ORIGINAL ARTICLE

Sustaining Footprints in Mothers' Heart: Exploring Experiences on Holistic Care for Infants in Neonatal Intensive Care Unit (NICU) among Mothers and Healthcare Team

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ABSTRACT

Introduction: Families are psychologically vulnerable after a/the birth of a sick infant. Providing holistic care can positively influence the family's ability to cope with crises and promote healthy parent-child relationships. Holistic care demands a change from task-oriented, healthcare provider-centred care to a collaborative, relationship-based model of family advocacy and empowerment. This study explores the experiences of holistic care rendered in NICU settings among healthcare teams and mothers. **Materials and methods:** This was a phenomenology study conducted in a tertiary hospital in Singapore. Five participants of mothers with infants admitted to the NICU and 18 members of the multidisciplinary team were interviewed using semi-structured interview questions. The data were audiotaped, transcribed verbatim and analysed using content analysis. **Results:** Thematic analysis of the data revealed four emerging themes from the health-care team and mothers' experiences separately on holistic care in the NICU. The themes are: 1) role of healthcare professionals as primary references 2) experiences in delivering holistic care, 3) perception working towards a shared goal, 4) challenges to deliver holistic care, whereas for mothers, the themes identified were 1) mothers' experiences ranging from negative to positive emotions, 2) finding alternatives to divert negative mindsets, 3) relationships between the health care system and family, 4) balancing parent-infant closeness and separation. **Conclusion:** This research highlighted the need for a holistic care approach from mother's experiences. A teamwork with caring individuals who offer consistency and support is the foundation of a therapeutic environment.
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INTRODUCTION

The excitement of welcoming a healthy baby into a family is generally the experience of every parent. However, it is far from their expectations when the baby has to be admitted into the Neonatal Intensive Care Unit (NICU) whereby sick infants are cared for in a critical care environment. The NICU is an area that requires continuous nursing care and skills that do not exist in other areas to initiate therapy or provide close and sophisticated monitoring. This environment usually causes a significant difference in the parental behaviours, healthcare professional communications and their interventions as well as the growth and development of the infants. This is supported by a previous study where the findings revealed that due to the sophisticated equipment and technologies as well as the physical appearances of the infants, the parents were prevented from being involved in the care of their infants [1]. Most importantly, the relationship between parents and infants may be affected.

Separation can cause a change in the parental role, leading to the parents having to rely on unreliable support resources regarding the condition of their infants. At times, the information obtained can be quite frightening and negative. Not being able to process the true condition of the infants leads to the lack of control of the communication between the healthcare professionals and the parents as the parents rather believe what they read on the internet [2]. Therefore, there is a deep concern to determine the needs and welfare of the parents and to create strategies to minimise the impact of the stress on the parents. In other words, to help the parents to cope and slowly accept the condition of the infants through professional support given by the team.

The mitigation of infant stress is an important development milestone for optimal positive outcomes.

This indirectly involves the participation of the multidisciplinary team. For instance, breastfeeding involves the lactation consultant to assess the confidence of mothers in expressing milk as well as proper techniques of latching on. Occupational therapists are involved in understanding the medical conditions of the infants and their individualised developmental vulnerabilities, input from family systems and their early socio-development [3]. The speech and language therapists teach parents the importance of talking and singing to their infants so that the infants can become familiar with their voices. Parentcraft sessions expose parents to the daily routine care of infants, and pharmacists respond to information requests from other health professionals as well as provide counselling to parents regarding drugs prescribed by doctors [4].

In order to provide all of these job roles, it not only starts with the healthcare team but also depends on the social-emotional status of the parents. Therefore, every team member plays an important role in engaging the parents to participate in the care of their infants. However, it is important to keep in mind that the healthcare team should provide the family with up-to-date, comprehensive, and unbiased information in a way that the family can understand and use to make informed choices and decisions. To ensure smooth transition of information, previous study proposed that to increase the efficiency of holistic care, continuity of patient care assignments is necessary to anticipate and follow up on the continuity workloads that burden families [5]. This finding is supported by Conner and Nelson in their study which found that parents' satisfaction in NICU includes assurance from healthcare teams, effective communication, up-to-date information regarding the current conditions of the infants, a proper orientation, offering parents the opportunity to participate in the care of their infants, as well as emotional, physical and spiritual support [6]. Certain positive signs may signal to the parents and the healthcare team that it is safe to begin developing a relationship with the infants, such as consistent weight gain, elimination of life support equipment and infants become more responsive and active or the infant is transferred from the NICU to level 2 care. It is also important for parents to take the time to bond with their infant and to communicate any concerns or questions they may have with the healthcare team.

According to Caldeira and Hall (2012), setting intentions, offering prayers, and assessing the hopes and expectations of the families can be incorporated into the plan of care, which can involve inviting their respective religious representatives to the hospital, performing prayers and blessings [7] and encouraging families to bring religious symbolic objects that they think might help in blessing and healing their infants that are normally inside the incubator. It is the responsibility of the entire team to coordinate the interventions and resources needed for the well-being of families. Encouragement and empowerment from allied healthcare professionals on care evaluation and spiritual needs need to take place in order for a total holistic approach to be delivered. Holistic care is an approach to caring for patients whose needs are addressed both physically, emotionally, socially, and spiritually. This is a comprehensive approach, with holistic care aiming at improving overall health and quality of life rather than seeking to treat illness [8]. It demands a change from task-oriented, healthcare provider-centered care to a collaborative, relationship-based paradigm of family advocacy and empowerment. Therefore, this manuscript aims to explore the experiences of the mothers and healthcare team on holistic care rendered in the NICU. While previous studies have explored the experiences of mothers in the NICU, this study aims to provide a unique perspective by also including the viewpoints of healthcare professionals. Additionally, this study aims to improve future work processes by considering the in-depth experiences of mothers and utilising a different research approach than previous studies [9].

MATERIALS AND METHODS

Study Design

This qualitative study was conducted via principles of phenomenology. Phenomenology attempts to uncover the self-awareness, reflection, and self-consciousness of a particular phenomenon of interest [10]. It focuses on exploring the lived experiences of people and understanding the meaning they attach to those experiences. The purpose of using in-depth interview for this study is to enable the participants' voices to be heard so that a thorough plan, assessment, and intervention can be done. In this study, the researchers likely used phenomenology to gain a deeper understanding of the experiences and perspectives of the participants related to holistic care.

Study Setting and Population

This study was carried out at Kandang Kerbau (KK) Women's and Children's Hospital in Singapore, specifically in the Neonatal Intensive Care Unit (NICU). The NICU has 40 beds and is dedicated to providing medical care to premature babies, infants who require surgery, and those in need of intensive medical care. The study population consisted of a team of healthcare providers (HCPs) who regularly follow up on the care of infants in the NICU, as well as mothers whose babies were admitted to the NICU. The HCPs included doctors, nurses, social workers, speech language therapists, physiotherapists, and lactation specialists. The inclusion criteria for HCPs were those who were connected to the NICU and consistently followed up on each family in the NICU. The exclusion criteria were multidisciplinary teams who were not ready to participate in this study. For mothers, the inclusion criteria were those who had infants admitted to the NICU for more than two weeks. Two weeks were sufficient for mothers to

create a substantial experience on holistic care with the multidisciplinary team [11]. Exclusion criteria were mothers with ill infants, infants under palliative care and mothers who could not speak English.

The team of HCPs working in the NICU were purposively selected from the database lists in the hospitals. They were invited to participate in the study through email or phone. The number of participants was approximately 2 to 5 from each discipline, or until the data saturation is reached for each one-to-one interview in a healthcare team. Data saturation is the point at which no new emerging data is obtained from the information [12]. Mothers were selected according to the inclusion criteria, and the estimated sample size was determined by reaching data saturation. The purposive sampling method was used to select mothers, and they were approached by the main researcher when they visited their child in the NICU.

Instruments

The in-depth interview guided questions were developed based on previous studies found in the databases such as CINAHL, google Scholar and MEDLINE. The researcher emailed and contacted the authors of the previous studies and explained the purpose of this current study. Out of the twenty authors, nine authors across the world responded to the email and shared the information regarding their study of holistic care in NICU. Based on their information, interview guided questions were developed, and piloted among 5 healthcare professionals in the NICU, KK Women's and Children's Hospital (Appendix A). A separate in-depth interview guide was developed to explore the experiences of mothers in holistic care in the NICU (Appendix B). The whole interview was conducted in the English language as English is the primary natively spoken language.

Data collection

The study recruited participants between May 2020 and December 2021. Before the one-on-one interview began, the process of the interviews that will be carried out was explained. Participant demographic information was collected after they consented to participating in the study. Each participant was labelled by alphabet numbers according to the sequence of the tape-recorded interviews. Thus, this whole process remains anonymous since no name was mentioned. The interviews were conducted by the first researcher in a private room with probing where necessary to clarify understanding. This whole interview process was a one-time participation, and if there is a need to clarify something, follow-up was done via email or phone [12].

Data Analysis

The data collection and data analysis were carried out concurrently to facilitate the data to be grouped in categories to form major themes. The interviews were tape-recorded, transcribed verbatim and listened to repeatedly to identify patterns and thoughts from the participants. The interviewer and two of the co-researchers maintained an audit trail to maintain the rigour and trustworthiness of the findings to establish confirmability of the research [13]. Using thematic analysis, the researchers met regularly to discuss the codes, refine categories, and reach a consensus on the coding. Similarly, thematic analysis was used to analyse similar codes to form major themes. According to Castleberry and Nolen (2018), these processes helped to obtain a good description of participants' feelings and experiences [14]. The study also ensured the consistency of the findings through precise and systematic data analysis to determine the credibility of the data [15]. The sub-themes were compared to derive more valid and generalisable themes, considering that the findings were from different disciplines and perceptions might differ. The trustworthiness and credibility of the data were assessed using criteria proposed by Lincoln and Guba (1985) [16]. In qualitative analysis, the method and its dependability are what constitute rigour. In order to support the analytic imagination required for comprehension and theory creation, it is crucial for the researcher to "immerse" themselves in the data, explore all the potential nuances and relationships, view the data from a variety of angles, and move from a micro- to macroview, in other words, by engaging in reflexivity. Independent assessments of the transcripts as well as the involvement of other investigators in this study, led to refinement of the themes, enhanced the analysis's validity through investigator triangulation. Transferability of the data findings were also attained through 'thick description' when the researcher used field notes to immediately documents events, personal feelings and behaviours observed as well as the researcher's reflections on them.

Ethical consideration

Formal ethical approval was obtained from the Ministry of Health board, Singhealth (CIRB Ref: 2019/2195) and from the Human Research Ethics Committee of USM (USM/JEPem/20120693). Informed consent was obtained from the participants before data collection took place.

RESULTS

Socio-Demographic Data of the Participants

There was a total of 23 participants in the study, including five mothers and 18 healthcare providers which consists of nurses (n= 7), physiotherapists (n=4), speech language therapists (n=3), doctors (n=2), medical social worker (n=1), lactation consultant (n=1). To protect the identities of the participants, numerical alphabets were used instead of their actual names. The demographic characteristics of the participants are provided in

Table I, which include information regarding age, duration of work experience and type of occupation.

Table I: Demographics of the mothers [M] and healthcare providers [HCT]

Numerical alphabets	Age	Work Experience (years)	Occupation
HCT1	38	5	Speech language therapist
HCT2	54	15	Consultant
HCT3	35	7	Medical officer
HCT4	41	9	Nurse
HCT5	28	4	Nurse
HCT6	32	6	Medical social worker
HCT7	48	12	Physiotherapist
HCT8	37	9	Nurse
HCT9	25	5	Nurse
HCT10	27	3	Physiotherapist
HCT11	43	12	Physiotherapist
HCT12	46	13	Nurse clinician
HCT13	56	22	Lactation consultant
HCT14	36	11	Speech language therapist
HCT15	27	7	Speech language therapist
HCT16	24	3	Physiotherapist
HCT17	30	8	Nurse
HCT18	35	9	Nurse
M1	34	-	Mother (housewife)
M2	30	-	Mother (teacher)
M3	28	-	Mother (business and financial operations)
M4	44	-	Mother (statistic analyst)
M5	38	-	Mother (Architecture and engineering)

Findings from the healthcare perspective

Following a detailed analysis of the data, four themes emerged from the perspective of the healthcare teams. The themes included the following aspects: the role of healthcare professionals as a primary reference, experience in delivering holistic care, perception of working towards a shared goal, and the challenges in delivering holistic care. Table II summarises these themes and subthemes from the healthcare perspective.

Table II: Summary of identified themes and common subthemes from the healthcare team perspective

Themes	Sub-themes
Role of healthcare professionals as primary references	•Develop trust, a cornerstone to relationship stability •En route to relationship sustainability •Provide rights to dignified and respectful care

CONTINUE

Table II: Summary of identified themes and common subthemes from the healthcare team perspective (CONT.)

Themes	Sub-themes
Experience in delivering holistic care	•Perceived attitudes and reactions of mothers •Input to achieve more positive maternal outcomes
Perception working towards a shared goal	•Acknowledge and respect each other's contribution •Building up teamwork and collaboration •Effective therapeutic communication chain
Challenges to deliver holistic care	•Information inconsistencies •Conflict caused by failed expectations •Differing organizational systems and processes •Workforce shortages

Theme 1: Role of Healthcare Professionals As Primary References.

The first theme that emerged from this study was role of healthcare professionals as main source of information for the mothers. In order for families to trust the healthcare team, the team must first establish trust among themselves. This can be achieved by sharing roles and responsibilities and building a sense of trust and collaboration within the team. The sharing of role and trust can be evidenced by one of the quotes below.

'I am not expecting the nurses to pace strictly, like 3 sucks, it can even go up to 5 sucks but even I know that this baby is safe I also won't do anything as I say earlier the nurse will be the one to be with the baby longer and they see the baby for few feeds so it will not be the case… If the baby can do it and the nurses know the safe boundary and they can increase the pacing, then I think that's fine.' (HCT1, 5 years of experience)

As the infants were admitted into NICU and the healthcare team knows the most regarding the condition of the baby, 1 participant mentioned how she treated the mothers where she is at work.

'We try to take patient centric, understanding approach, we might go on with their pace, we might focus on building rapport, building trust, let them feel safe, then if they don't see our services, we also don't push la' (HCT6, 6 years of experience)

A nurse, a medical social worker and speech language therapist reported that it is important to acknowledge the presence of the mothers whenever they came to visit their babies. This is imperative to reassure the mothers that they are not alone.

'Practically, I think presence helps, it might not that point in time that family will open to us, but later down the road when things get more settled. U know, after things get more settled and you follow up with them, they will be like, 'oh you were there when things happen'... (HCT6, 6 years of experience)

'Of course, I mean wat we do when we know that this relationship is rocky, we just walk by, and to show our presence a little bit more to show that we care for the baby and herself, talk to her a bit, not really about baby related, but like has she eaten already, buy pram already or not…' (HCT14, 11 years of experience)

In addition, it is the right of the infants to get dignified and respectful care. In this study, for the practice of giving donor milk, which at times will cause certain religious issues, it is crucial to respect the decision of the mother whether to feed the baby, after giving all the relevant information on the donor milk.

'The premier babies, regardless of the religions, they still will accept the donor milk. All the parents' decisions, I guess it all for the sake of the babies, like some Muslim parents right, they belief that the milk donated given to their babies, the babies will have second mother…' (HCT3, 7 years of experience)

Theme 2: Experience in delivering holistic care

The second theme identified was the experience in delivering holistic care. When an infant is admitted to NICU, it is common for mothers to experience situations that are beyond their control. They do not know how to care for their infants and the only thing they can do is actively question the healthcare team and maintain control so that they do not feel excluded from understanding the state of the baby. Thus, it is helpful to identify the psychologic tasks and emotional reactions. The medical staff frequently encounters the following circumstance:

'Sometimes the parents will question us 'why you can't do this? Why can't you do like that?' because they might have a slightly different view on how the child should be managed' (HCT2, 15 years of experience)

'But what I personally experience is the educated ones will normally take extra effort to read in advance and ask me questions before getting the updates from me regarding baby's condition, 'how's my child PDA, how's my child cranial scan' and so forth. So, they know what to ask you instead of you update them' (HCT3, 7 years of experience)

A member of the medical staff mentioned that certain mothers, however, tend to "overrule" the medical staff by recommending what should be done to their child. When this situation arises, she must defend the patient and give the justification for withholding the mother's ostensible therapy.

'I think for us when we communicate with them, we try to make it clear to them where and what the child's ability are and ermmm to tell them we sort of in the same page as them. We also want the child to resume full oral feeding but not ready yet... so we sort of set realistic goals with them and we sort of tell them where the child is at right now and what we are working towards la' (HCT1, 5 years of experience)

Theme 3: Perception working toward a shared goal

The complicated multidisciplinary nature of neonatal intensive care and the multiple hand-offs that take place in this shift-based environment necessitates effective and transparent staff teamwork and communication in order to deliver the best possible care. This leads to an emerging theme as a result of perception working toward a shared goal. For instance, during bedside rounds in this setting, team members from various disciplines reviewed the progress of the baby and the healthcare members gave their viewpoints on the baby's condition.

So far, we did join rounds, on Mondays, but after the circuit breaker, we join in corridor rounds, we join as well. We ask and when we know that there are babies who are stable enough for bottling, we will give our opinions. Then some of the doctors will ask, ' why this baby cannot start on bottling when his baby is already term and saturation can maintain'? then u know, we will normally give our comment. Like maybe saliva management not good. Nurses need to suction. And that's that, 2 way communication…' (HCT15, 7 years of experience)

One of the medical staff members commented that she was astounded that the patient's doctor had actually looked into her psychosocial history and recommended to her. She was perplexed that her skills, in addition to handling money matters, were used in the patient's treatment.

'I was also pleasantly surprised like one of the doctor like 'hey, based on what I see, err. The mother seems to have difficulty accepting the baby's condition. Are you able to follow up? Very rare. There has been doctors here and there, who flag out psychosocial concern… 'because you know, when comes to mind, MSW is just to deal with money..(HCT6, 6 years of experience)

The healthcare team shared their personal views on holistic care and a family-centred approach in order to deliver seamless patient care. To effectively administer this comprehensive care and to sustain it, it takes a 'whole village' of collaborative work among the healthcare providers, as quoted by the participants:

'so I guess holistic care means, the stakeholders, like all the stakeholders are involved, not just the medical teams and the patients but involving the parents, involving all the allied professionals as well…' (HCT1, 5 years of experience)

'to be culturally sensitive to the practices and beliefs of the NICU parents is of utmost importance…' (HCT3, 7 years of experience)

'..like the emotional needs and all that, preparing them for home and beyond.' (HCT14, 14 years of experience)

Theme 4: Challenges in delivering holistic care

The final theme identified within the data interviews findings with the health care professionals was the challenges faced in delivering holistic care. The common challenges are typically staffing issues. Healthcare team members often experienced burnout with minimal or no opportunity for interprofessional collaboration, thus reducing the space for shared decision-making in patient care.

'Some parents, they think that it is our job to care for their babies as they are paying for it. But neither they realise that we have to take care of other babies too… Sometimes we will need to take 4 cases of sick babies, all the morning rounds we just unable to follow… (HCT4, 9 years of experience)

Besides the clinical management, the doctors had also other work commitment as reported:

'…in addition to the patient care we do research, we do education, we do administrative and quality improvement and all those things, so we have each, most of the senior doctors have own portfolio, and then err… even though the percentage may vary, one of the doctor might do research, but they actually also involved in the clinical service…' (HCT2, 15 years of experience)

Consequently, in this study, as the healthcare team were not assigned permanently to NICU, it is hard to discuss with them the progress of the patients and this affects the overall team cohesiveness.

'Don't have. So I think usually discharge information, we see from the notes. Hardly there is face-to-face discussion…(HCT1, 5 years of experience)

Because you guys touch the baby at the certain time, only one of us to go round to see babies, I think the timing is a bit tricky, I think this is part of the NICU life. u know, u have to work within specific timing and timing of the babies (HCT11, 12 years of experience)

Findings from the Mothers' Perspective

After detailed data coding and categorisation into subthemes, the themes deduced from the interviews were: 1) range of layered emotions encountered by mothers, 2) finding alternatives to divert negative mindset, 3) relationship between healthcare system and family, and 4) balancing parent-infant closeness and separation. Summary of the themes and the subthemes are given in Table III.

Table III: Summary of identified themes and common subthemes from mothers' perspectives

Themes	Subthemes
Range of layered emotions encountered by mothers	•Positive feeling •Negative feeling
Finding alternatives to divert negative mindset	•Embraces spiritual beliefs as a form of support •Resorting to outsource and support
Relationship between healthcare system and family	•Nurturing positive relationship •Mothers' opinions on the health-care system •Negotiating personal struggles with voice •The importance of continuous interaction
Balancing parent-infant closeness and separation	•Professionalism, in the eyes of mothers •Mothers as advocates and active caregiving through guided participation •Mother's input for future care

Theme 1: Range of Layered Emotions Encountered by Mothers

Among the themes identified from mothers' perspectives was the expected range of layered emotions encountered by the mothers. The findings revealed that unexpected admissions of infants to NICU are subjected to experiencing negative emotions such as feeling helpless, frustrated and expression of anger towards the care and treatment received as reflected in the narratives:

'Yes, and I can't tell if you look at me as though like I am not educated which unfortunately for you 'I am' or you just...I don't know. Somewhere along the lines the systems are not well done...' (M2, 30 years old)

Another mother voiced out her concern on the attitude of one of the mothers who mistreated one of the nursing staff.

'I have seen one of the mother shouted at the nurse for not knowing the partner's baby's condition even though the nurse already explained to her that she is not the primary nurse' (M3, 28 years old)

However, mothers also articulated their positive emotions despite the conditions of their babies. They expressed their gratitude to the healthcare team for their unwavering support.

'she told me that's different team and she tries to reassure me like he will do his best like given the time that he has with my daughter so I thought that was very reassuring and the doctor actually sits down with me to explain…' (M3, 28 years old)
'…the nurses are the one who step in and stops the doctors because they (the nurses) know that my baby

cannot tolerate and might worsen her condition. They know best' (M2, 30 years old)

Besides that, the mothers try to take pride in themselves that they have come, thus far, to provide assistance and support to their babies.

'I believe that I am not a strong mother, but to think that I have come this far is so surreal for me…indeed a blessing from the ones above that my little fighter has gone this far and are preparing to be discharged… he is just a merely 500 grams baby and now…wow… .4,2kg…cannot even believe it' (M4, 44 years old)

'But a big thing you learn about being a NICU mom is that you're stronger than you think.' (M5, 38 years old)

Theme 2: Finding Alternatives to Divert Negative Mindset
The second theme identified was the mothers' ways of finding alternatives to divert negative mindset. In this study, all the mothers turn to religion for solace as a form of coping. In order to protect and bless the newborn, two of the mothers focused on acquiring religious artefacts or sacred objects for the infant as a show of belonging.

'Ermmm…I am a Buddhist and I totally believe that amulets can protect him. I will put the amulets at the bedside and inform the nurse…'(M4, 44 years old)

'I am a Catholic. I do pray for the psychological comfort, if not I will be in depress. Then I will put a rosary and a Jesus medal and baby's bedside, hoping the god will protect my baby and heal faster. (M1, 34 years old)

Besides spiritual needs, mothers tend to turn to other mothers in NICU for support.

'Then there is this culture of giving chocolates and sweets by one of the mothers. I think this is a good way to cheer up. So, this actually makes me think that this journey is not as hard as it seems la, like someone else is going through the same journey with me (M3, 28 years old)

Some mothers engage with social media, reaching out to mothers internationally.

'…found out myself the basic key terms used by the doctors when they update me and reaching out to mummies from all over the world. I have spoken to mummies in Singapore that have similar preterm babies, and I have spoken to mothers from Canada, mothers from US, see what their side have done differently… '(M2, 30 years old)

'I join the Facebook group also, mostly the U. S. ones about premise. That really helps me a lot. Like for instance, Scott is intubated for quite a long time, because of those Facebook groups rite, they are like suggesting the steroid duct protocol. So I went to discuss with the team doctor about this…' (M1, 34 years old)

Theme 3: Relationship between Healthcare System and Family
The relationship between the healthcare system and family was another theme identified. This theme emphasizes on how to establish positive relationships merely towards the attitudes of the healthcare professionals in attending to the mothers. As mentioned,

'…some nurses are more proactive, they will come and attend to my baby and even explain why the baby desaturates, like maybe due to post-feeding, positioning, or baby not comfortable. This actually allays my worries u know to a certain extent...'(M4, 44 years old)

Two mothers had a negative experience with one of the members of the healthcare team. She expressed her unhappiness towards the staff and the entire process.

'I just don't understand how it works here. Then what is the use of the family conference when the plan discussed in the conference was not followed?' (M2, 30 years old)

'I can sense the politics and I know who they are. It is that obvious. So far, I never make any complaints, I could but I have not because I don't think its intentional, I don't think is malicious…' (M4, 44 years old)

A mother commented that she appreciates the effort of a doctor in informing the medical social worker just when she needs it.

'Doctor will contact MSW to come, so they actually alerted MSW, even if the MSW is on medical leave, they will find a substitute to support mother at the bedside. Just when I need a company and support…' (M5, 38 years old)

On the other hand, mothers mentioned that she should be informed about her infant's treatment plan before a new treatment is initiated.

'I am being a quite reasonable parent, I never question their (the doctor and nurses) expertise, I never query about their decision making, until this things (a sudden adjustment of oxygen requirement) happens and it start to make like…' (M2, 30 years old)

Theme 4: Balancing Parent-Infant Closeness and Separation
Research into the needs of mothers in the NICU have found that the main priority is to safeguard the infant. Therefore balancing the parent and infant between closeness and separation was emerged as the 4th theme among the mothers. The stress of being separated from the babies can be alleviated through active guided participation of mothers in the NICU, as proposed by 3 of the mothers.

'.. the nurses actually encouraged me to do kangaroo care, of course with their assistance. Basically, I learnt a lot, not only from my baby's condition, how to recognize bradycardia, desaturations and apnea, but also some of the machines that my baby is using' (M4, 44 years old)

'Oh yes I did everything. From singing, praying to feeding. The nurses did encourage me to do, and I participated when possible so that I can take back my girl as soon as possible' (M2, 30 years old)

'The nurses did ask me to change diapers and do some tube feeding. I also did some kangaroo care but I still prefer to carry him the normal way.' (M1, 34 years old)

Mothers also gave their expectations and recommendations to inform future care.

'Sometimes there might be a misinterpretation of handing over the case. So perhaps right, we can assign the same nurse to take for like at least a week, let's say? (M3, 28 years old)

'Since this interview is about holistic care, then all those involved should really practice it and be sensitive to mother's feelings' (M4, 44 years old)

DISCUSSION

Providing holistic care is not merely about whether appropriate resources and facilities were available to mothers, neither it is about whether they were allowed to perform parenting tasks on their infants or not. It simply means the ability of the multidisciplinary team in creating a sense of shared identity and mission that motivates team members to be more open and trusting with one another as well as to offer constructive criticism and different viewpoints on a person's needs and opportunities.

The researchers described the findings as 'sustaining footprints in mothers' heart'. This metaphor coincides with what the study aims which is to explore the worries and needs of the mothers in the NICU and to address what the potential challenges are to overcome for the healthcare team to provide effective and memorable holistic care to the infants and families.

Mothers should gain a sense of security in this new environment before engaging in caregiving roles. The role of health care professionals were important especially when sharing the infant's medical conditions whereby mothers requested for the information to be accurate, current and comprehensive which are comparable to those of Alkozie, McMahon, and Lahav (2014) in examining maternal stress levels when newborns are in NICU [17]. This previous study shows that regular and consistent updates of infants reduce stress and secure relationships between mothers and healthcare personnel. Additionally, this organization uses discharge pathway forms to help remind the medical staff that the newborn must be examined at a specific gestation.

Early mutual social connectedness between the healthcare professionals, NICU infants and the parents will promote prolonged parental engagement, the behavioural and social development of the infants as well as the well-being of the families [18]. The current findings were similar to a previous study by Saunders and Halls [18] which adopted the polyvagal theory which explores the social connectedness between people involved in the trauma-informed care of infants in NICU.

It is typical for mothers to experience a demanding and ongoing psychosocial and emotional impact as a result of their infant being admitted to the NICU. Mothers expressed a variety of feelings, ranging from helplessness to concerns about the whole circumstance. Most mothers struggling with feelings of inadequacy and guilt in not delivering a healthy infant. The mothers may focus on concrete things, such as not eating well , the flu, the birth control pills or an unwanted pregnancy. Findings were similar to a previous qualitative descriptive study by Rihan et al. [19] where many mothers seemed to blame themselves for the infant's condition and questioned whether their specific actions had actually contributed to the infant's current condition. Some mothers place responsibility on themselves, while others shift the blame to others such as spouse, health care professionals and even God. However, all of this emotional upheaval can be lessened with the help of others around them, and most importantly, the medical staff must recognise and respond to their needs and direct patients to the proper personnel for aid. Beresford [20] describes a psychological process that parents will go through that will help them adjust to having a baby in the neonatal unit, particularly the impact of technology and how it affects the professional-parental relationships, followed by a focus on the parents' determination to return to normality and then the necessary adjustments into normal life. This psychological process strengthens the bond between the parent and child. One of the issues identified in this study can be adopted using one of the findings from a study by Jepkosgei et al. [21].

Neonatal care has become increasingly complex, necessitating teamwork and fostering collaboration among multiple disciplines in order to achieve a common goal, that is to improve patients' outcomes. Working together properly and effectively with healthcare professionals could strengthen relationships and lead to shared goals, as also proposed by Hadian Shirazi et al.[22]. The fundamental elements of a successful multidisciplinary neonatal intensive care unit (NICU) team include good communication, a shared understanding of the team's objective, a psychologically safe practise environment, and respect among team members. The presence of one disability is an indication for careful evaluation of other area of function. A full multidisciplinary evaluation is

recommended to help identify areas of strength, devise intervention plans, give parents realistic information for counselling, and locate resources for support. Having central case notes for each patient can help reduce the confusion and role duplication that occur in this study.

The patients in this study received a favourable and enlightening experience from the support groups, such as the "befriender" group. Mothers may have to spend time away from their support network if their child is in the NICU. Therefore, mothers turn to spirituality, religion, and rituals, which may also be a great source of strength, comfort, and hope for them, assisting them in setting care objectives and making difficult decisions [23]. It turns out that, in contrast to a prior study by Brelsford and Doheny [24], spirituality actually has little bearing on mothers' experiences in NICUs, and they can manage properly. Instead, family, peer-to-peer support, and medical assistance are more crucial. Numerous earlier studies have concentrated on the experiences of mothers and carers in NICUs, but none have addressed the support services provided to them during the time their infants are admitted [22].

Separation is undoubtedly the worst feature of having an infant in the neonatal unit. It prevents a mother from getting to know her baby and often threatens her perceptions of her ability to become a 'good mother'. Therefore, this study aims to hasten the time that the infant can be reunited with their mothers. Visitation policies that reflect the need of the mothers to have unlimited access to their infants has been implemented. The transfer of care from staff to parent is influenced by the stability or lability of the infants, the physical health of the mother, the level of support that mothers receive as well as the staff expectations. According to Gibson, Ross, Williams and de Vries [25] in their qualitative study, they found out that many parents were not prepared for the conflict between their own needs and their infants' needs. Thus, the multidisciplinary team tailored the way they communicated with the mothers with the aim to maximise their willingness to open to them. Breaking down information into small chunks and using it with a practical task, for instant, tube feeding, and constantly reviewing the mother's understanding and knowledge helps to minimize gaps in their knowledge.

Mothers frequently experience uncertainties, and their brains become clogged with information. It may occasionally be required for mothers to be assisted in creating queries because many of them are unsure of what to inquire about. "Do you understand why we need to mark the baby's hands with lines?", "Do you understand why we need to stop feeding the baby?" The encounter left all of the women feeling so overwhelmed that they had no idea what to ask the medical staff. These results concur with those of a study carried out by Arnold et al. [26] in two distinct newborn critical care units in the UK. Still, the prospective study in the Paris region by Guillaume et al.[27] discovered that some parents felt they were being treated as individuals when the personnel used their names. The nature of the relationships that families develop has been evidenced to have a profound influence on how the mothers respond to the experience of having an infant in the NICU [16] supported by a recent study by Tastekin and Bayhan [18, 28]

Graduate parents can offer emotional support and hands-on help to moms who are interested in breastfeeding, to parents whose babies are discharged on oxygen at home, and to parents of babies with unique medical needs such as tracheostomies, gastrostomy feeding, colostomies, and other related care. This is what has been practiced in the KK hospital whereby every week, they will locate a mother whose infant has been discharged to talk with parents of infants admitted in the NICU. Parents who share their feelings, reactions, and experiences can find support from "graduate parents" or parents of infants in NICU [29]. Feedback sessions of parental viewpoints and sharing of experiences can be a great catalyst for change.

The study findings shows that there is a gap in the communication between the healthcare professionals and the mothers. Failure in establishing a chain of communication can cause a detrimental effect in holistic care practices as evidenced by a study done in rural Rwanda [17]. When mothers were provided information about the newborn's condition in a caring manner, mothers usually feel more hopeful, confident and will place trust in the healthcare providers. The opinions of the mothers in this current study, the healthcare professionals were often presented as pessimistic, lacking empathy and impatient especially when the parents needed care and had high expectations for their infants. According to a study done by Miller, Serwint, & Boss (2021), if mothers sense the staff's genuine concern and interest in them and their infant, it is easier for them to leave their infant in the staff's care. A team member might say,'You look frightened or scare,' or 'this can be an overwhelming situation. Facilitating the parents' relationship with the infant is essential and can be done by offering the mothers opportunity to involve in infant's routine care [30].

When staffing is limited, the healthcare team had almost limited to no time to guide mothers in participating in the care of their babies. However, in this study, home care team, consisting of mostly nurses, has taken over the role of educating and encouraging mothers in participating in infant care. However, the findings of the healthcare team in a study in Iran by Negarandeh et al. (2021) stated that the staff believed that mothers are primarily responsible for the care and tend to rely on maternal presence [31]. This is congruent to a previous systematic review by Van Veenendaal et al. [32] whereby active participation by the mothers in infant care is a significant facilitator to the association between the holistic care and higher level of maternal self-efficacy, supported by

Thompson et al. [33] and Feeley et al. [34] that respect and encourage mothers to take part in the process while also encouraging self-care, which is another aspect of holistic care that leads to a sense of autonomy.

CONCLUSION

In summary, the health care organization and family should work together to provide infants and parents with respectful and dignified care. Teamwork and collaboration are required for establishing partnerships with families and working cross-departmentally on all care-related choices. Integrating holistic care principles practiced throughout the NICU stay facilitates better adaptation to the transition to home.

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