

IMPROVING THE SUPPORT OF NEONATES POST DISCHARGED FROM NEONATAL INTENSIVE CARE UNIT (NICU) OR SPECIAL CARE NURSERY (SCN)

Dr Sharon Linus-Lojikip

Clinical Research Centre, Ministry of Health Malaysia

Hospital Raja Permaisuri Bainun, Jalan Raja Ashman Shah, 30450 Ipoh, Perak

Email: sharonlojikip.crc@gmail.com

Nur Fatin Zulaikha

Clinical Research Centre, Ministry of Health Malaysia

Hospital Raja Permaisuri Bainun, Jalan Raja Ashman Shah, 30450 Ipoh, Perak

Email: fatinzulaikhakarudin@gmail.com

Norasnah Mt Isa

Kolej Sains Kesihatan Bersekutu Sultan Azlan Shah,

31250 Tanjung Rambutan, Perak

Email: asmah74@yahoo.com

Noor Hazilah Che Nordin

Kolej Sains Kesihatan Bersekutu Sultan Azlan Shah,

31250 Tanjung Rambutan, Perak

Email: hazilahchenordin@gmail.com

Norfariza Mustapha

Kolej Sains Kesihatan Bersekutu Sultan Azlan Shah,

31250 Tanjung Rambutan, Perak

Email: mohdfaizul3131@gmail.com

Kalpana Muniandy

Kolej Sains Kesihatan Bersekutu Sultan Azlan Shah,

31250 Tanjung Rambutan, Perak

Email: kalpana.1807@yahoo.com

Harvinderjit Kaur

Kolej Sains Kesihatan Bersekutu Sultan Azlan Shah,

31250 Tanjung Rambutan, Perak

Email: harvinpeter83@gmail.com

Lai Jia Min

Clinical Research Centre, Ministry of Health Malaysia

Hospital Raja Permaisuri Bainun, Jalan Raja Ashman Shah, 30450 Ipoh, Perak

Email: jiaminlai.crc@gmail.com

Dr Chin Pue Siah

Pediatric Department

Hospital Raja Permaisuri Bainun, Jalan Raja Ashman Shah, 30450 Ipoh, Perak

Email: pueisiah@gmail.com

Pn Haymalatha Rajagam

Kolej Sains Kesihatan Bersekutu Sultan Azlan Shah,

31250 Tanjung Rambutan, Perak

Email: haymalatha@yahoo.com

Dato' Dr Amar-Singh HSS

Clinical Research Centre, Ministry of Health Malaysia

Hospital Raja Permaisuri Bainun, Jalan Raja Ashman Shah, 30450 Ipoh, Perak

Email: amarhss@gmail.com

ABSTRACT

The wellbeing of previously ill neonates after being discharged from the Neonatal Intensive Care Unit (NICU) or Special Care Nursery (SCN), depends largely on the continuation of the nursing effort by their parents at home. Most parents are required to continue caring for these neonates without the presence of any healthcare professionals. Their readiness and coping skills to care for these neonates at home are therefore essential. Two new interventions have been devised to prepare and support parents at home, firstly the Discharge Preparation Plan (DPP). DPP was a personalised discharge plan containing specific practical

parenting and neonatal home care advice and delivered face-to-face by trained researchers to the individual parent before a neonate discharge. Secondly, two home visits within 72 hours post NICU/SCN discharge by Public Health Nurses (PHN). The home visits ensured that healthcare professionals addressed immediate health care needs at home. This study evaluated the usefulness of these two interventions, and it was conducted from 15th May to 31st August 2017 in Hospital Raja Permaisuri Bainun, Perak. Twenty-one consented parents with neonates hospitalised in NICU/SCN for >1 week, received the DPP and two home visits. Following the interventions, all parents reported feeling prepared caring for their neonate at home after receiving the DPP. Most parents rated breastfeeding (52%), coping with emotions (62%), and receiving support (67%) as the most uncomplicated issues faced by them. More than half felt easier coping with crying (71%), feeding (67%), and preventing infection (67%). Confidence in handling milk aspiration (14%) and baby emergencies (19%) were two areas that had unfavourable responses. All were also receptive and satisfied with the quality of the home visits. PHNs who delivered the home visits post NICU/SCN discharge were prepared to deliver the home visits (100%). The majority agreed that these were adequate to address the immediate health concerns at home (95%). Personalised DPP and sufficient home visits by PHNs are simple targeted interventions that may offer additional parental support to continue caring for neonates recently discharged from the NICU/SCN.

Key words: Neonates, discharge planning, parents, Public Health Nurses, home visit, intervention

INTRODUCTION

Neonates treated in the neonatal intensive care unit (NICU) or special care nursery (SCN) are usually admitted for the treatment and stabilisation of severe and critical illnesses of the newborn. These neonates are at higher risk of developing chronic medical conditions that require long term follow up (Berman et al., 2019). Notably, these neonates require continuation of health care and support after being discharged from the hospital (Boykova & Kenner, 2012). Once discharged from the NICU or SCN, parents usually become the main caregivers in administering the continuation of care for the previously-ill neonates at home.

Parents to these neonates often experience increased anxiety and stress due to the health issues associated with their previously ill neonates (Obeidat, Bond, & Callister, 2009). To help them cope with the stresses and continue caring for their recovering neonates confidently and independently at home, they needed to be prepared and supported through discharge and immediately after (Purdy, Craig, & Zeanah, 2015). Preparing parents for home care will also ensure a smooth transition from the acute care setting (NICU or SCN) to home care for these neonates.

Currently, there are no published articles that studied the types and extent of support that parents in Malaysia received if they have neonates admitted into the NICU or SCN. There are also no known interventions, established within any hospitals' local setting to equip and support these parents to care for their previously-ill child at home independently. This study, therefore, aims to improve the support for these parents by introducing preparation interventions for parents. The interventions were specifically developed to improve the support for parents in caring for their neonates at home. Personalised discharge preparation plan for parents to care for their neonates at home delivered by trained personnel, and alerting public health nurses (PHN) to conduct two home visits after a NICU or SCN discharge, are two interventions that were used and evaluated in this study.

METHODS

Overview of Study Design

This study is a quasi-experimental study that was conducted from 15th May until 31st August 2017 at Neonatal Intensive Care Unit (NICU) and Special Care Nursery (SCN) of Hospital Raja Permaisuri Bainun (HRPB) Perak. Two interventions to improve parental care at home for neonates discharged from NICU and SCN were devised, used and evaluated in this study. This study was conducted in three phases, namely Phase 1, where identification of eligible parents to enter into the study was made, Phase 2 where delivery of interventions happens and Phase 3 where the interventions were evaluated.

Description of the interventions for study

Two interventions aimed at improving parental support to care for their newly discharge neonates at home were devised. The descriptions of the intervention are as the following:-

1. Discharge preparation plan

This intervention is a personalised discharge preparation plan that contained practical neonates home care information and tips catered for parents with neonates of different needs. This plan intended to ensure that parents were prepared and ready to care for their neonates at home after an episode of a critical period in the early life of their neonates. The researchers (trained nurses) delivered this plan face to face to all participating parents, a day before their neonates were discharged home. The researchers trained the parents on specific caring techniques that the neonates might need at home. On average, the researcher spent 25 minutes to deliver the personalised discharge preparation plan to each participating parent.

A one-page guide was constructed to assist the researchers to deliver this intervention (please see Supplementary File 1 (a) and (b): Discharge Preparation Plan). This guide was constructed based on input from two senior paediatricians from HRPB. There were two sections in this discharge preparation plan. The first section contained practical information on handling common

newborn issues which include crying, safe sleeping environment, feeding, milk aspiration, infection prevention and handling emergencies. The second section contained practical information for parents in ensuring adequate feeding and self-care reminders. A copy of the discharge plan was given to each participating parent.

2. Home visits by the public health nurses

The second intervention involved collaboration from the Public Health Department of Perak State. For every neonate discharge of a participating parent, a Public Health Nurse (PHN) was contacted and assigned for a follow-up with the discharged neonate at home. PHN working in the area where the family is residing was contacted and informed of the neonates' discharged details. Details of the parents and neonates were communicated to the PHN for home visit preparation.

In this intervention, each assigned PHN conducted a total of two home visits within 72 hours post-NICU or SCN discharge for each neonate. This intervention intended to ensure the provision of post-natal care at home to mothers and neonates, to ensure additional healthcare support was given to the parents if the discharge occurs beyond the post-natal period, and to address immediate health care needs by the neonates and parents at home.

Phase 1: Identification of eligible parents to enter into the study

All parents of neonates who were admitted into NICU or SCN for more than one week and planned for discharges from the NICU or SCN from 15th May to 31st August 2017, were included in this study. The researchers identified all eligible parents through a daily examination of the neonates' admission records from NICU and SCN. Parents of neonates with congenital malformation or syndrome, teenage mothers, abandoned neonates, non-biological parents as caretaker and mothers with psychiatric disorders were excluded from the study. Written informed consent was obtained from each parent who agreed to participate in the study.

Phase 2: Delivery of interventions

In the NICU or SCN, a day before the participating parents brought their neonates home from the hospital, the discharge preparation plan was delivered. On the day of discharge, PHN in-charge of the parents' residing area, was notified and reminded of the home visits that should be performed within 72 hours post-discharge.

Phase 3: Evaluation of interventions

In this phase, parents and involved PHN were asked to evaluate the interventions. The researchers conducted a telephone survey for the evaluation. Each parent and PHN was contacted at the 7th-day post-NICU or SCN discharge, a time period where two home visits by the PHN should have already occurred. Verbal consent was sought during the telephone call before the researchers verbally administer the evaluation questions. In the telephone survey, the participating parents were asked to evaluate the quality and adequacy of home support received from the PHN, their coping with common neonatal issues and benefit received through the discharge preparation plan. The PHN who delivered the two home visits were also asked to evaluate the feasibility of the visits. Figure 1 illustrates the study methodology flow.

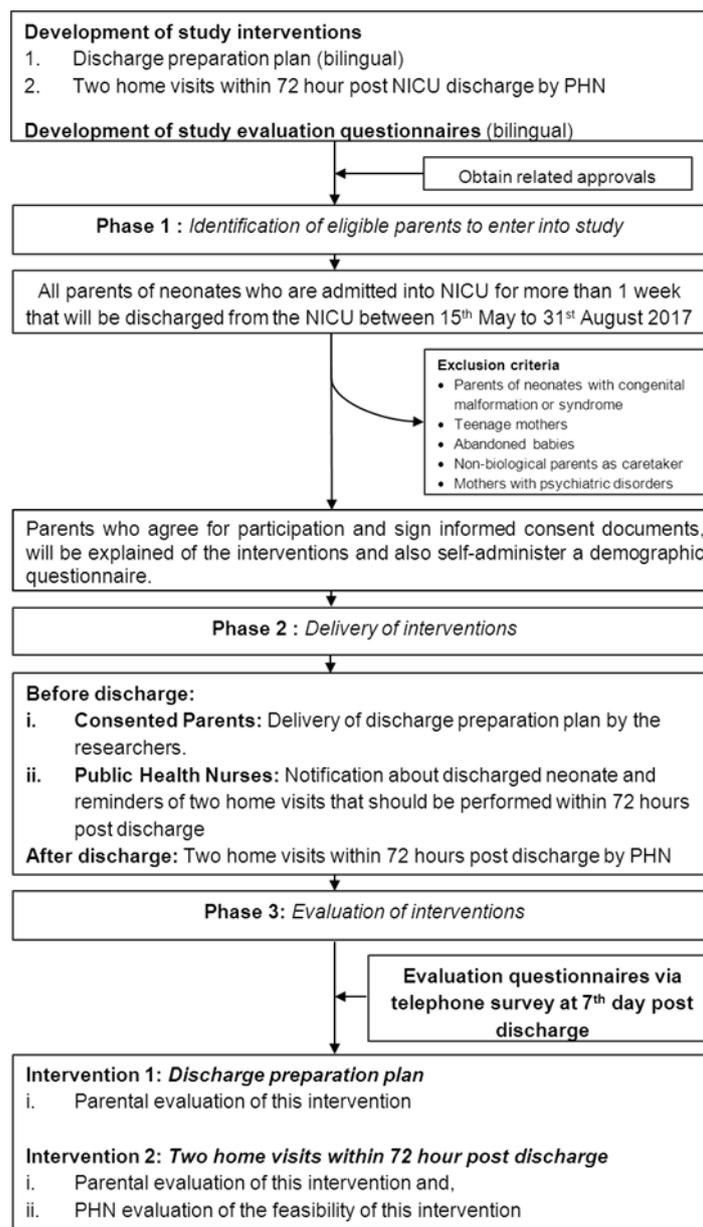


Figure 1. Study methodology flowchart.

RESULTS

Response rate, home visitations and telephone evaluation participation

A total of 21 eligible parents with suitable neonates were identified during the study period and were approached to enter into the study by the researchers. All the 21 parents consented to participate in the study and therefore received the DPP from the researchers. Twenty PHN were contacted to conduct home visits. One PHN received two families for home visitations. All the 20 contacted PHN conducted two home visits for all the parents within 72 hours post-NICU or SCN discharge. Most of the home visitations occurred during weekdays (34, 80.95%) as compared to weekends (8, 19.05%). All parents, who received the DPP and all PHN who conducted the home visits, agreed to be interviewed via telephone for verbal evaluation of the interventions.

Demography of parents

All the parents in this study were married mothers, and their median age was 30 years old (IQR 8). Most of them were of Malay ethnicity (13, 61.9%), received at least secondary school education (12, 57.1%), never worked/unemployed long-term (7, 33.3%) and stated to receive support mostly from their parents at home for childcare (15, 71.4%). Table 1 illustrates the participating parents' demography characteristics.

Table 1. Parents' (N=21) and their spouses' (N=21) characteristics

Characteristics	Frequency, n (%)	
	Participating parents	Spouse
Age (median in years)	30.00(8.0) *	30.00(9.0) *
Ethnicity		
Malay	13(61.9)	NA
Chinese	3(14.3)	NA
Indian	5(23.8)	NA
Marital status		
Married	21(100.0)	NA
Occupation		
Higher managerial	1(4.8)	1(4.8)
Lower managerial	2(9.5)	1(4.8)
Intermediate occupations	3(14.3)	5(23.8)
Small employers and own-account workers	2(9.5)	3(14.3)
Lower supervisory and technical occupations	0	1(4.8)
Semi-routine occupations	3(14.3)	7(33.3)
Routine occupations	3(14.3)	3(14.3)
Never worked and long-term unemployed	7(33.3)	0
Highest level of education		
Secondary	12(57.1)	11(52.4)
Tertiary	9(42.9)	10(47.6)
Supporting members at home for childcare		
Parents	15(71.4)	NA
Maid	0	NA
Husband	6(28.6)	NA

*Median (IQR); NA Not available

Characteristics of neonates

Twenty-one neonates were admitted into either SCN or NICU. Most of the neonates received direct admissions to SCN (13, 61.9%) as compared to NICU (8, 38.1%). The neonates that received direct admissions to SCN were generally heavier at birth with the median weight of 2.1 kg (IQR 1.1) and with shorter length of stay (LOS) in SCN before being discharged home (median LOS 8 days (IQR 4.0)). Please see Figure 2 for the distribution of neonates' admission, length of stay and weight. The reasons for direct SCN admissions were as the following: -

- a) Premature
- b) Poor weight gain
- c) Omphalitis
- d) Presumed sepsis
- e) Transient tachypnoeic of newborn (TTN), congenital talipes equinovarus (CTEV)
- f) Viral pneumonia
- g) Small gestational age (SGA) and infant of diabetic mother (IDM)
- h) Community-acquired pneumonia
- i) Low birth weight (LBW)

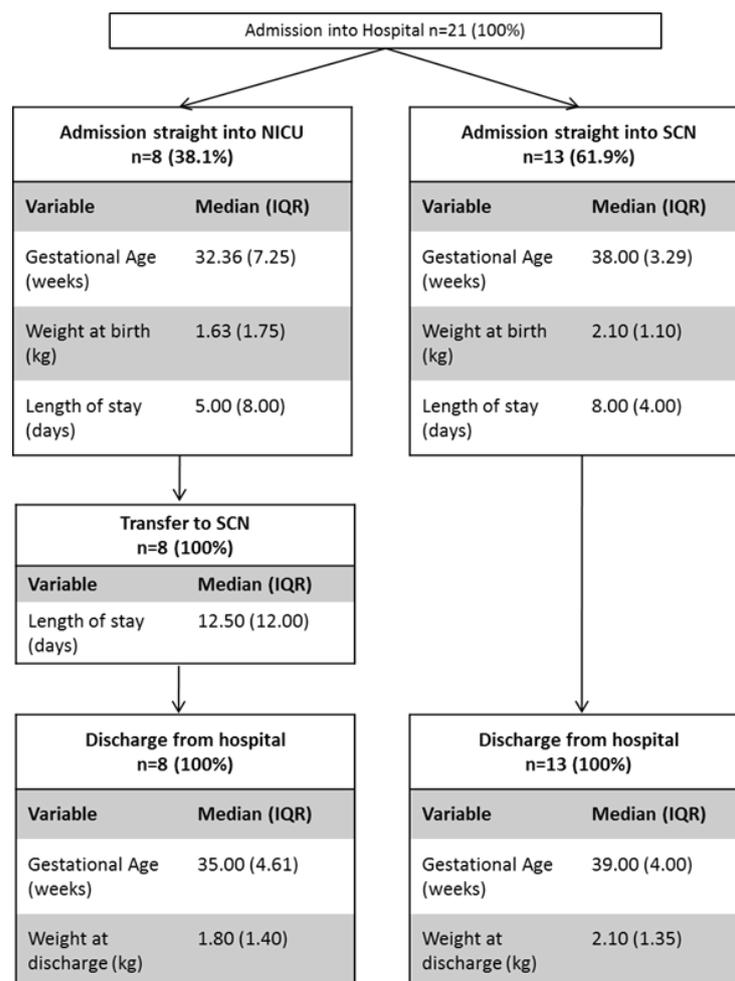


Figure 2. Diagram showing the distribution of neonates' admission, length of stay and weight.

Demography of the Public Health Nurses

Twenty PHN were contacted to conduct home visits in this study. Their median age was 32 years (IQR 7.3), with 7 median years of working experience as PHN (IQR 6.8), and had been conducting routine post-natal home visits for 5.5 median years (IQR 6.8). Half of the PHN had post-basic training in public health (10, 50%), and most had previous experience in managing premature babies during the routine post-natal visits (19, 95.0%). Only seven of them (35.0%) reported having previous experience in managing babies with special care during post-natal home visits. Please see Table 2 for PHN characteristics.

Table 2. Public health nurses characteristics (N=20)

PHN characteristics	Frequency, n (%)
Age (years)	32.00 (7.3)*
Duration working as a PHN (years)	7.00 (6.8)*
Duration working in this state (Perak) (years)	5.50 (5.8)*
Duration conducting post-natal visits as PHN (years)	5.50 (6.8)*
Post basic training	
Yes	10 (50.0)
No	10 (50.0)
Previous experience in managing premature babies through postnatal visits	
Yes	19 (95.0)
No	1 (5.0)
Previous experience in managing babies with special care through home visits	
Yes	7 (35.0)
No	13 (65.5)

* Median (IQR)

Response and feedback from participating parents

i. The usefulness of discharge preparation plan (DPP)

All parents reported that they felt prepared to bring their baby back home from NICU or SCN after the personalised discharge preparation plan was delivered to them (100%). All of the parents also reported that they were able to make prior preparation to bring their neonates back home from NICU or SCN (100%). Generally, all the parents reported favourable responses on coping with most neonatal issues at home (Please see Table 3). Two areas that had unfavourable responses were confidence levels in handling milk aspiration situation and handling baby emergencies.

Table 3. Ability to cope and manage common neonatal and parenthood issues at home after NICU discharge as reported by 21 parents using a rating scale

	Response, n (%)				
	1 (Hardest)	2	3	4	5 (Easiest)
Ability to cope with baby crying	0	0	5 (23.8)	15 (71.4)	1 (4.8)
Ability to put baby to sleep	0	0	6 (28.6)	11 (52.4)	4 (19.0)
Easiness of feeding the baby	0	0	2 (9.5)	14 (66.7)	5 (23.8)
Confidence level in handling milk aspiration	0	3 (14.3)	7 (33.3)	11 (52.4)	0
Confidence level in handling baby emergencies	0	4 (19.0)	7 (33.3)	10 (47.6)	0
Making changes at home to prevent infection	0	1 (4.8)	1 (4.8)	14 (66.7)	5 (23.8)
Ability to ensure adequate breastfeeding / feeding the baby	0	0	2 (9.5)	8 (38.1)	11 (52.4)
Emotional status at the time of interview*	0	0	2 (9.5)	6 (28.6)	13 (61.9)
Overall quality of support received at home*	0	0	0	7 (33.3)	14 (66.7)
Calmness level when the baby cry at night*	0	0	7 (33.3)	14 (66.7)	0

* Rating scale for these items is from 1 to 5 (1 being the worst, 5 being the best)

ii. Quality and adequacy of home visits experienced by parents who received home visitation by the PHN

All parents felt that the duration of time spent during the home visits was appropriate and the frequency of the scheduled visits adequate. Most also did not need more home visits. They generally did not think that the home visits by the PHN were intrusive. All of the parents reported that the visits enhanced their confidence in caring for their neonates and made them feel supported. The PHN were polite and kind towards their family and managed to address their neonates' special needs. Please see Table 4.

Table 4. Quality and adequacy of home visits as reported by 21 parents who received at least 1 home visit

	Response, n (%)		
	Yes	No	Unsure
Adequacy			
Time spent on home visits was appropriate	21(100)	0	0
Two visits within 72 hours are adequate	21(100)	0	0
More home visits are needed	1 (4.8)	20(95.2)	0
The home visits are intrusive	1 (4.8)	20(95.2)	0
Quality			

The visits enhanced confidence in caring for neonates	21(100)	0	0
The PHN was polite and kinds to the family	21(100)	0	0
PHN addressed the neonates special needs	21(100)	0	0
The visits made the parents feel supported	21(100)	0	0

Response and feedback from public health nurses (PHN)

i. Feasibility of 2 home visits within 72 hours post-NICU or SCN discharge

All of the PHN responded that they were prepared to provide home visit service to recently discharged babies from NICU or SCN. 12 (57.1%) PHN stated that the home visits post-NICU or SCN discharge were different from the usual routine postnatal visits. Please see Table 5. One PHN reported that additional staff to support the conduct of the home visits was needed. Another PHN also reported that more home visits were needed to support the care of a neonate. The neonate that required more visitation support was diagnosed with multiple gastrointestinal diseases (surgical) and required feeding support.

Table 5: Feasibility of home visit post NICU discharge by PHN

	Response, n (%)		
	Yes	No	Unsure
Prepared to provide healthcare service at home for babies recently discharged from NICU	21 (100)	0	0
Home visit post NICU discharge is different from the usual postnatal home care visit	12 (57.1)	9 (42.9)	0
More support is needed to conduct home visits for babies recently discharged from NICU	1 (4.8)	20 (95.2)	0

ii. Quality and adequacy of home visits as reported by the PHN

All of the PHN agreed the duration of time spent for the home visits and frequency of visits within 72 hours, were appropriate and adequate. Majority of the PHN reported that most of the families did not need more follow up visits (20, 95.2%). Most of them also disagreed that the home visits were intrusive to the families (16, 76.2%). The home visits enhanced the parents' confidence in caring for the neonates and made the parents felt supported as reported by the PHN. Please see Table 6.

Table 6. Adequacy and quality of home visits as reported by 20 PHN who conducted at least one home visit

	Response, n (%) (N=21 home visits)		
	Yes	No	Unsure
Adequacy			
Time spent on home visits was appropriate	21 (100)	0	0
Two visits within 72 hours are adequate	21 (100)	0	0
More home visits are needed for the family	1 (4.8)	20 (95.2)	0
The home visits are intrusive to the family	5 (23.8)	16 (76.2)	0
Perceived Quality			
Their visits enhanced parents' confidence in caring for the neonate	20 (95.2)	1 (4.8)	0
The visited family was receptive towards their service	21 (100)	0	0
They were able to address the neonates special needs	21 (100)	0	0
Their visits made the parents feel supported	21 (100)	0	0

DISCUSSION

This study offered targeted support to improve parental readiness and home support to care for neonates recently discharged from NICU or SCN. Generally, the personalised discharged preparation plan (DPP) used in this study enhanced parental readiness and preparation to care for their neonates at home after an episode of a critical period in the hospital. The two home visits by PHN within 72 hours post-discharge from the NICU or SCN, further supported the home care for these neonates. The DPP carefully addressed common issues and offered practical solutions to improve parental readiness and preparation to care for previously ill neonates at home. The participating parents benefited from this plan, and it eased the transition from hospital to home care for their neonates.

The two home visits by PHN within 72 hours post-discharge were mostly possible because of the cooperation from the public health department. With the home visits, health concerns occurring after hospitalisation can be addressed immediately by certified health care professionals, thereby decreasing the risk of deterioration of the neonates' health. Most parents and PHN agreed that all the special concerns concerning the care of the neonates were manageable and addressed during the home visits. Parents also widely agreed that the home visits were supportive. While most parents and PHN agreed that two home visits were

adequate to address the immediate health concerns for the neonates, through assessment from a PHN at home, a neonate with surgical diseases was thought to require more home visits for more comprehensive care. This indicated that health care professionals' assessment at home is valuable for the continuity of healthcare support for a neonate with complicated surgical issues.

From this study, we identified that confidence among parents in the management for milk aspiration and neonatal emergencies were insufficient despite training during the DPP delivery. Training or education sessions in these two areas needed to be improved. These training should be emphasised among parents with neonates born with conditions where risks for aspiration and medical emergencies are higher, such as neonates of low birth weight and managed for multiple medical conditions including prematurity, congenital heart disease, respiratory disease and for weight gain.

There are similar studies that were conducted in other countries that also aimed to improve parental support to care for neonates recently discharged from NICU or SCN. The studies delivered similar interventions through pre-discharged plans and home care services to the parents following discharges from the NICU (Broedsgaard & Wagner, 2005; Glazebrook et al., 2007; Lasby, Newton, & von Platen, 2004; Melnyk et al., 2006). In those studies, favourable and positive outcomes were observed and reported.

The reported observed benefits are various such as a longer provision of breast milk to the neonate, fewer visits to the emergency department, less unscheduled physician appointments, shorter length of stay for rehospitalisation, and increased overall maternal satisfaction. An important finding from the studies was that the parents felt secure returning home with their neonates after receiving the pre-discharge intervention. The intervention frameworks by the various studies were similar in this study. It differed in terms of intensity, methodology and duration. Despite the differences, notable positive responses and benefits were reported in this study as found in the other studies. Please see Table 7.

Table 7. Comparison with other studies

No	Author & year of publication	Type of study	Sample size	Site	Intervention/program contents	Intervention delivered by	Result
1	(Lasby et al., 2004)	Randomized controlled study	135 parents with infants <1,250 gm	Calgary	Consultations with the clinical nurse specialist (CNS): two pre-discharge for 4 months, 10–20 home visits. CNS available 14 hours per day, 5 days per week by pager	Home health care service if needed	Longer provision of breast milk, fewer visits to the emergency department (ED), less unscheduled physician appointments, shorter length of stay for rehospitalization, and increased maternal satisfaction.
2	(Paul et al., 2012)	Retrospective quantitative analysis	2,641 term or near-term infants without need for extended care	United States of America	Retrospective analysis of a financial database to infants with and without a home visit and their need for hospital services in the first 10 days of life because of jaundice and dehydration	Home health care nurse	Significant differences in readmission rate and ED visits; home visits are highly cost-effective.
3	(Broedsgaard & Wagner, 2005)	Non-experimental descriptive study	37 parents with infants <34 weeks gestation	Denmark	Educational/support groups once a month over 2 years beginning pre-discharge following discharge from the neonatal unit, one home visit by the coordinator nurse	Coordinator nurse (home visits)	Education group discussions were the most meaningful interventions; the program was beneficial and provided continuity of care; received support and guidance; felt secure returning home; same contact nurse is important.
4	(Melnyk et al., 2006)	Randomized controlled study	247 families with infants ≤34 weeks gestation, birth weight <2,500 gm	United States of America	Parents got audiotaped and written information in four phases: 1. 2–4 days after admission at NICU, 2. 2–4 days after the first intervention, 3. 1–4 days before discharge, and 4. 1 week after discharge via a home visit from research nurse	Research nurses	Less maternal stress in the NICU, stronger parental beliefs, more positive parent-infant interactions in the NICU, and less maternal anxiety and depressive symptoms after hospitalization. Parents in the COPE program interacted with the infants in a more developmentally sensitive manner than parents in the comparison program.
5	(Glazebrook et al., 2007)	Cluster-randomized controlled study	233 parents with infants <32 weeks gestation	United Kingdom	Educational session with a special trained nurse once a week at the NICU; the parents had the choice to continue this intervention at home for up to 6 weeks	NICU nurses	No significant differences in maternal responsiveness to infant's needs, the neurobehavioral development of the infant, in the caregiver-child interaction, and the appropriateness of the environment to foster proper development.

6	(Willis, 2008)	Program with descriptive analysis	57 families with infants <37 weeks gestation or low birth weight	United States of America	Educational/support groups once a week for 10 weeks. One week postdischarge home visit by a community agency; second week: telephone call and offer of additional home visits (50% agreed)	NICU nurse as program coordinator	Satisfaction survey after the 10-week program, use of a 5-point Likert scale; parents' responses ranged from 4 to 5, they felt their needs were met; narrative feedback was habitually positive.
7	(Lindberg, Christensson, & Ohrling, 2009)	Qualitative study	10 parents with infants <34 weeks gestation	Sweden.	Contact via video camera on a 24-hour basis from the time the patient was on leave until the infant was completely discharged from the NICU	NICU nurses	Interview results in four categories: security provided by access to staff, support through face-to-face meetings, control through freedom to choose when and how to use the equipment, and other uses of video conferencing.
8	This study	Quantitative study	21 parents with neonates admitted into NICU/SCN for critical disease ≥ 1 week	Malaysia	Personalized discharge preparation plan for each parent and 2 home visits by public health nurses within 72 hours post-NICU/SCN discharge	NICU nurses and PHN staff	The personalized discharged plan resulted in positive feedback by parents on the management of common neonatal care issues. The home visits made the parents felt further supported and improved confidence in taking care of their child at home.

This study is not without limitations. Data on incidences of neonatal emergencies and rehospitalisations that would objectively measure the value of the interventions were not quantified in this study. Remarkably, the requirement for two home visits within 72 hours post-discharge from NICU or SCN, had added additional workload to the PHN, primarily when the visits were conducted during weekends. This study is also limited by the small number of participating parents. Hence, the study findings may not be representative of a larger population setting. In the future, it would be beneficial to conduct a similar study in a larger population with an extended period to ascertain the sustainability of the interventions and long-term effects. The PHN should also be well-trained to address issues commonly faced by neonates with a history of NICU or SCN admission. There should also be sufficient resources given to the PHN to deliver additional home visits for these neonates.

CONCLUSION

In conclusion, personalised discharge preparation plan and sufficient home visits by PHN are simple targeted interventions, that can be used to improve parental support to continue the care for neonates recently discharged from NICU or SCN, at home. The implementation of these interventions, however, requires cooperation from the state health department and development of a training module that can be used to train parents in a widespread manner. Long-term study with monitoring of appropriate parameters, is also needed to measure whether the interventions are effective in supporting parents, reducing NICU or SCN re-admissions, and if they are sustainable.

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DECLARATION

SLL prepared the first draft manuscript. All authors revised and contributed significantly to the write up of the final version of the manuscript. All authors approved the final version of the manuscript for publication and accepted all responsibilities for its publication.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This study was registered in the National Medical Research Register (NMRR), Ministry of Health, Malaysia (NMRR-17-946-35789). It received ethical approval/clearance from the Medical Research & Ethics Committee (MREC) of the Ministry of Health, Malaysia ((11) KKM/NIHSEC/P17-827). Participation in the study by the parents and PHN were voluntary and prior informed consent was obtained from each participating parent and PHN.

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COMPETING INTEREST

The authors declare that they have no competing interests.

AUTHOR'S CONTRIBUTION

SLL, NMI, NHCN, NM, KM, HK, FZ, LJM, CPS, HR, and AHSS were involved in the protocol development for the study. NMI, NHCN, NM, KM and HK contributed in the data collection. FZ, LJM, NMI, NHCN, NM, KM and HK also contributed in the data analysis. All authors contributed to the write up of the final report of the study.

Supplementary File 1 (a): Discharge Preparation Plan (English language)

NICU DISCHARGE PREPARATION PLAN FOR YOUR BABY

Baby of: _____
Date of discharge: _____
Gestational age (on discharge): _____
Diagnosis: _____
Weight (on discharge): _____

Dear Mommy/Daddy,

Congratulations! It is time to bring your baby back home. Your baby was admitted into NICU, so your baby will need extra care and attention at home. Let's go through some practical information and tips to help you feel prepared and ready to care for your baby at home. Please tick (✓) if you have received the briefing from the nurse.

FOR BABY

If your baby cries a lot

- Especially at 8–12 weeks of life, crying episodes will get intensified and increased.
 - This crying is not related to sickness or ability of the caregiver.
 - Never shake the baby when the baby is crying.
 - Always try to remain calm and keep the baby safe.
 - Enlist the help of trusted family members or friends who can help when you are tired or need a break.
- ! TIPS _____

Safe sleeping environment

- Establish a regular pattern of naps and night sleep.
 - Use a firm mattress with no pillow.
 - Keep the bedroom at normal room temperature.
 - Place baby on his or her back during sleeping.
 - Have a dedicated safe bed just for your baby.
 - Never sleep with your baby on the same bed.
- ! TIPS _____

Feeding the baby

- Follow the feeding instructions by NICU staff nurses if your baby is on tube feeding.
 - Remember to feed your baby every 2-3 hours, or on demand.
 - Burping in the middle and at the end of the feeding will keep the baby comfortable.
- ! TIPS _____

If you suspect milk aspiration

- Turn your baby's body and face to the left or right side to drain excess milk or vomitus.
 - Try to ensure the nose and mouth are cleared of any fluids.
 - Gently stimulate the baby and check if the baby is breathing.
 - Immediately call for help, initiate BLS if needed, and go to nearest hospital if the baby is unresponsive.
- ! TIPS _____

If your baby turns blue or is unresponsive

- Don't panic. Remain calm. Call for help.
 - RECALL STEPS FOR BLS LEARNT IN NICU.
 - Start BLS and immediately go to the nearest hospital.
- ! TIPS _____

Prevent infection

- Establish visiting rules and stick to them:-
 - o Do not allow smoking in the home.
 - o Anyone who is ill or feels that they may become ill, to postpone their visit.
 - o Teach everyone to do proper hand washing prior to touching the baby.
 - o Limit the frequency and duration of times guests visit.
 - o Limit initial contact with small children (other than those who already live in the house).
- Wash hands (or use a hand sanitizer) before handling baby.
- Keep pets away and try to remove dust.
- Sterilize feeding or breast pumps equipment regularly.
- Do not feed the baby with stale milk.

FOR PARENTS

Ensure enough breastfeeding

- The following signs indicate that your baby is getting enough milk through breastfeeding:-
 - o Your baby wakes up on his or her own every 2-3 hours.
 - o Your baby latches and stays on the breast for more than 10 minutes before falling asleep.
 - o Your baby sucks and swallows in a nice rhythmic pattern, taking 8-10 bursts of sucking and swallowing before pausing for 5 – 10 seconds.
 - o You can hear swallowing.
 - o When you pump after breastfeeding you remove less milk that you do if you did not breastfeed.
 - o Your baby is having 6-8 wet diapers and several dirty diapers every day.
 - o Your baby is gaining weight about 125gm to 200 gm/week and growing well.
 - If your baby does not wake up on his or her own to feed, has a weak suck and falls asleep after only 5 minutes of breastfeeding, your baby may not be feeding enough.
- ! TIPS _____

Take care of your emotions and yourself

- Try to rest when your baby sleeps and get enough sleep.
 - Keep open communication with your friends, neighbours, family members and spouse.
 - Talk to someone about your feelings especially when you feel tired, overwhelm, sad or angry.
 - Get enough healthy food to eat and drink enough fluids.
 - Don't be afraid to ask for help from your partner or family members.
 - Remember to maintain your hygiene.
- ! TIPS _____

Special needs for baby

REMINDERS

You will be visited by the public health nurse at your home, at least twice within 72 hours after your baby is discharged from the NICU. The nurse in-charge of visiting you is : _____ and her contact number is : _____.

If you have any questions or doubts about the care of your baby, the nurse will address them during the home visits. You may also call the NICU or SCN if you have any emergencies at **05-2087204 (NICU)** or **05-2087166 (SCN)** of **Pediatric Department, Hospital Raja Permaisuri Bainun, Ipoh Perak.**

Supplementary File 1 (b): Discharge Preparation Plan (Malay language)

PLAN PERSEDIAAN DISCAJ BAYI DARI NICU

Bayi kepada: _____
 Tarikh discaj: _____
 Umur (pada discaj): _____
 Penyakit: _____
 Berat (pada discaj): _____

Kepada ibubapa,

Tahniah! Tiba masanya bayi anda pulang ke rumah. Bayi anda pernah dimasukkan ke NICU, jadi penjagaan dan perhatian yang rapi diperlukan. Beberapa tips dan informasi di bawah ini akan membantu anda bersedia untuk menjaga bayi anda di rumah. Sila tandakan (✓) jika telah anda dilatih oleh jururawat.

UNTUK BAYI

Jika bayi anda menangis berlanjutan

- Bayi berumur 8-12 minggu akan mengalami tangisan yang berpanjangan.
- Tangisan ini bukan disebabkan kesakitan atau ketidakbolehan ibubapa menjaga bayi.
- Elak goncang bayi dengan kuat jika bayi menangis.
- Sentiasa berada dalam keadaan tenang & pastikan bayi selamat.
- Dapatkan bantuan ahli keluarga jika anda memerlukan masa reha
! TIPS _____

Cara tidurkan bayi yang selamat

- Galakkan corak tidur yang tetap dan tidur pada waktu malam
- Gunakan tilam lembut tanpa bantal
- Suhu bilik yang normal (tidak panas/sejuk)
- Pastikan bayi tidur terlentang, bukan meniarap.
- Tidurkan bayi di katil yang berlainan daripada ibu/anak lain.
- Jangan berkongsi katil dengan bayi kecil.
! TIPS _____

Penyusuan

- Jika bayi anda menggunakan tiub untuk menyusu, ikut arahan yang telah diberikan oleh kakitangan NICU.
- Ingat! Susukan bayi anda mengikut keperluan atau 2-3jam sekali.
- Sendawakan bayi di pertengahan dan selepas penyusuan untuk kesesuaian bayi.
! TIPS _____

Jika bayi anda tersedak susu

- Mengiringkan badan dan muka bayi untuk alirkan lelehan susu atau muntah.
- Pastikan hidung dan mulut tiada sebarang cecair.
- Beri rangsangan dan periksa pernafasan bayi.
- Dapatkan bantuan dan segera ke hospital.
! TIPS _____

Jika bayi kebiruan atau tiada respon

- Jangan panik. Bertenang dan segera dapatkan bantuan.
- Lakukan BLS seperti yang telah diajar di NICU.
- Segera ke hospital berdekatan.
! TIPS _____

Elak jangkitan kuman

- Ingatkan pelawat supaya:
 - Tidak merokok di rumah.
 - Nasihatkan pelawat yang sedang mendapat jangkitan tidak melawat buat sementara waktu.
 - Nasihatkan pelawat membasuh tangan dengan bersih sebelum menyentuh bayi.
 - Limitkan masa dan kekerapan melawat.
 - Kurangkan bayi berdekatan dengan kanak-kanak lain selain yang berada di dalam rumah.
- Jauhkan dari haiwan peliharaan dan pastikan tiada habuk.
- Pastikan pam susu di cuci dengan teknik yang betul.
! TIPS _____

UNTUK IBU/BAPA

Pastikan susu badan anda mencukupi

- Berikut adalah tanda bayi cukup susu semasa penyusuan:
 - Bayi bangun untuk menyusu setiap 2-3jam.
 - Bayi melekap pada payudara lebih dari 10minit sebelum tertidur.
 - Terdengar bunyi hisapan dan bunyi menelan.
 - Lakukan perahan jika bayi anda tidak menyusu.
 - Bayi akan kencing dan berak 6-8 kali sehari.
 - Berat badan bayi bertambah 6-8oz setiap minggu.
- Jika bayi anda tidak bangun untuk menyusu, hisapan yang lemah dan kerap tidur selepas 5minit menyusu, bayi mungkin tidak mendapat susu yang cukup.
! TIPS _____

Penjagaan emosi

- Dapatkan rehat semasa bayi tidur.
- Bertukar pendapat dan pengalaman bersama rakan-rakan, ahli keluarga, jiran dan pasangan.
- Luahkan perasaan kepada seseorang apabila merasa penat, sedih atau marah.
- Makan makanan dan minuman yang berkhasiat dan minum air secukupnya.
- Jangan bimbang untuk meminta pertolongan dari pasangan dan ahli keluarga.
- Sentiasa menjaga kebersihan diri.
! TIPS _____

Keperluan khas untuk bayi anda

PERINGATAN

Anda akan dilawat oleh jururawat kesihatan sekurang-kurangnya dua kali dalam masa 72 jam selepas bayi discaj dari NICU. Jururawat yang akan membuat lawatan ialah : _____ dan boleh dihubungi di talian: _____.

Jika terdapat sebarang pertanyaan atau keraguan dalam penjagaan bayi anda, jururawat kesihatan akan membantu anda semasa lawatan ke rumah. Anda juga boleh menghubungi NICU/SCN jika berlaku kecemasan di talian **05-2087204 (NICU)** atau **05-2087166 (SCN)** **Jabatan Pediatrik, Hospital Raja Permaisuri Bainun, Ipoh Perak.**