity), and (3) an extubated infant who is ready to transition to acute care or a step-down setting (low acuity). Respondents were asked to report how frequently ("never," "sometimes," "often," or "always") IFDC interventions would be performed in each scenario.

Before disseminating the survey, C4-MNP members pilot tested it to assess the questions' clarity and readability. The survey was moved into a database in REDCap (Research Electronic Data Capture), a secure, web-based application designed to support data capture for research and quality improvement.<sup>39</sup> Participating centers were asked to identify 1 nurse working in the pediatric ICU setting to complete the survey. Data were reviewed at the end of the collection period to ensure that only 1 survey was submitted per institution. No identifying data were collected from participants. This project was exempt from institutional review board review because it aimed to determine nursing practice across ICUs and thus was not considered human subjects research.

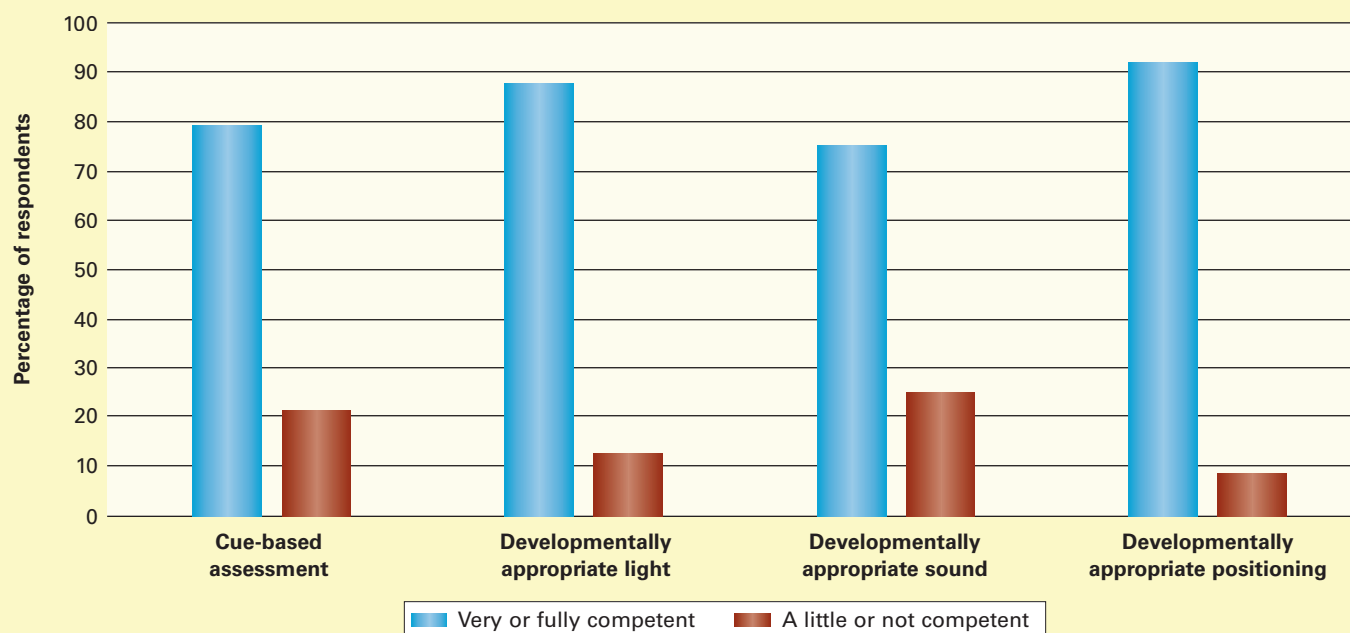
### Data Analysis

Survey data were collected and managed in REDCap, hosted at Boston Children's Hospital in 2018. We used descriptive statistics to summarize responses; with the  $\chi^2$  test, we assessed differences in reported IFDC practices and prior IFDC-related education, which allowed us to compare practices across the 3 clinical scenarios of varying infant acuity. We used the SPSS statistical package for stratified analysis.

## Results

### Demographics

Of the 45 cardiovascular programs currently participating in C4-MNP, 38 were active and could participate when we released the survey. Of those 38 programs, a representative from 25 of them completed the survey, for a response rate of 66%; 21 of those participating sites (84%) were designated as pediatric cardiac ICUs. For the purposes of the project, participants were recruited from C4-MNP programs to ensure assessment of pediatric cardiac critical care nursing practice; we excluded neonatal ICUs caring for patients with CHD. Of the 25 respondents, 20 (80%) were staff nurses; the others were in unit leadership roles. Respondents had a wide range of years of experience (Table 1).



**Figure 1** Perceived competence in performing various components of individualized family-centered developmental care.

### Nursing Practice

Most respondents (18 [72%]) reported that their ICUs did not have a standardized IFDC nursing guideline, though 15 (63%) reported that IFDC is incorporated into routine ICU nursing practice. Most respondents reported feeling very or fully competent to perform various general IFDC interventions including cue-based care and provision of developmentally supportive light, sound, and positioning (Figure 1). The timing of IFDC nursing practices, however, varied across ICUs (Table 2).

Only 8 institutions (33%) had an ICU guideline or policy identifying which patients with catheters and tubes were safe for parents or caregivers to hold. About half of respondents (13 [54%]) reported determining that it was safe to hold patients with catheters and tubes (regardless of type) after discussion with an attending surgeon or ICU physician, whereas 11 respondents (46%) indicated that safe holding was determined after a collaborative discussion among an interdisciplinary team consisting of the bedside nurse, a respiratory therapist, and an ICU physician. All respondents reported that their ICUs allowed holding of infants with a central venous catheter or a peripherally inserted central catheter and nasogastric or nasojejunal tubes, but not those with an open sternum or those receiving extracorporeal membrane oxygenation. Mobility varied when other devices were in place (Figure 2). Most reported that the frequency of holding is dependent on the presence of catheters and tubes (21 [88%]), parents or caregivers being present at the bedside (19 [79%]), and having

time available during their shift (16 [67%]). Approximately half of respondents reported that infants are held either when they cry (11 [46%]) or when ancillary staff are available (11 [46%]).

Among respondents, 17 (71%) reported often or always using nonpharmacologic IFDC interventions such as positioning, holding by a parent, parent participation in providing comfort, and nonnutritive sucking during stressful interventions. The amount of time that IFDC interventions were used before sedation or anxiolytic medications were administered for comfort varied: less than 5 minutes (4 [17%]), 5 to 15 minutes (13 [54%]), 16 to 30 minutes (5 [21%]), or more than 30 minutes (2 [8%]). The decision to administer sedation or anxiolytic medication was based on hemodynamic instability (23 [96%]), maintaining catheter and tube integrity (22 [92%]), and pain (21 [86%]). Failed attempts at nonpharmacologic interventions (21 [86%]), consoling by bedside nurse (19 [79%]) and parents (19 [79%]), and parental stress around their infant's inconsolability (14 [58%]) also were reported. Additional rationales for medication administration included nursing assignment/patient care ratio (8 [33%]), acuity within the unit (6 [25%]), and the time needed for cue-based assessment and IFDC (2 [8%]). During painful or stressful interventions at the

**Frequencies of specific IFDC practices across the 3 clinical scenarios revealed significant differences for 11 of 14 IFDC practices.**

**Table 2**  
**Timing of individualized family-centered developmental care (IFDC) practices**

Practice	No. (%)
<b>Developmentally appropriate light (n=22)</b>	
The duration of my shift	18 (82)
With basic care only	1 (5)
With stressful interventions only	0 (0)
During sleep only	2 (9)
I am unable to control light in my clinical setting	1 (5)
I do not practice this domain of IFDC	0 (0)
<b>Developmentally appropriate sound (n=21)</b>	
The duration of my shift	13 (62)
With basic care only	1 (5)
With stressful interventions only	0 (0)
During sleep only	3 (14)
I am unable to control sound in my clinical setting	3 (14)
I do not practice this domain of IFDC	1 (5)
<b>Positioning (n=24)</b>	
The duration of my shift	5 (21)
Every 2 h	16 (67)
Every 4 h	0 (0)
With basic care only	2 (8)
With stressful interventions only	0 (0)
I do not practice this domain of IFDC	1 (4)
<b>Safe holding<sup>a</sup> (n=24)</b>	
Amount of holding dependent on presence of catheters and tubes	21 (88)
After extubation has occurred	13 (54)
When parents or caregivers are at bedside	19 (79)
When there is time in my shift for me to hold patient	16 (67)
When patient is crying	11 (46)
During feeding only	2 (8)
When a clinical assistant or volunteer is available	11 (46)
<b>Cue-based assessment<sup>a</sup> (n=24)</b>	
One time each shift	0 (0)
Every 4 h	2 (8)
With basic care	9 (38)
Continuously as part of my nursing assessment	22 (92)
With stressful interventions	7 (29)
I am not competent in cue-based assessment	2 (8)

<sup>a</sup> Respondents could select more than one response.

bedside, respondents reported using various measures to soothe infants: sedation (23 [96%]), nonnutritive sucking with sucrose or breast milk (22 [92%]), parents' presence (21 [86%]), IFDC positioning/holding (18 [75%]), support from a child life specialist (15 [63%]), and music therapy (12 [50%]).

Regarding documentation of IFDC nursing practice, 16 (67%) documented IFDC in the medical record. All respondents documented positioning and pain assessments; however, documentation was less consistent for light (7 [30%]), sound (7 [30%]), cue-based assessment (5 [22%]), and holding (18 [78%]). Most respondents (19 [83%]) reported documenting nonpharmacologic IFDC interventions. In addition, only 3 respondents (13%) used

nurse-to-nurse communication about IFDC at shift changes.

Unit-based IFDC education for nurses during orientation (11 [46%]) was more prominent than hospital-wide IFDC education (6 [25%]). Respondents who reported that their nurse orientees receive unit-based IFDC education mentioned various methods: lecture format (6 [55%]), simulation training (2 [18%]), nursing huddles (2 [18%]), and online training (1 [9%]).

### Interdisciplinary Neurodevelopmental Care

Only 7 participants (29%) reported that their ICUs had a dedicated inpatient neurodevelopmental team. Most respondents were not aware of how often neurodevelopmental assessments were performed (19 [83%]), nor whether a specific tool was used for assessment (23 [96%]). Approximately half (11 [46%]) were not aware of who performed neurodevelopmental assessments in their ICUs. Obtaining a neurodevelopmental consult was reported to be the standard of care in 8 ICUs (35%).

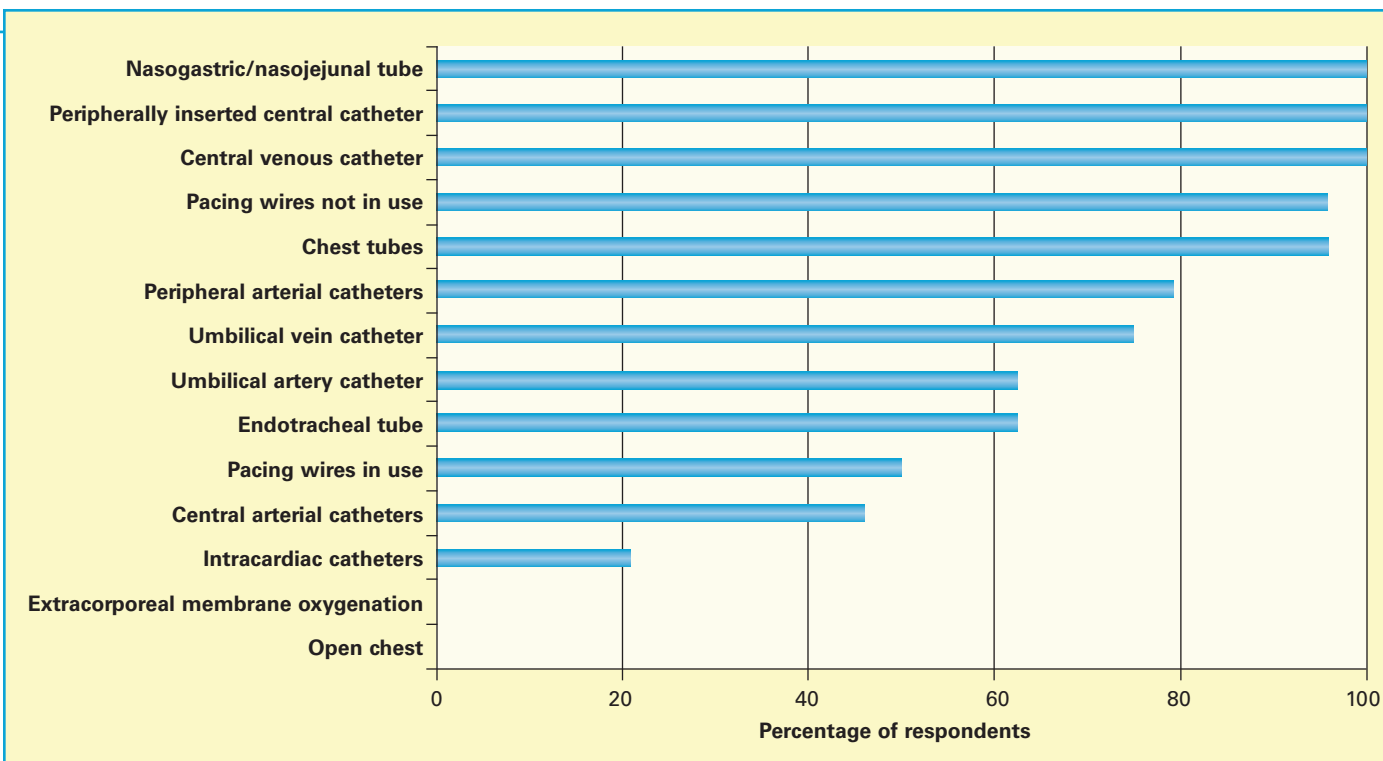
Only 7 (29%) respondents reported that their institutions have formal neurodevelopmental rounds in the ICUs. One-third of respondents (8 [32%]) reported that neurodevelopmental concerns are presented during daily rounds. All 8 of those respondents also noted that it is the bedside nurse who presents these concerns.

### Parent Education and Support

More than half of participants (14 [58%]) reported that parents receive education about IFDC during their infant's hospitalization through methods including verbal instruction (12 [86%]), hands-on/real-time instruction (6 [43%]), and video (1 [7%]). These respondents also identified different members of the health care team who educated parents: the bedside nurse (7 [50%]), a neurodevelopmental specialist (2 [14%]), a child life specialist (1 [7%]), and other professionals such as rehabilitation therapists (4 [29%]). Fewer than half of ICUs (10 [42%]) have a formal system for follow-up after discharge to support infant neurodevelopment.

### Comparative Analyses

Frequencies of specific IFDC practices ("often" or "always" vs "sometimes" or "never") across the 3 clinical scenarios revealed significant differences for 11 of 14 IFDC practices. Respondents reported less frequent use of IFDC practices in the higher-acuity clinical scenarios (Table 3). Allowing holding with skin-to-skin contact was the practice provided least often across all levels of acuity.



**Figure 2** Tubes, wires, catheters, and clinical conditions in which holding the infant was deemed safe.

In the high-acuity clinical scenario, we found no significant difference in the provision of IFDC based on receipt of IFDC-related education. Within the moderate-acuity scenario, IFDC-related education included in unit-based orientation significantly affected IFDC practices. Among nurses who had received IFDC-related education, 91% reported that they often or always incorporate cue-based assessment—significantly more than the 50% of nurses who did not receive IFDC-related education who reported this practice ( $\chi^2_1 [n=23] = 4.54, P = .03$ ). Among that same group of nurses, 82% reported often or always promoting holding by parents or staff—again significantly more than the 39% of nurses who reported this practice but had not received IFDC-related education ( $\chi^2_1 [n=24] = 4.61, P = .03$ ); 64% reported often or always letting parents assume care, also significantly more than the 23% of nurses who allowed this practice but who had not received education ( $\chi^2_1 [n=24] = 4.03, P = .05$ ). For the low-acuity clinical scenario, 100% of nurses previously educated on IFDC reported often or always using developmentally supportive positioning (the infant placed midline or with their extremities flexed, for example); this proportion was again significantly higher than the 69% of nurses who had not been educated about IFDC and who used such positioning ( $\chi^2_1 [n=24] = 4.06, P = .04$ ).

## Discussion

This state-of-practice assessment provides what is, to our knowledge, the first report on IFDC in current nursing practice in ICUs where infants with CHD receive care. Prior studies have highlighted variability in IFDC among interdisciplinary practice teams.<sup>20,29</sup> Our findings indicate that IFDC practice also varies specifically within nursing. Most respondents reported that their ICUs do not have IFDC standards or procedures to guide nursing practice, demonstrating the need for ICUs to develop guidelines and procedures to support standardization of IFDC in nursing practice. A lack of institutional and unit-based infrastructure has been cited as a barrier to providing IFDC in pediatric cardiac care settings.<sup>17,29</sup> Although respondents perceived a high level of competency for most IFDC practices such as developmentally supportive positioning and cue-based care, care was inconsistently operationalized across ICUs, and levels of acuity varied, indicating a gap between competency and practice. This study adds to the growing body of evidence that increased patient acuity is perceived as a barrier

**Nurses can educate parents on how to read their infant's behavioral cues and how to participate in care, even during critical illness.**

**Table 3**  
Individualized family-centered developmental care (IFDC) interventions across 3 acuity levels

IFDC intervention	No. (%) of 24 respondents						P <sup>d</sup>
	High-acuity scenario <sup>a</sup>		Moderate-acuity scenario <sup>b</sup>		Low-acuity scenario <sup>c</sup>		
	Never/sometimes	Often/always	Never/sometimes	Often/always	Never/sometimes	Often/always	
Provide age-appropriate light to allow for normal sleep cycles and minimize stress	11 (46)	13 (54)	5 (21)	19 (79)	2 (9) <sup>e</sup>	20 (91) <sup>e</sup>	.01
Eliminate unnecessary noise in and around the bed space	12 (50)	12 (50)	8 (33)	16 (67)	6 (26) <sup>e</sup>	17 (74) <sup>e</sup>	.22
Incorporate cue-based assessments	13 (57) <sup>e</sup>	10 (44) <sup>e</sup>	7 (30) <sup>e</sup>	16 (70) <sup>e</sup>	4 (17) <sup>e</sup>	19 (83) <sup>e</sup>	.02
Position infant midline, extremities flexed, contained, hand to face	11 (46)	13 (54)	9 (38)	15 (62)	4 (17)	20 (83)	.09
Avoid frog-leg positioning of infant	10 (42)	14 (58)	6 (25)	18 (75)	1 (4)	23 (96)	.009
Avoid "W" positioning of infant's arms	10 (42)	14 (58)	6 (25)	18 (75)	1 (4)	23 (96)	.009
Provide boundaries, swaddling, and containment for infant	10 (42)	14 (58)	2 (9) <sup>e</sup>	21 (91) <sup>e</sup>	1 (4)	23 (96)	.001
Promote holding by parents or staff members	21 (88)	3 (12)	10 (42)	14 (58)	2 (8)	22 (92)	<.001
Nonpharmacologic support (eg, nonnutritive sucking, sucrose, bundling, music)	15 (62)	9 (38)	2 (8)	22 (92)	1 (4)	23 (96)	<.001
Holding by parents	22 (92)	2 (8)	13 (54)	11 (46)	1 (4)	23 (96)	<.001
Offer breastfeeding	22 (96) <sup>e</sup>	1 (4) <sup>e</sup>	21 (88)	3 (12)	10 (42)	14 (58)	<.001
Offer skin-to-skin contact	23 (96)	1 (4)	22 (92)	2 (8)	15 (65) <sup>e</sup>	8 (35) <sup>e</sup>	.007
Cluster care	6 (25)	18 (75)	2 (9) <sup>e</sup>	21 (91) <sup>e</sup>	1 (4)	23 (96)	.08
Parents assume care (eg, diaper change, swaddling)	17 (71)	7 (29)	14 (58)	10 (42)	1 (4)	23 (96)	<.001

<sup>a</sup> Intubated newborn who is sedated and paralyzed and has additional catheters or tubes.

<sup>b</sup> Intubated infant who is not sedated or paralyzed but has additional catheters or tubes.

<sup>c</sup> Extubated newborn who is ready to transition to an acute care/step-down setting.

<sup>d</sup> Values <.05 are significant.

<sup>e</sup> Data are missing.

to providing IFDC.<sup>20,29</sup> The IFDC practice reported least often was supporting skin-to-skin care, even in the clinical scenario with the least acuity. One reason may be that, according to most respondents, their ICUs do not have holding guidelines. Studies have demonstrated the benefits of skin-to-skin care for infants with CHD: it promotes comfort, sleep, physiological stability, and cognitive learning.<sup>40-43</sup> Recent quality improvement initiatives have demonstrated the safety and feasibility of unit-based

holding guidelines and promotion of skin-to-skin care.<sup>44,45</sup> Furthermore, skin-to-skin care is recognized as an essential intervention to support and promote breastfeeding in vulnerable hospitalized infants.<sup>44-47</sup> Targeting the promotion of skin-to-skin care in pediatric ICUs may be a helpful first step to increase the frequency of IFDC and its standardization in nursing practice.

Most respondents reported that nonpharmacologic comfort measures were integrated into infants'

care. The timing of and decision-making for the use of sedation/analgesic medications varied, however, as other assessments of the state of nursing practice have demonstrated.<sup>37</sup> Nurse-driven sedation protocols may standardize the use of sedation and analgesic medications.<sup>48,49</sup> Little research has examined the use of nonpharmacologic comfort measures and their effectiveness in reducing pain among infants after cardiac surgery; however, recent studies of massage and skin-to-skin care have demonstrated feasibility and initial evidence of pain reduction.<sup>43,50</sup> More research is needed to provide evidence that can inform the integration of nonpharmacologic comfort measures into nursing practice.

Fewer than one-third of respondents reported that their ICUs had dedicated inpatient neurodevelopmental teams that perform rounds, consult, or formally assess the development of infants during their stay in the ICU. Pediatric ICUs need to invest in infrastructure and systems that are required to create and support teams with expertise in infant development, formal developmental assessment, and parental mental health in order to address the complex developmental needs of this patient population and their families.<sup>29,34,35</sup> Like Miller et al,<sup>29</sup> we also found that documentation of neurodevelopmental assessments and the provision of IFDC practices varied, as did communication about IFDC in the shift report. Documentation challenges may be specific to the capabilities of each ICU's electronic medical record. Standardizing IFDC documentation fields in the electronic medical record would provide ICU nurses with the ability to track IFDC throughout infants' hospitalizations and support communication among care providers. In addition, documentation is critically needed in order to design future research linking IFDC practice with neurodevelopmental outcomes in infants with CHD.

Not all ICUs reported that new nurses receive education about IFDC, and unit-based education was more prominent than hospital-wide education. Prior IFDC-related education increased the reported frequency of IFDC practices. Formal educational programs are needed for nurses who work with this unique patient population; one has recently been described and implemented.<sup>51</sup> Among our sample of nurses, the availability of formalized unit-based IFDC education was associated with the provision of IFDC, including cue-based assessment, safe holding, parents' assistance in basic care, and positioning. Education provided to ICU nurses may increase the incorporation of IFDC into nursing care.<sup>51</sup> In addition, only half of respondents reported that parents

are provided education about IFDC. Parent engagement and involvement in care continues to be identified as an area for improvement across interdisciplinary neurodevelopmental teams.<sup>20,29</sup> Nurses can educate parents on how to read their infant's behavioral cues and how to participate in care, even during critical illness. Respondents also reported less participation of parents in care when the infant is more critically ill. Research has shown that parents' roles alter when they are unable to care for their infant in the ICU after cardiac surgery, resulting in stress, anxiety, and depression.<sup>18,19,52-58</sup> Engaging parents in care is a core component of IFDC that, when properly integrated, may reduce alterations in parents' roles and support their mental health outcomes, as some ICUs have demonstrated.<sup>53,54,58</sup>

### Limitations

The design of this project, which used a self-report survey, has inherent limitations. Practice of IFDC was not measured objectively at each site, and so the results should be interpreted with caution.

Levels of acuity were not chosen on the basis of any specific standard measure. We did, however, attempt to capture, on the basis of our collective clinical experience, 3 general levels that may influence nurses' approach to IFDC. We designed our survey by synthesizing the literature and incorporating expert opinion, giving it face validity, but we did not assess its reliability. Future studies could use formally developed instruments such as the quality of developmental care scale.<sup>59</sup> Only 1 respondent from each participating ICU completed the survey. We acknowledge that practice may vary within and across ICUs, so this may have influenced our results.

### Conclusions

This assessment of the state of nursing practice demonstrates that some IFDC practices are currently being incorporated into the care of infants with CHD in ICUs, but practice varies. Development of IFDC guidelines, nursing education, and nursing documentation of IFDC are areas that should be targeted in order to optimize neurodevelopmental outcomes. Future work will aim to convene a C4-MNP working group to implement IFDC guidelines across pediatric

Development of IFDC guidelines, nursing education, and nursing documentation of IFDC are areas that should be targeted in order to optimize neurodevelopmental outcomes.



critical care settings, identify and implement IFDC initiatives for testing across programs, and further develop quality measures for future benchmarking that assesses compliance and the impact of IFDC on this patient population.

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#### FINANCIAL DISCLOSURES

None reported.

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