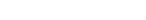
#### **ORIGINAL ARTICLE**



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# Indonesian mothers' beliefs on caring practices at home for preterm babies after hospital discharge: A qualitative study

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#### **Abstract**

**Purpose:** Premature birth may be associated with infant health problems and frequently requires in-hospital and then at-home specialized care. Studies investigating home-caring experiences of mothers of preterm infants in developing countries are limited. This study was to explore preterm mothers' experiences of caring practices at home 1 month after their infant's discharge from a neonatal unit.

**Design and Method:** A descriptive qualitative study using in-depth interviews with eight purposively sampled mothers who had been discharged home from neonatal unit in one city in Indonesia. All interviews were audio-recorded, transcribed verbatim, and analyzed using thematic analysis.

**Result:** Three main themes emerged: (1) transition to independent motherhood, (2) focus on care of infant after discharge, and (3) barriers and enablers for care. The mothers managed their infant care at home by focusing on feeding and managing infant health problems. They faced on myth and culture as one of the barriers.

Conclusions: Comprehensive discharge education for mothers of preterm infants and their families is required to enhance mothers' caring abilities and overcome barriers is sufficient. Nurses/midwives need to improve care related to the well-being of mothers and their infants in preparation for, and after, discharge from the neonatal unit.

#### KEYWORDS

hospital discharge, independent motherhood, myth and culture, neonatal intensive care unit, premature infant

#### WHAT IS ALREADY KNOWN?

Some studies have focused on parents' emotional experiences after their infants' discharge from the neonatal unit; however, little is known about mothers' caring practices for their preterm infants at home in the first month after discharge.

### WHAT THIS PAPER ADDS?

This paper shows assuming home-caring practices for preterm infants by Indonesian mothers were initially challenging as they

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faced wide cultural variations and beliefs from their families that impacted on mothers' and infants' daily lives and health. Mothers of preterm infants described a gradual process whereby they achieved independent motherhood after discharge from the neonatal unit. Home-caring focus areas included feeding (weight gain) and maintaining infant health; along with managing internal factors and family/community beliefs/traditions that influenced their caring practices at home.

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#### 1 | INTRODUCTION

Globally, infant deaths in the first month of life were approximately 2.5 million in 2018 (UNICEF, 2019; World Health Organization, 2014), with preterm birth being the leading cause of neonatal death (World Health Organization, 2014). Indonesia is ranked fifth highest for preterm birth rates in the world, with preterm births accounting for approximately 15.5 per 100 live births in Indonesia (World Health Organization, 2018). Prematurity is related to infant health problems and often requires the care of the neonatal unit such as special care nursery (SCN) or neonatal intensive care unit (NICU) to sustain life and minimize health complications (Australian Institute of Health and Welfare, 2019). The focus of the NICU is to provide lifesaving care for infants, and as such, the focus may not prioritize strengthening the bond between mother and infant (Phillips-Pula et al., 2013). Mothers of infants hospitalized in the NICU may therefore have limited opportunities for hands-on caregiving and interacting with their infants (Phillips-Pula et al., 2013). Lack of contact with their infants can limit mothers' opportunities to learn the early cues and needs of their infants (Phillips-Pula et al., 2013; Vazquez & Cong, 2014) and weaken potential mother-infant bonding and attachment (Phillips-Pula et al., 2013).

Parenting their infant within the neonatal unit may be both a terrifying and crucial task for parents (Vazquez & Cong, 2014). This experience may impact the mother's psychological well-being, as she may fear for her infant's life, and lack confidence in caring for her infant (Whittingham et al., 2014). The psychological impact on the mother can also influence the formation of maternal attachment, disrupt the achievement of maternal roles, challenge the transition to motherhood, and have an impact on the health of the infant (Lowdermilk et al., 2012; Medina et al., 2018; Perry et al., 2014; Whittingham et al., 2014). The stress, anxiety, and fear that may be experienced by mothers during an infant's admission to the neonatal unit can continue and may even worsen when their infant is discharged, especially in the early days after hospital discharge (Adama et al., 2016).

The discharge of the preterm infant from the hospital can be a difficult transition for parents, especially mothers, as they usually assume the responsibility for daily care for their preterm infant at home (Phillips-Pula et al., 2013). The mother's feelings on receiving information that her infant can go home can fluctuate from ready to go home, relief to anxiety, rushing to leave the hospital, and uncertainty (Aydon et al., 2018). Mothers often question their ability to care for their infants at home without the support of staff and technology that have been readily available in the hospital (Jefferies, 2014). A mother's lack of readiness to take care of her preterm infant at the time of hospital discharge is associated with potential adverse consequences that may increase the length of hospital stay, increase acute care episodes (visits to the clinic or emergency department or hospital readmissions), and reduce the mother's ability to care for the infant at home (Beheshtipoor et al., 2013; Karbandi et al., 2015; Mohammaddoost et al., 2016; Peyrovi et al., 2016; Vonderheid et al., 2016).

One study found that care of premature infants after going home from the NICU was influenced by mothers' fears that something negative would happen to their infants outside the safety net of the NICU (Adama et al., 2016). Another described how mothers obtained confidence as their infant's health increased, and they identified the infant's needs, as a learning process by using external resources, trial-and-error, and an internal intuitive sense, especially in identifying and dealing with infant discomfort (Murdoch & Franck, 2012). The greatest obstacles expressed by mothers in caring for their preterm infants at home were related to feeding, feelings of insecurity, and requiring adequate support following discharge (Souza et al., 2010). Some studies have focused on parents' emotional experiences after the infant's discharge from NICU, and little is known about mothers' caring practices for their preterm infants at home. On the whole, most of what is known about mothers experiences' come from developed countries, such as the United States, Australia, Sweden, and Taiwan, where there are hightech neonatal centers and significant support for families after discharge (Adama et al., 2016).

The American Academy of Pediatrics (AAP) has released a policy statement for guidelines on discharge of the high-risk neonate in 1998, updated in 2008, and reaffirmed in 2018 (AAP Publications Reaffirmed, 2019; Committee on Fetus and Newborn American Academy of Pediatrics, 2008). One of the AAP regulations is focused on discharge planning guidelines that describe the preparation of mothers of preterm infants to care for their infants at home (Committee on Fetus and Newborn American Academy of Pediatrics. 2008). Indonesia, a developing country, does not yet have such guidelines, even though regulation number 10 issued in 2015 by the Minister of Health of the Republic of Indonesia has designated parenting education services as one important requirement of neonatal services (Indonesian Ministry of Health, 2015) Indonesia faces wide cultural variations and beliefs from various tribes that impact on new mothers' daily lives and the health of both mothers and infants (Rahayu & Hasballah, 2017). On the other hand, mothers' readiness for hospital discharge in Indonesia is lower than that reported in developed countries (Hariati, Sutomo, et al., 2020). In this context, this qualitative research examined the experiences of Indonesian mothers in caring for their premature infants at home after the first month after discharge from the NICU.

#### 2 | METHODS

#### 2.1 Design

The study sought to explore the experiences of mothers of preterm infants about their transition to independent motherhood after hospital discharge, their caring practices at home, and barriers that they faced in the early days at home after hospital discharge. A descriptive qualitative study was used to explore, analyze, and describe experiences, while preserving the abundance, and breadth and depth of women's stories to obtain understanding of their experiences

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(Matua & Van Der Wal, 2015). In-depth interviewing techniques were used and the researchers encouraged mothers to describe their experiences by asking open-ended questions (Tong et al., 2007).

#### 2.2 | Participants

The mothers of preterm infants were chosen using purposive sampling guided by several inclusion criteria. These were (1) a mother who gave birth to a premature infant who had been treated in the neonatal unit for at least 1 week, (2) infants who had been discharged less than 1 month from the neonatal unit, and (3) mothers who could speak Bahasa Indonesia. After ethical approval was received, participants were recruited following a review of medical records of a tertiary hospital in South Sulawesi, the national referral hospital in eastern Indonesia with the largest neonatal unit facility in the region. After obtaining ethical approval for the study and permission from the hospital's research department, the researcher accessed the contact details of potential participants from the records. Potential participants were contacted by phone by the lead researcher and an interview was organized with those who agreed to participate.

#### 2.3 Data collection

Data collection was carried out between June and October 2018. The first author interviewed participants in their homes after explaining the study objectives, process, confidentiality, and their right to withdraw at any time and seeking written informed consent. The interview began with questions around demographic data, of mother and infant. Mothers' demographic data included age, parity, education, occupation, family structure, and type of birth. Infants' demographic data consisted of gestational age, birth weight, length of stay in the neonatal unit, and weight on discharge. A total of eight mothers of preterm infants participated in the study. Four of the mothers were primigravida. All were living with their families (nuclear or extended family) after hospital discharge.

In-depth, semi-structured interviews aimed at exploring the participants' perceptions and experiences were used in this study. An interview guide with key open-ended questions and associated probes was used to help the interviewer ensure that the research question was addressed. The questions focused on mothers' initial feelings around taking their infant home, readiness to care for their infants at home, experiences of infant care, obstacles mothers faced to caring for their infant, support received at home, and the discharge education they received before discharge from hospital.

Interviews were conducted in Bahasa Indonesia by the first author, ranged from 30 to 60 min in duration, and were recorded using a smartphone application. The interviewer also made field notes immediately after the interview to record additional reflections and participant details. Participants were recruited for the study until no new information emerged from the interviews. Data saturation was achieved after eight interviews.

#### 2.4 | Data analysis

Interviews were transcribed verbatim and analyzed in Bahasa Indonesia. The analyzed data was translated into English after determining the meaning of words, coding, categories, and themes. The English version of the analyzed data was back-translated into Bahasa to ensure meanings did not deviate from participants' original intent.

Content analysis was performed to enhance understanding of the mothers' experiences to identify themes and patterns among the themes (Polit & Beck, 2018). Three phases of content analysis, as described by Elo and Kyngäs (2008), were used: identifying, analyzing, and interpreting themes within the data. Analysis began by entering interview transcriptions into Open Code version 3.6. The preparation phase involved reading transcripts several times to build a general sense of the mothers' experiences and then reflecting on their meanings as a whole. The next phase was organizing the data. This phase involved making meaning of data by segmenting it into codes, and these were then collated into meaningful groups and patterns to be formed into categories that were named using content-characteristic words (Elo & Kyngäs, 2008). The next step in this phase involved generating initial subthemes by grouping together categories that had the same meaning units and finally the themes revealed by grouping the subthemes. All researchers checked and discussed the collated data for each subtheme and theme to ensure the analysis was not different from the data and reflected meanings evident across the data set. The last phase was reporting the research. This involved defining, refining, and assessing the suitability of themes to tell the story about the data. Finally, writing the final report was performed once all researchers had decided on the themes that addressed the research aim (Elo & Kyngäs, 2008: Polit & Beck, 2018; Vaismoradi et al., 2013).

Credibility, dependability, transferability, and confirmability were used to establish trustworthiness by Lincoln and Guba (1985). Member checks were used for established credibility and undertaken with two mothers who were invited to read the results of the thematic analysis for their feedback and correction to ensure accuracy of interpretation. Finally, we used reflection and feedback in combining the data into a description of the findings. Dependability was obtained by reporting in detail the processes undertaken in the study to facilitate future researchers in replicating the work. Transferability was achieved by providing detailed and forceful descriptions of findings supported by appropriate quotations. Confirmability was sustained through peer debriefing among the research team to discussing findings until consensus was reached about the reported findings (themes and subthemes) (Holloway & Wheeler, 2010).

#### 2.5 | Ethical considerations

Ethical approval was obtained from the Medical Research Ethics Committee. Informed oral and written consent was collected from mothers before data collection. De-identified audio files, transcripts, and analysis are securely stored as per ethics approval and used only



for reporting research outcomes. Codes are used in reporting data to ensure no participant is identified.

#### 3 | RESULT

Eight mothers of premature infants participated in the study. Half were primigravids and the remaining four had previous birth experiences. Half (n = 4) had bachelor's degrees and the remaining four had graduated from senior high school. Seven of the eight mothers were housewives. The majority (n = 7) lived with extended families. Six of the eight premature infants had birthweights under 2000 g. The range of infants' weights on discharge from the hospital was between 1400 and 2450 g. The length of stay in the hospital was between 11 and 30 days. Demographic data are shown in Table 1.

Analysis of interview transcripts revealed three themes: "Transition to independent motherhood," "focus on care of infant after discharge," and "barriers and enablers for care." Subthemes were also identified that further elucidate the experiences of mothers of caring for their premature infants at home after hospital discharge. These themes and subthemes are shown in Table 2

#### 3.1 | Transition to independent motherhood

Mothers' experiences were marked by a need for adaptation and development of maternal capabilities. Mothers felt insecure in the initial days after discharge but developed acceptance in taking care of their infants at home independently. This transition to independent motherhood was described by mothers as gradually learning how to take care of their preterm infants, taking responsibility for the care and also in receiving caring support from their family. Mothers generally began learning these skills in the neonatal unit. In the neonatal unit ward, staff empowered the mothers to independently care for their infants once the infants were physiologically stabilized and close to discharge. After discharge, mothers continued to learn to take care of their infants gradually day-by-day, often supported by their extended families' experience.

#### 3.1.1 | Initial independent motherhood

Mothers began their transition to independent motherhood in the neonatal unit ward, where parent visits were encouraged without limitation. In the early days, staff undertook all care for the admitted infant until they were physically stable. Gradually, mothers were encouraged to take care of their infants' care once their condition stabilized. Mothers received education about technical knowledge of infant care in neonatal unit from the nurses before they provided initial independent care. The care that the mothers could perform independently in the neonatal unit included basic physical care such as changing diapers, breastfeeding, cup-feeding (several hospitals in Indonesia use cup-feeding as the first alternative feeding, then

**TABLE 1** Descriptive characteristics of participants (N = 8)

	Mothers cl	Mothers characteristic	c				Infant characteristic	eristic		
Age Participants (years)	Age (years)	Gravida	Gravida Education Occupation	Occupation	Family structure	Type of birth	Birth weight (g)	Gestational age (weeks)	Length of stay (days)	Weights on discharge (g)
₽	32	4	Bachelor	Housewife	Sister and parents	Cesarean section	1100	30	30	1800
7	18	Н	High school Housewife	Housewife	Husband and parents in law	Vaginal	1400	30	12	1750
ဇာ	36	4	Bachelor	Housewife	Husband and children	Cesarean section	2100	32	14	2400
4	30	Н	Bachelor	Housewife	Parents in law	Cesarean section	2350	34	11	2450
72	38	ဇ	High school Housewife	Housewife	Husband, children, and parents	Vaginal	1000	28	24	1400
9	36	2	Diploma	Housewife	Husband and children	Vaginal	1400	28	26	1700

Infant characteristic	Gestational age Length of Weights on	(g) (weeks) stay (days) discharge (g)	30 17 1760	34 25 1900
Infant o	Birth	weight (g)	1560	1360
		Type of birth	Vaginal	Cesarean
		Family structure	ployee Husband and parents	Husband, parents, and
		Gravida Education Occupation	Bachelor Private employee	Housewife
		Education	Bachelor	Bachelor
Mothers characteristic		Gravida	7	2
Mothers ch	Age	articipants (years)	36	27
		Participa	7	œ

TABLE 1 (Continued)

bottle-feeding before the infant can feed directly from the mother to prevent the infant suffering nipple confusion), weighing the infant, and kangaroo mother care (KMC) especially about KMC skill practices and knowledge about KMC benefit. This independent care by mothers was, however, supervised by neonatal staff. The neonatal staff initiated the schedule of care for mothers and monitored the results of caring that the mothers did.

While my infant was in hospital, I started breastfeeding my infant and weighed my infant after breastfeeding. If my infant's body weight was not reaching the volume of milk target, then I was asked to reheat breastmilk and give it to my infant by cup feeding. (Mother 5)

#### 3.1.2 | Taking responsibility for care at home

Despite providing care to their infants in the neonatal unit, mothers expressed fear and did not feel confident in relation to providing their infant's care in the early days after NICU discharge. However, they stated that they were passionate about caring for their infants. All participants stated they accepted becoming mothers of premature infants and took part in the daily care of their infants. Mothers felt insecure in the initial days after discharge. However, caring for premature infants every day at home grew their confidence and skills in motherhood.

At that time, I ventured to go home. I felt anxious all day, but because I did it every day, I was finally able to do it. (Mother 2)

Five of the eight mothers said they believed the difficulties of caring for a premature infant were similar to caring for normal term infants, although with greater intensity. Three of these mothers were multiparous so they had previous experience enabling comparison.

I was particularly challenged in taking care of my infant. It was almost the same as infants in general. But I had to undertake more intensive monitoring of my infant. (Mother 7)

## 3.1.3 | Caring assistance from family

Hospital discharge was a difficult transition for mothers in the early days after hospital discharge because they began as primary caregivers of their infants at home without nursing/midwifery and technology support. This prompted mothers to enhance their caring efforts at home assisted by family. This transition was further enabled when mothers received support from their families, including from their husbands, mothers-in-law, mothers, sisters, and other

Themes	Subthemes	
Transition to independent motherhood	Initial independent motherhood	
	Taking responsibility for care at home	
	Caring assistance from family	
Focus on care of infant after discharge	Feeding complexity	
	Infant health concerns	
	Maintaining the infant body temperature at home	
Barriers and enablers for care	Basic knowledge from the neonatal unit ward	
	Lack of knowledge about infant's needs	
	Myth and culture-related to preterm infant care	

**TABLE 2** Overview of the themes and subthemes

people at home. Families provided support, especially around infant care information, based on their previous experiences and with the practical caring support of infants in the initial days after hospital discharge. Seven participants lived with their extended families after giving birth. These participants received assistance with caring for their infants from close family members. One of the mothers said that after she returned from the hospital, she was helped by and learned about caring for her infant from her extended family.

For the initial 40 days after giving birth my mother was with me, so she helped me. After 40 days I took care of my infant by myself. (Mother 4)

## 3.2 | Focus on care of infant after discharge

Difficulties in caring for preterm infants were experienced by some mothers after hospital discharge. A number of concerns about problems in caring for their infants after hospital discharge were raised by mothers. The infants' small size caused them psychological stress and impeded their parental roles, resulting in their perceived inability, and lack of confidence to care for their infants at home. Participants managed their infants by focusing on feeding their infants to increase their infants' weight, focusing on any infants' health problems, and ensuring the infants were kept warm.

#### 3.2.1 | Feeding complexity

Future growth and development of the preterm infant were of concern for the mothers. They feared that the growth and development of their infant would be impaired in the future. They particularly worried about the infant's weight in the early days and all focused on feeding to enhance their infants' weight. They focused on infant feeding to enhance the infant's weight sharply every day to that of a full-term infant. To achieve this, they followed complicated feeding programs they received on discharge or self-researched

information to guide their feeding protocols. They reported feeding their infants every 2–3 h using breastfeeding, expressing milk, and/or using formula. One mother said:

You have to consider when and how much milk to give. It's best to do it every two hours. Because I read on the internet that low birth weight infants were given 90 ml of milk every 3 hours or every 2 hours. and so, I prefer to give milk every two hours. (Mother 3)

Six mothers stated that they used bottle-feeding because they had breast milk production challenges or were not confident in breastfeeding. One participant used bottle-feeding so she could measure the amount of milk her infant consumed. Another mother was not confident that she was feeding her infant adequately from the breast, so she decided to bottle-feed directly after breastfeeding.

I was confused. When I breastfeed my infant, this question always comes up in my mind, is it enough for her? I always think about how much is enough nutrition for her. Therefore, every time after breastfeeding her, I then expressed my breastmilk and then gave the milk by bottle-feeding too. So, I knew how much she drinks. I sometimes think about what the best way is. (Mother 2)

#### 3.2.2 | Infant health concerns

The first months at home were challenging for mothers of preterm infants. Participants worried about the infant's health problems after discharge. The mothers stated that after hospital discharge, they performed routine observations of their infants because they feared something untoward would happen with the infant's health. They cared for their infant's health at home, including checking the infant's breathing regularly, routinely attended periodic check-ups at the hospital, and avoided the infant being cold at home. Participants

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explained that they always checked the infant's condition to reduce their anxiety around undesirable health outcomes.

> I check her breathing all the time because I'm afraid she will stop breathing. (Mother 7)

#### 3.2.3 Maintaining the infant body temperature at home

Hospital policy in Indonesia requires mothers of premature infants to be confident with KMC before leaving the neonatal unit to support the maintenance of the infant's body temperature. Most of the mothers interviewed continued KMC when they first went home. The mothers explained that they were focused on maintaining the temperature of infants at home using KMC. However, use of KMC quickly became irregular and all mothers reported stopping KMC in the first week at home. Implementation of KMC at home varied from 1 to 7 days after a hospital discharge. The frequency of KMC also varied from one to three times daily. The use of KMC each day and the timeframe for stopping were different for each mother. There were several reasons why mothers stopped the implementation of KMC in this study, including they felt their infant was healthy, not jaundiced, the infant's weight had risen, and personal reasons expressed by mothers such as feeling tired, having trouble with housework, and frequently, because their family was against KMC and advocated other methods for keeping the infant warm. Five mothers reported carrying out KMC for more than the first 3 days. One mother said that she stopped KMC after 3 days as the infant's health had improved:

> I did KMC for three days after returning home from the hospital, but I didn't it anymore because my infant was healthy. KMC was difficult and I needed to be helped by others as I cannot do it alone. (Mother 8)

Two mothers experienced pressure against implementing KMC from their families that led them to cease. The family members were unhappy with the infant's position during KMC, believing that infants should not be positioned like frogs as it could harm their legs and cause them to become bowlegged.

> They are old people, so they say why are infants given this position? Why are you using a frog position? They said infants should not be positioned like that, it can harm their legs. (Mother 1)

#### 3.3 Barriers and enablers for care

The demanding nature of caring for a premature infant at home meant mothers faced a variety of challenges and needed to overcome barriers to good care. Barriers came from various sources, including the mothers themselves, their families, and their environment. Mothers attempted to provide the best care for their infants but often had limited knowledge about the infants' needs and needed to contend with their families' beliefs in myths and culture-related factors that disrupted care. The beliefs came from family members' previous experience and forefathers, wisdom passed from one generation to another. The family was often against KMC and bathing the infant at home. They suggested the mothers warming and bathing their infants based on family culture. To manage these barriers, mothers reported receiving education and being empowered in the neonatal unit about their infant's needs. Despite this, they still faced barriers to implementing this care at home because cultural practices at home were different from the health education received in the hospital.

# 3.3.1 | Basic knowledge from the neonatal

The participants had obtained health education about physical infant care from nurses and doctors in the neonatal unit and without home care supervision after discharge. This supported them to supplement their basic knowledge about caring for their premature infant at home. They received education about feeding, changing diapers, and KMC. One participant stated:

> I was taught about giving milk to the infant, how to carry my infant, and change diapers. I tried to remember everything that I was taught. (Mother 5)

#### 3.3.2 Lack of knowledge about infant's need

Infant care at home was not only about basic physical needs but included behaviors and health needs. Mothers had received education in the neonatal unit ward only about physical care of the infant, but at home they encountered behaviors and health needs from their infants that they needed to understand. Some mothers expressed confusion regarding treating premature infants at the beginning of their time at home. Participants reported encountering infant needs related to feeding (from breast, bottle, and cup), and infant bathing. They expressed confusion about health needs such as immunization and how to manage the sick infant. They also faced behavioral problems such as crying or infants staying awake at night. Participants reported feeling stressed when their infant cried and not knowing how to calm them.

> I feel stressed when my infant cries, I do not know what he wants, whether he wants to suckle-but he has suckled.? I don't know why he cries so much. (Mother 4)

# 3.3.3 | Myth and culture-related to preterm infant care

Culture adopted by the family was often a supporting factor and an obstacle to the success of the mother caring for her infant at home. Participants in this study all came from Makassar, Indonesia. Most of the mothers lived with their extended families after being discharged from the hospital. The trust of family members at home was one factor that caused mothers confusion in caring for their premature infants at home. Indonesian culture has several beliefs related to managing premature infants. These include the use of lights, flash-lights, or water bottles to warm the infant at home rather than KMC. While mothers believed these methods were not the best, they did not have enough power to repudiate their family member beliefs.

Infants may not be positioned like that (referring to KMC), they should just be heated with lights. Mothers said they were given lights, flashlights, or warm water to keep their infants temperatures stable. Initially, I tried to follow the hospital instructions but over time because there was no support from my family. I stopped KMC and just swaddled my infant, but I still refused light or water bottles to warm my infant. (Mother 1)

Six mothers lacked knowledge about infant bathing and were afraid to bathe their infants at home. Five of them believed that preterm infants should not be bathed because they had been born preterm. They always thought their infants were underweight. Families believed that small infants should not be bathed. The mothers and their families were scared that their infants would die if they bathed them, so they reported not bathing their infants.

One time I wanted to bathe my infant, but his father said do not to bathe my infant. He was traumatized because of the experience of his cousin who had a premature infant. His cousin bathed his infant and eventually the infant died. So, I just wiped my infant's skin in the folds instead of bathing. (Mother 7)

# 4 | DISCUSSION

Hospital discharge has been described as a challenging moment for mothers of premature infants, causing fear, anxiety, and insecurity (Adama et al., 2016; Griffin & Pickler, 2011; Phillips-Pula et al., 2013; Souza et al., 2010). This results from limited experience and ability to care for the preterm infant after discharge and the additional health needs of their infants (Adama et al., 2016; Jefferies, 2014). This study contributes new information about the experiences of Indonesian mothers around caring for their premature infants during the first month at home following discharge from the NICU. Findings demonstrate that these Indonesian mothers

expressed initial fears and lack of confidence related to infant care in the early days after NICU discharge, but this condition did not persist for long. They felt that caring for premature infants became the same as caring for term infants by the end of the first month after discharge. This is different from other findings in developed countries where fear and anxiety persisted in some parents for more than 6 months (Adama et al., 2016; Phillips-Pula et al., 2013). Our findings confirm that Indonesian mothers were determined to do their best in caring for their premature infants' physical needs rather than focusing on maternal psychological issues. They believed acceptance of responsibility of their roles as mothers was key to enhancing their infant's health, growth, and development in the future. Our findings concur with another study involving Indonesian adolescent mothers where mothers focused on the most important role of care for their infants, rather than reporting their own psychological problems (Erfina et al., 2019a).

In addition, caring support from mothers' families was important and supplemented their acceptance and ability in caring for their preterm infants. Family support included providing information based on their own previous experiences and assistance in caring for the infant in the initial days after discharge. Our findings revealed that most of these Indonesian mothers were living with their extended families after birth or discharge from the neonatal unit. This allowed the mothers to have continuous support in caring for the infant from their families. In line with another study, where mothers received important support at home from their parents (Erfina et al., 2019b), mothers and mothers-in-law who helped to solve problems faced (Rahayuningsih et al., 2015), and the mothers perceived their partners as the most important form of support (Adama et al., 2016). Support from family reduces stress, anxiety. mitigates, feelings of isolation, sadness, has a positive influence, decreases postpartum depression, and improves caring ability (Committee on Fetus and Newborn American Academy of Pediatrics, 2008; Murdoch & Franck, 2012; Phillips-Pula et al., 2013; Rahayuningsih et al., 2015).

The mothers of premature infants in this study showed that they focused care of their infants' physical needs, including boosting the infant's weight through feeding, maintaining body temperature, and managing the infant's health problems. The majority of mothers were focused on feeding to build up the infant's weight. They had been given complex feeding plans, possibly including breastfeeding, expressing breast milk, and using formula (Cartwright & Boath, 2018). Most mothers reported a lack of confidence with breastfeeding providing adequate nutrition, so they fed after breastfeeding their infants with expressed breast milk or formula. Schedules for infant feeding every 2 or 3 h were formed by mothers in a positive effort to manage feeding problems. Similarly, one UK study found that the mothers were setting alarms and waking infants up for feeding (Cescutti-Butler et al., 2019). Infant feeding schedules are effective in keeping the milk supply for breastfeeding mothers and to optimize infant growth (O'Connor & Unger, 2013). This finding in line with another study where the primary concern of mothers was feeding to increase their infants' weight, not only during NICU care but also

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when the infant was home (Burnham et al., 2013). Similarly, another study explained that mothers had improved feeding situations since being in NICU by learning how to feed their infants, using strategies to time feedings, and by obtaining sufficient nutrition for themselves to be able to breastfeed (Hasselberg et al., 2016). Indeed, infant weight monitoring and in-home milk intake measurement should be encouraged as it appears to support feeding adequacy and enhances maternal satisfaction after discharge from the NICU (Ahmed & Sands, 2010). Mothers experienced apprehension over infant feeding and the infant's weight gain that resulted from lack of confidence in their ability to care for their infants independently and responsibility about their infant's well-being (Pickler et al., 2012).

Another focus of prematurity care at home is the implementation of Kangaroo Mother Care (KMC) to maintain the infant's temperature. KMC was initiated by the World Health Organization (WHO) to reduce infant mortality in developing countries such as Indonesia (Department of Reproductive Health and Research WHO, 2003). KMC is used as one method of care within the national policy for discharging infants from the NICU in Indonesia. Indonesian mothers perform KMC since in hospital (Hariati, McKenna, et al., 2020). In this study, the duration of implementation of KMC by mothers of premature infants at home varied from just 1 day to more than 1 week, with the variable implementation of KMC episodes lasting 1-2 h. This is in contrast with findings of another study in South India that showed the duration of KMC at home was 30.2 days and the average duration per day was 1.3 h (Raajashri et al., 2018). Another study in Nigeria found the duration of KMC/day at home was 3.25 ± 2.85 h (Opara & Okorie, 2018). In contrast with this study, the most common reason for stopping KMC at home in another study in Nigeria was that the infant became uncomfortable and mothers did not know that somebody else could assist with KMC (Opara & Okorie, 2018). KMC can cause physical and emotional difficulties for the mother, and often requires support from family members, health practitioners, or other mothers (Seidman et al., 2015).

The transcultural nursing theory of Leininger (1984) states that it is important for nurses to pay attention to cultural diversity and values adopted by patients in applying nursing care, because if ignored, there could be a cultural shock (Raile Alligood Martha, 2014). Indonesian family beliefs in myths were also reported as barriers to caring for preterm infants at home. Our study found that another reason for discontinuing KMC implementation at home was because mothers believed enhancing the infant's warmth could be performed by using lights, flashlights, or placing a warm water bottle beside the infant. Indonesian families also believed that preterm infants should not be bathed because this could be harmful to the infant. Various cultural beliefs are inherent across Indonesian society and often cannot be separated from daily life (Rahayu & Hasballah, 2017). Diversity in culture and distinct characteristics of a particular culture is something that can facilitate or impede the receipt of healthcare and can be harmful to the infant's health (Brooks et al., 2016; Rahayuningsih et al., 2015). Factors occurring with the microsystem (ethnicity), mesosystem (extended family network), and macrosystem (cultural background) can impact on a mother's environment for parenting experiences, particularly physical and social settings in which premature infants and their mothers are mutually involved (Brooks et al., 2016).

The mothers of premature infants' lack of knowledge about their infants' needs were revealed as another barrier for caring for preterm infants at home. The discharge education program will enhance the mother's knowledge (Hariati, Sutomo, et al., 2020). Mothers need the information to care for their infants, such as routine care and how to deal with unwanted events (Burnham et al., 2013). They need a strong understanding of all important information and instructions several times before NICU discharge because new instructions given until the day of return home may be completely lost when experiencing stress in the early days after going home (Phillips-Pula et al., 2013). For this reason, comprehensive health education is needed as part of nursing care before mothers with premature infants return home from the neonatal unit.

#### LIMITATIONS

There are a number of limitations in this study. First, the study was undertaken in one location in Indonesia. However, this hospital was a national referral hospital in the eastern part of Indonesia and had the largest neonatal unit facility in the region. Second, many potential participants were located outside of Makassar and we were unable to reach them, and their issues may have been different. Nevertheless. this study was undertaken using in-depth interviews that may reflect broader experiences of caring for premature infants at home.

#### | IMPLICATIONS FOR PRACTICE

This study adds to the body of knowledge that assists nurses and midwives in adjusting care given to mothers of premature infants, which can help them through the transition to becoming mothers and improve the outcomes of their infants' care. Neonatal unit staff have significant roles in enhancing the mother's knowledge, skill, and perceived readiness before discharging the preterm infant from the neonatal unit to home. They need to perform comprehensive discharge planning to improve mothers' competencies in caring for their infants. Moreover, this study provides information on which to begin the design of methods, approaches, and topics needed for discharge teaching with mothers of preterm infants during their infant's hospitalization in the neonatal unit. Nurses and midwives need to educate husbands and parents about KMC to prevent overcome cultural myths about KMC. The complexity of feeding that was found in this study must be taken into consideration for health education before discharge in order to increase compliance and decrease mothers' stress.

#### CONCLUSION

Indonesian mothers of preterm infants experienced insecurity in the initial days after hospital discharge, but quickly became confident in caring for their infants through support from their families and others. After hospital discharge, mothers' caring focused on feeding, their infant's health, and maintain their infant's body temperature. They faced several problems arising from Indonesian myths and culturally related views on preterm infants, as well as a lack of knowledge about their infants' needs. There is a challenge for nurses to provide comprehensive services for high-risk mothers and premature infants before going home from the neonatal unit. This study provided insights regarding how Indonesian mothers care for their premature infants at home after discharge. Further research should examine more deeply other cultural practices and family influences applied to managing premature infants and the impact of these on outcomes, as this is a crucial issue for mothers' caring practices for preterm infants after hospital discharge.

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#### **CONFLICT OF INTERESTS**

The authors declare that there are no conflict of interests.

#### **AUTHOR CONTRIBUTIONS**

Suni Hariati had primary contribution to conceptualization and methodology of the study, carried out the investigation, data curation, visualization, and writing—original draft. Retno Sutomo, Lely Lusmilasari, and Andi D. B. Febriani were embroiled in conceptualization and methodology, visualization, and review of the manuscript. Lisa Mckenna and Sonia Reisenhofer were significantly involved in data curation, visualization, and writing—review and editing the manuscript.

#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

#### **ETHICS STATEMENT**

The ethical approval for this recent study was obtained from Hasanuddin University Medical Faculty Ethics Committee (admission number: 356/H4.8.4.5.31/PP36-KOMETIK/2017). This study conforms to the provisions of the Declaration of Helsinki in 1995 (as revised in Edinburgh 2000). All study participants provided informed consent, and their anonymity was preserved.

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