Boston Children's Hospital
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Dear Colleagues,

We are pleased to inform you that we have completed the analysis of surveys for the Consortium for Congenital Cardiac Care - Measurement of Nursing Practice (C4-MNP) state of practice assessment regarding individualized family centered developmental care (IFDC) for infants with congenital heart disease (CHD) in the intensive care setting.

The purpose of the C4-MNP state of practice assessment regarding IFDC was to describe the current state of IFDC nursing practice in the critical care setting for infants less than six months of age with CHD.

The survey questions were developed by Meena LaRonde MSN, RN, CCRN of Boston Children's Hospital in collaboration with Amy Jo Lisanti PhD, RN, CCNS, CCRN-K of Children's Hospital of Philadelphia.

The invitation to participate was sent to 38 C4-MNP centers and 25 completed the survey for a response rate of 66 percent. Below, please find the aggregate result report.

We would like to extend our heartfelt appreciation for your continued commitment to this collaborative as we work to improve outcomes for pediatric cardiovascular patients and their families.

Sincerely,

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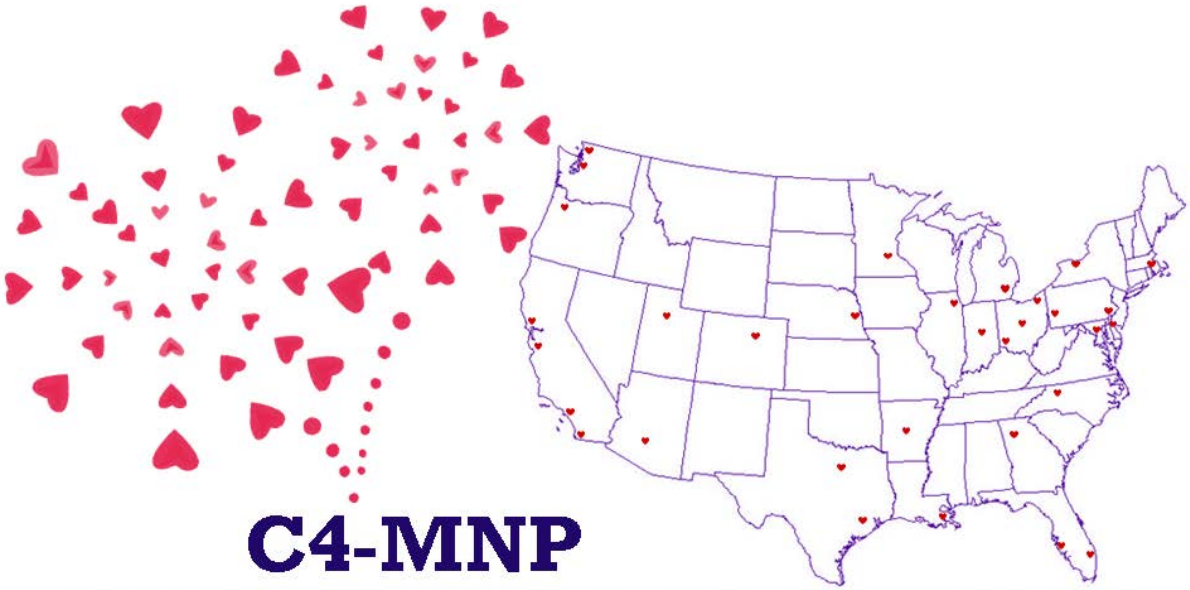
Consortium for Congenital Cardiac Care – Measurement of Nursing Practice

State of Nursing Practice Assessment Aggregate Result Report:

Individualized Family Centered Developmental Care

for Infants with Congenital Heart Disease in the Intensive Care Setting

January 28, 2019 – March 4, 2019



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Executive Summary

Survey Overview

Individualized Family Centered Developmental Care (IFDC) is a standard practice in the neonatal intensive care (NICU) setting to address documented alterations in newborn brain development in premature babies. Similar alterations in brain development have been observed in newborns with congenital heart disease (CHD), putting children with CHD at risk for cognitive, behavioral and physical alterations in development. The literature has demonstrated the benefits of IFDC in the critical care setting in NICU populations; however, incorporating IFDC into nursing care for CHD patients has been variable. The goal of this survey was to describe the current state of IFDC nursing practice in the critical care setting for infants less than six months of age with CHD.

Key Findings

The response rate was 66% (25 centers), with 84% of centers identifying as a CICU. Eighty percent of respondents were staff nurses with the majority having 1-9 years of clinical experience. Seventy-two percent of respondents did not have an IFDC guideline in place, yet 63% of respondents reported that IFDC was part of their daily practice. Most respondents reported feeling "very" or "fully" competent with the defined aspects of IFDC. However, when asked about IFDC practices in CICU clinical scenarios, including infants transitioning to acute care, IFDC interventions were not consistently used.

Data were further stratified to assess differences in IFDC practices based on years of nursing experience and IFDC education during unit orientation. The stratified analyses demonstrated that nurses with 5+ years of experience performed proper positioning of infants with lines and tubes more consistently than nurses with 0-4 years of experience. Additionally, units that included IFDC education as part of orientation yielded statistically significant results regarding compliance with specific aspects of IFDC care (cue-based assessment, parent/staff holding and parent involvement in daily care) for intubated and sedated infants with lines and tubes.

Among responding centers, 50% reported having an interdisciplinary neurodevelopmental team, suggesting that the lack of internal supports may affect consistency in IFDC practice. Most respondents were unaware of the interdisciplinary aspect of IFDC and were unable to identify resources to assist with providing parent and staff education.

Conclusions

The findings demonstrate the need for centers to develop IFDC guidelines for clinical practice. Although respondents perceived a high level of competency in IFDC, operationalizing this care was inconsistent, indicating a gap between competency and practice. Guideline development, and IFDC education for CICU nurses, could increase the use of developmentally appropriate protective interventions for this population. The findings also demonstrate the need for centers to more consistently perform neurodevelopmental assessments to identify those at risk, provide interdisciplinary support for those infants, and create a more formal structure for IFDC implementation. Next steps include convening a C4-MNP working group to develop nursing practice and policy guidelines, identify and implement IFDC initiatives for testing across programs, and develop quality measurement for future benchmarking.

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Demographics

1. Please describe your unit.

Respondents (N=25)	
Unit Type	**Frequency (%)**
PICU	1 (4.0)
CICU	21 (84.0)
Combination Unit	3 (12.0)

2. What is your current job title?

Respondents (N=25)	
Job Title	**Frequency (%)**
Staff Nurse	20 (80.0)
Clinical Nurse Specialist	1 (4.0)
Nurse Educator	3 (12.0)
Nursing Administration	1 (4.0)

3. Please identify your years in this position.

Respondents (N=25)	
Years of Experience	**Frequency (%)**
< 1 Year	1 (4.0)
1-4 Years	9 (36.0)
5-9 Years	8 (32.0)
10-14 Years	4 (16.0)
> 15 Years	3 (12.0)

4. Please identify how many years you have worked providing care to newborns and infants.

Respondents (N=25)	
Years of Experience	**Frequency (%)**
< 1 Year	0 (0.0)
1-4 Years	7 (28.0)
5-9 Years	9 (36.0)
10-14 Years	6 (24.0)
> 15 Years	3 (12.0)

Nursing Practice

1. Does your unit have an IFDC guideline or policy for infants < 6 months of age in place?

Respondents (N=25)	
IFDC Policy	**Frequency (%)**
Yes	7 (28.0)
No	18 (72.0)

Of the 7 sites responding 'Yes,' 6 provided a description of their policy:

IFDC Policy Descriptions
Care Partnership Pyramid
Best practices for positioning, feeding, environment, touch/stimulation, and pain control for infants undergoing cardiac surgery
Family centered care, light and noise reduction strategies, special positioning tools
We have therapeutic positioning policies for infants and back to sleep.
Hospital wide policy on developmental care (in place many years), unit specific developmental care "flower" 1-2 years
No screen time <18mo, 2hr screen time for 18mo-3yrs, cluster care to decrease interruptions, feed in a quiet and conducive environment similar to mother feeding the infant

2. How long has the IFDC guideline or policy been in place?

Respondents (N=6)	
IFDC Policy	**Frequency (%)**
≤ 1 Year	2 (33.3)
2-5 Years	2 (33.3)
> 5 Years	2 (33.3)

3. Is IFDC part of daily nursing care and practice in your clinical setting?

Respondents (N=24)	
IFDC Practice	**Frequency (%)**
Yes	15 (62.5)
No	9 (37.5)

Of the 15 sites responding 'Yes,' 13 described their IFDC practices as part of daily nursing care:

IFDC Practice in Daily Nursing Care
Discussed on daily rounds
We provide developmental care weekly, which then outline positioning/holding/therapy goals for the next week that staff and family can help do while at the bedside. Our nurses are good at reducing environmental stressors by dimming lights or playing soothing noises.
Nursing staff is educated on best practices during weekly developmental rounds, hanging signs in room describe optimal infant positioning and how to create most developmentally appropriate environment.
Nurse manages patient room and setting, dictates safety of parent holding child
Our unit utilizes positioning aids with neonates. We use boundaries in the beds and encourage holding when appropriate. Additionally, our unit as a whole does a good job reducing stimulation when able and attempting to schedule cares around when the infants are awake.
We keep lights down in infant rooms or cover their eyes/face if we need to turn on the bright lights. We reposition our babes and allow parents to hold when medically stable. Parents are involved in rounds, and we incorporate them in cares as often as possible.
Nursing attempts to use developmentally appropriate positioning, using sleep sacks or fluidized positioners. Nursing encourages parental involvement into patient care when medically stable. Nursing attempts to use appropriate lighting cycles throughout the day. Lights on during the day, lights off at night.
Cue based feeding, family centered care and parental engagement with stepping stones sheet for discharge
Somewhat: I think there are some missed opportunities to recognize stress cues and use developmental care to assist
We do not currently have guidelines but have formed a committee to educate staff and develop guidelines. IFDC is discussed daily in rounds.
Our CTICU utilizes the NPASS for neonatal pain assessment tool, State Behavioral Scale and Cornell Assessment of Pediatric Delirium and Withdrawal Assessment Tool. Then interventions include reduction of environmental stressors like light and sound, or we utilize calming music in the room and music therapist visiting our patients. We also now use developmental positioning after recent in-services and have been using parental engagement, holding their baby as often as possible during visits when baby is stable, and safety is assured with staff assistance.
Family centered care is the cornerstone of our practice. Parents are encouraged to hold their child as soon as it is safe and are taught ways to soothe their child. PT/OT team members are actively involved in our assessments to provide developmentally appropriate interventions to reduce stress. We enforce quiet hours as much as possible. Patients are repositioned q2 hours and as needed and swaddled when appropriate.
We teach new employees and re-educate older staff to provide best, most efficient care dependent upon hemodynamics stability of patient.

Of the 9 sites responding 'No,' 9 described barriers that prevent IFDC practices from occurring:

Barriers to IFDC Practice in Daily Nursing Care
Knowledge, professional
Environmental, social, professional, and personal
Environmental, we have a POD structure and difficult to accommodate light and sound
Environmental, educational
The unit is now split in 3 ICUs - neonatal, regular, heart failure
There is no formal, written policy or guideline
Environmental
We do not have defined policy/guidelines for developmental care; however, we are in the beginning stages of establishing a developmental care team. Our staff does not routinely do cue-based assessments and interventions; a likely barrier is lack of education. Bedside nurses are mindful of reducing negative environmental stimuli, but due to the acuity of our patients and having an open bay area without private rooms, we can't always adjust light/noise levels. We have been working to educate staff on appropriate positioning and holding, we just rolled out new positioner devices. Lack of parent involvement can sometimes be a barrier.
Post-operative care, unit culture

4. Is there an assessment tool used to guide nursing-based neurodevelopmental assessment and care in your clinical setting for patients < 6months of age?

Respondents (N=24)	
Assessment Tool	**Frequency (%)**
Yes	2 (8.3)
No	22 (91.7)

Of the 2 sites responding 'Yes,' 2 described their assessment tool:

Neurodevelopmental Assessment Tools
Neuroprotective Guidelines
Weekly developmental rounds; multidisciplinary team evaluates each patient in respect to (1) environment, (2) positioning/movement, (3) feeding, (4) comfort/pain management, (5) family needs, (6) therapies and (7) discharge planning for developmental needs. Educate staff and parents, make referrals as needed. Developmental rounds note charted by cardiac surgery NP.

Nursing Practice: Cue-Based Assessments

1. Do you feel competent in cue-based assessments of infants < 6 months during basic cares?

Respondents (N=24)	
Competency	**Frequency (%)**
Fully competent	9 (37.5)
Very competent	10 (41.7)
A little competent	4 (16.7)
Not competent	1 (4.2)

2. Do you feel competent in cue-based assessments of infants < 6 months during stressful interventions in the CICU?

Respondents (N=24)	
Competency	**Frequency (%)**
Fully competent	5 (20.8)
Very competent	13 (54.2)
A little competent	3 (12.5)
Not competent	3 (12.5)

3. If you are competent in cue-based assessment, how often do you perform it?

Respondents (N=24)	
Frequency	**Frequency (%)**
One time each shift	0 (0.0)
Every 4 hours	2 (8.3)
With basic cares	9 (37.5)
Continuously as part of my nursing assessment	22 (91.7)
With stressful interventions	7 (29.2)
I am not competent in cue-based assessment	2 (8.3)

Nursing Practice: Developmentally-Appropriate Light

1. Do you feel competent providing developmentally appropriate light (low ambient light during the day, darkness at night, use of eye shield when light needed for interventions and care) when caring for infants < 6 months old during basic cares in the CICU?

Respondents (N=24)	
Competency	**Frequency (%)**
Fully competent	10 (41.7)
Very competent	11 (45.8)
A little competent	1 (4.2)
Not competent	2 (8.3)

2. Do you feel competent providing developmentally appropriate light (low ambient light during the day, darkness at night, use of eye shield when light needed for interventions and care) when caring for infants < 6 months old during stressful interventions in the CICU?

Respondents (N=23)	
Competency	**Frequency (%)**
Fully competent	7 (30.4)
Very competent	7 (30.4)
A little competent	6 (26.1)
Not competent	3 (13.1)

3. Please identify any barriers to providing developmentally appropriate light (low ambient light during the day, darkness at night, use of eye shield when light needed for interventions and care) in your clinical setting. Check all that apply.

Respondents (N=24)	
Barriers to IFDC appropriate light	**Frequency (%)**
Light source does not allow for adjustment	9 (37.5)
Nursing preference based on acuity of patient	20 (83.3)
Physician preference based on acuity of patient	14 (58.3)
Personal preference	4 (16.7)
Parent preference	7 (29.2)
I did not know this was part of IFDC	1 (4.2)
Other	3 (12.5)

Note: Column totals exceed 100% due to option of selecting multiple responses.

Of the 3 sites responding 'Other,' 3 described barriers to developmentally appropriate light:

Barriers to Providing Developmentally Appropriate Light in the Clinical Setting
Awareness of situation that is going to require overhead lights.
If on ECMO, different specialists prefer different lights on to visualize pump.
Lighting for bedside procedures.

4. If you are competent in providing developmentally appropriate light (low ambient light during the day, darkness at night, use of eye shield when light needed for interventions and care) when caring for infants < 6 months old in the CICU, how often to you provide it?

Respondents (N=22)	
Frequency	**Frequency (%)**
The duration of my shift	18 (81.8)
With basic cares only	1 (4.5)
With stressful interventions only	0 (0.0)
During sleep only	2 (9.2)
I am unable to control light in my clinical setting	1 (4.5)
I do not practice this domain of IFDC	0 (0.0)

Nursing Practice: Developmentally Appropriate Sound

1. Do you feel competent providing developmentally appropriate sound levels (equivalent to quiet conversation, library level sound) when caring for infants < 6 months old during basic cares in the CICU?

Respondents (N=24)	
Competency	**Frequency (%)**
Fully competent	8 (33.3)
Very competent	10 (41.7)
A little competent	2 (8.3)
Not competent	4 (16.7)

2. Do you feel competent providing developmentally appropriate sound levels when caring for infants < 6 months old during stressful interventions in the CICU?

Respondents (N=24)	
Competency	**Frequency (%)**
Fully competent	4 (16.7)
Very competent	9 (37.5)
A little competent	6 (25.0)
Not competent	4 (20.8)

3. Please identify barriers to providing developmentally appropriate sound levels in your clinical setting. Check all that apply.

Respondents (N=24)	
Barriers to providing IFDC appropriate sound	**Frequency (%)**
Physical layout of the unit	16 (66.7)
Culture of the unit	16 (66.7)
Culture of the staff	14 (58.3)
Barriers outside my control	20 (83.3)
Parents' presence	14 (58.3)
Ancillary staff	11 (45.8)
I did not know this was part of IFDC	2 (8.3)

Note: Column totals exceed 100% due to option of selecting multiple responses.

4. If you are competent in providing developmentally appropriate sound levels (equivalent to quiet conversation, library level sound) when caring for infants < 6 months old in the CICU, how often to you provide it?

Respondents (N=21)	
Frequency	**Frequency (%)**
The duration of my shift	13 (61.8)
With basic cares only	1 (4.8)
With stressful interventions only	0 (0.0)
During sleep only	3 (14.3)
I am unable to control sound in my clinical setting	3 (14.3)
I do not practice this domain of IFDC	1 (4.8)

Nursing Practice: Developmentally Appropriate Positioning

1. Do you feel competent positioning infants < 6 months in the CICU using IFDC appropriate positions (midline, flexed extremities, hands close to face, containment provided)?

Respondents (N=24)	
Competency	**Frequency (%)**
Fully competent	8 (33.3)
Very competent	14 (58.3)
A little competent	2 (8.4)
Not competent	0 (0.0)

2. If you are competent positioning infants < 6 months in the CICU using IFDC appropriate positions (midline, flexed extremities, hands close to face, containment provided), how often do you reposition?

Respondents (N=24)	
Frequency	**Frequency (%)**
The duration of my shift	5 (20.8)
Every 2 hours	16 (66.7)
Every 4 hours	0 (0.0)
With basic cares only	2 (8.3)
With stressful interventions only	0 (0.0)
I do not practice this domain of IFDC	1 (4.2)

Nursing Practice: Safe Holding

1. Is there a policy or guideline in your clinical setting that defines which CICU patients are safe for holding by parents or caregivers?

Respondents (N=24)	
Safe Holding Policy or Guideline	**Frequency (%)**
Yes	8 (33.3)
No	16 (66.7)

2. Does the guideline for safe handling identify patients that should NOT be held?

Respondents (N=8)	
Safe Handling for Patients Not To Be Held	**Frequency (%)**
Yes	7 (87.5)
No	1 (12.5)

3. In patients with lines and tubes, regardless of the type, who determines if a patient < 6 months old can be held by a parent or caregiver?

Respondents (N=24)	
Who Determines Safe Holding	**Frequency (%)**
Bedside RN	5 (20.8)
Attending Physician	7 (29.2)
Fellow or NP	0 (0.0)
Attending CV surgeon	1 (4.2)
Interdisciplinary team	11 (45.8)
Other	0 (0.0)

4. Which tubes/lines and clinical conditions are deemed as "safe" for holding infants < 6 months old in your unit? Please check all that apply.

Respondents (N=24)	
Lines/Tubes Safe for Holding	**Frequency (%)**
Endotracheal tube	15 (62.5)
Intracardiac lines	5 (20.8)
Central venous line	24 (100.0)
Peripheral arterial lines	19 (79.2)
Central arterial lines	11 (45.8)
UV catheter	18 (75.0)
UA catheter	15 (62.5)
PICC lines	24 (100.0)
NGT/NJT	24 (100.0)
Open chest	0 (0.0)
Chest tubes	23 (95.8)
Pacing wires in use	12 (50.0)
Pacing wires not in use	23 (95.8)
ECMO	0 (0.0)

Note: Column totals exceed 100% due to option of selecting multiple responses.

5. When are patients < 6 months old allowed to be held in your unit? Check all that apply.

Respondents (N=24)	
When patients allowed to be held	**Frequency (%)**
While on peripherally cannulated ECMO	0 (0.0)
While on centrally cannulated ECMO	0 (0.0)
Open chest	0 (0.0)
Only after chest has been closed	16 (66.7)
Intubated	16 (66.7)
Once extubated	16 (66.7)
Once intracardiac lines have been removed	17 (70.8)
Once CVLs have been removed	6 (25.0)
Once UV or UA lines have been removed	10 (41.7)
Once central arterial lines have been removed	10 (41.7)
Once peripheral arterial lines have been removed	8 (33.3)
Other	2 (8.3)

Note: Column totals exceed 100% due to option of selecting multiple responses.

Of the 2 sites responding 'Other,' 2 provided the following responses:

When are patients <6 months old allowed to be held in your unit?
Generally OK to hold if clinically stable, OK with ETT/intracardiac over a day old, chest closed off ECMO, will make exceptions
Once patient is hemodynamically stable and tolerates positioning, babies can be held even if intubated with central and arterial lines.

5. When caring for infants < 6 months old in the CICU, how often is your patient being held? Please check all that apply.

Respondents (N=24)	
Frequency of Holding	**Frequency (%)**
Amount of holding is dependent on the presence of lines and tubes	21 (87.5)
Once extubation has occurred	13 (54.2)
When parents or caregivers are at bedside	19 (79.2)
When there is time in my shift for me to hold patient	16 (66.7)
When the patient is crying	11 (45.8)
During feeding only	2 (8.3)
When a clinical assistant or volunteer is available	11 (45.8)

Note: Column totals exceed 100% due to option of selecting multiple responses.

Nursing Practice: IFDC Interventions

1. During your shift, do you provide the following IFDC interventions to an INTUBATED newborn that is NOT sedated and paralyzed AND has additional lines/tubes?

Respondents (N=24) (N=23)*				
	Frequency (%)			
IFDC Interventions	**Never**	**Sometimes**	**Often**	**Always**
Provide age appropriate light to allow for normal sleep cycles and minimize stress	1 (4.2)	4 (16.6)	12 (50.0)	7 (29.2)
Eliminate unnecessary noise in and around the bed space	1 (4.2)	7 (29.1)	10 (41.7)	6 (25.0)
Incorporate cue-based assessment*	2 (8.7)	5 (21.7)	12 (52.2)	4 (17.4)
Position the infant midline, extremities flexed, contained, hands to face	1 (4.2)	8 (33.3)	8 (33.3)	7 (29.2)
Avoid frog-leg positioning of the infant	0 (0.0)	6 (25.0)	12 (50.0)	6 (25.0)
Avoid “W” positioning of the infant’s arms	0 (0.0)	6 (25.0)	14 (58.3)	4 (16.7)
Provide boundaries, swaddling and containment for the infant*	0 (0.0)	2 (8.7)	11 (47.8)	10 (43.5)
Promote holding by parents or staff member	3 (12.5)	7 (29.2)	8 (33.3)	6 (25.0)
Non-pharmacologic support (eg: non-nutritive sucking, sucrose, bundling, music)	0 (0.0)	2 (8.3)	13 (54.2)	9 (37.5)
Holding by parents	3 (12.5)	10 (41.7)	8 (33.3)	3 (12.5)
Offer breastfeeding	17 (70.8)	4 (16.7)	1 (4.2)	2 (8.3)
Offer skin to skin	13 (54.2)	9 (37.4)	1 (4.2)	1 (4.2)
Cluster care*	1 (4.3)	1 (4.3)	10 (43.6)	11 (47.8)
Parents assume care (eg: diaper change, swaddling)	2 (8.3)	12 (50.0)	8 (33.4)	2 (8.3)

2. Please list any barriers to providing these interventions to an INTUBATED newborn that is NOT sedated and paralyzed AND has additional lines/tubes?

Of the 24 centers that participated, 15 provided the following responses:

Barriers to providing IFDC care to intubated newborn that is NOT sedated and paralyzed
Hemodynamic status
Our unit culture rarely has parents holding intubated infants, will occasionally permit for very stable long-term intubated infants or for children at end of life. Main barrier is that the patients are usually intubated around post-op period and are critically ill/unstable. For patients that are more stable, intubated longer periods parents will be more engaged in cares. Staff resistance is a large factor - they fear that patients' safety will be compromised.
Knowledge, comfort
Not having family presence at the bedside; if restraints are needed for patient unpredictability with lines/tubes
Patient is not breastfeeding while intubated, need further information on developmental positioning,
Safety of patient with lines and tubes
The practice of our unit does not involve doing skin to skin in post-operative cardiac patients. Additionally, with our intubated patients we do not close the doors, especially if they are not paralyzed or sedated. As a result, those infants are exposed to more noise and light than the extubated patient would be.
Staffing limitations, time limitations, family fear of causing harm, patient agitation
Physician preference, less support overnight for these activities, stability and reserve of the patient
How sick newborn is, whether you have another patient, ability of respiratory therapist to assist in holding, comfort/availability of parents
When hemodynamic instabilities like hypo/hypertension, desaturations, heart rate changes and increase work of breathing that may be related to movements or positioning or parents holding the baby.
Bedside nursing comfort moving intubated patient. Parent's comfort level holding intubated patient. Availability of resources to help safely move patient. Lack of education regarding appropriate positioning techniques.
Cannot breastfeed with an endotracheal tube in place.
Safety of the patient (appropriate # of staff, equipment, training)

3. During your shift, do you provide the following IFDC interventions to an INTUBATED newborn that IS sedated and paralyzed AND has additional lines/tubes?

Respondents (N=24) (N=23)*				
IFDC Interventions	**Frequency (%)**			
	Never	**Sometimes**	**Often**	**Always**
Provide age appropriate light to allow for normal sleep cycles and minimize stress	2 (8.3)	9 (37.5)	8 (33.3)	5 (20.9)
Eliminate unnecessary noise in and around the bed space	1 (4.2)	11 (45.8)	8 (33.3)	4 (16.7)
Incorporate cue-based assessment*	6 (26.1)	7 (30.4)	8 (34.8)	2 (8.7)
Position the infant midline, extremities flexed, contained, hands to face	3 (12.5)	8 (33.3)	7 (29.2)	6 (25.0)
Avoid frog-leg positioning of the infant	0 (0.0)	10 (41.7)	7 (29.3)	7 (29.2)
Avoid “W” positioning of the infant’s arms	0 (0.0)	10 (41.7)	9 (37.5)	5 (20.8)
Provide boundaries, swaddling and containment for the infant	4 (16.6)	6 (25.0)	7 (29.2)	7 (29.2)
Promote holding by parents or staff member	13 (54.2)	8 (33.3)	2 (8.3)	1 (4.2)
Non-pharmacologic support (eg: non-nutritive sucking, sucrose, bundling, music)	5 (20.8)	10 (41.7)	5 (20.8)	4 (16.7)
Holding by parents	15 (62.4)	7 (29.2)	1 (4.2)	1 (4.2)
Offer breastfeeding*	20 (87.0)	2 (8.7)	1 (4.3)	0 (0.0)
Offer skin to skin*	20 (83.3)	2 (12.5)	1 (4.2)	0 (0.0)
Cluster care	2 (8.3)	4 (16.7)	10 (41.7)	8 (33.3)
Parents assume care (eg: diaper change, swaddling)	9 (37.5)	8 (33.3)	3 (12.5)	4 (16.7)

4. Please list any barriers to providing these interventions to an INTUBATED newborn that IS sedated and paralyzed AND has additional lines/tubes?

Of the 24 centers that participated, 12 provided the following responses:

Barriers providing IFDC care to intubated, sedated and paralyzed newborn
Hemodynamic status
With sedated/paralyzed patients there is a lot of instability in BP, respiratory status - cannot risk additional variables such as stimulation, risk of loss of ETT.
VS instability; fresh post-op back from OR/initial first few hours of recovery
Patient acuity considered prohibitive to these interventions
Generally, if a child is still requiring sedation and paralytic, they are likely not stable enough to be held in my opinion. When an infant is intubated with various lines and tubes, parents are not encouraged to change diapers d/t the risk of something being pulled. Parents are generally encouraged to assume care post-extubation.
Staffing limitations, time limitations, family fear of causing harm. We will offer most interventions to parents if patient is sedated however if patient is sedated and paralyzed, we do not promote holding or parents assuming care due to acuity of patient.
Acuity of patient, attending physician preference, less support overnight
Comfort of family members, acuity of patient
Our paralyzed patients are not stable enough for holding/swaddling and positioning.
Acuity of newborn
When patients remain unstable/labile pressures/desaturations/active signs of pulmonary hypertension, parents /staff comfort level.
Patient's chemically paralyzed and sedated are often critical ill and requiring frequent interventions. Patient safety requires them to remain in bed and for nursing to assume all cares.
Patient Safety, (proper training in how to move patient safely, # of people to safely move patient)

5. During your shift, do you provide the following neurodevelopmental interventions to an EXTUBATED newborn that is ready to transition to acute care/step-down setting?

Respondents (N=24) (N=23)* (N=22)**				
IFDC Interventions	**Frequency (%)**			
	Never	**Sometimes**	**Often**	**Always**
Provide age appropriate light to allow for normal sleep cycles and minimize stress**	0 (0.0)	2 (9.1)	7 (31.8)	13 (59.1)
Eliminate unnecessary noise in and around the bed space*	0 (0.0)	6 (26.1)	9 (39.1)	8 (34.8)
Incorporate cue-based assessment*	1 (4.3)	3 (13.0)	10 (43.5)	9 (39.2)
Position the infant midline, extremities flexed, contained, hands to face	0 (0.0)	4 (16.7)	11 (45.8)	9 (37.5)
Avoid frog-leg positioning of the infant	0 (0.0)	1 (4.2)	14 (58.3)	9 (37.5)
Avoid “W” positioning of the infant’s arms	0 (0.0)	1 (4.2)	14 (58.3)	9 (37.5)
Provide boundaries, swaddling and containment for the infant	0 (0.0)	1 (4.2)	11 (45.8)	12 (50.0)
Promote holding by parents or staff member	0 (0.0)	2 (8.3)	9 (37.5)	13 (54.2)
Non-pharmacologic support (eg: non-nutritive sucking, sucrose, bundling, music)	0 (0.0)	1 (4.2)	11 (45.8)	12 (50.0)
Holding by parents	0 (0.0)	1 (4.2)	10 (41.6)	13 (54.2)
Offer breastfeeding	2 (8.3)	8 (33.3)	10 (41.7)	4 (16.7)
Offer skin to skin*	3 (13.0)	12 (52.2)	13 (17.4)	4 (17.4)
Cluster care	0 (0.0)	1 (4.2)	12 (50.0)	11 (45.8)
Parents assume care (eg: diaper change, swaddling)	0 (0.0)	1 (4.2)	13 (54.2)	10 (41.6)

6. Please list any barriers to providing these interventions to an EXTUBATED newborn that is ready to transition to acute care/step-down setting.

Of the 24 centers that participated, 10 provided the following responses:

Barriers to providing IFDC care to extubated, ward-ready newborn
Culture
Many of our infants are not tolerating oral feeds - so less breastfeeding. In addition providers (MD and nurses) are not very well informed/educated in best practices for promoting breastfeeding. Fear of inability to control amount of milk consumed/measure exact amount of milk transfer causes barrier to encouraging moms. Many nurses do not feel comfortable assisting moms with latching and breastfeeding issues, lactation consultant is busy and not stationed on our unit.
Not having parent/family at bedside; patient with oral aversion/not breastfeeding; patient has a roommate
We generally are still doing strict intake and output in CICU, and breastfeeding doesn't generally allow very accurate monitoring. Additionally, with poor feeders, breast feeding is difficult, as you cannot do a slower flow.
Staffing limitations, patient acuity and assignments, time limitations, family fear, lack of family at bedside, lack of family education
Parents often leave at night or want to rest, we are not well educated on skin to skin and our patients rarely breastfeed
Can't always control environment, ex. noise levels and lighting in surrounding space
If parents not available, unit staffing is a barrier.
Parent involvement, education regarding appropriate positioning, busy assignments
Not many. Parental involvement and education

7. During stressful interventions, how often do you use non-pharmacologic IFDC interventions to soothe your patient before considering prn sedation/anxiolytic? Ex: IFDC positioning, parent holding, parent participation in comfort measures, non-nutritive sucking.

Respondents (N=24)	
Frequency	**Frequency (%)**
Never	0 (0.0)
Sometimes	7 (29.2)
Often	9 (37.5)
Always	8 (33.3)

8. How long do you use IFDC non-pharmacologic interventions to comfort any of the above listed patients before administering prn sedation/anxiolytic medication?

Respondents (N=24)	
Time Prior to Sedation Or Anxiolytic Medication	**Frequency (%)**
<5 minutes	4 (16.7)
5-15 minutes	13 (54.2)
16-30 minutes	5 (20.8)
>30 minutes	2 (8.3)

9. If you choose to administer sedation/anxiolytic medication, what makes you decide to do so? Please check all that apply.

Respondents (N=24)	
Rationale for Sedation Or Anxiolytic Medication	**Frequency (%)**
Hemodynamic instability	23 (95.8)
Safety for integrity of lines and tubes	22 (91.7)
Elevated pain score	21 (87.5)
Bedside RN unable to console	19 (79.2)
Parents unable to console	19 (79.2)
Parental stress in the setting of inconsolability	14 (58.3)
Nursing assignment (covering another nurse, 2-patient assignment)	8 (33.3)
Time it takes to assess cues and provide IFDC care	2 (8.3)
Once non-pharmacologic measures have failed	21 (87.5)
Acuity within the CICU	6 (25.0)

Note: Column totals exceed 100% due to option of selecting multiple responses.

10. During painful/stressful bedside procedures and care which of the following measures are utilized to best support the child? This does not include surgical bedside procedures during which a baby is under anesthesia. Please check all that apply.

Respondents (N=24)	
IFDC During Painful Procedures	**Frequency (%)**
Sedation	23 (95.8)
Non-nutritive sucking with sucrose or breastmilk	22 (91.7)
Parent presence	21 (87.5)
Child Life Specialist	15 (62.5)
Music therapy	12 (50.0)
IFDC positioning and holding	18 (75.0)
Other	0 (0.0)

Note: Column totals exceed 100% due to option of selecting multiple responses.

Nursing Practice: Documentation and Communication

1. Do you document the IFDC you provide in the medical record?

Respondents (N=24)	
IFDC Documentation	**Frequency (%)**
Yes	16 (66.7)
No	8 (33.3)

2. Where do you document the IFDC care you provide? Check all that apply.

Respondents (N=24)	
Location of IFDC Documentation	**Frequency (%)**
Nursing Flowsheet	19 (79.2)
Nursing Progress Note	4 (16.7)
Nursing Care Plan	3 (12.5)
I do not document the care	6 (25.0)

Note: Column totals exceed 100% due to option of selecting multiple responses.

3. How often do you document the IFDC you provide?

Respondents (N=24)	
Frequency of IFDC Documentation	**Frequency (%)**
Once a shift	3 (12.5)
Q4h	4 (16.6)
Other	13 (54.2)
I do not document the care	4 (16.7)

Of the 13 sites that responded 'Other,' 13 provided responses:

How often do you document IFDC?
Positioning, swaddling, holding documented q2. If pain score elevated, charting q1hr. Many non-pharmacological measures can be documented with this assessment.
Q2h
As often and frequently as I provide interventions. It may be multiple times an hour because patient is in middle of procedure or difficult to console, or may be every 2-3 hours if patient is receiving good sleep and needs IFDC during touch/care times.

When I provide the care, I document it
There is an option under pain in the flowsheet that we use to document non pharmacological interventions
Document as we do it.
Only document holding/positioning as changed and use of sucrose/pacifier/decreased environmental stimuli/holding feeding/music on pain record as needed
As provided
Our CTICU standard is every 2 to 4 hours related to patient unit acuity.
We document turning/repositioning q2 and non-pharmacological interventions with pain scores, beyond that we do not routinely document developmental cares or have a designated place in our medical record to do so.
Document turns and positioning q2 hours, document parent holding times
With every assessment and position change
Q4 and prn

4. What aspects of IFDC care do you document? Please check all that apply.

Respondents (N=23)	
IFDC Care Documented	**Frequency (%)**
Light	7 (30.4)
Sound	7 (30.4)
Holding	18 (78.3)
Positioning	23 (100.0)
Cue-based assessment	5 (21.7)
Use of non-pharmacologic comfort measures	19 (82.6)
Parent presence	20 (87.0)
Pain assessment	23 (100.0)

Note: Column totals exceed 100% due to option of selecting multiple responses.

6. Is there standardized nursing shift-to-shift communication regarding IFDC?

Respondents (N=24)	
Nursing Communication	**Frequency (%)**
Yes	3 (12.5)
No	21 (87.5)

Nursing Practice: Nursing Education

1. Is IFDC education included in hospital-wide nursing orientation?

Respondents (N=24)	
Hospital IFDC Education	**Frequency (%)**
Yes	6 (25.0)
No	18 (75.0)

2. If yes, what is the format?

Respondents (N=6)	
IFDC Education Format	**Frequency (%)**
Simulation training	0 (0.0)
Lecture format	3 (50.0)
Online training	3 (50.0)
Nursing huddles	0 (0.0)

3. If yes, who teaches it?

Respondents (N=4)	
IFDC Educator	**Frequency (%)**
Nursing staff	3 (75.0)
Child life specialist	0 (0.0)
Neurodevelopmental therapist	0 (0.0)
Other: Modules for New Grads	1 (25.0)

4. Is IFDC education included in unit-based nursing orientation?

Respondents (N=24)	
Unit IFDC education	**Frequency (%)**
Yes	11 (45.8)
No	13 (54.2)

5. If yes, what is the format?

Respondents (N=11)	
Format	**Frequency (%)**
Simulation training	2 (18.2)
Lecture format	6 (54.5)
Online training	1 (9.1)
Nursing huddles	2 (18.2)

6. If yes, who teaches it?

Respondents (N=10)	
IFDC Educator	**Frequency (%)**
Nursing staff	7 (70.0)
Child life specialist	0 (0.0)
Neurodevelopmental therapist	1 (10.0)
Other: NP, PT, or RN on Neurodevelopmental Team (1) Physicians that encourage IFDC (1)	2 (20.0)

7. Are there opportunities for continuing education for nurses regarding IFDC?

Respondents (N=24)	
Continuing IFDC Education	**Frequency (%)**
Yes	10 (41.7)
No	14 (58.3)

8. If yes, what is the format?

Respondents (N=10)	
Format	**Frequency (%)**
Simulation training	1 (10.0)
Lecture format	5 (50.0)
Online training	3 (30.0)
Nursing huddles	1 (10.0)

9. If yes, who teaches it?

Respondents (N=10)	
IFDC Educator	**Frequency (%)**
Nursing staff	5 (50.0)
Child life specialist	0 (0.0)
Neurodevelopmental therapist	2 (20.0)
Other: Online education modules (2) NP, PT, OT (1)	3 (30.0)

Interdisciplinary Neurodevelopmental Care Practice

1. Who performs a formal neurodevelopmental assessment on your patients?

Respondents (N=24)	
Performs Neurodevelopmental Assessment	**Frequency (%)**
Child life specialist	0 (0.0)
Physician/NP	3 (12.5)
Neurodevelopmental therapist	4 (16.7)
Psychologist	2 (8.3)
CNS	0 (0.0)
Bedside RN	0 (0.0)
I do not know	11 (45.8)
Other: Team includes RN, NP, child life, PT/OT (2) Multiple contributors (1) Neonatologist (1)	4 (16.7)

2. Which assessment tool is used for the formal neurodevelopmental assessment?

Respondents (N=24)	
Assessment Tool	**Frequency (%)**
Newborn Individualized Developmental Care and Intervention Program (NIDCAP) Observation	0 (0.0)
NIDCAP Nursery Certification and Environmental Measurement	0 (0.0)
Assessment of Preterm Infants' Behavior (APIB)	0 (0.0)

Newborn Behavior Observation (NBO)	0 (0.0)
Newborn Behavior Assessment Scale (NBAS)	0 (0.0)
NICU Network Neurobehavioral Scale (NNN)	0 (0.0)
Bayley Scale of Infant Development	1 (4.2)
Ages and Stages (ASQ)	0 (0.0)
Vineland	0 (0.0)
Other	0 (0.0)
I am not aware	23 (95.8)

3. How often are neurodevelopmental assessments performed?

Respondents (N=23)	
Frequency of Assessments	**Frequency (%)**
Once a shift	0 (0.0)
Daily	0 (0.0)
Weekly	3 (13.0)
Biweekly	0 (0.0)
Monthly	0 (0.0)
Never	1 (4.3)
I do not know	19 (82.7)

4. Does your unit have a dedicated inpatient neurodevelopmental team?

Respondents (N=24)	
Dedicated Inpatient Team	**Frequency (%)**
Yes	7 (29.2)
No	12 (50.0)
I do not know	5 (20.8)

5. If yes, please list all team members. Check all that apply.

Respondents (N=7)	
Inpatient Team Members	**Frequency (%)**
Bedside RN	6 (85.7)
CNS	2 (28.6)
NP	6 (85.7)
Child Life Specialist	6 (85.7)

Neurodevelopmental Therapist	4 (57.1)
Physician	3 (42.9)
Unit-based nurse champion	3 (42.9)
Other: PT/OT, social work	1 (14.3)

Note: Column totals exceed 100% due to option of selecting multiple responses.

6. How are clinical findings from the neurodevelopmental team assessment communicated?

Respondents (N=23)	
Communication of Findings	**Frequency (%)**
Directly to Bedside RN	1 (4.3)
At daily patient rounds to interdisciplinary team	4 (17.5)
Directly to parents/family	0 (0.0)
Documented in medical record	4 (17.4)
I do not know	9 (39.1)
Other	5 (21.7)

Of the 5 sites responding 'Other,' 5 provided the following responses:

Other Communication of Findings
Directly to bedside nurse; if parents present - directly to them, documented in progress notes
Weekly therapy goals are posted at the patient's bedside; bedside nurses are encouraged to join the neurodevelopmental rounds if available to
Occasionally information/clinical findings detailed in PT/OT child life specialist progress notes. Otherwise I do not know.
We do not have that team to make neurodevelopmental assessments
All of the above

7. Is obtaining a neurodevelopmental consult a standard of care for all infants < 6 months old with congenital heart disease?

Respondents (N=23)	
Is consult standard of care?	**Frequency (%)**
Yes	8 (34.8)
No	12 (52.2)
I do not know	3 (13.0)

8. From the list below, please select the diagnoses that qualify for a neurodevelopmental assessment for infants < 6 months of age. Check all that apply.

Respondents (N=24)	
Qualifying Diagnoses	**Frequency (%)**
All infants undergoing cardiac surgery	13 (54.2)
Single ventricle patients	9 (37.5)
TOF/PA	8 (33.3)
PVS	8 (33.3)
Pulmonary Hypertension	9 (37.5)
Premature infant <37weeks GA	9 (37.5)
Infants with genetic syndrome	9 (37.5)
Infants with multiple comorbidities	8 (33.3)
ECMO	8 (33.3)
None	2 (8.3)
I do not know	6 (25.0)
Other: I assume all patients would qualify, but we have no policy that details such qualifications.	1 (4.2)

Note: Column totals exceed 100% due to option of selecting multiple responses.

9. Are neurodevelopmental concerns discussed during daily medical rounds?

Respondents (N=24)	
Neurodevelopmental Concerns at Daily Rounds	**Frequency (%)**
Yes	8 (33.3)
No	15 (62.5)
I do not know	1 (4.2)

10. Who presents these concerns?

Respondents (N=8)	
Who Presents Neurodevelopmental Concerns	**Frequency (%)**
Bedside RN	8 (100.0)
NP	3 (37.5)
Attending	4 (50.0)

Child Life Specialist	0 (0.0)
Neurodevelopmental Therapist	0 (0.0)
Parent	2 (25.0)
Other: OT (1); Neonatologist (1)	2 (25.0)

Note: Column totals exceed 100% due to option of selecting multiple responses.

11. Does your clinical setting have formal neurodevelopmental rounds?

Respondents (N=24)	
Neurodevelopmental Rounds	**Frequency (%)**
Yes	7 (29.2)
No	14 (58.3)
I do not know	3 (12.5)

12. When neurodevelopmental rounds occur in your unit, who leads them?

Respondents (N=20)	
Neurodevelopmental Rounds Leaders	**Frequency (%)**
Nursing	0 (0.0)
Medical Staff	2 (9.5)
CNS	1 (4.8)
Neurodevelopmental Therapist	3 (14.3)
Psychologist	0 (0.0)
I do not know	10 (52.4)
Other: Nurse practitioner (2); NP, PT, OT (1); Interdisciplinary developmental care team (1)	4 (19.0)

13. When neurodevelopmental rounds occur in your unit, how often do they occur?

Respondents (N=22)	
Frequency	**Frequency (%)**
Daily	1 (4.5)
Weekly	7 (31.8)
Biweekly	0 (0.0)
Monthly	0 (0.0)
Never	6 (27.3)
I do not know	8 (36.4)

Parent Education and Support

1. Are parents educated in neurodevelopmental care while inpatient?

Respondents (N=24)	
Parent Education	**Frequency (%)**
Yes	14 (58.3)
No	10 (41.7)

2. If yes, what is the format for parent education? Please check all that apply.

Respondents (N=14)	
Parent Education Format	**Frequency (%)**
Verbal instruction	12 (85.7)
Written instruction	6 (42.9)
Video format	1 (7.1)
Hands-on/real time instruction	6 (42.9)
Other: Education usually comes from PT/OT. Typically verbal; occasionally hands on.	1 (7.1)

Note: Column totals exceed 100% due to option of selecting multiple responses.

3. Who provides neurodevelopmental teaching to parents?

Respondents (N=14)	
Parent Educator	**Frequency (%)**
Bedside RN	7 (50.0)
Child life specialist	1 (7.1)
Neurodevelopmental Specialist	2 (14.3)
Other	4 (28.6)

Of the 4 sites responding 'Other,' 4 provided the following responses:

Other Parent Educator
Bedside nurse primarily, but also have hanging written documents that parents can see. If present during weekly developmental rounds then will get education during that session.
Therapy, and in neurodevelopmental rounds
PT/OT, child life, and occasionally other members of the health care team
CV Surgery educator

4. How is parent education documented?

Respondents (N=14)	
Parent Education Documentation	**Frequency (%)**
Medical Record/Flowsheet	7 (50.0)
End of shift nursing note	1 (7.2)
Nursing care plan	3 (21.4)
Subspecialty (if education not provided by bedside RN)	2 (14.3)
No formal format for documentation	1 (7.1)

5. Is there a formal system for follow-up after discharge in regard to neurodevelopmental care?

Respondents (N=24)	
Post-Discharge Follow-up	**Frequency (%)**
Yes	10 (41.7)
No	14 (58.3)

Of the 10 sites that responded 'Yes,' 10 provided the following responses:

Post-discharge neurodevelopmental care
LEAD Program
Unsure of this - possibly during clinic visits
Patients can be seen in the neurodevelopmental clinic...they usually have an appointment scheduled at the time of discharge.
Uncertain on this question but I believe there is follow up by cardiology
Unsure of formal system process
Patient and family follow up with neuropsychologist outpatient
The TIPs program through Monroe-Meyer Institute for kids who meet certain criteria.
Clinical outcomes clinic
Cardiac Kids Follow Up program (eligible at 3 months if had cardiac surgery or were hospitalized greater than 10 days)
High Risk Infant Follow-Up clinic

Stratified Analyses

Methods

Stratified analyses were conducted using a series of chi-square tests to assess differences in frequency of IFDC practices ('Never/Sometimes' vs. 'Often/Always') based on two categorical variables:

(1) Years of Nursing Experience ('0-4 Years' vs. '5+ Years') and
(2) IFDC Education included in Unit-Based Orientation ('Yes' vs. 'No').

Below are the results that were statistically significant at a 0.05 level.

Results

Differences based on years of nursing experience:

1. For an INTUBATED newborn that is NOT sedated and paralyzed AND has lines/tubes:

Avoiding Frog-Leg Positioning of the Infant – Often/Always		
Years of Experience	**Frequency (%)**	**χ^2 (p-value)**
0-4	5 (50)	5.71 (< 0.05)
5+	13 (93)	

Differences based on IFDC education included in unit-based orientation:

1. For an INTUBATED newborn that is NOT sedated and paralyzed AND has lines/tubes:

Incorporating Cue-Based Assessment – Often/Always		
IFDC Education included in Unit-Based Orientation	**Frequency (%)**	**χ^2 (p-value)**
Yes	10 (91)	4.54 (< 0.05)
No	6 (50)	

Promoting Holding by Parents or Staff – Often/Always		
IFDC Education included in Unit-Based Orientation	**Frequency (%)**	**χ^2 (p-value)**
Yes	9 (82)	4.61 (< 0.05)
No	5 (39)	

Letting Parents Assume Care – Often/Always		
IFDC Education included in Unit-Based Orientation	**Frequency (%)**	**χ^2 (p-value)**
Yes	7 (64)	4.03 (0.05)
No	3 (23)	

2. For an EXTUBATED newborn that is ready to transition to acute care/step-down setting:

Positioning of the Infant in Midline, Extremities Flexed – Often/Always		
IFDC Education included in Unit-Based Orientation	**Frequency (%)**	**χ^2 (p-value)**
Yes	11 (100)	4.06 (< 0.05)
No	9 (69)	