Cardiology in the Young

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Supporting parenting during infant hospitalisation for CHD

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Abstract

Objective: To characterise the parenting priorities of mothers and fathers of infants hospitalised with CHD and generate recommendations to support parenting during infant hospitalisation. *Study design:* Through online crowdsourcing, an innovative research methodology to create an online community to serve as a research sample, 79 parents of young children with CHD responded to questions about parenting during hospitalisation via private social networking site. Responses were analysed using qualitative research methods. *Results:* Three broad themes were identified: (1) establishing a bond with my baby, (2) asserting the parental role, and (3) coping with fear and uncertainty. Parents value provider support in restoring normalcy to the parenting experience during infant hospitalisation. *Conclusions:* Care teams can support parenting during infant hospitalisation by promoting parents' roles as primary caretakers and decision-makers and attending to the emotional impact of infant hospitalisation on the family.

Original Article

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CHD is among the most common causes of ICU admission for infants.[1] Infants with CHD who require cardiac surgery spend weeks or even months in the hospital exposed to invasive tubes and lines, mechanical ventilation, and at times mechanical circulatory support, which restrict parents' ability to independently engage in their infant's care, including holding, comforting, and spending time alone with their infant.[2,3] In many cases, this period of critical illness and hospitalisation occurs immediately or soon after birth, at a time when the parent–infant bond and, for first-time parents, the parenting role is in the formative stages of development.[4]

Parents of hospitalised infants with CHD experience stress resulting from limited opportunities to participate in typical parenting tasks,[5,6] as well as difficulties bonding with their critically ill infant.[7] Alterations to the expected parenting role and difficulties establishing the parent–infant bond can have long-term negative outcomes for the child, parent, and family.[8,9] Prior research indicates that alterations to the parenting role in the cardiac critical care setting is associated with anxiety symptoms in mothers,[2] and that parent mental health influences emotional, behavioural, and quality of life outcomes for children with CHD.[10-12] Parents who feel disempowered with regard to their parenting role may also be less likely to advocate for their infant's needs within the hospital setting and following discharge.[13] Research in other high-risk populations demonstrates a relationship between early parent–infant bonding and child neurodevelopmental and behavioural outcomes,[14-17] and preliminary findings within the CHD literature have demonstrated an association between early bonding difficulties and later developmental delays.[8] Early parenting behaviours and the developing parent–infant bond may be modifiable factors contributing to neurodevelopmental impairments common among children with CHD.[18]

Understanding the parenting actions and values that mothers and fathers prioritise within the context of paediatric critical illness allows providers to support parents in optimal medical decision-making and reduce stress associated with alterations to the parenting role.[19] For infants with CHD, who may be particularly susceptible to the deleterious effects of parental stress and disrupted bonding, understanding and supporting parenting priorities are likely important to promoting a trajectory of healthy neurodevelopmental outcomes. However, no studies to our knowledge have engaged parents in the process of identifying parenting priorities during infant hospitalisation for CHD. Through innovative crowdsourcing methodology, this qualitative study aimed to characterise priorities for parenting an infant with CHD in the hospital and

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generate recommendations to support parenting practices during infant hospitalisation to promote positive child, parent, and family outcomes.

Materials and methods

Participants and recruitment

The current study included 79 parents who provided responses regarding parenting an infant with CHD in the hospital as part of a larger qualitative study. Inclusion criteria for the larger study were having a child born with CHD 1 to 7 years prior to study participation who underwent open-heart surgery in the first year of life, being able to read and write in English, and access to the internet on a computer, tablet, or mobile device. Bereaved parents were included. A study announcement containing the direct link to a brief online recruitment survey was posted to the social media pages of several CHD-specific patient and family advocacy organisations (e.g., Pediatric Congenital Heart Association, Mended *Little* Hearts), including one dedicated to families of children with single-ventricle physiology (Sisters by Heart). The recruitment survey collected basic demographic (e.g., race, ethnicity, education level) and child clinical (e.g., single-ventricle versus two-ventricle physiology) information from parents potentially interested in study participation and was completed by 249 parents over a 1-week period. By applying an algorithm that considered the frequencies of each demographic and clinical characteristic among those who completed the recruitment survey, a subset of parents (n = 179) representing diversity in backgrounds and experiences were invited to participate in the larger study. Of the invited parents, 108 participated in the larger qualitative study and 79 contributed responses related to parenting during hospitalisation. This study was approved by the Nemours Institutional Review Board and informed consent was obtained electronically prior to study procedures.

Procedures and measures

A stakeholder advisory council consisting of four parents of children with CHD who underwent cardiac surgery during infancy and six multidisciplinary care providers from four paediatric hospitals convened regularly throughout the study to provide guidance on study methodology and interpretation of results. Qualitative data were collected through online crowdsourcing methodology. Crowdsourcing is an internet-based activity that allows large groups to collaboratively identify problems and propose solutions to the mutual benefit of the organisation generating the task and the community-generating results.[20] Crowdsourcing has been used to efficiently engage community stakeholders in the process of identifying the needs and lived experiences of patients and their families.[21-23]

Participants created deidentified accounts on Yammer, a private online social networking site. Over a 6-month period, a total of 37 open-ended study questions were posted to the online group. Questions were generated by the study team and refined by the stakeholder advisory council. Three questions were specifically aimed at capturing experiences of parenting an infant with CHD in the hospital and recommendations to support parenting (e.g., "How did your baby's care team support your participation and involvement with your baby's care in the ICU/hospital?" "How do you wish that your baby's care team had supported your participation and involvement with your baby's care in the ICU/hospital?"), while the remaining 34 questions captured other relevant psychosocial domains. Parents responded to study questions through the Yammer app on their tablet or mobile device or by e-mail. To facilitate collaborative efforts at problem-solving among participants, parents could view each other's responses and "like" or comment on these responses. All dialogues were included as qualitative data.

Data analysis

Qualitative data were analysed using an inductive thematic approach, focused on subjective perceptions, feelings, and experiences.[24] Parent responses to open-ended questions and dialogue between participants were extracted from Yammer and uploaded into Dedoose Version 8 (SocioCultural Research Consultants, LLC, Los Angeles, CA). The qualitative codebook was developed through an iterative process with input from the stakeholder advisory council. After finalising the codebook, four participants' complete responses were independently coded by four raters to establish inter-rater reliability (0.81–0.90 pooled Cohen's kappa coefficient) and disagreements were resolved through reflection and discussion. The remaining participants' responses were divided among the four raters. Responses double-coded with "hospitalizations/surgeries" (indicating that the response described an experience during hospitalisation) and either "parenting" or "education/preparation/knowledge" (to capture responses related to decision-making) were reviewed. Broad themes regarding experiences of parenting an infant with CHD in the hospital and recommendations to support parenting were identified. Then, participant responses were organised by theme and examined to identify distinct subthemes supporting each theme. To identify general trends in the qualitative data, frequencies and cross tabulations were generated. Each participant response was assigned a number corresponding to a theme and coded by the select demographic variables for which there were sufficient sample diversity (i.e., education level and household income). Themes are described in terms of relative distribution to illustrate the extent to which they are more or less common.

Results

Participants were 79 parents (60 mothers and 19 fathers) whose child underwent one or more open-heart surgeries in the first year of life (72.2% in the first month; Table 1). Two-thirds (67.1%) of children of study participants were hospitalised for over a month across the first year of life and nearly half were discharged with a feeding tube (49.4%). Participants were diverse with regard to education level, household income, and urban–rural classification, although the majority identified as non-Hispanic White (89.9%). Participants did not differ significantly from the groups of parents who were invited to participate (n = 179) or did participate (n = 108) in the larger study with regard to sociodemographic characteristics (gender, race/ethnicity, education level, and urban–rural classification). Participants' children received care across 41 United States paediatric hospitals.

Qualitative themes

Three broad themes regarding parenting priorities emerged from the qualitative data, with several subthemes supporting each broad theme (Table 2). Specific recommendations and actions to support parenting priorities during infant hospitalisation were also identified from parent responses and organized around these broad themes and subthemes (Table 3). The relative distribution of

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Table 1. Sociodemographic and clinical characteristics (n = 79)

	Frequency (%)
Parent characteristics	
Race/Ethnicity	
Non-Hispanic White	71 (89.9)
Black or African-American	2 (2.5)
Hispanic/Latino	5 (6.3)
Asian	3 (3.8)
Education level	
High school/GED	25 (31.6)
Associates degree	11 (13.9)
Bachelor's degree	19 (24.1)
Graduate degree	24 (30.4)
Annual household income	
<$50,000	25 (31.6)
$50,000–$99.999	25 (31.6)
$100,000 or more	28 (35.4)
Married/partnered	75 (94.9)
Urban–rural classification	
Urban	15 (19.0)
Suburban	43 (54.4)
Rural	21 (26.6)
Child characteristics	
Prenatal cardiac diagnosis	51 (64.6)
Single-ventricle cardiac physiology	38 (48.1)
Premature birth	18 (22.8)
Suspected/confirmed genetic syndrome	15 (19.0)
Age at first surgery	
Less than 1 month	57 (72.2)
1–3 months	10 (12.7)
4–9 months	11 (13.9)
>1 open-heart surgery	57 (72.2)
Days in hospital during infancy (<12 months)	
<30 days	21 (26.6)
30–59 days	21 (26.6)
60–90 days	16 (20.2)
>90 days	20 (25.3)
Discharged with feeding tube	39 (49.4)

Note. Some participants endorsed more than one race.

themes was similar across parents with varying levels of education and household income.

Establishing a bond with my baby

Fostering a strong bond with their infant was described by almost all parents as an important aspect of parenting in the hospital. This theme was supported by four subthemes: *becoming my baby's primary caregiver, learning how to provide care in the hospital, feeling confident when providing care, and making the hospital feel like home*. Parents reported the need for a "normal" newborn experience, which was easily disrupted by restrictions on physical contact with their infant, limited opportunities to soothe or feed their infant, and their infant's nurse frequently assuming a primary caretaker role during the initial days of hospital admission. Many parents described feeling distressed about how the disruption in bonding would affect their long-term relationship with their infant and expressed gratitude for medical teams who prioritised parent involvement in care. Parents described that involvement in care fostered a sense of control when they would otherwise feel helpless to impact their infant's medical progress. Some parents described feeling that medical staff prioritised convenience over infant developmental needs by delaying parent involvement or discouraging parent participation in care. Prioritising parent involvement was particularly salient for bereaved parents, who described that they were often told by medical staff to wait for "firsts" (e.g., feeding or bathing their infant for the first time), which were never realised.

Support for breastfeeding was an especially relevant aspect of bonding for many parents. Parents acknowledged that accommodating breastfeeding, particularly in the cardiac ICU, could be cumbersome for nurses, but indicated that feeding their infant was an important aspect of bonding during hospitalisation. Parents recommended that medical staff provide lactation support to parents and understand the importance of breastfeeding for many mothers. Parents described that when holding or feeding was not indicated due to their infant's medical status, they appreciated being encouraged by medical staff to read to, talk to, or spend time near their infant.

Parents urged that medical teams should understand and acknowledge that parents may be less likely to engage in the infant's care due to uncertainty, rather than disinterest. They described feeling fearful that they may accidentally hurt their infant while trying to provide care, and feeling helpless to protect their infant from discomfort. Many parents described feeling that they had been "thrown into the deep end" without sufficient supports, which contributed to increased anxiety around, and avoidance of, participation in care. Parents relied on bedside nurses to provide hands-on teaching around medical care (e.g., dressing changes, nasogastric tube care) and accommodations for typical infant care (e.g., diaper changes, bathing). Practical education, including explicit instructions about what aspects of care parents could or could not provide, and encouragement from nursing staff helped parents to build their confidence in their infant's care and further restored normalcy to the experience of bonding with their infant during hospitalisation. Similarly, parent participation in speech, occupational, and physical therapies provided parents with knowledge of their infant's developmental needs and allowed parents to feel confident in supporting developmental progress in the hospital.

Parents also appreciated support from staff to help the hospital feel like home. Parents described that parenting their infant involved being able to create care routines and provide care independently of medical staff. Many parents described the difficulty of feeling that they had to "ask permission" to engage with their infant. Making decisions about when and how to provide care helped to empower parents, build parenting efficacy, and reestablish parents as primary caregivers in the hospital. Parents reported that opportunities to allow siblings to visit their infant were important parenting experiences. They indicated that spending time alone with their infant and other siblings supported bonding as

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Table 2. Themes and representative quotes

Theme	Subtheme	Representative quotes
Establishing a bond with my baby	*Becoming my baby's primary caregiver*	I wish they had considered how involved we wanted to be, especially in the ICU. We really wanted to have a "normal" newborn experience, and it would have been great if they had recognised it and helped us try to be as normal as possible. They could have asked us what we wanted to do or if there was anything we weren't comfortable doing. *Father 1*
	Learning how to provide care in the hospital	Teaching us how to do things from the beginning . . . We would've felt more empowered if we could have known things from the beginning and been physically caring for her more. You feel so helpless already with CHD, but not being able to feed your baby or change their diaper just makes you feel useless entirely. *Father 24*
	Feeling confident when providing care	When we moved from CVICU to the step-down unit, we were unprepared for the change in level of care . . . we were now more responsible for the care of his needs but the medical care still scared me and there wasn't the same 1-on-1 to ask questions, walk us through it. We just had to figure it out for ourselves. *Mother 150*
	Making the hospital feel like home	I was able to learn a lot and was encouraged to care for my baby the way I felt was beneficial. It was nice to have their guidance but not be forced to do things their way so I could learn to parent and bond with my baby in an almost normal way, despite being inpatient. *Mother 32*
Asserting my role as a parent	*Becoming my baby's primary decision-maker*	One doctor would always ask our permission to listen to our son with a stethoscope. After a few months I asked him why he asked our permission. He told me that when a baby is critically ill, that sometimes the only decision that a mom gets to make regarding care is allowing him to listen to their baby. *Mother 137*
	Learning about my baby's medical condition	I felt powerless to help. I couldn't feed him, hold him and could barely touch him . . . I tried to cope by learning everything I could about his diagnosis. I asked endless questions, I read journal articles, I memorised what drugs he was on and what they all did. This helped to at least make me feel like I was a small part of the team keeping this sweet baby alive. *Mother 74*
	Advocating for my baby's needs	[During] previous hospital stays I [felt] like I was on a different side than the team . . . they had their side and parents had their side. That made it so I wasn't able to open up to them or advocate the best I knew how for [my baby]. I have learned over time that we are on the same team . . . I have been more able to express myself *Mother 53*
	Acting according to our family's values and preferences	There was a lactation specialist who was . . . insisting that I get back to breastfeeding and ignoring my stress over potentially hurting my baby . . . She was a knowledgeable professional but she wasn't very supportive . . . to a mom who just went through something traumatic . . . Pumping was what worked for us and she could have been more respectful and encouraging of our choice. *Mother 109*
Coping with fear and uncertainty	*Sharing my experiences without fear of judgement*	There were some nurses . . . we were comfortable sharing our frustrations and stresses with . . . Those who would hear us out and address our concerns in rounds. They understood hospital-related stresses better than most. There were others we didn't trust or didn't agree with . . . they added to the stresses we were already experiencing. *Father 94*
	Receiving support to care for myself	I also wish someone would have told me that anxiety and PTSD are common for heart parents and that it is completely normal to feel overwhelmed, worried, scared, helpless and isolated. I don't think I was prepared for all of those feelings and I certainly didn't know what to do with them when I was so focused on trying to help my baby. *Mother 92*

CVICU, Cardiovascular intensive care unit; PTSD, Post traumatic stress disorder.

a family during hospital admissions and facilitated sibling adjustment.

Asserting my role as a parent

Mothers and fathers both reported that asserting their parenting role was key to parenting their infant during hospitalisation. This theme was supported by four subthemes: *becoming my baby's primary decision-maker, learning about my baby's medical condition, advocating for my baby's needs, and acting according to our family's values and preferences*. When medical providers listened to parent concerns and acknowledged parents as the experts in their infant's unique care needs, parents felt that they were able to effectively advocate for their infant, act as their infant's primary decision-maker, and ensure their infant received the highest quality of care. Parents commonly reported that it was helpful when medical providers cultivated an environment where parents were viewed as trusted and valued members of the care team. This was supported by a family-centred approach to bedside rounds and regular care team meetings held away from the bedside to discuss progress, plans, and parent concerns. Several fathers described feeling that they were treated as less important than mothers by medical teams, and that providers often talked and listened more to mothers than fathers. They recommended that medical teams treat fathers as equivalently engaged caregivers to support fathers' ability to parent during hospitalisation.

Parents reported that frequent, open sharing of information about their infant's diagnosis and treatment supported their parenting need to participate in decision-making about their infant's care. Receiving education about medications, surgeries, and procedures, and being oriented to the monitors, lines, and tubes involved in their infant's care were particularly helpful for parents. Parents described that they preferred to know as much information as possible, even when that information was potentially scary or upsetting, so they had a complete understanding before making medical decisions.

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Table 3. Recommendations to support parenting during infant hospitalisation

Theme	Recommendations	Actions*
Establishing a bond with my baby	Prioritise parent involvement in care	• Invite parents to participate in the daily care routine • Encourage parents to comfort and interact with their infant • Ensure parents have the opportunity to support infant milestones
	Educate parents on how to adapt typical infant care tasks in the hospital setting	• Explicitly instruct parents on which aspects of care they can provide • Provide lactation support and prioritise parent holding and breastfeeding even when logistically challenging
	Gradually increase parent involvement in care	• Increase nursing support around transitions and when new care tasks are introduced • Ensure expectations for parent involvement are consistent across staff
	Help the hospital feel like home	• Ensure that parents have quiet time alone with their infant and infant's siblings • Support parents in establishing care routines
Asserting my role as a parent	Support parents in becoming primary decision-makers	• Provide parents with enough information about their infant's condition (even when information is potentially upsetting) to make informed medical decisions • When parents are present, ask permission before providing non-emergent care
	Openly share information with parents	• Elicit parent preferences for receiving information about their infant's condition and prognosis and share information according to these preferences
	Treat parents as trusted and valued care team members	• Listen to parent concerns and encourage shared decision-making during bedside rounds
	Show acceptance of parenting values	• Withhold judgement for parenting practices • Recognise when hospital protocols conflict with parenting values and demonstrate flexibility when possible
Coping with fear and uncertainty	Attend to parent emotional experiences	• Invite parents to share their experiences with medical providers • Recognise when parent disengagement in care may be due to anxiety rather than disinterest
	Encourage self-care	• Alter hospital protocols that require parents to be present at the infant's bedside at all times • Normalise experiences of stress and anxiety during hospitalisation • Provide psychosocial supports in the hospital for parents

*Actions listed represent parent participant recommendations and wishes, organised by theme and edited for clarity and brevity.

Many parents reported experiencing judgement from care team members at various times during hospitalisation, such as when spending time away from the bedside to engage in self-care or care for their other children. These parents described that it was helpful when medical providers respected their values and preferences and that negative comments about parenting choices often led to ruptures in trust between parents and providers. While parents understood the need for specific hospital protocols, they emphasised that some flexibility was necessary to accommodate each family's unique circumstances.

Coping with fear and uncertainty

Many parents reported that a major barrier to parenting in the hospital was the fear and uncertainty of caring for a medically unstable infant in an unfamiliar environment. This theme was supported by two subthemes: *sharing my experiences without fear of judgement and receiving support to care for myself*. Being emotionally available to their infant was described as a key parenting role, which was well supported by care teams who fostered open communication about emotional experiences and encouraged parental self-care. Parents who had regular opportunities to discuss their emotional health with a psychosocial provider noted that this was important for normalising their emotional experiences. Several parents described worrying that the medical team would not allow them to participate in their infant's care if they expressed emotional distress. Parents also reported feeling that their infant's medical team held expectations for parent involvement in care that did not allow for self-care (e.g., being present at the baby's bedside at all times). When care teams did not normalise parental emotional experiences during hospitalisation, parents reported that they often delayed seeking treatment for symptoms of anxiety, depression, and post-traumatic stress.

Discussion

The current study used innovative crowdsourcing methodology to engage parent stakeholders in the process of identifying priorities for parenting an infant with CHD in the hospital and generating recommendations to support parenting priorities during hospitalisation. Parents in this study voiced the need for medical teams to support their role as primary caretaker and decision-maker, and for teams to acknowledge and support the emotional impact of parenting a critically ill infant. Support for these parenting priorities may reduce stress associated with alterations to the expected parenting role during hospitalisation and ultimately promote healthy family functioning and positive neurodevelopmental and behavioural outcomes for infants with CHD.

Past studies of parenting priorities during hospitalisation have identified that parents seek to act as the person who knows their child best by meeting their child's needs and making decisions in their child's best interest.[25] In the current study, parents described the need for support around becoming the person who knows their infant best. Parents face many barriers in bonding with their infant in the cardiac critical care setting. Providers can encourage

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this essential experience by providing education on infant care and medical needs, and by inviting and supporting parent partnership in care.[26] Models of care, such as Individualised Family-centred Developmental Care, may meet this parenting need by engaging parents in the process of learning to read and respond to their infant's unique behavioural cues.[3]

Parents in this study also reported the need for support around becoming their infant's primary decision-maker. Palliative care research indicates that parents of older children view communication with their child's medical provider as vital during critical illness.[27] Recognising parents as key collaborators in treatment planning also helps to empower parents in critical care settings.[28,29] Provider support for parenting values and decision-making preferences may strengthen the relationship between medical teams and families so that provider and parent goals are aligned, while also promoting parenting role attainment. Empowered parents may also more effectively advocate for their infant's health needs after discharge,[13] including detecting problems early and alerting medical professionals to the need for anticipatory care.[30]

Parents' emotional experiences and mental health must be addressed to support both parent–infant bonding and parental decision-making. Parents of critically ill infants who experience anxiety, depression, or post-traumatic stress symptoms may be less engaged in their baby's care[31,32] and be more passive in their decision-making style.[33] Parents in the current study expressed the need for their infant's providers to normalise the emotional distress related to infant critical illness and encourage self-care to support mental health.

Both mothers and fathers identified psychosocial support as a critical facilitator of engaged parenting.

Parenting needs were similar across parents with varying levels of education and household income. Future research should examine how parenting needs during infant hospitalisation may differ by other parent or family characteristics not explored in this study due to limited sample diversity (e.g., race/ethnicity, primary language). Survey tools exist to identify parenting values and clarify parent preferences during end-of-life decision-making in the paediatric ICU.[34] Creation of a tool to identify parenting priorities and preferences for infants hospitalised with CHD could further aid cardiac critical care teams in initiating individualised parenting supports during hospital admissions.

Several limitations should be noted. While study participants were diverse with regard to education level, household income, and urban–rural classification, this sample was not ethnically or linguistically diverse. As recruitment and data collection for this study primarily took place online, parents without access to the internet were also not represented in this sample. Racial/ethnic and cultural differences are known to impact parents' preferences for communication in the paediatric critical care setting[35] and likely also impact parenting priorities, but such differences could not be examined in this study. Further, fathers comprised only 24% of the sample, and themes described in this study may not fully capture fathers' parenting priorities. Future research is needed to understand how fathers' parenting can best be supported during infant hospitalisation. Nearly half of participants had a child with single-ventricle physiology, possibly limiting the generalisability of study findings to families of infants with more complex forms of CHD and longer hospital stays. Additionally, participants' children were born between 1 and 7 years ago, and it is possible that time since infant hospitalisation may have influenced responses or that some responses may reflect needs that have been addressed by recent hospital policy changes. Finally, the collaborative nature of crowdsourcing methodology and in particular, parents' ability to view comments from other participants prior to submitting their own responses, could have influenced some responses. Unlike in-person data collection (e.g., focus groups), however, participants were de-identified and had time and space to voice their opinions in writing rather than succumbing to a dominant group member.

Conclusions

The hospital setting encompasses modifiable factors that can be altered to potentially reduce parental distress and promote positive developmental outcomes for infants with CHD. By supporting the parenting needs outlined in this study (i.e., promoting parents' roles as primary caretakers and decision-makers and attending to the emotional impact of infant hospitalisation on the family), providers may facilitate a positive trajectory of responsive parenting practices during a critical period, while also fulfilling the ethical imperative to act in the best interest of their patient through shared decision-making and family-centred care.

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Conflicts of interest. None.

Ethics standards. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008, and have been approved by the institutional committees.

References

1. Ibiebele I, Algert CS, Bowen JR, Roberts CL. Pediatric admissions that include intensive care: a population-based study. BMC Health Serv Res 2018; 18: 264. doi: 10.1186/s12913-018-3041-x
2. Lisanti AJ, Golfenshtein N, Medoff-Cooper B. The pediatric cardiac intensive care unit parental stress model: refinement using directed content analysis. Adv Nurs Sci 2017; 40: 319–336. doi: 10.1097/ANS.0000000000000184
3. Lisanti AJ, Vittner D, Medoff-Cooper B, Fogel J, Wernovsky G, Butler S. Individualized family-centered developmental care: an essential model to address the unique needs of infants with congenital heart disease. J Cardiovasc Nurs 2019; 34: 85–93. doi: 10.1097/JCN.0000000000000546
4. Perry RE, Blair C, Sullivan RM. Neurobiology of infant attachment: attachment despite adversity and parental programming of emotionality. Curr Opin Psychol 2017; 17: 1–6. doi: 10.1016/j.copsyc.2017.04.022
5. Lisanti AJ, Allen LR, Kelly L, Medoff-Cooper B. Maternal stress and anxiety in the pediatric cardiac intensive care unit. Am J Crit Care 2017; 26: 118–125. doi: 10.4037/ajcc2017266
6. Sood E, Karpyn A, Demianczyk AC, et al. Mothers and fathers experience stress of congenital heart disease differently: recommendations for pediatric critical care. Pediatr Crit Care Med 2018; 19: 626–634. doi: 10.1097/PCC.0000000000001528
7. Jordan B, Franich-Ray C, Albert N, et al. Early mother-infant relationships after cardiac surgery in infancy. Arch Dis Child 2014; 99: 641–645. doi: 10.1136/archdischild-2012-303488
8. Laing S, McMahon C, Ungerer J, Taylor A, Badawi N, Spence K. Mother–child interaction and child developmental capacities in toddlers with major

birth defects requiring newborn surgery. Early Hum Dev 2010; 86: 793–800. doi: 10.1016/j.earlhumdev.2010.08.025
9. Woodward LJ, Bora S, Clark CAC, et al. Very preterm birth: maternal experiences of the neonatal intensive care environment. J Perinatol.2014; 34: 555–561. doi: 10.1038/jp.2014.43
10. DeMaso DR, Calderon J, Taylor GA, et al. Psychiatric disorders in adolescents with single ventricle congenital heart disease. Pediatrics 2017; 139: e20162241. doi: 10.1542/peds.2016-2241
11. Ernst MM, Marino BS, Cassedy A, et al. Biopsychosocial predictors of quality of life outcomes in pediatric congenital deart disease. Pediatr Cardiol 2018; 39: 79–88. doi: 10.1007/s00246-017-1730-6
12. Visconti KJ, Saudino KJ, Rappaport LA, Newburger JW, Bellinger DC. Influence of parental stress and social support on the behavioral adjustment of children with transposition of the great arteries: J Dev Behav Pediatr 2002; 23: 314–321. doi: 10.1097/00004703-200210000-00003
13. Ashcraft LE, Asato M, Houtrow AJ, Kavalieratos D, Miller E, Ray KN. Parent empowerment in pediatric healthcare settings: a systematic review of observational studies. Patient 2019; 12: 199–212. doi: 10.1007/s40271-018-0336-2
14. Gerstein ED, Poehlmann-Tynan J, Clark R. Mother-child interactions in the NICU: relevance and implications for later parenting. J Pediatr Psychol 2015; 40: 33–44. doi: 10.1093/jpepsy/jsu064
15. Maguire DJ, Taylor S, Armstrong K, et al. Long-term outcomes of infants with neonatal abstinence syndrome. Neonatal Netw 2016; 35: 277–286. doi: 10.1891/0730-0832.35.5.277
16. McGoron L, Gleason MM, Smyke AT, et al. Recovering from early deprivation: attachment mediates effects of caregiving on psychopathology. J Am Acad Child Adolesc Psychiatry 2012; 51: 683–693. doi: 10.1016/j.jaac.2012.05.004
17. Neel MLM, Stark AR, Maitre NL. Parenting style impacts cognitive and behavioural outcomes of former preterm infants: a systematic review. Child Care Health Dev 2018; 44: 507–515. doi: 10.1111/cch.12561
18. Wernovsky G, Licht DJ. Neurodevelopmental outcomes in children with congenital heart disease—what can we impact? Pediatr Crit Care Med 2016; 17: S232–S242. doi: 10.1097/PCC.0000000000000800
19. Battista V, Feudtner C. Threats to parents' roles during the process of their child dying in the paediatric intensive care unit. Evid Based Nurs. 2016; 19: 118–118. doi: 10.1136/eb-2015-102297
20. Brabham DC. Crowdsourcing. Cambridge, MA: MIT Press; 2013.
21. Pierce JS, Aroian K, Caldwell C, et al. The ups and downs of parenting young children with type 1 diabetes: a crowdsourcing study. J Pediatr Psychol 2017; 42: 846–860. doi: 10.1093/jpepsy/jsx056
22. Wray J, Cassedy A, Ernst MM, Franklin RC, Brown K, Marino BS. Psychosocial functioning of parents of children with heart disease—describing the landscape. Eur J Pediatr 2018; 177: 1811–1821. doi: 10.1007/s00431-018-3250-7
23. Hilton LG, Azzam T. Crowdsourcing qualitative thematic analysis. Am J Eval 2019; 40: 575–589. doi: 10.1177/1098214019836674
24. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006; 3: 77–101. doi: 10.1191/1478088706qp063oa
25. Ames KE, Rennick JE, Baillargeon S. A qualitative interpretive study exploring parents' perception of the parental role in the paediatric intensive care unit. Intensive Crit Care Nurs 2011; 27: 143–150. doi: 10.1016/j.iccn.2011.03.004
26. Klug J, Hall C, Delaplane EA, et al. Promoting parent partnership in developmentally supportive care for infants in the pediatric cardiac intensive care unit. Adv Neonatal Care 2020; 20: 161–170. doi: 10.1097/ANC.0000000000000679
27. Butler AE, Copnell B, Hall H. When a child dies in the PICU: practice recommendations from a qualitative study of bereaved parents*. Pediatr Crit Care Med 2019; 20: e447–e451. doi: 10.1097/PCC.0000000000002040
28. Craig JW, Glick C, Phillips R, Hall SL, Smith J, Browne J. Recommendations for involving the family in developmental care of the NICU baby. J Perinatol 2015; 35: S5–S8. doi: 10.1038/jp.2015.142
29. Umberger E, Canvasser J, Hall SL. Enhancing NICU parent engagement and empowerment. Semin Pediatr Surg 2018; 27: 19–24. doi: 10.1053/j.sempedsurg.2017.11.004
30. Dobrolet NC, Nieves JA, Welch EM, et al. New approach to interstage care for palliated high-risk patients with congenital heart disease. J Thorac Cardiovasc Surg 2011; 142: 855–860. doi: 10.1016/j.jtcvs.2011.01.054
31. Mirghafourvand M, Ouladsahebmadarek E, Hosseini MB, Heidarabadi S, Asghari-Jafarabadi M, Hasanpour S. The effect of creating opportunities for parent empowerment program on parent's mental health: a systematic review. Iran J Pediatr 2016; 27: e5704. doi: 10.5812/ijp.5704
32. Kasparian NA, Kan JM, Sood E, Wray J, Pincus HA, Newburger JW. Mental health care for parents of babies with congenital heart disease during intensive care unit admission: systematic review and statement of best practice. Early Hum Dev. 2019; 139: 104837. doi: 10.1016/j.earlhumdev.2019.104837
33. Anderson WG, Arnold RM, Angus DC, Bryce CL. Passive decision-making preference is associated with anxiety and depression in relatives of patients in the intensive care unit. J Crit Care 2009; 24: 249–254. doi: 10.1016/j.jcrc.2007.12.010
34. October TW, Fisher KR, Feudtner C, Hinds PS. The parent perspective: "being a good parent" when making critical decisions in the PICU. Pediatr Crit Care Med 2014; 15: 291–298. doi: 10.1097/PCC.0000000000000076
35. Zurca AD, Wang J, Cheng YI, Dizon ZB, October TW. Racial minority families' preferences for communication in pediatric intensive care often overlooked. J Natl Med Assoc 2020; 112: 74–81. doi: 10.1016/j.jnma.2019.09.005

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