

Research Article

Mothers' needs regarding partnerships with nurses during care of infants with congenital heart defects in a paediatric cardiac intensive care unit

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ABSTRACT

Objectives: We investigated mothers' needs in forming partnerships with nurses based on children's postoperative recovery in a paediatric cardiac intensive care unit.

Design: This was a descriptive study using prospective data.

Setting: Data were collected from 36 mothers enrolled in a mother–nurse partnership program.

Main outcome measures: We investigated mothers' need for information and participation activities using a self-made survey tool, as well as the duration of mothers' care participation and physical engagement and psychological connectedness.

Results: The mothers desired information on their infants' postoperative stability in the early recovery phases and information on infants' transfer and care in the later phases. Mothers' mean duration of care participation increased as infants' recovery progressed (15.82 ± 8.76 minutes in the second phase of recovery to 29.46 ± 4.53 minutes in the fifth phase; $F = 19.54$, $p < .001$). Mothers' physical engagement and psychological connectedness also increased with infants' recovery ($F = 200.95$, $p < .001$; $F = 93.27$, $p < .001$, respectively). Mothers generally passively participated at first and gradually developed more positive and enthusiastic participation as infants recovered.

Conclusion: Infants' condition heavily influenced mothers' needs regarding partnerships. Thus, nurses must individually provide mothers with information and encourage them to participate in care.

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Implications for Clinical Practice

- Nursing care should be targeted to mothers of infants who underwent cardiac surgery based on the infants' recovery phase.
- Critical care nurses could provide a timely suitable nursing program that reflects mothers' preparation by understanding changes in the mothers' information, participation in care, physical engagement, and psychological connectedness based on their infants' recovery.
- A collaborative program can be implemented to facilitate maternal participation in infant care using the present family centred care strategies; in this way, mothers can actively participate in caregiving with nurses' help.

Introduction

Advances in perioperative care over the past few decades have improved the surgical outcomes of congenital heart defects (CHD)

(Jacobs et al., 2016). With the improved survival rate of CHD, researchers are increasingly focusing on parent–infant relationships. An infant's CHD diagnosis can be a crisis for parents due to its numerous related stressors, such as the uncertainty of surgical outcomes, loss of parental control, changes in infants' physical appearance and fear of the technological atmosphere of the paediatric intensive care units (PICU) (Wei et al., 2016). Mothers of infants with CHD particularly experience considerable psychologi-

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cal distress during the children's treatment (Re, Dean, & Menahem, 2013). Most infants with CHD require aggressive treatment in early infancy, including repeated surgeries and intensive care, but hospitalisation during this period can separate mothers from their children, negatively influencing mother–infant connectedness and limiting mothers' opportunities to learn infant care (Curley & Meyer, 2001). Family-centred care (FCC) is key to addressing these problems. FCC is defined as “a way of caring for children and their families within health services that ensures that care is planned around the whole family, not just the individual child/person” (Shields et al., 2012).

FCC can be built based on partnerships between parents and nurses in Paediatric Intensive Care Units (PICUs). The partnership between parents and nurses was defined as “a relationship based on cooperation with each other to provide optimal child health care” (Choi & Bang, 2013). Information sharing between the nurse and parent and parental participation in their infant's care that is facilitated by the nurse are core components of such partnerships (Mastro, Flynn, & Preuster, 2014). Parents of children with congenital heart defects need information about what will happen (Sjoberg, Svedberg, Nygren, & Carlsson, 2017). Specifically in PICUs, parents need open, timely, and understandable information—especially mothers, who are likely to attempt to stay with their child for as long as possible and participate in the child's care (Jee et al., 2012). Parents can participate in pain management (Siew et al., 2011), comfort care (Skene, Franck, Curtis, & Gerrish, 2012) and the feeding process (Gianni et al., 2016). Education aimed at increasing mothers' sensitivity regarding infants' cues for feeding facilitates their interaction with infants and helps in more effective feeding (McCusker et al., 2010).

However, despite the emphasis of FCC on parental involvement, we have limited understanding of the information, caregiving skills and activities that mothers desire throughout their child's recovery. Researchers have mainly examined the parents' level of need or introduced the types of participation activities, without considering the child's condition or recovery phase. Parents have reported a high need for information, with scores of 8.77 and 8.58 on the Parental Satisfaction Instrument (10-point Likert scale) and a score of 3.64 on the modified Critical Care Family Needs Inventory (4-point Likert scale) in a review study (Foster, Whitehead, & Maybee, 2016). Two other reports explored the activities in which parents could participate while their child was in the PICU (Curley & Meyer, 2001; Martens, De Loof, & Idrissi, 2008), while several studies examined these activities for parents of children in the neonatal ICU (NICU). One of these studies emphasized the necessity of enhancing parent–child connectedness and having nurses invite parental participation, and introduced several participation activities for parents to paediatric critical care nurses (Curley & Meyer, 2001). These authors reported that parents could have contact with their child, and nurses should help to identify physical similarities between the child and parents, as well as give infants opportunities to recognize their mothers' voices in the PICU. All such participation could help to facilitate infants' recovery by helping connect infants and parents and helping infants distinguish parents from others. Interventions to facilitate connectedness between mother and infant based on maternal participation can actually influence premature infant weight gain and shorten the length of hospital stay (White-Traut et al., 2015). In another study investigating possible participatory activities for mothers in the PICU, researchers classified participation as active and passive. The former type includes feeding, hygiene, wound care, medication, and monitoring, while the latter includes 24-access to the child, perceiving real time changes in the child's progression, and being present during procedures (Martens et al., 2008). Most mothers (83%) do perceive that it is possible to participate in oral feeding, whereas only about a quarter (26.4%) believe

that they could participate in oral medication (Franck & Spencer, 2003). Pye and Green (2003) recommended that mothers participate in changing diapers, oral feeding, and oral care when their child is admitted to the Paediatric Cardiac Intensive care Unit (PCICU) following cardiac surgery.

Furthermore, mothers' preferred information and participation activities might differ with the infants' condition and their own psychological distress levels during the postoperative period. So far, no research has investigated this possibility. We therefore investigated the needs and preferences for information and maternal participation in infant care according to the recovery phase of infants with CHD during the acute postoperative period in the PCICU. We also explored the relationship between participation level and infants' recovery. We were guided by five research questions: What information do mothers require at different phases of infants' recovery during their infants' PCICU admission? What care activities do mothers prefer to do at different recovery phases during their infants' PCICU admission? What activities do mothers participate in after negotiating with the nurses? How long do mothers participate in infants' care during visiting hours? How did the observed mothers' physical engagement and psychological connectedness change throughout infants' recovery?

Methods

Study design

This was a descriptive study of secondary data prospectively collected during the facilitation of a structured program featuring nurses and mothers whose infants had undergone cardiac surgery.

Setting

The study was carried out in a PCICU in Seoul, Republic of Korea. The PCICU had 11 beds, 22 staff nurses, one charge nurse, one unit manager and one clinical nurse specialist (CNS) (temporarily two CNSs). Most patients admitted to the PCICU had CHD.

Participants

Participants were 36 mothers enrolled in the mother–nurse partnership program during restrictive visiting hours between June and December 2016. Program enrolment was consecutive. The infants all received first-stage complex CHD surgery within 3 months of birth, and complex CHD was defined in risk categories 3 to 6 (according to the Risk Adjustment in Congenital Heart Surgery [RACHS] method).

Ethical approval

This study received institutional review board approval (IRB No. 2017–0242) from A hospital, Seoul, Republic of Korea. We explained the necessity, aims, and methods of this study and obtained mothers' informed consent.

Program development

A structured program was developed in five stages. First, ten pieces of research were selected through a literature review using PubMed, CINAHL, EMBASE and covering a period of 20 years. Programs' methods, contents, and core partnership components were investigated. Second, in-depth interviews were conducted with eleven mothers to explore their needs. A concept analysis method was performed to determine the kind of information that mothers want to know and activities in which they participate. Third, a draft

version of the program was developed using contents derived from the previous two steps. Fourth, a practical validity and a content validity of the draft version were evaluated. Ten nurses evaluated necessity and applicability. Six experts, including five nursing professors and one physician, evaluated the contents' validity. Content validity indexes (CVI) were calculated for both (Polit & Beck, 2006). Contents with an item-CVI score of less than 0.8 were removed from the draft version. Necessity's sum-CVI scores were 0.99 for phase 1 and 1.00 for phases 2–5, and applicability's sum-CVI scores were 0.96 for phase 1 and 0.94 for phases 2–5 by nurses. Sum-CVI scores by experts were 0.97 for phase 1 and 0.96 for phases 2–5. A draft version was then modified based on nurses' and experts' comments. Fifth, pilot test was conducted with two mothers, and a final program was then completed. A booklet was developed including expected infant progression and information to reflect mothers' knowledge needs. A survey tool was also developed to facilitate the program and enhance communication between mothers and nurses based on interviews and a literature review.

Program implementation

The structured program involved nurses identifying what mothers could do at every phase of the infant's recovery and encouraged mothers participate in care (Uhm & Kim, 2019). The program focused on five phases of infants' recovery: the immediate postoperative period (phase 1), early ventilator weaning period (phase 2), late ventilator weaning and early post-extubating period (phase 3), post-extubating period (phase 4), and transfer preparation period (phase 5). Nurses provided individualised information on infants to mothers, including events since the mother's last visit, hemodynamic stability, laboratory value, feeding state, etc. Nurses also assessed what mothers wanted to know about infants' recovery and mothers' care preferences, and reflected those desires in the care provided to the infants. The program also allowed mothers to participate in infant care, and allowed mothers to freely select activities, such as feeding, hygiene, and changing diapers, that they wanted to perform in each phase. They negotiated these activities with nurses according to the infants' condition. When mothers did not know what to do, the nurses introduced expected activities suiting the infants' condition, which were flexibly applied. For instance, a preferred activity was repeatedly allowed if the mother wanted to practice it.

Outcome measures

All measures for the outcome variables were self-developed for this study.

Desired information was surveyed as the types of information that mothers wanted to know most, or other information that provides basic patient information regarding overnight events, infused medications, current vital signs, pain management, laboratory results, ventilator weaning, and feeding.

Preferred care activities were descriptively surveyed as the types of activities in which the mothers wanted to participate in their infants' care.

Participation in care was descriptively surveyed as the types of activities that mothers actually participated in their infant's care after negotiating with nurses. Based on a previous study, activities were divided into those that were active and those that were passive (Martens et al., 2008).

The length of participation was the time that mothers participated in their infants' care, and it was measured in minutes.

Physical engagement and psychological connectedness with the infant includes engagement as "a measure of the totality of children's behaviours, providing a holistic picture of children's everyday experience in childcare" (Raspa, McWilliam, & Ridley, 2001).

In this study, physical engagement with infants was defined as levels of physical involvement in infant care. Higher physical engagement indicated more enthusiastic, active physical involvement in care and a close physical involvement with the infant (Welch et al., 2013). Physical engagement was rated on a visual analogue scale ranging from 0 (weak engagement) to 10 (strong engagement) according to nurses' observations. Meanwhile, connectedness is defined as "the degree to which individuals or groups are socially close, interrelated, or share resources" (Prevention, 2013). Connectedness to parents and family is defined as "feeling loved, cared for, valued, and respected by one's parents" (Foster et al., 2017). Psychological connectedness indicated the degree of emotional bonding between parent and child, such as pleasure in proximity and acceptance, as well as the degree to which the bond was mutual and sustained over time (Lezin, Rolleri, Bean, & Taylor, 2004). In this study, psychological connectedness was defined as the degree of emotional bonding between parent and child such as saying the infant's name, smiling at the infant, keeping eye contact with the infant. They also rated psychological connectedness on a similar visual analogue scale ranging from 0 (weak connectedness) to 10 (strong connectedness) by nurses' observation.

Data collection

The period of data collection ranged from June 2016 to December 2016. Daily data during each program phase were collected through direct questioning and observation using a survey tool. Data regarding mothers' desired information and mothers' preferred care activities were collected through open-ended questioning. Nurses checked boxes on the survey tool corresponding to the information that mothers wanted to know more about, or other materials regarding basic patient information by nurses. Mothers' participation in care after negotiating with nurses was checked by nurses using a survey tool. The length of participation, as well as mothers' physical engagement and psychological connectedness with infants, were collected through observation. Nurses checked how long mothers participated in infant care during visiting hours using the survey tool. A CNS also used the survey tool to evaluate participants' physical engagement and psychological connectedness and picked up the survey tool daily from the nurses. The ICCs for the physical engagement and psychological connectedness levels were 0.928 ($p = .001$) and 0.945 ($p = .001$), respectively.

All data recorded on the survey tool were input into a spreadsheet daily by the CNSs. It took approximately 60 minutes to fill in the data daily. Participants' characteristics were assessed using a self-administered questionnaire.

Data analysis

First, we described the desired information, preferred activities, and participation in care among mothers in terms of frequency. Second, the length of participation, physical engagement and psychological connectedness levels were described with means and standard deviations. We calculated the intra-class correlation (ICC) between the two CNSs to evaluate the inter-rater reliability. Third, we examined differences in the length of participation, physical engagement and psychological connectedness among mothers according to infants' recovery phase using repeated measures analysis of variance.

Results

Thirty-six mothers (33.00 ± 3.76 years old) participated in the program. Most mothers learned before birth (via foetal diagnosis) that their babies had CHD, and 83% were primiparous. All infants

were diagnosed with complex CHD and underwent total correction, shunt operations, pulmonary artery banding, etc. The infants of the mothers who participated in the program were 19.89 ± 21.98 days old and had a mean body weight of 3.14 ± 0.63 kg on the day of the operation. Ventilator weaning started on postoperative day 2 (2.19 ± 1.69) because muscle relaxants were administered to most infants. The first feeding generally took place on postoperative day 3 (3.06 ± 1.53) (Table 1). The ICU stay was 10.53 ± 7.24 days. The average age of the infants was 30.42 ± 22.8 days old on completion of the program. The mean duration of each phase was 1.76 ± 1.30 days for the first phase, 1.71 ± 1.13 days for the second phase, 3.28 ± 3.18 days for the third phase, 1.50 ± 0.88 days for the fourth phase, and 2.46 ± 2.12 days for the fifth phase. The third phase, with low ventilator support and post-extubation state, was the longest due to infants' re-intubation, post-extubation stridor or tachypnoea.

Table 1
Characteristics of participants (N = 36).

Variables	Characteristics	Categories	Frequency (%)
Mothers	Delivery	Normal	14 (38.9)
		C/Sec	22 (61.1)
	Parity	Primiparity	30 (83.3)
		Multiparity	6 (16.7)
Foetal diagnosis		Yes	33 (91.7)
		No	3 (8.3)
Infants	Gender	Male	18 (50.0)
		Female	18 (50.0)
	Diagnoses	PA with VSD	8 (22.2)
		TGA (IVS or VSD)	7 (19.4)
		IAA or CoA (VSD)	6 (16.7)
		DORV (CoA, VSD)	3 (8.3)
		PA with IVS	3 (8.3)
		FSV, HLHS variant	3 (8.3)
		TAPVR	2 (5.6)
		Other complex disease [†]	4 (11.1)
	Postoperative opened sternum	Yes	14 (38.9)
		No	22 (61.1)
	Postoperative use of muscle relaxant	Yes	31 (86.1)
		No	5 (13.9)
One-stage total correction	Yes	20 (55.6)	
	No	16 (44.4)	

PA = pulmonary atresia; VSD = ventricular septal defect; TGA = transposition of the great arteries; IVS = intact ventricular septum; IAA = interrupted aortic arch; COA = coarctation of the aorta; DORV = double outlet right ventricle; FSV = functional single ventricle; HLHS = hypoplastic left heart syndrome; TAPVR = total anomalous pulmonary venous return; POD = post-op day.

[†] Other complex disease = truncus arteriosus, congenital MR, multiple VSD (pulmonary artery banding), TOF (shunt).

Table 2
Frequency of additional information needed (N = 36).

	Phase 1	Phase 2	Phase 3	Phase 4	Phase 5	Sum
Current status	10	5	4	3	1	23
Nutrition and feeding	8	8	9	14	17	56
Specific issues [†]	0	8	18	3	6	35
Transfer	4	7	5	15	10	44
Nursing ^{††}	2	3	8	12	17	39
Facilities & environment	4	3	5	5	3	20
Prognosis & further treatment	3	4	3	1	7	18
Hospital cost support	5	2	4	1	2	14
Developmental support	1	1	2	1	2	7
Diagnosis	3	1	0	1	0	5
Sum	40	42	58	56	65	261

[†] Abnormal laboratory values, specific procedure or treatment, complications, etc.

^{††} Bathing, umbilical care, etc.

Desired information

Even after nurses provided individualized explanations about infants' conditions, mothers desired additional information. As shown in Table 2, mothers needed 261 pieces of information, with each mother needing 7.3 pieces on average during infants' PCICU admission. Their information needs gradually increased as their child's recovery progressed. During the early phases, mothers needed information on infants' current status and whether the operation was successful, and whether the child could overcome unstable periods. Once the infants were stabilized and began ventilator weaning, mothers' concerns became more specific, such as pain control, laboratory results, invasive procedures and complication management. Once infants were extubated and stabilized, mothers became interested in transferring infants to the general ward. Finally, after transfers were decided, mothers wanted information on nutrition and specific infant nursing care. Mothers also paid attention to the facilities, environment, prognosis, further treatment, hospital cost support and developmental support and diagnosis.

Preferred care activities

The participating mothers preferred 234 activities, which were negotiated with nurses. Each mother preferred on average 6.5 activities during PCICU admission and 1.6 activities in each phase. During the early phases, mothers mentioned wanting to touch their child and put gloves and socks on their infants. In later phases, mothers preferred more active participation, such as feeding and holding infants. In the early phases, seven mothers mentioned not knowing what they should do and five mothers refused participation in care because of fear or they felt that the care was too complicated. Several mothers were afraid of waking the infants. Several mothers wanted to engage in activities not covered in the program, which they asked to be allowed to participate in, such as taking off gloves or socks or opening the infant's diaper to observe the infant's skin. All mothers wanted to participate in care after infants had stabilised. Specifically, mothers began asking for more care participation after seeing the infant open her or his eyes and begin to move, as the muscle relaxants and sedatives were gradually tapered off and ventilator weaning began (Table 3). However, some mothers still refused to participate in care because they were scared that they might disturb the infant's tube and lines.

Participation in care

The mothers participated in 596 activities, with each mother participating in 16.6 activities during PCICU admission on average,

Table 3
Preferred care activities (N = 36).

Preferred activities	Phase 2	Phase 3	Phase 4	Phase 5	Sum
Activities within program	28	42	30	56	156
Specific needs	5	9	3	3	20
None or only observation	5	7	3	4	19
No preference	7	10	4	1	22
Refusal	5	6	3	3	17
Sum	50	74	43	67	234

Table 4
Participation in care (N = 36).

Kinds of activities		Phase 2	Phase 3	Phase 4	Phase 5	Sum	
Active	Bottle feeding	–	–	32	34	66	
	G-tube feeding	10	24	3	6	43	
	Changing diapers (applying cream on buttocks)	11	30	28	25	94	
	Touching	24	19	6	3	52	
	Covering hand/foot	19	17	5	2	43	
	Holding/cuddling	–	–	8	32	40	
	Hygiene †	20	27	8	9	64	
	Positioning (swaddling the child)	5	19	24	16	64	
	Putting on clothes or hat (taking off hand/foot covering)	1	2	7	17	27	
	Others ††	6	15	3	3	25	
	Subtotal	96	153	124	147	518	
	Passive	Seeking similarity/calling infant by name	6	5	3	1	15
		Playing or comforting, singing	5	16	8	11	40
		Hanging a mobile	1	3	1	–	5
Taking pictures, putting focus book/reading book		1	5	3	3	12	
Letting the infant listen to music		–	2	1	1	4	
Subtotal		13	31	16	16	76	
Sum	109	184	140	163	594		

† Putting lotion on skin, oral care, bathing, cutting nails.

†† Massage chest percussion, temperature measurement, cord care.

and 4.1 per recovery phase (Table 4). Depending on infants' conditions, nurses had mothers participate in preferred care activities as much as possible. In the early phases, mothers could not participate actively in care beyond touching the infants or putting on gloves and socks because infants were generally unstable. During the ventilator weaning phase, most mothers participated in tube feeding and changing diapers. Mothers also fed their infants by bottle, which was one of the most preferred activities.

Nurses helped mothers to safely hold and cuddle their infants (Fig. 1). They also showed mothers how to lay the infant on a bed, swaddle them, or apply a pillow, after which they encouraged

the mothers to do it themselves. Furthermore, nurses encouraged the mothers to seek similarities between their infants and themselves and to call their infants by name, to foster mother–infant attachment. Several mothers read to or sang for their infant to stimulate infants' senses and promote development.

Mothers' requests were mostly accepted in negotiation. However, seven mothers mentioned participating in infant bathing with nurses, but mothers of four patients did not participate in such bathing. The reasons given were commonly due to infants' unstable conditions. In certain rare situations, it is impossible in the PCICU, because of a shortage of additional nursing staff, to help

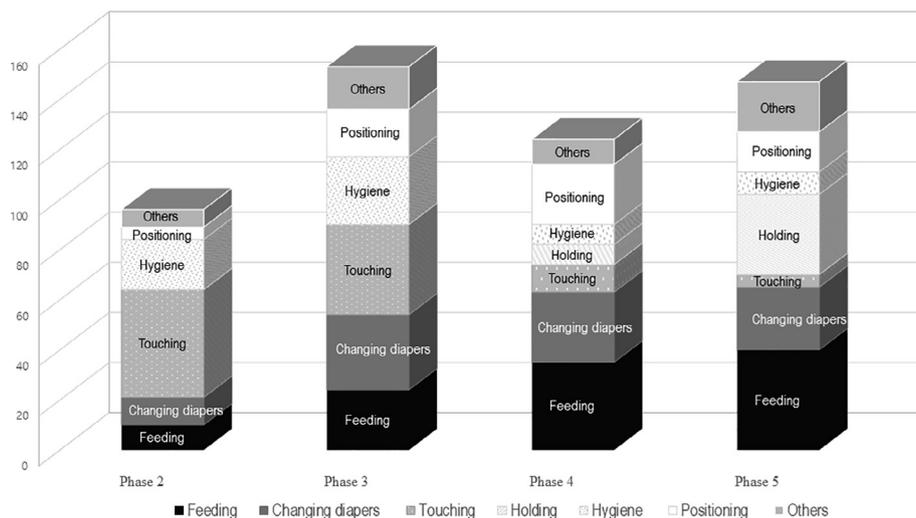


Fig. 1. Kinds of active participation in care. †Touching, including applying hand or foot cover.

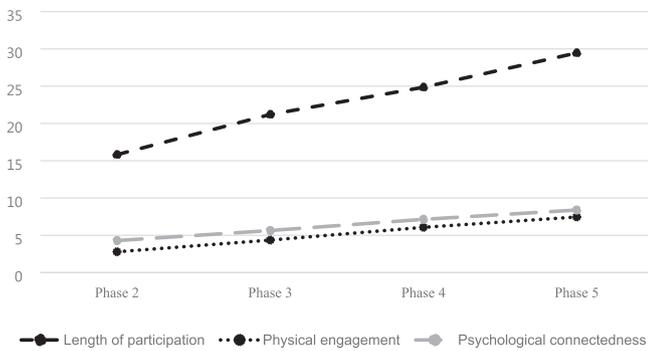


Fig. 2. Changes in participation level over time.

parents with bathing in complex circumstances such as bedside operations.

Length of participation

The mean duration of care participation increased steadily with each successive phase. In the second, third, fourth, and fifth phases, mothers participated in care for 15.82 ± 8.76 , 21.21 ± 10.42 , 24.86 ± 7.95 , and 29.46 ± 4.53 min, respectively ($F = 19.536$, $p < .001$).

Physical engagement and psychological connectedness

Observed physical engagement and psychological connectedness among mothers also increased with recovery phase. The physical engagement score was 2.79 ± 1.42 in the second phase, 4.36 ± 1.22 in the third phase, 6.07 ± 1.12 in the fourth phase, and 7.46 ± 1.23 in the fifth phase, and these differences were significant ($F = 200.949$, $p < .001$). The psychological connectedness was 4.29 ± 1.51 in the second phase, 5.64 ± 1.22 in the third phase, 7.14 ± 1.15 in the fourth phase, and 8.39 ± 0.99 in the fifth phase, and these differences also were significant ($F = 93.267$, $p < .001$) (Fig. 2).

Discussion

Nurses have the opportunity to collaborate with mothers of infants recovering from cardiac surgery in the PCICU, through which they can share information with parents and encourage parents to participate in infant care. We found that mothers' needs for participating in care differed with infants' recovery phase, as does their level of physical engagement and psychological connectedness with infants.

Desired information

Mothers needed information on various subjects, including whether their child had stabilised and how to care of him or her. Previous research on the needs of parents with children who underwent congenital heart disease was conducted using a qualitative design, which only identified parents' need for information without providing a detailed understanding of the types of information they need (Dahav & Sjostrom-Strand, 2018). Another study explored the types of information that parents needed and their satisfaction levels in PICUs, which found that parents had a greater need for information on treatment and further investigation (Beranger et al., 2018). The present study's findings correspond to those of a previous study showing that information-related needs were a high priority (Jee et al., 2012). To our knowledge, our study is the first to investigate parental needs according to the infant's recovery phase. We expanded on previous findings

by showing that needs entirely differed depending on the infant's recovery phase. In other words, mothers need individualized and tailored information depending on their child's condition. During the early phase, mothers wanted to confirm whether their child's surgery had been successful and if the infant had stabilized. This reflects the findings of studies wherein mothers reported fearing the potential loss of their child (Harvey, Kovalesky, Woods, & Loan, 2013; Simeone et al., 2018). Parents of neonates also perceived that NICU nurses expected them to merely 'monitor and follow through' in nursing care for young infants (Jaramillo Santiago, Osorio Galeano, & Salazar Blandon, 2018).

Following stability, mothers most wanted to know about nutritional support, which is similar to what another study found that mothers recognised that feeding is crucial to infants' recovery and growth and that receiving adequate nutrition can be challenging for infants with CHD (Medoff-Cooper et al., 2016). Notably, half the participants were primiparas, and thus might have found it difficult to provide basic care such as feeding or changing diapers; this might explain their increasing demand for a partnership with nurses. This is similar to what was found in a previous study showing that parents of young infants wanted more information and greater involvement in their infants' care (Orr et al., 2017). Additionally, mothers were highly interested in pain control and comfort, which was also identified in a previous study (Franck, Oulton, & Bruce, 2012). Mothers had no need for knowledge of specific issues, such as complications and laboratory values, in the immediate postoperative period; they were only interested in whether their children might experience late complications when they had been assured that the surgery was successful. In a previous study (Kosta et al., 2015), the parents of infants with CHD reported difficulties related to the volume, timing, quality, and sources of information about the hospitalisation, which made it difficult for them to manage the uncertainty that came with their child's medical course after surgery. Therefore, timely information should be provided regarding each child's medical course. Parents also had concerns regarding complications and abnormal laboratory levels because they were informed of possible postoperative morbidities when signing the consent form for the CHD operation (Brown et al., 2017), suggesting that mothers need to have concrete information to assure the child's medical course.

Some mothers also wanted specific information about hospital cost support. This finding is supported by other studies noting mothers' financial strains due to the medical bills for staged operations (Mughal et al., 2011). Simultaneously, mothers wanted to know more concrete methods of caring for their infants independently, not just in the general ward. This is consistent with a study showing that parents recognise that they should stay informed about their child's care during the transitional period (Berube, Fothergill-Bourbonnais, Thomas, & Moreau, 2014). When their child is transferred to the general ward, many parents experience both uncertainty and happiness (Obas, Leal, Zegray, & Rennick, 2016). Our study showed that mothers in the post-extubation period also had an increased need for information for the transfer and concrete nursing care methods, which should provide some insight as to when nurses should help mothers prepare transitional care.

Preferred care activities and participation in care

A novel finding of this study was that mothers wanted to participate in different care activities depending on the recovery phase. Most mothers were willing to participate in care of their child in the PICU. A qualitative study similarly showed that parents have a need to be involved in the care of their children (Dahav & Sjostrom-Strand, 2018). During the early phases of recovery, mothers wanted to passively participate, such as by hanging mobiles and covering infants' feet. Several mothers refused to participate

in infant care for various reasons or were confused about what to do. These findings support another study indicating that parents of a child with critical illness experienced significant decisional conflict during the acute stage of recovery, due in part to their elevated psychological distress, which could lead to these passive behaviours (Stremler, Haddad, Pullenayegum, & Parshuram, 2017). Furthermore, passivity could be engendered by the infants' appearance in the early postoperative period (i.e. filled with various invasive lines and an opened sternum). Indeed, Lisanti et al. (2017) reported that infants' appearance and behaviour were the greatest stressors for parents. Mothers were concerned about even simple activities, such as changing diapers and hygiene, given that most of the mothers were primiparas. Because the ability to deal with specific needs is crucial for the FCC for young infants (Shimizu & Mori, 2018), individualised approaches following an assessment of the mothers' preferences should be considered to promote mothers' participation in care.

In the later stages, mothers wanted to participate in more active care, including feeding, holding and bathing. These activities are comparable with those given in NICUs, including thermoregulation, nutrition and feeding, and skin-to-skin care (Raiskila, Axelin, Rapeli, Vasko, & Lehtonen, 2014). The mothers also wanted to learn infant care, and thus recognized the nurses as role models who could give them coaching and feedback on their parenting. Many nurses encouraged mothers to participate in infant care and mothers began participating in activities other than their preferred ones after negotiating with nurses despite their initial passivity.

These findings support those of a study showing that parental participation could be promoted by providing sufficient counselling based on the parents' needs and creating facilities to support such participation (Palomaa, Korhonen, & Polkki, 2016). As for actual participation, which can differ from desired participation (Romaniuk, O'Mara, & Akhtar-Danesh, 2014), nurses' caregiving guidance can have both negative and positive influences. That is, nurses could have helped mothers participate in caregiving by bridging the gaps between how parents want to be involved and what they perceive clinicians want them to do (Richards, Starks, O'Connor, & Doorenbos, 2017); however, nurses might also seemingly 'force' parents' participation by highlighting the apparent hierarchy between parents and nursing staff, with the former being unable to make decisions independently (Serlachius et al., 2018). Therefore, nurses should forge trusting relationships with parents of critically ill children, after which they can assess parents' preferences for care participation to avoid any discrepancies between parents' expectations and nurses' perceptions (Coyne, 2015).

As noted above, we found that there were no nurses' disagreements regarding mothers' needs in negotiations. However, seven mothers wanted to participate in infant bathing with the nurses, but the nurses could not do so because of the infants' unstable conditions or a shortage of staffs to help bathing within visiting hours in four infants. We found that mothers had concerns about bathing; consequently, nurses should modify the program to provide more opportunities for mothers to participate in bathing. Given that nurses' workload could preclude negotiation between nurses and mothers, it is important for hospitals to have a sufficient workforce and skill mix to ensure effective nurse–mother collaboration and to encourage mothers to participate in care activities that require more time, such as bathing.

Length of participation, physical engagement and psychological connectedness

No previous studies, to our knowledge, have explored parents' length of participation in care or their level of physical engagement and psychological connectedness with their child during the recovery period. However, family nurture interventions, which typically

involve maternal–infant interactions such as exchange of scented clothing, sustained touch, soothing vocals, eye contact and wrapped or skin-to-skin holding, have been implemented to establish mother–infant emotional connections in NICUs (Welch et al., 2013). The observed increase in duration of participation over time was likely due to mothers' preparation for the infants' transfer to the general ward and discharge, which led to decreasing anxiety and increasing parental self-efficacy in the PICU (Uhm & Kim, 2019). Other studies have found that physical engagement and psychological connectedness influence maternal behaviour. For example, one study showed that longer duration of skin-to-skin contact was associated with more exclusive breastfeeding (Bramson et al., 2010). Similarly, another study found that while swaddling the infants led to decreases in maternal responsiveness to the infant and positive affective involvement with the infant, skin-to-skin contact after birth and early sucking positively influenced mother–infant interaction (Bystrova et al., 2009).

Future research should examine whether Korean mothers are comparable to mothers in other countries as far as the level of infant care participation.

Study limitations

This study has several limitations. First, we analysed only quantitative data because this was a secondary data analysis. A mixed method study containing qualitative data is also necessary to ascertain the needs of mothers. Second, the program aimed at promoting mothers' participation in care was implemented under a restrictive visiting policy. Thus, our study should be replicated in an environment with a 24-hour open visiting policy. Third, we used visual analogue scales to measure physical engagement and psychological connectedness because there was no other validated scale. Fourth, this study focused on mothers' needs because fathers often participate less frequently in their infants' care. Fathers' experiences and needs should be evaluated in future studies and compared with mothers' experiences, because fathers are similarly crucial for FCC.

Conclusion

The mothers of infants who underwent cardiac surgery desired different pieces of information according to infants' recovery phase. Similarly, they had different preferred participation activities depending on infants' recovery phase, and could participate actively in caregiving with nurses' help. With a thorough understanding of the mothers' needs of information and participation, PICU nurses could provide a timely suitable nursing program for mothers' preparation through understanding changes in the mothers' physical engagement and psychological connectedness based on their infants' recovery. PICU nurses should also modify or update ongoing programs to promote better partnerships between mothers and nurses through meticulous investigation of changing maternal needs and experiences under the present FCC strategies. Such efforts could promote more effective FCC.

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Ethical statement

This study was performed after institutional review board approval (IRB No. 2017-0242) in Asan Medical Hospital, Republic of Korea. The research meets the ethical guidelines.

Declaration of Competing Interest

The authors declare that they have no conflict of interests.

Acknowledgement

This manuscript is a secondary data analysis using data obtained from the first author's doctoral dissertation conducted in 2016 (Department of Nursing, Yonsei University). Explanations of the participants, program, and survey tool were obtained from the dissertation. The data analysis and findings regarding mothers' needs are unique to this paper, and this study also received institutional review board approval. The abstract has been selected for a poster presentation at the 22nd East Asian Forum for Nursing Scholars (EAFONS) 2019, to be held on January 17 and 18, 2019, in Singapore.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.iccn.2019.07.003>.

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