## **Final Technical Report**

for

## **Research Project**

Management of Low Birth Weight Infants at Primary and Referral Health Care Facilities in six regions in Indonesia: an explanatory mixed method study

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Disclaimer

### Study Report

Management of Low-Birth-Weight Infants at Primary and Referral Health Care Facilities in Six Regions in Indonesia: An Explanatory Mixed Method Study

#### Submitted to:

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#### List of Abbreviations

AMP Audit Maternal Perinatal or Maternal and Perinatal Death Audit

ANC Antenatal Care
AOR Adjusted Odds Ratio

BAZNAS Badan Amil Zakat Nasional or National Zakat Amil Agency

BBLR Berat Bayi Lahir Rendah or Low Birth Weight
BEMONC Basic Emergency Obstetric and Newborn Care

BPD Bronchopulmonary Dysplasia

BPFK Balai Pengamanan Fasilitas Kesehatan or Security Centers of

**Health Facilities** 

BPJS Badan Penyelenggara Jaminan Sosial or National Social Insurance

Agency

CED Chronic Energy Deficiency

CEMONC Comprehensive Emergency Obstetric and New born Care

CI Confidence Interval

COVID-19 Coronavirus Disease 2019

CPAP Continuous Positive Airway Pressure
CPPT Integrated Patient Progress Record
CSSD Central Sterile Supply Department

DHO District of Health Officer

DIKTI Direktorat Pendidikan Tinggi or Directorate General of Higher

Education, Research and Technology

DPJP Dokter Penanggung Jawab Pasien or Doctor in Charge of the

Patient

DRS Dokter Spesialis or Spesialist

EMAS Expanding Maternal and Nenonatal Survival

ENAP Every Newborn Action Plan

e-PPGBM elektronik-Pencatatan Pelaporan Gizi berbasis Masyarakat or

Recording and Reporting Community-Based Nutritional App

ER/IGD Emergency Room/ Instalasi Gawat Darurat

EVB e-Village Budgeting
FGD Focus Group Discussion
FKTP First Level Health Facilities
GDS Random Blood Glucose Test

GKIA Maternal and Child Health Movement

GP General Practitioners

HIV Human Immunodeficiency Virus

HR Heart Rates

HRH Human Resources for Health

IBI Ikatan Bidan Indonesia or Indonesian Midwife Association

IDAI Indonesian Paediatrician Association

IDHS Indonesian Demographic and Health Survey

IDI Ikatan Dokter Indonesia or Indonesian Medical Doctors Association

IEC Information, Communication, And Education

IEC International Electrotechnical Commission

IMD Early Initiation of Breastfeeding

IMR Infant Mortality Rates

IMV Intermittent Mandatory Ventilation
IPANI Indonesian Pediatric Nurse Association

IQ Intelligence Quotient IUFD Intrauterine Fetal Demise

JICA Japan International Cooperation Agency

Kesbangpol Kantor Kesatuan Bangsa dan Politik or Unity of Nations and Politics

KII Key Informant Interviews
KMS Kangaroo Mother Care

KPK Corruption Eradication Commission

LBD Lewy Body Dementia
LBW Low Birth Weight

LMIC Low- or Middle-Income Country

MCEE Maternal Child Epidemiology Estimation

MCH Maternal and Child Health

MD Medical Doctor

MNH Maternal and Neonatal Health

MoH Ministry of Health

MPDN Maternal Perinatal Death Notification
MUAC Mid-Upper Arm Circumference

NAP National Action Plan

NEST360 Newborn Essential Solutions and Technologies

NGO Non-Governmental Organization
NICU Neonatal Intensive Care Unit
NMR Neonatal Mortality Rates

OGT Orogastric Tube
OR Odds Ratio

OSCE Objective Structured Clinical Examination

P4K Childbirth Planning and Complication Prevention Program

PEEP Positive End-Expiratory Pressure
PERINASIA The Indonesian Society of Perinatology

PICU Pediatric Intensive Care Unit

PMK Regulation of the Minister of Health

PMT Pemberian Makanan Tambahan or Supplementary Food

PNC Postnatal Care

PNPK National Guidelines for Medical Services

POGI OBGYNs Association

PONED Basic Emergency Neonatal Obstetric Services

PPNI Indonesian National Nurses Association

PPV Positive Pressure Ventilation

QUAL Qualitative QUAN Quantitative

Rifaskes Facility-Based National Health Research

ROP Retinopathy of Prematurity

RR Respiration Rates

RS Rumah Sakit or Hospital

RSUD Rumah Sakit Umum Daerah or District/ Provincial General Hospital

SDG Sustainable Development Goals

SEARO South-East Asia Region
SEZ Special Economic Zones
SGA Subjective Global Assessment
SIKDA Regional Health Information System

SISRUTE Integrated Referral System

SKI Survei Kesehatan Indonesia or Indonesian Health Survey

SOP Standard Operational Procedure

SpOG Obsgyn Specialist SR Surveillance

SSGI Indonesian Nutrition Status Survey

SUMMIT Supplementation with Multiple Micronutrient Intervention Trial

TBD To Be Determined

TTS Timor Tengah Selatan or South Central Timor

TTV Vital Sign

UGM Gadjah Mada University

UKK Unit Kerja Koordinasi or Coordination Work Unit

UNICEF United Nations International Children's Emergency Fund USAID United States Agency for International Development

USG Ultrasound Sonography
VTP Positive Pressure Ventilation
WHO World Health Organization

## Background

The Sustainable Development Goals (SDG) target to reduce neonatal mortality to at least as low as 12 per 1,000 live births by 2030. Globally, among 5.2 million children died before completing age of five in 2019, 52.8% of the death occur in the neonatal period. Significant proportion of the deaths are contributing by condition associated with low birth weight and preterm birth. Based on the WHO-MCEE method and data on causes of child death for 2000-2016, prematurity is the main cause of death for children under 5 years (40%), followed by congenital anomalies (29%) and birth asphyxia (12%).

World Health organization estimates that 20 million babies will be born with low birth weights every year with the majority in South Asia<sup>4</sup>. Low birth weight (LBW) is defined as a baby born with a birth weight of less than 2500 grams regardless of gestational age. The prevalence rate of LBW worldwide is about 15.5% of all live births. About 96% of newborns with LBW are born in developing countries – about 72% in Asia and 22% in Africa while the incidence of LBW in developing countries (17%) is more than double the incidence in developed regions (7%).<sup>5</sup>. A systematic review of the literature up to 2011 and meta-analysis reported an odds ratio of 8.5 associated with neonatal mortality in full-term newborns (≥37 gestation weeks) with a birth weight <2.5kg<sup>6</sup>. Another study in Brazil, a cohort study about neonatal mortality between 2011 and 2012 also showed that LBW is one of the associated factors<sup>7</sup>.

Around 11% of children in Indonesia were born with LBW in 2020. LBW is a major public health concern as it will be the leading cause of neonatal mortality in Indonesia by 2020. Based on data from the 2020 Maternal and Child Health Profile, the Eastern Region of Indonesia is an area with a higher LBW compared to the Western Region of Indonesia. Most of the provinces in the Eastern Region of Indonesia have a percentage of LBW incidence above the national level with South Sulawesi province ranking first in LBW incidence (17.8%), while the province with the lowest percentage

<sup>1</sup> World Health Organization. (2022). Accelerate Reduction Of Maternal, Neonatal And Under Five Mortality. Regional office for South-East Asia: World Health Organization. Retrieved from <a href="https://apps.who.int/iris/bitstream/handle/10665/329426/3MCH-eng.pdf?sequence=3&isAllowed=y">https://apps.who.int/iris/bitstream/handle/10665/329426/3MCH-eng.pdf?sequence=3&isAllowed=y</a>

<sup>&</sup>lt;sup>2</sup> World Health Organization. (2020). *Children: improving survival and well-being*. Geneva: World Health Organization. Retrieved from <a href="https://www.who.int/news-room/fact-sheets/detail/children-reducing-mortality">https://www.who.int/news-room/fact-sheets/detail/children-reducing-mortality</a>

<sup>&</sup>lt;sup>3</sup> World Health Organization. (2018). WHO methods and data sources for country-level causes of death 2000-2016. Geneva: World Health Organization. Retrieved from https://terrance.who.int/mediacentre/data/ghe/healthinfo/Deaths/GHE2016\_COD\_methods.pdf

<sup>&</sup>lt;sup>4</sup> World Health Organization. (2014). Global nutrition targets 2025: low birth weight policy brief. Geneva: World Health Organization. Retrieved from https://www.who.int/publications/i/item/WHO-NMH-NHD-14.5

<sup>&</sup>lt;sup>5</sup> World Health Organization. (2004).Low birth weight: country, regional and global estimates. New York and Geneva: United Nations Children Education Fund and World Health Organization. Retrieved from <a href="https://apps.who.int/iris/handle/10665/43184">https://apps.who.int/iris/handle/10665/43184</a>

<sup>&</sup>lt;sup>6</sup> Malin GL, Morris RK, Riley R, Teune MJ, Khan KS. (2014). When is birthweight at term abnormally low? A systematic review and meta-analysis of the association and predictive ability of current birthweight standards for neonatal outcomes. BJOG;121(5):515-26.

<sup>&</sup>lt;sup>7</sup> Lanksi, S., Friche, A. D. L., Silva, A. D., Campos, D., Bittencourt, D. A. S., & Carvalho, M. D. (2014). Birth in Brazil survey: neonatal mortality profile, and maternal and child care. Cad Saúde Pública, 30(11), 1-15.

<sup>8</sup> BPS. (2020). Profil Kesehatan Ibu dan Anak 2020. Jakarta: Badan Pusat Statistik. Retrieved from <a href="https://www.bps.go.id/publication/2020/12/31/b9a9aa33ab5a3cc23311d0a1/profil-kesehatan-ibu-dan-anak-2020.html">https://www.bps.go.id/publication/2020/12/31/b9a9aa33ab5a3cc23311d0a1/profil-kesehatan-ibu-dan-anak-2020.html</a>

of LBW incidence is Sumatera Barat (8%). Social hierarchies, ecological and cultural diversity, large geographic area may result in differences between provinces and districts<sup>9</sup>.

There are many factors associated with low birth weight, including maternal (early complications of pregnancy), nutrition (malnutrition), environmental (exposure to toxins), medical (maternal illness), lifestyle (tobacco use), cultural practices and health factors (twins, foetuses have congenital abnormalities or conditions, placental defects that interfere with the growth of the baby and cause intrauterine growth restriction). 10,111. Study in Indonesia found that fewer than four ANC visits [AOR = 1.86; 95% CI = 1.44-2.42], uneducated mothers [AOR = 2.09; 95% CI = 1.00-4.37], and mothers who finished only primary school [AOR = 1.45; 95% CI = 1.05-2.00] were significantly associated with the incidence of LBW 12. Another study done by Sebayang, 2012 13 through an analysis of the birth weight cohort from the SUMMIT study in West Nusa Tenggara found that determinants of LBW and SGA were similar, thus including infant sex (being male infant was protective of LBW). Women with higher levels of education were 13% less likely to have LBW, babies born in the rainy season had a 22% increased likelihood of LBW, and babies from poor and very poor families were more likely to be born with LBW 32% and 44% respectively, mothers with low maternal mid-upper arm circumference (MUAC) are 47% more likely to have a low birth weight baby (OR = 1.47; 95% CI: 1.31–1.65, P < 0.0001). Short women had almost twice the odds of having LBW babies (OR = 1.93; 95% CI: 1.67–2.22, P < 0.0001).

LBW babies are more prone to health problems than normal weight babies. These babies are more likely to die within the first month of life, and those who survive are at higher risk of stunted growth, lower IQs, and chronic adulthood conditions such as obesity and diabetes, while also facing lifelong consequences. <sup>14</sup> Ensuring affordable, accessible and appropriate health care is critical for preventing and treating low birth weight<sup>3</sup>. Efforts to reduce maternal mortality and morbidity have therefore resulted in improved child survival, i.e if pregnancy care is fully integrated with appropriate neonatal and post-neonatal medical and nutritional care for preterm and small for gestational age infants.

In Indonesia, the challenges associated with the management of LBW infants are hospital resources (budget and infrastructure), high patient volumes and referrals. A

<sup>9</sup> Suparmi, S., Chiera, B., & Pradono, J. (2016). Low birth weights and risk of neonatal mortality in Indonesia. *Health Science Journal of Indonesia*, 7(2), 113-117.

<sup>10</sup> Sutan, R., & Berkat, S. (2014). Does cultural practice affects neonatal survival-a case control study among low birth weight babies in Aceh Province, Indonesia. BMC pregnancy and childbirth, 14(1), 1-13.

<sup>11</sup> Deshpande, J. D., Phalke, D. B., Bangal, V. B., Peeyuusha, D., & Bhatt, S. (2011). Maternal Risk Factors for Low-Birth-Weight Neonates: A Hospital Based Case-Control Study in Rural Area of Western Maharashtra, India. National Journal of Community Medicine, 2(03), 394-398.

<sup>12</sup> Safitri, H. O., Fauziningtyas, R., Indarwati, R., Efendi, F., & McKenna, L. (2022). Determinant factors of low birth weight in Indonesia: Findings from the 2017 Indonesian demographic and health survey. Journal of Pediatric Nursing, 63, e102-e106.

<sup>13</sup> Sebayang, S. K., Dibley, M. J., Kelly, P. J., Shankar, A. V., Shankar, A. H., & SUMMIT Study Group. (2012). Determinants of low birthweight, small-for-gestational-age and preterm birth in Lombok, Indonesia: analyses of the birthweight cohort of the SUMMIT trial. Tropical Medicine & International Health, 17(8), 938-950.

<sup>14</sup> UNICEF. (2022). Low birthweight. Geneva: United Nations Children's Fund. Retrieved from <a href="https://data.unicef.org/topic/nutrition/low-birthweight/">https://data.unicef.org/topic/nutrition/low-birthweight/</a>

major challenge is also the lack of access to adequate post-discharge care for underweight infants and the failure of patients to return with their babies for follow-up visits. In addition, the challenges faced by families concerned distance and fees associated with medical use. The distance between her home and medical facilities made it difficult to make the frequent hospital visits necessary for a low birth weight baby. Extra effort to improve feeding, attention to warmth and early treatment of infection was also noted to be effective in neonatal death reduction. Based on a three-delay model described by Thaddeus and Maine, 1994. preventing maternal mortality are collated with preventing neonatal mortality, as the neonatal period is a time of vulnerability and deserves top priority for responsible governments when making decisions about laws, policies, programs and funding. 29,20

Efforts are planned to improve neonatal care to achieve the SDG goal of reducing under-five mortality. Most deaths in moderately preterm infants and in babies born full term but with restricted growth in utero can be prevented by special attention to warmth, nutrition, and prevention or early treatment of infection.<sup>21</sup>. Recently, WHO introduced new guidelines for LBW management. The guidelines consist of new evidence-based recommendations for improving the care of preterm or low birth weight infants. The 25 recommendations greatly expand the 'what', 'where' and 'how' to improve survival, health and well-being for preterm and low birth weight babies. This includes caring for LBW with kangaroo mother care (KMC) and involving family members in caring for newborn babies.<sup>22</sup>. Related to family involvement, a study in Iran by Negarandeh, 2021.<sup>23</sup> showed that the culture of support in the NICU was one of compassionate support. Two themes that emerged from the data were inadequate provision of maternal support needs (inadequate follow-up to maternal care, maternal monitoring and allocation of care, and inadequate sharing of medical information); Providing support in special situations (reassurance and support for mothers with disabilities by providing important information).

In line with the updated WHO guideline of LBW management and Indonesian Ministry of Health (MoH) regulation No. 21/2021 concerning antenatal, intrapartum, and postnatal care, the MoH intends to introduce national guidelines for small baby care packages in 2022. The MoH is currently working with the Indonesian Academy

<sup>15</sup> Pratomo, H., Uhudiyah, U., Sidi, I. P., Rustina, Y., Suradi, R., Bergh, A.-M., Rogers-Bloch, Q., & Gipson, R. (2012). Supporting factors and barriers in implementing Kangaroo Mother Care in Indonesia. *Paediatrica Indonesiana*, *52*(1), 43–50. https://doi.org/10.14238/pi52.1.2012.43-50

<sup>&</sup>lt;sup>16</sup> Pratomo, H., Uhudiyah, U., Sidi, I. P. S., Rustina, Y., Suradi, R., Bergh, A. M., ... & Gipson, R. (2012). Supporting factors and barriers in implementing kangaroo mother care in Indonesia. Paediatrica Indonesiana, 52(1), 43-50.

<sup>17</sup> Shah, P., & Ohlsson, A. (2002). Literature review of low birth weight, including small for gestational age and preterm birth. Toronto Public Health, 96-100.

<sup>18</sup> Thaddeus, S., & Maine, D. (1994). Too far to walk: maternal mortality in context. Social science & medicine, 38(8), 1091-1110.

<sup>&</sup>lt;sup>19</sup> Schumacher, R., Swedberg, E., Diallo, M. O., Keita, D. R., & Kalter, H. (2002). Mortality study in Guinea. *Investigating the causes of death in children under*, 5.

<sup>&</sup>lt;sup>20</sup> Darmstadt, G. L., Bhutta, Z. A., Cousens, S., Adam, T., Walker, N., De Bernis, L., & Lancet Neonatal Survival Steering Team. (2005). Evidence-based, cost-effective interventions: how many newborn babies can we save? The Lancet, 365(9463), 977-988.

<sup>21</sup> Yasmin, S., Osrin, D., Paul, E., & Costello, A. (2001). Neonatal mortality of low-birth-weight infants in Bangladesh. Bulletin of the World Health Organization, 79(7), 608-614.

<sup>&</sup>lt;sup>22</sup> WHO recommendations for care of the preterm or low birth weight infant. Geneva: World Health Organization; 2022. Licence: CC BY-NC-SA 3.0 IGO.

<sup>&</sup>lt;sup>23</sup> Negarandeh, R., Hassankhani, H., Jabraeili, M., Abbaszadeh, M., & Best, A. (2021). Health care staff support for mothers in NICU: a focused ethnography study. *BMC Pregnancy and Childbirth*, *21*(1), 1-12.

of Pediatrics to develop standards for newborn care at the health system level. There are 5 levels of newborn health care: primary level (first level: Non-BEmONC Puskesmas and 2nd level: BEMONC Puskesmas), referral maintenance (3rd level: CemONC Level 1), specialized (4th level) and super specialized (5th level) and type of care, health system requirement, and standards of care are clearly defined for each level. To ensure the availability of comprehensive and continuous neonatal care, healthcare workers at all levels should be aware of the resources available at their next referral. The MoH is also updating the existing guidelines of BEmONC and CEmONC to incorporate with the national guidelines of LBW management at the primary health care and the level of care. The guideline includes essential newborn care, integrated antenatal care, integrated management of neonatal and childhood illness, and LBW package. The guidelines of LBW management at primary health care has been piloted in some districts in Indonesia supported by UNICEF, Momentum-USAID, and JICA. Several gaps were identified as a result of the pilot project, including: lack of information on the actual burden of LBW managed at the Puskesmas level, lack of up-to-date information on the management of her LBW infant at the primary and referral level, and the readiness of both the health facility and health workers to provide be in order. Caring for small newborns to implement new LBW management guidelines.

Therefore, strengthening the management for neonatal care must be explored further. To fill this gap, his study aims to inform the strategy of rolling out LBW management at primary and referral health care facilities in Indonesia.

## Study Objectives

#### Aim

To inform strategy of rolling out optimal LBW management by assessing the burden and quality of LBW infant care at primary (BEmONC and non-BEmONC) and referral (CEmONC) health facilities in Indonesia

#### Objectives

- To assess health facility (primary and referral) role and capacity in implementing care of the LBW aligned with Every Newborn Action Plan (ENAP) levels of care
- 2. To assess capacity of health workers and families in providing care to small newborns
- 3. To assess the essential evidence-based care practices for LBW infants at the primary and referral level facilities
- 4. To understand the enablers to provision of essential newborn care for small newborns at primary and referral level
- 5. To understand the pathway of referring LBW infants with complications, its barriers and enablers from primary to referral level.

#### Study Design and Methodology

#### Study Design

Using a mixed-methods approach, this study focused on exploring the practice of LBW management at the primary and referral case in some regions in Indonesia, purposively selected to provide overview how the LBW infant care provided in different setting/context, such as high/low prevalence of LBW, fiscal capacity, and different health system level. This study also allowed a comprehensive explanation and deep understanding of an issue or phenomenon.<sup>24</sup>.

To guide the study, the team adapted the conceptual framework for improving the quality of care of small newborns.

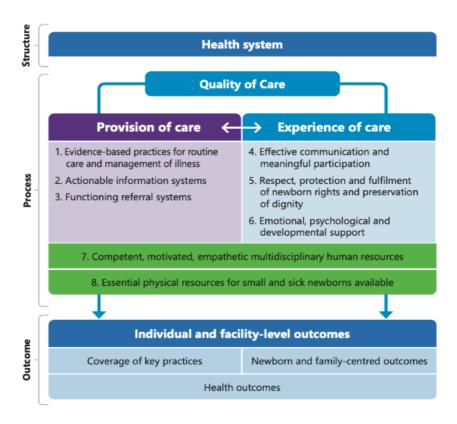


Figure 1. Framework for improving the quality of care of small newborn.<sup>25</sup>

Figure 1 shows the framework that we used for this project. The framework was developed by WHO and emphasizes eight standards for the improvement of the quality of care of small newborns. The standards reflect the three themes of quality

<sup>&</sup>lt;sup>24</sup> Aberdeen, T. (2013). Yin, RK (2009). Case study research: Design and methods . Thousand Oaks, CA: Sage. *The Canadian Journal of Action Research*, *14*(1), 69-71.

World Health Organization. (2020). Standards for improving the quality of care for small and sick newborns in health facilities. Geneva: World Health Organization. Retrieved from <a href="https://www.who.int/publications-detail-redirect/9789240010765">https://www.who.int/publications-detail-redirect/9789240010765</a>

of care of small and newborns, namely (1) provision of care, (2) experience of care, and (3) health system resources.

Quality provision of care should meet three standards, namely:

1. Evidence-based practices for routine care and management of illness according to WHO guidelines

This standard includes essential care for all newborns, as well as specific/special care for small newborns.

2. Information systems that enable collection, analysis, and use of data to ensure early appropriate action to improve the care of every small newborn

Health care facilities should have a functioning information system in place to collect and analyze data, which can provide feedback on the service provision. This should include, but not limited to, standardized registers, clinical records, observation charts, patient cards, and data collection forms that ensure confidentiality.

3. Timely referral system through integrated newborn service pathways with continuity of care, including transport

Some newborns require specialized care and thus may have to be referred to a higher-level facility. A functioning referral system should include competent providers who are able to determine cases that require urgent referral and provide pre-referral treatment, informed receiving facility, and appropriate transport with a specialist transport team. Transfer should be conducted in the kangaroo mother care position with their mother when possible.

Clients' experience of care is built upon these three standards:

4. Effective and meaningful communication with small newborns and their families that corresponds to their need and preferences, as well as supports and encourages parents to participate throughout the care pathway

Providers should practice empathy and cultural competence when communicating information to parents or caregivers, who often feel left out from the care pathway. This should also include the availability of translation/interpretation services to resolve communication barriers when needed, so that parents can be well-informed and actively participate in the decision-making of their newborn.

5. Respected, protected, and fulfilled rights of all newborns in all settings during care, transport, and follow-up

Providers should prevent all discrimination against newborns, including biases related to gender, ethnicity, disability, or preexisting medical conditions. All providers should understand the charter of newborn rights and communicate newborn rights

to parents/caregivers in the most understandable way. One of the basic rights of newborns is the right to be registered and given an identity.

6. Supportive care and follow-up to all small newborns, and emotional and psychosocial support to families to strengthen their capability

Providers need to ensure that all small newborns stay with their caregivers or with minimal separation, including rooming-in during hospitalization. KMC should be initiated as soon as possible after birth to all preterm newborns or newborns with LBW. Parents should be supported in the provision of KMC.

In addition to the provision and experience of care, health system resources, consisting of the human and physical resources, play an important role in shaping the quality of care for small newborns. Health system standards consist of:

7. The availability of competent, motivated, empathetic, multidisciplinary staff to provide routine care, manage complications, and provide developmental and psychological support throughout the care pathway

Very sick or extremely premature newborns require higher ratios of staff to patients than other paediatric patients. However, there are no international standards for staffing ratios for small newborn care. In Indonesia, while the national BEmONC.<sup>26</sup> and CEmONC.<sup>27</sup> guidelines provide the minimum number of staff at primary and referral care facilities, no certain staff-to-patient ratio was referenced.

8. The availability of adequate physical environment, with adequate water, sanitation, waste management, energy supply, medicines, medical supplies and equipment for routine care and management of complications in small newborns

The physical environment should be safe, organized, and well-maintained. In addition, it should also include a functioning unit or area for KMC to allow mothers and caregivers to learn and practice caring for their newborns.

This study applies an explanatory mixed methods design.<sup>28</sup>, in which qualitative data helps explain initial quantitative results. The design puts greater emphasis in the quantitative aspect of the research. Thus, the study starts with the collection and analysis of quantitative data on LBW management at the primary and referral health facilities. Qualitative data collection will be conducted to enrich the quantitative findings and provide a deeper context of LBW case management and the quality of care in the districts.

<sup>26</sup> Ministry of Health Republic of Indonesia. (2013). *Pedoman Penyelenggaraan Puskesmas Mampu PONED*. Jakarta: Kementerian Kesehatan.

<sup>&</sup>lt;sup>27</sup> Ministry of Health Republic of Indonesia. (2008). *Pedoman Penyelenggaraan Pelayanan Obstetri Neonatal Emergensi Komprehensif (PONEK)* 24 Jam di Rumah Sakit. Jakarta: Kementerian Kesehatan.

<sup>&</sup>lt;sup>28</sup> Creswell, J., & Creswell, J. (2018). Research Design: Qualitative, Quantitative, and Mixed Methods Approaches (Fifth Edit).
SAGE Publications Ltd.

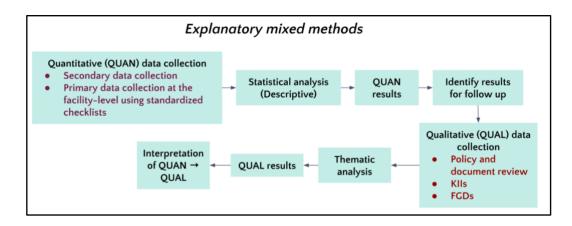


Figure 2. The quantitative (QUAN) components were conducted using the following methods.

#### a. Secondary data collection

#### District-level data (to provide a context)

We collected published data (2020-2022) on the district-level health system profile, which consisted of number of health care facilities, human resources for health, and relevant MNH statistics, including but not limited to the number of live birth, LBW, maternal mortality rate, infant mortality rate, neonatal mortality rate, and neonatal mortality subject to LBW. This information was to provide a district-level context of LBW management capacity.

#### Facility-level data

To assess whether LBW burdens differ among primary and referral-level facilities, we collected secondary data from all Puskesmas and Hospitals on the number of LBW cases managed (born at or referred to the facilities) from 2020-2022. However, not all facilities could show the data.

#### b. Primary data collection

To assess the capacity of *Puskesmas* and district hospitals in providing care for LBW (selected quality measures in the conceptual framework), including health workers' capacities, health facility's infrastructure, equipment, materials and supplies, information system, and referral system, we used standardized checklists and a case review form to be delivered in sampled health care facilities. The primary data collection was not to provide generalizable results on the capacity of *Puskesmas* and district hospitals. However, findings from the primary data collection could provide a deeper insight on the capacity of primary and referral-level facilities in handling LBW cases.

We used four standardized checklists, namely 1) checklist to assess Puskesmas's capacity, 2) checklist to assess hospital's capacity, 3) checklist to assess communication and capacity for referral in Puskesmas and Hospitals, and 4) case review form. The first and second checklist was developed by adapting and modifying the Expanding Maternal

and Neonatal Survival (EMAS) instrument, an instrument available in Indonesian language which has been developed by USAID's EMAS program and tested nationwide. The checklist was translated in Bahasa Indonesia. The third checklist was developed by adapting and translating NEST360 instrument module 1a section 5-6 for communication and transport capacity for referral. The fourth checklist was developed by adapting a Clinical Review Form developed by the Neonatal Death Audit Team of Sardjito Hospital, Yogyakarta, one of national-level referral hospitals in Indonesia.

The qualitative component (QUAL) focused on exploring contextual factors in LBW management issues, both the beneficiaries and stakeholders' experiences and professional evaluation of LBW care. Three data collection methods will be applied:

#### a. Document review

The study started with document review to understand context in the selected districts, including the health financing in the regions, and particularly the contextual background of LBW, also the district's capacity in managing LBW. We systematically reviewed national and local policies related to LBW management, district capacity in managing LBW, and sociocultural context.

#### b. Key Informant Interviews (KII)

Interviews were be done with national level stakeholders from IDAI, IBI, IPANI/PPNI, BPJS, and other related government officials as identified in discussions to understand their experiences and professional evaluation on LBW management, and also from districts level stakeholders, thus includes DHO officials, the mothers and other caregivers of the deceased LBW babies. We also interviewed other identified stakeholders, such as caregivers of surviving LBW infants other than mothers and staff of primary and referral health facilities to explore issues found in the FGDs with mothers of survived LBW babies and with health facilities management.

#### c. Focus Group Discussions

The FGDs were done with mothers of surviving LBW infants. This method is chosen to explore not only their experiences in taking care of LBW babies, but to delve into community traditions, norms and practices in LBW care.

#### d. Case-based assessment

This method was done to assess:

- 1.Essential care provided by health providers to LBW babies and mothers in the health facility, such as breastfeed, KMC, and CPAP for LBW with respiratory distress.
- 2.Care provided by health providers to LBW babies and mothers in the health facility in emergency situations.

An OSCE-like assessment in which the object of the service substituted with a phantom, not actual patient (human) were conducted. The OSCE-like assessment were based on Management Guidelines For Low Birth Weight Infants In Primary and Referal Health Care

Facilities by Indonesian MOH and reflects the factual cases found in health facilities. We developed the cases in continuous consultancy with senior neonatologists, who were assigned to evaluate the performances of health providers in selected facilities. The OSCE-like assessment will be observed by neonatologists in two provinces/districts (one district in West Java, one district in East Nusa Tenggara). This observation results were used to triangulate information from FGDs.

In addition, we conducted a clinical review for selected cases (survival and death of LBW infants) to understand the missed opportunities, what has worked well, and possible different LBW outcomes that might happen if the standard treatment is met.

#### Research Setting and Sampling

In this study we assessed mainly the low-birth weight baby (<2500 grams) regardless of its gestational age (preterm or term) and condition (sick or not sick), their mother and other possible caregivers, the health care providers of LBW babies, and other policy maker related to LBW. To ensure that the study covered areas with middle to high LBW prevalence and various fiscal capacities and geographical characteristics, we conducted this study in the following districts.

Table 1. Study Area

Province	District	Rationale*
North Sumatra	Deli Serdang	Second highest contributor of total number of LBW in North Sumatra Province. <sup>29</sup> , high fiscal capacity. <sup>30</sup> , located in the westernmost part of the country, good accessibility, 61.8% <i>puskesmas</i> with BEmONC capacity. <sup>31</sup>
West Java	Garut	District with the second highest rate of LBW in West Java Province (2.20%). <sup>32</sup> , very high fiscal capacity, good accessibility, 44.8% <i>puskesmas</i> with BEmONC capacity. <sup>33</sup>

<sup>29</sup> Badan Pusat Statistik Provinsi Sumatera Utara. (2022). Jumlah Bayi Lahir, Bayi Berat Badan Lahir Rendah (BBLR), BBLR Dirujuk, dan Bergizi Buruk menurut Kabupaten/Kota di Provinsi Sumatera Utara 2019-2021. Retrieved August 26, 2022, from <a href="https://sumut.bps.go.id/indicator/30/485/1/jumlah-bayi-lahir-bayi-berat-badan-lahir-rendah-bblr-bblr-dirujuk-dan-bergizi-buruk-menurut-kabupaten-kota-di-provinsi-sumatera-utara.html">https://sumut.bps.go.id/indicator/30/485/1/jumlah-bayi-lahir-bayi-berat-badan-lahir-rendah-bblr-bblr-dirujuk-dan-bergizi-buruk-menurut-kabupaten-kota-di-provinsi-sumatera-utara.html</a>

<sup>30</sup> Minister of Finance. (2021). Minister of Finance Decree No. 116/PMI<.07 /2021. Retrieved August 26, 2022, from www.jdih.kemenkeu.go.id

<sup>31</sup> Ministry of Health Republic of Indonesia. (2016). Data Dasar Puskesmas 2015. Retrieved from Kementerian Kesehatan Republik Indonesia website: <a href="https://pusdatin.kemkes.go.id/resources/download/pusdatin/lain-lain/Data-Dasar-Puskesmas-2015.pdf">https://pusdatin.kemkes.go.id/resources/download/pusdatin/lain-lain/Data-Dasar-Puskesmas-2015.pdf</a>

<sup>&</sup>lt;sup>32</sup> Dinas Kesehatan Provinsi Jawa Barat. (2021). *LKIP 2020*. Bandung. Retrieved from <a href="https://e-renggar.kemkes.go.id/file\_performance/1-020037-2tahunan-427.pdf">https://e-renggar.kemkes.go.id/file\_performance/1-020037-2tahunan-427.pdf</a>

<sup>33</sup> Dinas Kesehatan Kabupaten Garut. (2022). Data Puskesmas di Kabupaten Garut. Retrieved June 23, 2022, from <a href="https://dinkesgarut.com/page/detail/data-puskesmas-di-kabupaten-garut">https://dinkesgarut.com/page/detail/data-puskesmas-di-kabupaten-garut</a>

Province	District	Rationale*
Aceh	Nagan Raya	Middle fiscal capacity, 14 <sup>th</sup> highest LBW rate in Aceh Province. <sup>34</sup> , good accessibility, 14.3% <i>puskesmas</i> with BEmONC capacity. <sup>35</sup> , located in the westernmost part of the country
East Java	Pamekasan	Middle fiscal capacity, 18 <sup>th</sup> highest LBW rate in East Java Province (3.97%). <sup>36</sup> , located on a separate island of Madura, good accessibility, 25% puskesmas with BEmONC capacity. <sup>37</sup>
West Nusa Tenggara	Lombok Utara	Highest LBW rate in West Nusa Tenggara Province (6.98%). <sup>38</sup> , very low fiscal capacity, post-disaster region. <sup>39</sup> , good accessibility, 62.5% of <i>puskesmas</i> with BEmONC capacity. <sup>40</sup>
East Nusa Tenggara	Timor Tengah Selatan (TTS)	Highest contributor of total number of LBW in East Nusa Tenggara Province (LBW rate of 8.32%).41, low fiscal capacity, east Indonesian region, good accessibility, 13.3% <i>puskesmas</i> with BEmONC capacity

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<sup>34</sup> Diskominfo Provinsi Aceh. (2022). Bayi Berat Badan Lahir Rendah (BBLR) Menurut Jenis Kelamin, Kabupaten/Kota Tahun 2021. Retrieved August 26, 2022, from OpenData Aceh website: <a href="https://data.acehprov.go.id/dataset/bayi-berat-badan-lahir-rendah-bblr-menurut-jenis-kelamin-kabupaten-kota/resource/be1c0a38-c20c-4cab-bcee-474be354825d">https://data.acehprov.go.id/dataset/bayi-berat-badan-lahir-rendah-bblr-menurut-jenis-kelamin-kabupaten-kota/resource/be1c0a38-c20c-4cab-bcee-474be354825d</a>

<sup>35</sup> Ministry of Health Republic of Indonesia. (2016). Data Dasar Puskesmas Kondisi Desember 2015: Provinsi Aceh. Retrieved from Kementerian Kesehatan Republik Indonesia website: <a href="https://pusdatin.kemkes.go.id/resources/download/pusdatin/data-dasar-puskesmas/2015/01.%20Data%20Dasar%20Puskesmas%20Aceh%202015.pdf">https://pusdatin.kemkes.go.id/resources/download/pusdatin/data-dasar-puskesmas/2015/01.%20Data%20Dasar%20Puskesmas%20Aceh%202015.pdf</a>

<sup>36</sup> BPS Provinsi Jawa Timur. (2019). Jumlah Bayi Lahir, Bayi Berat Badan Lahir Rendah (BBLR), dan Bergizi Kurang di Provinsi Jawa Timur Menurut Kabupaten Kota, 2018. Retrieved August 26, 2022, from <a href="https://jatim.bps.go.id/statictable/2019/10/09/1675/jumlah-bayi-lahir-bayi-berat-badan-lahir-rendah-bblr-dan-bergizi-kurang-di-provinsi-jawa-timur-menurut-kabupaten-kota-2018-.html">https://jatim.bps.go.id/statictable/2019/10/09/1675/jumlah-bayi-lahir-bayi-berat-badan-lahir-rendah-bblr-dan-bergizi-kurang-di-provinsi-jawa-timur-menurut-kabupaten-kota-2018-.html</a>

<sup>37</sup> Ministry of Health Republic of Indonesia. (2016). Data Dasar Puskesmas Kondisi Desember 2015: Provinsi Jawa Timur. Retrieved August 26, 2022, from <a href="https://pusdatin.kemkes.go.id/resources/download/pusdatin/data-dasar-puskesmas/2015/15.%20Data%20Dasar%20Puskesmas%20Jatim%202015.pdf">https://pusdatin.kemkes.go.id/resources/download/pusdatin/data-dasar-puskesmas/2015/15.%20Data%20Dasar%20Puskesmas%20Jatim%202015.pdf</a>

<sup>38</sup> BPS Provinsi Nusa Tenggara Barat. (2017). Jumlah Bayi Lahir, Bayi Berat Badan Lahir Rendah (BBLR), BBLR Dirujuk, dan Bergizi Buruk Menurut Kabupaten/Kota di Prov NTB, 2016. Retrieved August 26, 2022, from <a href="https://ntb.bps.go.id/statictable/2017/11/16/193/jumlah-bayi-lahir-bayi-berat-badan-lahir-rendah-bblr-bblr-dirujuk-dan-bergizi-buruk-menurut-kabupaten-kota-di-prov-ntb-2016.html">https://ntb.bps.go.id/statictable/2017/11/16/193/jumlah-bayi-lahir-bayi-berat-badan-lahir-rendah-bblr-bblr-dirujuk-dan-bergizi-buruk-menurut-kabupaten-kota-di-prov-ntb-2016.html</a>

 $<sup>^{39}</sup>$  AHA Centre. (2018). Situation U No. 1 M 6.4 Lombok Earthquake (29 Jul 2018) & M 7.0 Lombok Earthquake (5 Aug 2018), Indonesia. Retrieved from <a href="https://ahacentre.org/wp-content/uploads/2018/08/AHA-Situation\_Update\_no\_1\_M-7.0-Lombok-Earthquake-final.pdf">https://ahacentre.org/wp-content/uploads/2018/08/AHA-Situation\_Update\_no\_1\_M-7.0-Lombok-Earthquake-final.pdf</a>

 $<sup>\</sup>frac{40}{\text{Dinas Kesehatan Kabupaten Lombok Utara.}} (2019). \\ \text{Laporan Kinerja Tahunan 2019. Retrieved from } \underline{\text{https://dinkes.lombokutarakab.go.id/wp-content/uploads/2021/09/LAKIP-2019-PRINT.pdf}}$ 

<sup>41</sup> BPS Provinsi Nusa Tenggara Timur. (2017). Jumlah Bayi Lahir, Bayi Berat Badan Lahir Rendah (BBLR), BBLR Dirujuk, dan Bergizi Buruk 2015-2017. Retrieved August 26, 2022, from <a href="https://ntt.bps.go.id/indicator/30/223/1/jumlah-bayi-lahir-bayi-berat-badan-lahir-rendah-bblr-bblr-dirujuk-dan-bergizi-buruk.html">https://ntt.bps.go.id/indicator/30/223/1/jumlah-bayi-lahir-bayi-berat-badan-lahir-rendah-bblr-dirujuk-dan-bergizi-buruk.html</a>

The study took place in three health care facilities in each district, namely one non-BEmONC *Puskesmas*, one BEmONC *Puskesmas*, and one highest referral-level hospital (public/private) available in the district. To determine the *Puskesmas* to be the study site, we considered *Puskesmas* that have high number of delivery cases in 2022 in the district, not too difficult to be accessed by the data collector (considering the time and resources that we have), and the *Puskesmas* should be approved by the district health office. The procedure for sampling the *Puskesmas* were provided below:

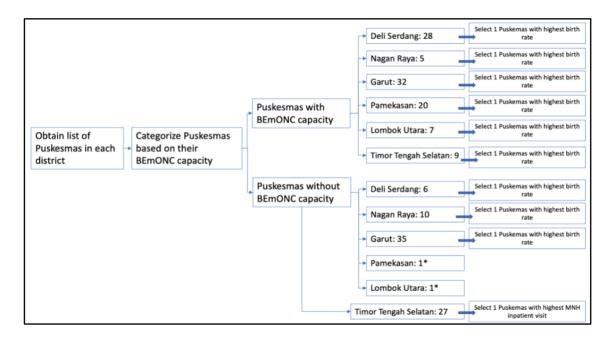


Figure 3. Puskesmas Sampling

\*All *Puskesmas* in the district have inpatient services. Thus, we categorize non-BEmONC *Puskesmas* in the district based on the accreditation status as well.

The categorization of BEmONC capacity among *Puskesmas* was based on the availability of inpatient services in the facility. The exceptions are Pamekasan and Lombok Utara Districts, where all the *Puskesmas* have inpatient services. For these two districts, we categorize the non-BEmONC *Puskesmas* based on the accreditation of the *Puskesmas*—those that were not accredited yet are categorized under non-BEmONC *Puskesmas*.

As for the hospital, we selected one public hospital from each district. In Indonesia, hospitals are classified as class A, B, C, and D. Class A hospitals are in the highest level of referral. In our study, there were 3 hospitals class B, and 3 hospitals class C

Our selected facilities encompass public primary level and public referral level facilities.

In order to gather information from both the beneficiary's and provider's points of view in each health facility mentioned above, we conducted FGD through a purposive sampling. The estimated numbers of FGD informants at the district-level are given on Table 2 below.

Table 2. Number of FGD Informants at The District-Level

FGD	Category	Number of informants per FGD	Number of FGD per district	Total number of informants (6 districts)
Mothers of survived LBW	2 Puskesmas	6-8	1 FGD	48 people
	1 Hospital	participants		
(1) Health care facility management  (2) MNH programmers  (3) Staff of primary and referral facilities (This composition includes doctors/specialized doctors, midwives, and nurses Perina/NICU)	1 Puskesmas	6 participants	2 FGD	72 people
	1 Hospital	6-8 participants	1 FGD	48 people
Total			4 FGDs	168 people

In addition to FGDs, we also conducted KII with stakeholders at the district and national level. The KIIs aim to triangulate the findings of FGDs, particularly in terms of contextual issues and determinants of LBWs, as well as capacity of health workers. To ensure the timeliness of the project, all KIIs with the national level stakeholders were conducted online, while KIIs with the district health offices were conducted offline. The numbers of KII informants are given on Table 3.

Table 3. Number of expected KII Informant

KIIs	Number of Informants	Total
National level		

TOTAL		78 KII
DHO	1 person	6 KII
Primary and referral health facility's staff	TBD (estimated 3 persons, to explore issues identified in the FGD with staff of health facilities)	18 KII
Caregivers of surviving LBW babies	TBD (estimated 3 persons, to explore issues identified in the FGD of surviving LBW baby's mothers)	18 KII
Caregivers of deceased LBW babies	Minimum 3 persons (1 participant from each health facilities)	18 KII
Mothers of deceased LBW babies	Minimum 3 persons (1 participant from each health facilities)	18 KII
BPJS Kesehatan  Kabupaten level (total=6 Kabupaten)	1 person	1 KII
Ministry of Health, Nutrition and MCH directorate Kementerian Kesehatan (Direktorat Gizi dan Kesehatan Ibu dan Anak)	1 person	1 KII
Medical doctor association Ikatan Dokter Indonesia (IDI)	1 person	1 KII
Paediatrician association Ikatan Dokter Anak Indonesia (IDAI), terutama UKK Neonatus	1 person	1 KII
OBGYNs association Perkumpulan Obstetri dan Ginekologi (POGI)	1 person	1 KII
Paediatric nurse association Ikatan Perawat Anak Indonesia (IPANI)	1 person	1 KII
Midwife association Ikatan Bidan Indonesia (IBI)	1 person	1 KII

The actual number of participants of FGD and KII in each district is available in Annex 1.

#### Data collection and research procedure

The study was <u>conducted in three phases</u>, namely (1) preparation, (2) implementation, and (3) reporting.

#### Preparation

This study started with the development of a detailed work plan (including the studied districts), standard checklist instruments, as well as KII and FGD guides. The standard checklist was developed and adapted with technical support provided by our advisory team. Our advisory team consists of neonatologists and medical doctors. The work plan and the instruments were consulted to WHO and MOH. Upon the finalization of the work plan and the instruments, we proceeded with the application of ethics approval from the Ethics Commission of Faculty of Medicine, Public Health, and Nursing, Universitas Gadjah Mada (No KE/FK/0488/EC/2023) also WHO South-East Asia Region (SEARO) (2023. 12. MP). Then we proceed with the application of national-level permission from the Ministry of Home Affair (since this study is conducted in several provinces) (No 400.5/4506/Polpum)

We conducted two-day online training to the field staffs which covered (1) the overall explanation about this project and (2) facility-level standard checklist. Once the field staff are recruited and trained, we will begin with the application of local permission from *Kesbangpol*, DHOs, and facilities at the district-level. The whole preparation phase is expected to finish in the second month of the project.

#### Implementation

We did the implementation after the ethics issued from the Ethics Commission of Faculty of Medicine, Public Health, and Nursing, Universitas Gadjah Mada. Simultaneously with the ethical clearance process. we conducted a document and policy review, as well as obtain secondary datasets, such as Susenas or Indonesian Demographic and Health Survey (IDHS) 2017. We reviewed policies and reports from DHO and MOH, as well as previous studies on determinants of LBW and LBW management in Indonesia.

After the issuance of district-level permission, the field staffs started the data collection. In preparation for the data collection, we conducted three series of online initiation meetings:

- 13 July 2023 for district health level. The participants of this meeting were: two officials from the MoH, and 10 DHO officials (head of DHO, head of MNH department, nutritionists, health promotion staff, midwives)
- 26 July 2023 for primary health care level. The participants of this meeting were: three DHO
  officials, and 24 Puskesmas staff (village midwives, midwives coordinators, GP, head of
  Puskesmas, nutritionist)
- 3. 4 August 2023 for district hospitals. The participants of this meeting were: three DHO officials and 9 Hospital staff (head of perinatal ward, head of NICU, medical service section head, and nurses)

We delivered standard checklists at the selected facilities to assess facility capacity in implementing LBW care, capacity of health workers, as well as the referral pathway and its barriers. The checklists were completed by the head of facilities, MNH programmer and staff of *Puskesmas*, and MNH ward paediatricians/GPs/nurses at district hospitals.

While delivering the standard checklist, field staffs helped researchers identify potential FGD informants to <u>assess districts' capacity</u>. All FGDs in the district level were conducted face to face.

#### **Data Analysis**

#### Document/policy review

The findings from document/policy review were summarized and narrative approaches were used to report the findings of the document/policy review.

#### Quantitative

Descriptive statistics were performed to summarize the results of facility secondary data collection. We used Microsoft Excel and Stata to analyze the survey questionnaire.

#### Qualitative

The results of FGDs and KIIs were recorded and transcribed verbatim. A thematic analysis was used to analyze the results of qualitative data collection. Researchers discussed the codes and the themes to be used in the analysis and any discrepancies were resolved with the assistance of a third personnel.

Combining findings from document/policy review, quantitative research, and qualitative research

Results from the desk review, quantitative research, and qualitative research were combined and compared descriptively. This was to enable us to develop new insights from all data types. Findings that oppose or support one another were investigated to obtain a comprehensive understanding and interpretation within the research scope.

Our advisory team provided feedback in this process, providing their interpretation of the result and guidance towards the analysis.

#### Study Limitation

The study did not estimate the burden of LBW in each district and facility. Although we had number of LBW cases in district, the results should not be interpreted as a generalization, since generalization would require an epidemiological study with a higher number of sample sizes as well as varieties of regions and health care facilities. However, the study could provide an overview of LBW management across Indonesian districts and level of care with heterogeneous social and economic characteristics, as well as health system capacities, which might serve as an input for further studies in the future.

As expected, not all the required data could also be retrieved. This might be due to the way that some data was recorded. For instance, there was some data that was only available at Puskesmas level and not at the district level, or unavailability of medical records of LBW babies in the Puskesmas, specifically the deceased LBW babies. Another reason was the way that the data was stored. In some districts, data was still stored manually in the warehouse and not put in order. We tried to compensate for the missing data with other secondary data sources. For instance, using Puskesmas level data instead of District level data, or using national level data estimate, when possible.

In several districts, including Pamekasan, Nagan Raya, Garut, and North Lombok, study participants, particularly LBW mothers, fathers, and families, exhibited limited fluency in Bahasa Indonesia. Despite their familiarity with the language, they faced challenges expressing opinions and emotions effectively. To address this barrier, collaboration with local researchers and the engagement of translators became necessary.

Early interaction with study participants, whether DHO officials or mothers of LBW infants, was initiated through local researchers and health facility personnel. The establishment of trust between UGM researchers and participants within a brief timeframe, coupled with the constrained data collection period, compelled us to prioritize specific elements of the research framework.



Inviting mothers and caregivers of LBW babies, particularly those who had experienced loss, posed considerable challenges that required us to reconfigure our data collection methods. This entailed a shift from FGDs to in-depth interviews, or vice versa, as a strategic adjustment to accommodate the participants' circumstances. We also adjusted our plan to provide a convenient atmosphere for participants to talk with us, with some

opting for meetings at health facilities and others choosing home visits.



As previously elucidated, qualitative methods were employed to complement quantitative approaches. Consequently, our focus was directed more towards probing health care aspects. In delineating the care experience, emphasis was placed on capturing the perspectives of parents and other caregivers regarding the services received from health facilities, and health care practices at home.

#### Findings and Discussions

Findings from the study are structured according to the study framework (see Fig. 1). The first section described the context of the health system as well as the context of the study district to give better understanding of the setting. The second section explored the factors that influence the quality of provision of care, namely the use of evidence-based practices for routine care and management of LBW, actionable information systems and functioning referral systems. This section also discussed findings on resources that enable quality of care, namely the human resources and essential physical resources to care for LBW infants. These factors combined, in turn influenced the quality of care from the perspective of the parents and caregivers of LBW infants. The third section explored the quality of care as experienced by parents and caregivers.

Health system and study district contexts

#### **National Context**

Indonesia is among the most populous and the largest archipelagic country in the world, encompassing approximately 17,000 islands.<sup>42</sup> inhabited by approximately 270 million people.<sup>43</sup>. The situation posed unique opportunities and challenges for health service delivery in the country.

The government had been showing stronger commitment to strengthen the supply-side readiness, as shown by the increasing number of public primary health care facilities (locally termed as *Puskesmas*) (from 10,134 in 2019 to 10,292 in 2021) and referral hospitals (from 2,877 in 2019 to 3,042 in 2021). The hospitals were further divided into several classes based on their level of referral, namely class A, B, C, and D. Class A hospitals were at the highest level in the referral system. While there had been no change in the number of class A hospitals from 2019-2021, the number of class B, C, and D hospitals had been increasing.

Despite the progress, some supply-side issues persisted. In terms of human resources for health (HRH), for instance, the ratios of doctors and specialists had consistently remained below 1 per 1,000 people. For paediatricians and obstetrician-gynaecologists, these ratios stood at

<sup>&</sup>lt;sup>42</sup> Mahendradhata, Y., Trisnantoro, L., Listyadewi, S., Soewondo, P., Marthias, T., Harimurti, P., & Prawira, J. (2017). *The Republic of Indonesia Health System Review*. In Health Systems in Transition (Vol. 7).

<sup>43</sup> Central Bureau of Statistics (2020). Population Size based on the 2020 Population Census by Provinces and Sexes (people), 2020 [Jumlah Penduduk Hasil SP2020 menurut Wilayah dan Jenis Kelamin (Orang), 2020]. Badan Pusat Statistik. Retrieved November 17, 2023, from https://www.bps.go.id/indicator/12/2131/1/jumlah-penduduk-hasil-sp2020-menurut-wilayah-dan-jenis-

November 17, 2023, from <a href="https://www.bps.go.id/indicator/12/2131/1/jumlah-penduduk-hasil-sp2020-menurut-wilayah-dan-jenis-kelamin.html">https://www.bps.go.id/indicator/12/2131/1/jumlah-penduduk-hasil-sp2020-menurut-wilayah-dan-jenis-kelamin.html</a>

<sup>&</sup>lt;sup>44</sup> The Indonesian Health Profile, 2019-2021

approximately 16 and 18 per 1,000,000 individuals, respectively.<sup>45</sup>. On the other hand, midwives and nurses had seen a flourishing trend with their numbers steadily on the rise. Providing perinatal/neonatal services

Table 4. Proportion of Hospitals with at Least 4 personnel Providing Perinatal/Neonatal Services

Hospital type	% with at least 4 personnel providing perinatal/neonatal				
	services				
	% with at least 4	% with at least 4	% with at least 4		
	Physicians	Nurses	Midwives		
	Based on ownership				
Ministry of Health (the	54.5	90.9	45.5		
national government)					
Provincial government	44.2	72.1	60.5		
District/ municipal	30.3	78.7	75.3		
government					
	Based on class				
Class A	50	75	62.5		
Class B	44	81.5	66.7		
Class C	17.8	71.1	73.3		
Class D	0	100	100		

Source: Health Facility Research, 2019.46

Table 7 presents findings from the 2019 Health Facility Research, encompassing data from 532 hospitals, constituting approximately 18.5% of all hospitals in Indonesia. It was estimated that most hospitals in Indonesia, regardless of the ownership and classes, had a minimum of 4 nurses providing perinatal/neonatal services. The research also showed that most hospitals owned by the provincial and district governments had at least 4 midwives providing perinatal/neonatal services. In contrast, less than 50% of provincial and district hospitals met the threshold of four physicians providing perinatal/neonatal services. This trend was more pronounced in class C and class D hospitals, both belonged to the lower levels of the referral system.

<sup>&</sup>lt;sup>45</sup> National Health Profile 2021

<sup>&</sup>lt;sup>46</sup> Ministry of Health Republic of Indonesia. (2019). *Laporan Riset Fasilitas Kesehatan 2019: Rumah Sakit.* Retrieved from <a href="https://repository.badankebijakan.kemkes.go.id/id/eprint/4896/">https://repository.badankebijakan.kemkes.go.id/id/eprint/4896/</a>

Table 5. Estimated proportions of hospitals with neonatal and paediatric intensive care unit, neonatal/perinatal services, and integrated care policy

Hospital type	% with PICU	% with NICU	% providing neonatal/ perinatal services	% with integrated care policy			
Based on ownership							
Ministry of Health (the national government)	90.9	90.9	100	100			
Provincial government	81.8	88.6	97	93			
District/municipal government	50.6	68.5	100	85.4			
Based on class							
Class A	100	100	100	100			
Class B	71.6	84	100	91.4			
Class C	37	56.5	97.8	80			
Class D	0	0	100	100			

Source: Health Facility Research, 2019.47

The table underscores that nearly all hospitals, except for the class C provincial government-owned, offered neonatal/perinatal services. Notably, every hospital under the MOH and every class A hospital had integrated care policies for mothers and newborns. However, the availability of such policies varied among different hospital classes, with percentages ranging from 80-91% for class C and class B hospitals, and 85-93% for provincial and district hospitals. Regarding intensive care units, fewer district hospitals, as well as class C and class D hospitals, were equipped with NICU and PICU, compared to the other hospital types.

With reference to health outcomes, Indonesia had seen a progress in the decline of infant and neonatal mortality rates over the past decade. <sup>48</sup> Infant Mortality Rates (IMR) had declined from 26.9 per 1,000 live births in 2011 to 18.9 per 1,000 live births in 2021. <sup>49</sup> Similarly, Neonatal Mortality Rates (NMR) had decreased from 16.8 in 2011 to 11.3 in 2021. <sup>50</sup> In terms of LBW, the rates had undergone a reduction from 3.4% in 2019 to 2.5% in 2021. <sup>42</sup> While the country had reached the Sustainable Development Goal (SDG) target pertaining to neonatal and infant mortality, more needs to be done to ensure that all newborns receive the essential treatment,

<sup>&</sup>lt;sup>47</sup> Ministry of Health Republic of Indonesia. (2019). *Laporan Riset Fasilitas Kesehatan 2019: Rumah Sakit.* Retrieved from <a href="https://repository.badankebijakan.kemkes.go.id/id/eprint/4896/">https://repository.badankebijakan.kemkes.go.id/id/eprint/4896/</a>

<sup>48</sup> https://data.unicef.org/country/idn/

<sup>&</sup>lt;sup>49</sup> UN Inter-agency Group for Child Mortality Estimation. (2021). Mortality rate, infant (per 1,000 live births) - Indonesia. Retrieved November 17, 2023, from <a href="https://data.worldbank.org/indicator/SP.DYN.IMRT.IN?view=cha&locations=ID">https://data.worldbank.org/indicator/SP.DYN.IMRT.IN?view=cha&locations=ID</a>

UN Inter-agency Group for Child Mortality Estimation. (2021). Indicator: Neonatal mortality rate. Retrieved November 17, 2023, from UNICEF Data Warehouse website: <a href="https://data.unicef.org/resources/data">https://data.unicef.org/resources/data</a> explorer/unicef f/?ag=UNICEF&df=GLOBAL DATAFLOW&ver=1.0&dq=IDN.CME MRM0. <a href="https://data.unicef.org/resources/data">https://data.unicef.org/resources/data</a> explorer/unicef f/?ag=UNICEF&df=GLOBAL DATAFLOW&ver=1.0&dq=IDN.CME MRM0.

emergency and complicated cases can be handled accordingly, and preventable infant and newborn deaths could be eradicated.

#### Study districts context

The study was conducted in 5 districts that each have different resources in terms of availability of human resources and healthcare facilities.

Table 6. Characteristic of the district

	District						
	Nagan	Deli	Garut	Pamekasan	Lombok	Timor	
	Raya	Serdang			Utara	Tengah	
						Selatan	
						(TTS)	
Population	173,510	2,415,031	2,759,490	914,700	231,278	462,135	
Area (km2)	3,364	2,497	3,065	792	810	3,955	
Number of							
Puskesmas	14	34	67	21	8	27	
Number of							
BEmONC							
Puskesmas	0	20	30	0	8	4	
Number of In-patient							
Puskesmas	7	8	33	21	8	4	
Number of PHC							
collaborated with							
BPJS	24	139	138	67	8*	36	
Number of hospitals							
collaborated with							
BPJS	1	18	8	8	1	1	

The region with the highest population was Garut with a total of 67 community health centers and eight hospitals. Even though it was not the district with the smallest population, North Lombok had the fewest number of community health centers, namely 8. In Nagan Raya and Pamekasan, there were no BEmONC health centers at all. Meanwhile in North Lombok, all community health centers had been trained in BEmONC skills although not all had received the letter stating their BEmONC status. In TTS, the ratio of BEmONC and non-BEmONC health centers was 1:6. Meanwhile, for Garut and Deli Serdang the ratio ranged between one to two. WHO recommended in Monitoring Emergency Obstetric Care was to have five EmONC facilities with at least 1 CEmONC for every 500,000 population.<sup>51</sup>.

Furthermore, the highest number of PHCs collaborating with BPJS were in Deli Serdang and Garut, namely 139 and 138. Pamekasan also had quite a number of PHCs collaborating with BPJS, namely 67. By looking at the BPS data, we can calculate that more than 65% of primary care in Deli Serdang offered BPJS health insurance, while in Pamekasan almost all primary care clinic offered BPJS health. It showed the variety between districts. Meanwhile, TTS and Nagan Raya had 36 and 24 level health facilities respectively. the first to collaborate with BPJS. Deli Serdang had 18 hospitals collaborating with BPJS, followed by Garut and Pamekasan which had 8 hospitals collaborating with BPJS. Meanwhile, in Nagan Raya, North Lombok and TTS only had 1 hospital that collaborates with BPJS.

Table 7. Puskesmas Characteristics

	District							
	Nagan Raya	Deli Serdang	Garut	Pamekasan	Lombok Utara	Timor Tengah Selatan (TTS)		
% Puskesmas carry out classes for pregnant women	100	100	100	100	52	100		
% Puskesmas conduct P4K	100	100	100	100	85,6	100		
No. of Auxiliary health center	49	109	142	34	30	0		
% active Posyandu	100	100	75.9	61,4	100	100		

All Puskesmas in 5 out of 6 districts carried out classes for pregnant women and P4K, only North Lombok did not reach 100%. Garut and Deli Serdang had the most auxiliary health centers, namely 142 and 109 respectively, while in TTS there were no auxiliary health centers. In Nagan Raya, Deli Serdang and TTS had 100% active posyandu, while in Garut and Pamekasan respectively had 75.9% and 61.4% active posyandu. Previous studies showed that group prenatal care such as class for pregnant women was suitable for the LMIC settings

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<sup>51</sup> World Health Organization & Family Health International (Organization) & Joseph L. Mailman School of Public Health. Averting Maternal Death and Disability & UNICEF & United Nations Population Fund. (2009). Monitoring emergency obstetric care: a handbook / World Health Organization. Geneva, Switzerland: World Health Organization

as the women can share the same support, cultural, and traditional practices and can improve the perinatal outcomes.<sup>52</sup>. A systematic review by Byerley wt al. (2017) showed that high-risk pregnant women could get more benefits by involved in group prenatal care.<sup>53</sup>.

Table 8. Characteristics of Health Facilities

	District					
Total	Nagan Raya	Deli Serdang	Garut	Pamekasan	Lombok Utara	TTS
Hospital based on class	;					
Type A	0	0	0	0	0	0
Type B	0	4	1	1	0	0
Type C	1	13	1	0	1	1
Type D	0	5	5	7	0	2
CEmONC Hospital	0	4	1	2	1	1
Hospital based on ownership status						
Public RS	1	4	2	3	1	1
Private RS	0	18	5	5	0	2
Private Clinics						
Private midwife practice	50	333	252	46	4	8
Private doctor practice	27	116	134	72	28	10
Pratama/ primary clinics*	9	187	140	15	0	5
Main clinics**	1	1	9	2	2	1

<sup>\*</sup>pratama/primary clinic: first-level clinics of a network system of health services aimed at providing basic or primary medical services.

Deli Serdang had 22 hospitals, the highest numbers of hospitals, among the six sampled districts,4 of them are type B. Other districts that had type B hospitals are Garut and Pamekasan. Meanwhile, Nagan Raya, North Lombok and TTS had class C hospitals as the

<sup>\*\*</sup>main clinic: Advanced level clinic of a network of health services with more specific health services focused on more serious medical treatment and more complicated medical procedures with the help of more advanced medical equipment, receive referral patients from Pratama Clinic who require follow-up action or treatment.

<sup>&</sup>lt;sup>52</sup> Jafari, F., Eftekhar, H., Fotouhi, A., Mohammad, K., & Hantoushzadeh, S. (2010). Comparison of maternal and neonatal outcomes of group versus individual prenatal care: a new experience in Iran. *Health care for women international*, 31(7), 571–584. https://doi.org/10.1080/07399331003646323

<sup>&</sup>lt;sup>53</sup> Byerley, B. M., & Haas, D. M. (2017). A systematic overview of the literature regarding group prenatal care for high-risk pregnant women. *BMC pregnancy and childbirth*, 17(1), 329. https://doi.org/10.1186/s12884-017-1522-2

highest referral level. Private midwifery practice, primary clinics and main clinics were also most commonly found in Deli Serdang, Garut, followed by Pamekasan. TTS had the fewest physician independent practices.

In the context of private midwifery practices, Deli Serdang and Garut had notable figures of 333 and 252, respectively. Nagan Raya and Pamekasan had modest figures of 50 and 46 private midwife practices, respectively. North Lombok and TTS had the fewest midwife independent practices. The same thing also happened for pratama clinics, where Deli Serdang and Garut had many pratama clinics. In contrast, Pamekasan, Nagan Raya, and TTS exhibited lower numbers of clinics, less than 20. Notably, North Lombok remained devoid of pratama clinics, setting it apart from the rest.

#### Determinants in the district

With regard to the maternal and newborn health outcomes in the district, there were slight variations although the patterns are quite similar.

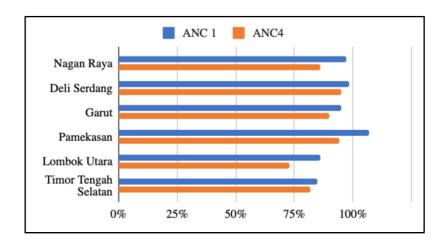


Figure 4. Coverage of First ANC and Fourth ANC in the Study Sites in year 2022

First ANC was considerably high among all districts, with the highest was in Pamekasan for 107% (probably this included also the ANC participants who were not the Pamekasan residents), and the lowest in TTS and Lombok Utara accounted for 85% and 86%. Meanwhile, in all districts, the fourth ANC was decreasing for around 5-11 digits.

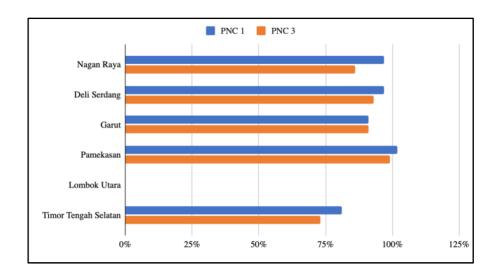


Figure 5. Coverage of First PNC and Fourth PNC in the Study Sites in year 2022

Figure 5 depicted the coverage of PNC visits. Most districts had more than 95% of PNC first visit coverage, and only TTS who had 81% of first visit PNC coverage. For the third visit PNC coverage, more figures were decreasing for 3-12%. Only Garut had the same coverage of first and third PNC visits. Unfortunately, we did not have such data in Lombok Utara.

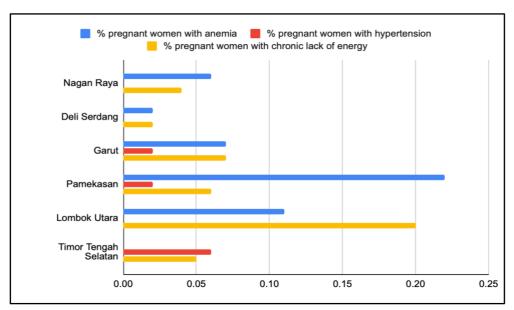


Figure 6. Percentage of women with Anemia, hypertension, and chronic lack of energy in the study sites in 2022.

Figure 6 indicated the percentage of women with Anemia, hypertension, and chronic lack of energy in the study sites in 2022. We could see that each districts had their own characteristics in terms of pregnant women's health problems. For instance, the percentage of pregnant women with anaemia was considerably high in Pamekasan, accounted for 22%. Meanwhile Lombok Utara had the highest percentage of pregnant women with chronic lack of energy (20%). Furthermore, TTS had the highest percentage of pregnant women with hypertension.

In Deli Serdang, the three conditions affected only a small proportion of pregnant women, with only 2% of the pregnant women suffering from anemia, and also 2 % have the low weight.

Subnational responses to risk factors of LBW varied. Some risk factors were addressed as part of the overarching program priority such stunting or maternal neonatal health. North Lombok enacted Peraturan Bupati (Regent's Regulation) no 7 year 2022 on the Minimum Service Standard for Puskesmas, in line with the national policies. Although there was no specific local level policy to address LBW issues, the local government was embedding the risk factors into their stunting program. For instance, North Lombok and Garut conducted several programs including pre-marital health education in collaboration with the local religion office (where the bride and groom usually registered themselves to be married). In addition, the health office through Puskesmas also conducted *Aksi Bergizi* in schools to ensure boys and girls receive education about health and nutrition as well as prevention of child marriage. Iron supplements are also distributed among adolescent girls. As for pregnant women, the district health office of Garut established a program called *Melani* to detect and treat high-risk pregnant women (e.g. those who were too old) at the community-level as early as possible.

Based on the understanding of the health workers in all study hospitals, the risk factors for LBW were high-risk pregnancies, which include 4 factors: the mother's age during pregnancy was too young, the mother's age during pregnancy was too old, the distance between pregnancies was too close, and pregnancy was too frequent. The nutritional status of the mother during pregnancy such as Chronic Energy Deficiency (CED) also influenced, as well as the low economic status of the mother. In addition, based on the history of previous pregnancies, if the first child was LBW, then the possibility of the second and third child being LBW was greater. This was usually caused by the mother's weak uterus. The mother's health condition during pregnancy also affected the occurrence of LBW. The findings in the North Lombok, TTS, and Pamekasan study hospitals explained that even though the mother's gestational age was above 36 weeks, if there was severe preeclampsia, the baby would likely be born LBW. In the Pamekasan study hospital, severe preeclampsia was the second-highest cause of maternal mortality in 2022. The high incidence of severe preeclampsia in the Pamekasan region was thought to be due to the high salt diet commonly consumed by pregnant women.

According to the local, North Lombok and Garut had a high incidence of child marriage. In North Lombok especially, although the local government had been working through Education Office and Religion Office to curb child marriage, some of the cases were due to teenage pregnancy. There was a sanction for the Head of the Village if there was a child marriage happens in the village, but this policy had backfire, somewhat. The Head of the Village was reluctant to report child marriage cases exactly because the Village will be fined for it. On the other hand, there was a culture that when a boy/man had taken a girl/woman out the house (elope), it was taboo for the parent to ask their child to be returned. Therefore, teenage birth in North Lombok was guite common.

Moreover, some other cultural context might affect the probability of missing services. In North Lombok, there was a superstition about supernatural forces that might threaten the existence of babies in their mother wombs. Therefore, it was believed that pregnant women should hide their pregnancy during the first few months. Pregnant women would only start seeing health

workers/midwives for their first check up in their second trimester, making it difficult for midwives to educate pregnant women earlier on ensuring their health and nutrition during pregnancy. This was exacerbated with the fact that mother in law was the prominent figure to be the trusted source of 'health' information including on matters around nutrition and the need for access to care.

A small number of religious groups also prohibited pregnant mothers from being helped by non-female health workers. At the primary care level, midwives usually provided care and treatment for pregnant women and mothers of newborns, however in case of LBW especially those with complications, the babies usually needed to be referred to hospitals, whereas the specialist doctors (obgyn and paediatricians) in the hospitals were mostly males. The males/husbands in these families (of conservative religion) usually forbade their wives to be treated at health facilities if there was any chance that their wives might be cared for by male doctors and would tell their wives to give birth with the help of the traditional birth attendants instead.

Another socio-cultural-gender balanced context also happened in other districts. For instance in TTS, based on the observation and conversation with the district health office and the health workers, the unintended pregnancies happened quite a lot in the area. High school or undergraduate students were pregnant, and they hid it from their families. They might come to the families when the pregnancy was too obvious to hide. Sometimes it was when they reached the third term of the pregnancy, which might be difficult to intervene. The other issue is similar cases also happened for the migrant workers, who worked overseas or in other countries, who came home only when the time to deliver the baby. Pregnancy outside marriage is very taboo in the community, and in many cases will bring shame to the family. A comprehensive reproductive education is not reaching those who need it. In addition, access to family planning is limited only to married couples.

Socio-cultural-gender role issues also apparent in decision-making. The condition in Pamekasan District was similar to TTS and North Lombok, where not all mothers can make decisions independently regarding care for themselves and their babies.

"The power of in-laws" Mum, if in the city maybe yes (children can get better information than their parents), for those who get an education. In the village, it's the grandparents who make the decisions, so they have to follow (the grandparents' advice)... That's why if postpartum mothers live in a large family environment, they cannot be 100% independent in deciding what was best for their children because the guidelines were the mothers who have had children first." FGD Pamekasan Hospital

They also faced problems with the "4Ts": too young, too old, too often, and too many, as reflected in unintended pregnancy, and child marriage as observed by staff of healthcare providers. Thus, addressing high infant mortality faces real challenges. Health workers, especially in rural areas, struggle to convince mothers to deliver in health facilities. Many health workers feel that religious, community, and political leaders prioritize popularity over supporting hospital deliveries, leading to community reluctance.

"Despite our efforts to educate them about the importance of hospital births, they remain unconvinced. Their past experiences weigh heavily, as they believe that hospital births still result in infant mortality."

"This belief becomes a strong influence, leading them to prefer surrendering to this outcome rather than enduring the inconvenience of hospital stays and repeated trips."

Low birth weight (LBW) babies are not perceived as needing special care; they are often treated the same as healthy babies, even if premature. On the other hand, people believed that surviving LBW babies "nyabeh oleh nenemu" which means they found their life after losing it, as their fate. Talking about fate, communities in Pamekasan resist hospital referrals, believing it's fate, which is reinforced by religious beliefs. Village leaders (Klebun) often oppose referrals, leading to transportation and facility issues at health centers. Some religious leaders, like Ibu Nyai, prefer traditional home births.

# Coverage of the key LBW interventions

In the instrument, we also asked the data about the number of LBW babies treated in the health facilities, the number of LBW babies who got exclusive breastfeeding, the complications of LBW babies, such as hypoglycaemia, hypothermia and, respiratory distress, and LBW babies who received kangaroo mother care (KMC). However in not all cases can be obtained in all districts, because the data is not collected in the district level.

	Year		
	2020	2021	2022
District	(Number of LBW cases reported (total birth), %)		
Nagan Raya	60 (2,834), 2%	47 (2,753), 2%	81 (2,834), 3%
Deli Serdang	90 (44,322), 0%	49 (41,900),0%	45 (42,372), 0.1%
		1517 (51,150),	
Garut	1539 (52,631), 3%	3%	1494 (48,170), 3%
Pamekasan	436 (13870), 3%	384 (13677),3%	399 (13737), 0.2%
North Lombok	NA	NA	NA
TTS	1478 (10,336),14%	1421 (9,491),15%	1289 (9,205), 14%

Table 9. LBW compared to total birth\*

\*Notes: This data we gathered here are from the DHO. We do not clarify their definition of LBW here, whether the numbers there represented all LBW cases, or only LBW with complications and whether stillbirth is inclusive. Data for LBW birth in North Lombok was not available at district level and required data collection for each Puskesmas.

The incidence of infants with LBW exhibits considerable variation across diverse geographical regions. LBW incidence is a matter of concern within the TTS district, reached a substantial proportion of 14% in 2022. On the other hand, Pamekasan, and Deli Serdang have very low figures, ranging from 0.1% to 0.3% in the reference year. In the region of Nagan Raya and Garut, LBW proportion constitutes 3% of the total birth recorded within the corresponding year. We acknowledge that poor recording and reporting still is likely a major

issue, as the figures provide in general except in NTT are lower than the prevalence of LBW based on the Basic Health Research 2018.

KMC is not consistently practiced across the sampled region and poorly recorded in the existing midwifery report. Data on KMC is only available in TTS district. In 2020, 39% of LBW babies got the KMC practice, while in 2022, the coverage was decreasing to be 30%. The assumption here why only TTS recorded the KMC data may because of in TTS based on the interview with the Dinkes staffs, they implemented the Small Baby Books for the LBW, where in the book they recorded the KMC practices as well. Meanwhile, the neonatal death due to LBW did not have a consistent pattern. Unfortunately, the reported data did not mention specifically the reason for LBW deaths, however LBW deaths data was separated from neonatal death related to asphyxia and congenital anomalies.

Table 10. Neonatal deaths associated with LBW

	Year			
District	2020	2021	2022	
	(in Number (total death), %)			
Nagan Raya	9 (37), 24%	11 (38), 29%	10 (50), 20%	
Deli Serdang	10 (29), 34%	7 (15), 47%	8 (25), 32%	
Garut	67 (196), 34%	76 (219), 35%	36 (292), 12%	
Pamekasan	11 (39), 28%	11 (51),21%	19 (53),36%	
North Lombok	17 (50),34%	21 (48),44%	18 (37),50%	
TTS	21 (82),26%	18 (78),23%	14 (71),20%	

Table 10 provides information on neonatal deaths due to (or associated with) LBW compared to the total nenonatal death. In the last three year, LBW accounted to 20% - 50% of all neonatal death in the six regions. Interestingly, the trend of neonatal death due to LBW is increasing in some places such as in North Lombok. In other areas such as in TTS and Garut, the trend is decreasing, while in Nagan Raya, Pamekasan, and Deli Serdang, the LBW deaths increased in 2021 compared to 2020, but then it decreased in 2022. Further analysis or study is required to investigate determinants contributing to this trend.

#### Provision of Care

Evidence-based practices for routine care and management of illness.

### Document review

WHO had established a comprehensive set of guidelines concerning the management of neonatal and LBW infants. In 2017, WHO published a document featuring updated recommendations on newborn health, encompassing a wide range of topics, such as immediate post-birth newborn care, postnatal care, newborn immunization, newborn resuscitation, the management of suspected neonatal sepsis, care for newborns born to HIV-infected mothers, management of preterm and LBW infants, and the treatment of severe

conditions.<sup>54</sup>. As per these recommendations, the care of preterm and LBW infants emphasized key areas including the prevention of hypothermia immediately after birth, Kangaroo Mother Care (KMC) and thermal care, the use of oxygen therapy, as well as continuous positive airway pressure (CPAP) and surfactant therapy for newborns with respiratory distress syndrome. The guidelines also addressed alternative methods for feeding LBW infants, including the use of a mother's own milk or donor human milk and the potential need for supplementation. In light of emerging evidence, WHO introduced updated recommendations in 2022, which further elaborated on preventive and promotive care, the management of complications, and the importance of providing support to families caring for preterm or LBW infants.<sup>55</sup>

In Indonesia, management of LBW has been an iterative process. In 2014, the Ministry of Health issued the National Action Plan (NAP) for Neonatal Health. The NAP states that the target in 2025 is for the neonatal mortality rate to be reduced to 9 per 1000 live births. Meanwhile, output targets related to LBW include 75% of mothers who had premature/LBW babies implementing PMK and receiving standard services, as well as home visits for LBW. In the manual for the implementation of BEmONC facilities (2013), it was stated that one of the limitations of BEmONC services is the management of handling LBW. This included diagnosing LBW and the complications that often arise, determining the causes of LBW and predisposing factors, treating complications in LBW, being able to arrange drinking/fluids for LBW, and also providing exclusive breastfeeding.

In 2021, the Ministry of Health issued guidelines for LBW management in primary health care. This guideline also covered post-treatment follow-up care at referral health facilities (secondary and tertiary) and care from the time the baby is born. BEmONC facilities can provide spontaneous delivery services, posterior presentation with an estimated fetal weight of 2000-2500 grams, or gestational age 37-40 weeks. If the LBW born is in a stable condition, without complications, then treatment can be continued at the health facility. All deliveries with an estimated fetal weight <2000 grams, or gestational age <37 weeks can only be treated in hospital.

To what extent do the health workers understand the recent guideline of LBW management? We explored them through the clinical simulation and the qualitative findings below

55 WHO recommendations for care of the preterm or low birth weight infant. Geneva: World Health Organization; 2022. Licence: CC BY-NC-SA 3.0 IGO

<sup>&</sup>lt;sup>54</sup> WHO recommendations on newborn health: guidelines approved by the WHO Guidelines Review Committee. Geneva: World Health Organization; 2017 (WHO/MCA/17.07). Licence: CC BY-NC-SA 3.0 IGO.

#### Puskesmas

Through our simulation, we had identified that decisions pertaining to therapy and interventions at Puskesmas are typically made by general practitioners (GPs), especially in cases where no improvement is observed during resuscitation or when infants necessitate a referral. Our examination of health workers within the BEmONC team at two Puskesmas had unveiled good practices as well as opportunities for enhancement.

Some participants demonstrated sufficient skills in the management of preterm infants/LBW babies (particularly those requiring resuscitation), but some others were not as knowledgeable and skilled in these aspects. For instance, participants did not prepare a resuscitation place and assess risk factors for asphyxia during the delivery simulation. Assessment of conditions at birth were not performed thoroughly. Some participants also lacked knowledge about the various sizes of suction catheters, the duration of Positive Pressure Ventilation (PPV), the use of laryngeal mask, evaluation of airway, heart rate, oxygen saturation, and signs of cyanosis, as well as post-resuscitation care. These findings insinuated the need for more frequent and intensive training in resuscitation for health workers in Puskesmas (doctors, midwives, and nurses).

Our participants in Puskesmas demonstrated appropriate skills in providing essential care for LBW babies, including assigning identity, administering vitamin K, Hepatitis B-0 vaccine, eye ointment, and umbilical cord care. However, in both Puskesmas, measurement of anthropometry could be improved by using standardized tools. One Puskesmas used a measuring tape to measure body length, while the other used non-digital scales to weigh the baby.

We observed an overall insufficient capacity among the participants in lactation management, early breastfeeding initiation, and breastfeeding counseling. While our participants could perform some steps in the early initiation of breastfeeding (such as positioning the baby on top of the mother's and enabling skin-to-skin contact) and provide a correct answer on the duration of early breastfeeding initiation (60 minutes), monitoring vital signs and danger signs were not performed thoroughly. Most of our participants did not receive training in breastfeeding counseling and, thus, did not provide breastfeeding counseling to mothers. While some nurses reported giving breastfeeding counseling, our paediatrician consultant observed incorrect breastfeeding practices among mothers who visited the facility.

Similarly, in terms of KMC, our observation suggested rooms for improvement among the participants. While some participants could perform some steps of KMC (preparing and placing and positioning the baby on top of the mother's chest, many participants were not aware of the procedures of KMC, as well as what to monitor during KMC. This is in line with our qualitative findings from FGDs with mothers and family members. Most of the mothers were not able to provide further explanation about KMC other than "hugging the babies close to the chest".

Skills in alternative feeding, as well as hypoglycaemia and hypothermia management were lacking among the participants. None of the participants seemed familiar with the use of feeding tubes. One Puskesmas usually used a cup for alternative feeding, while the other used pipettes. There was a lack of training in alternative feeding among the nurses and midwives. Participants in one Puskesmas also lacked the knowledge about evaluation of feeding in LBW babies, e.g. the frequency of urination in a day. If hypoglycaemia occurs, management is based on the doctor's instructions. Thus, signs of hypoglycaemia were unknown to the nurses and midwives. Among the nurses at one Puskesmas, there was some proficiency in hypothermia management, but temperature monitoring was infrequently conducted. Furthermore, at the other Puskesmas, none of the midwives could provide explanations about temperature monitoring for LBW babies.

In terms of infection, participants in one Puskesmas reported that an infection was diagnosed by the doctors, supporting examination was carried out through complete blood count, and first-line antibiotics included ampicillin and gentamicin. Whereas in the other Puskesmas, not all participants were able to provide information on the specific antibiotic regimens used within the facility.

## Hospital

At the hospital level, we the assessed maternal and neonatal teams in two hospitals, one in type B hospital and one in hospital type C.

In the preparation before the baby is born, the observation by the neonatologist revealed that before the birth of a premature baby, the preparations made include preparing the equipment, place and staff. Equipment was available in the delivery room, but its function and usability were not checked. The resuscitation table was located near the birthing area and preparations are made by covering it with linen and warming the resuscitation table. There was no action to review the condition of the fetus and look for risk factors for asphyxia. The impression was to improve the review before the baby is born to look for risk factors for asphyxia and prepare equipment. Meanwhile, the early breastfeeding initiation is carried out in LBW infants who do not require resuscitation. The staff (midwives) seemed skilled at performing IMD on premature babies. However, babies with IMD are not monitored for their clinical condition and invasive procedures are carried out. Similar approaches also happened in the other hospital.

For the initial step of neonatal resuscitation it showed that in one hospital, the neonatal nurse properly assesses the condition at birth. When carrying out the first steps, they were not in sequence and there were things that were not done. The initial steps took a long time (more than 1 minute). Meanwhile in the other hospital participants demonstrated sufficient skills in performing the initial steps. skills in assessing breathing effort and heart frequency were also appropriate. Furthermore, for the post resuscitation stabilization and transportation, both hospitals showed insufficient knowledge about post-resuscitation stabilization and transportation. Post-resuscitation stabilization was carried out by measuring temperature and signs of respiratory distress. Blood glucose level, heart rate monitoring, and capillary refill time were not carried out. The baby was transported to the neonatal ward without using transportation equipment.

In the essential neonatal care for small babies, both hospitals showed sufficient knowledge, even in one hospital the participants forgot to give identification to the baby. The anthropometry carried out by the nurse is birth weight and head circumference. Measure body length with a measuring tape, not a standard measuring board. Doctors also carried out other physical examinations.

In terms of alternative feeding, in one hospital the nurse was able to check the sucking and swallowing reflexes. Nurses were able to identify how to provide alternative feeding to LBW infants and can teach the baby's mother how to give breastmilk with a spoon/cup by the nurse. The paediatrician determined daily fluid requirements and their increase. The breast milk given is from the baby's mother; there was no donor breast milk. However, in the other hospitals showed inadequacy skills in performing alternative feeding.

For the kangaroo mother care (KMC), both hospitals showed the nurses demonstrated sufficient knowledge about KMC, namely goals, preparation, criteria, monitoring, and family counselling. However, no records about the number of infants receiving KMC were available in the facility. posters on the algorithm of KMC were visible in the KMC room. KMC is carried out once a day, in the morning, afternoon or evening shift with a duration of around 2-4 hours.

In terms of respiratory distress, both hospitals showed similar skills. Nurses were able to determine the severity of respiratory distress by assessing the Downes score. Regarding the respiratory frequency parameter, the nurse did not calculate the frequency correctly. Monitoring the development of respiratory distress was not carried out adequately every 3 hours, namely the Downes score and oxygen saturation. Nurses were able to operate continuous positive airway pressure (CPAP) devices. In respiratory emergencies (apnea), nursing management and initial emergency response actions are inadequate. The impression was the way to assess respiratory frequency was incorrect. Nursing actions for respiratory emergencies are inadequate.

For emergency cases such as hypoglycaemia and seizures in both hospitals the nurses and midwives showed different skills and knowledge. In one hospital they were able to describe hypoglycaemia and seizure management. But in the other hospital, hypoglycaemia management is based on paediatrician instructions, namely 10% dextrose bolus, glucose infusion rate, and fluid requirements. Post-correction of hypoglycaemia monitoring was not explained correctly in both hospitals. Nurses only know that seizures in neonates are of the tonic or clonic type. If the baby has a seizure, the nurse would report it to a paediatrician to administer medication. Supportive care for infants with seizures is the administration of nasal oxygen alone.

In general, LBW services at the hospitals in the two districts need much improvement. The skills of nurses or midwives who handle LBW infants need to be improved.

# Qualitative findings from National Levels

These were the findings of the qualitative interviews at the national level related to LBW Management in Indonesia. To implement the guidelines and regulations related to LBW Management, health workers are prepared with various continuing education tools. For

instance, a team of doctors, nurses and midwives are trained in BEmONC and CEmONC care, or at least training on maternal neonatal emergency care. Trainings were held by the government or in collaboration with professional organizations

"Several midwives told me that they have funding from DIKTI for their training, which is for the resuscitation of newborn babies." (IBI)

"We are collaborating with the Ministry of Health, including some of the trainers from IBI, trainers for emergency, obstetric, and neonatal emergencies, to train several provinces. If I'm not mistaken, since three years ago. In that case, we have been continuously doing that with emergency management of mothers and babies, including resuscitation and how to stabilize for referral and also how to prevent infection, and so on." (IBI)

The Ministry of Health perceived that in terms of competency and use of evidence-based practice regarding essential neonatal care (including for emergency and LBW cases) there should not be any challenges, since it has been included in the available guidelines and also refreshed through various training sessions. Training from the Ministry of Health included blended learning MCH for Puskesmas doctors (the material ranges from ANC to death management, including material on implementing LBW at the Puskesmas), which then followed by on-the-job training at the respective district/city hospitals

"The KIA blended learning training is for Puskesmas doctors, which may range from ANC to managing the most deaths in babies. One of the materials related to babies is LBW, the implementation of LBW at FKTP. For the training itself, the method is blended learning, so there are online sessions and lectures carried out via Zoom, then continued with on-the-job training at each city district hospital." (Dit GKIA, Kemenkes)

Following maternal neonatal emergency training, there was also practice/on-the-job training in the hospital for 2 weeks.

"Gadar Matneo (Maternal Neonatal Emergency) also has a practice at the hospital for two weeks, one week is maternal material, and one week is material related to newborn babies. We do this in stages, so we (Kemenkes) only trains facilitators" (Dit GKIA, Kemenkes)

PPNI (Indonesian National Nurses Association) also has a curriculum to build competence that is suitable to the different levels of required care.

"For nurses in the hospital, we have basic training for neonates, our trainings covered level 1, 2 and 3 ... Level 1 is for healthy babies or jaundice babies, Level 2 is for babies that need certain therapy such as intravenous therapy, Level 3 is for emergency situation." (PPNI)

IPANI (Indonesian Pediatric Nurses Association) played a role in increasing competence and inducting pediatric nurses, issuing training certificates for pediatric nurses/community nurses

"We have a program, ToT, so we can go to the DPW (region) to enlighten our friends according to their respective fields to provide better services .... So far, we have focused on programs for independent practice and strengthening them. PPNI took the initiative to train village nurses" (PPNI)

"Well, this is for community nursing, yes, village nurses. IPANI provides what is called a certificate. We have conducted 18 batches of training to increase the competence of our pediatric nurse friends through IPANI in the regions, providing this service." (PPNI)

IDAI, as a professional organization, also plays a role in translating evidence-based practice into routine care and management of illness by applying those knowledge into curriculum (preservice education) and update knowledge via conferences and seminar as well improving skills via practical workshop (after-service training)

"As usual, this collaboration with the Ministry of Health has several target locations. It is supplemented, using a blended learning program, not just about neonatology but also from other fields, such as pediatric respirology, pediatric nutrition, etc. So, it is integrated. The aim is that later, these general doctors at Puskesmas will not only focus on neonatology knowledge, but if the baby survives, he will continue to grow into a child, and he will be continuously monitored. So he/she is also equipped with pediatric knowledge. So the general practitioners, nurses and midwives are equipped with knowledge, from neonates to children" (IDAI)

However, the implementation of the guideline might be affected by some factors. One a general guideline itself was not deemed sufficient by professional organization, and it might need a set of more specific guidelines. Second, the capacity of a BEmONC to implement guidelines might be hindered by lack of trained human resources. Although the staff were usually trained prior to a facility becoming a BEmONC facility, the staff might not be available anymore due to transfer and rotation. Therefore, BEmONC facilities need to be reviewed regularly to ensure that they actually have capacity to function as a BEmONC facility.

"We need PNPK guidelines, National Management Guidelines, like PNPK for handling LBW, PNPK for handling newborn jaundice, PNPK for stabilization and transportation, ... these don't yet exist, but we are making them, in the process of making them." (IDAI)

"This year, we are revising the Poned guidelines. One of the points that we included in the revision is that Poned's status is reviewed every three years." (Dit GKIA, Kemenkes)

Qualitative findings from Study Sites related to Evidence Based Practice

Below are the qualitative findings from the hospitals and the Puskesmas MCH coordinators and the health workers. In the interviews, we explored how the FGD participants perceived the LBW related management, including the prevention steps, early detection and intervention, and the treatment.

### **ANC**

One of the efforts to detect LBW cases was through antenatal care (ANC). Based on the results of FGDs with Puskesmas BEmONC North Lombok and Non BEmONC Pamekasan, it was explained that pregnant women can conduct their pregnancy checks at private midwives, Polindes or Puskesmas. Midwives were always available at the Polindes, if you go to the Polindes, the mother will be asked for her data and anamnesa was carried out then an examination was carried out, the data collected will be recorded in the register book. If the patient was positively pregnant, the patient will be asked to do an integrated ANC examination at the Puskesmas, followed by a visit to Posyandu once a month.

All Puskesmas in this study explained that integrated ANC at Puskesmas includes the 10T component with 6 ANC examinations, namely K1 to K6 in accordance with the provisions of Permenkes 21 of 2021, where 4x ANC was carried out by midwives, plus 2x ANC with a doctor for ultrasound, namely at K1 and K5. In addition, pregnant women will also get other examinations such as:

## Laboratory examination

Triple Elimination and measurement of Hb levels, especially in the 1st trimester and 3rd trimester of pregnancy. Provision of iron supplements for all pregnant women at least 90 tablets. The health center will ensure that the iron supplements was consumed. BEmONC Deli Serdang explained that the way to ensure that iron supplements was consumed was through anamnesa, so that if the mother lies, it will be known by health workers. BEmONC Deli Serdang health workers also explained that the MCH book has a self-monitoring list, which was a record of how much iron supplements have been taken. The health center provides a briefing on the impact of not taking iron supplements, including the side effects of taking iron supplements, at all monthly classes for pregnant women. Each village has one class per month for pregnant women, with a total of 11 villages in the BEmONC study health center area in Deli Serdang. According to health workers, if pregnant women care about their own health and the health of their babies, they will definitely come to the classes.

# **Nutrition**

In all participating health centers, Mid Upper Arm Circumference (MUAC) is measured (in the first ANC) to determine. The MUAC value was less than 23 cm considered as the pregnant woman is experiencing chronic protein deficiency. The mother will receive additional food (Biscuit PMT) supplementary food, namely PMT, (please specify the type of PMT). In Non BEmONC Nagan Raya, Posyandu cadres monitor the PMT consumption. Pregnant women are weighed once a week during home visits by village midwives and Posyandu as part of this monitoring programme, which guarantees a thorough and careful approach to maternal nutrition and well-being.

In the BEmONC TTS region, if a pregnant woman was found to have SEZ, health workers will visit the woman's home and assess her diet and directly observe her nutrient consumption. During the visit, health workers will provide education on proper diet, including examples of proper nutrition. Based on direct observation experience in the community, usually the

processing of food ingredients was still not in accordance with the needs and most SEZ mothers just eat as long as they were full, but do not pay attention to balanced nutritional needs. In Pamekasan District, in general, most people consume less vegetables.

Furthermore, pregnant women who were detected as high risk will be marked by stickers at home (BEmONC Deli Serdang).

In the Garut BEmONC area, home visits by midwives or nurses were carried out for diseaseprone families, including high risk pregnant women, high risk neonates and high risk postpartum mothers. The results of the examination by the health worker will be the basis for the mother and baby to be referred to the Puskesmas. If the mother's or baby's problem can be solved by management at the Puskesmas, then appropriate management will be implemented immediately, but if it requires referral, then the mother or baby will be referred to a higher health facility.

Based on the explanation of Non BEmONC Pamekasan, if based on the ANC results, the baby's predicted weight was around 2000 grams at birth, then the mother will not be given education to be referred, because with a baby's birth weight above 2000 grams and a good condition, it was sufficient to be handled by a midwife.

"...usually we (Puskesmas) if it was still above two (kilos), we don't educate ... above two kilos was healthy, usually enough monitoring by the midwife. But if it's below two (kilos), we still educate and refer. But this referral was if you want it, ... if you don't want it, the nutritionist will monitor it".

FGD Non BEmONC Pamekasan

Whereas at BEmONC Garut, if your baby were predicted to be at risk of LBW, you will be referred to an Sp.OG doctor so that the mother's pregnancy can be maintained.

"For example, if the patient comes to the Puskesmas, if the fetus was small (potential LBW) we collaborate with Sp.OG to maintain the pregnancy ... using the Whatsapp group, sometimes calling directly the duty doctor Sp.A ... Once the baby was born, we collaborate with Sp.A. ... using Whatsapp groups, sometimes we call directly to the Sp.A. duty doctor..."

FGD BEmONC Garut

There were challenges in conducting ANC, one of which was patient willingness. Based on the explanation of the resource person at the Garut BEmONC FGD, it was explained that there were still pregnant women who were reluctant to check their pregnancy conditions at the Puskesmas so that detection of high-risk pregnant women was difficult.

"The officer has done the maximum counseling, from the Whatsapp group there is, the patient does not want (ANC 6 times) ... we have gone to the house, if the patient does not want it, it was difficult. The difficult ones were closed pregnancies such as MBA (married by accident) suddenly giving birth or ... there were still those who believe in paraji"

Based on information from BEmONC Lombok, if there was a mother who will give birth with complications or there was a possibility of giving birth to LBW, it will be immediately consulted via telephone to the SpOG doctor at the Hospital, if the SpOG doctor asks to be referred, then BEmONC Lombok will immediately call the Hospital ER to make a referral.

Based on the explanation of Pamekasan Study Hospital, for mothers who were predicted to be at high risk for early delivery, the pregnancy was attempted to be maintained with the help of medication. However, in some cases, if signs of labor appeared even though the gestational age was not yet at term, delivery had to be performed.

"...usually when these patients come to us at the hospital, they were conserved, as much as possible maintained. ... given reinforcement to the uterus. If the contractions disappear, the opening does not progress, there were no signs of labor, (pregnant women) were discharged by the doctor. But in most cases, they (pregnant women) come back again with premature labor".

FGD Pamekasan Hospital

#### MANAGEMENT OF LBW AT PRIMARY HEALTH CENTER

Based on BEmONC Deli Serdang's experience with mothers who give birth to LBW at the Puskesmas, LBW will be examined first whether it needs to be referred or not. Monitoring was carried out for 1x24 hours, where the baby's condition was confirmed first, whether the baby wants to suckle or not, whether there were problems with digestion, was there a problem with the ability to survive in a new environment, after ensuring that the LBW's condition was stable, then the LBW can be discharged. If the condition was not stable, the LBW will be treated at the health center for a maximum of 3x24 hours, and if the condition does not improve, the LBW will be referred to the hospital. In some cases, it was necessary to install an OGT before the baby was referred. OGT installation was done to fulfill the baby's nutritional needs while waiting for the baby's condition to stabilise before referral, because in LBWs it was often found that the suction and swallowing reflexes were still weak. Once the baby was stable, a new referral will be made.

At BEmONC Garut, health workers claimed to have treated 1 LBW within 1X24 hours due to waiting for the Sisrute queue. Similar to BEmONC Deli Serdang, while waiting for referral, LBW were monitored for temperature, muscle tone, fluid needs, whether the baby was willing to suckle or not, and how the mother breastfeeds. Monitoring by health workers was done every 2 hours at the Puskesmas. In managing LBW, BEmONC Garut feels the need to be careful and immediately refer LBW to the hospital due to limited equipment.

"... karena alat Puskesmas tidak sesuai standar, kalau kita menahan (tidak segera merujuk BBLR) takut disalahin"

FGD BEMONC Garut

## Management of Respiratory Distress in Health Centers

Based on the FGD results, almost all health centers in this study admitted that they have never handled respiratory distress in LBW, except Puskesmas in TTS.

Even if they have, BEmONC Deli Serdang explained that when LBW were born, the condition was first assessed while keeping the baby warm. Adjust the baby's position and if there were symptoms of respiratory distress, suction the mucus, then assess the baby's condition. If there was still respiratory distress, adjust the baby's position again and then perform resuscitation assistance. For babies with severe asphyxia, BEmONC Deli Serdang explained that it will use a T-piece resuscitator. After resuscitation was complete, assess the baby's condition again, and if resuscitation was successful, then further treatment will be carried out. If resuscitation was unsuccessful, resuscitation will be performed again. If two resuscitations fail to improve the baby's condition, referral will be made. Resuscitation equipment was available at BEmONC Deli Serdang, but was never used because there were no cases. In addition, because the hospital was close by, it was easier for the health center to make direct referrals.

"T-piece resuscitators were used for babies born with asphyxia. ... If it's severe asphyxia with swallowed amniotic fluid, hypoxia, you have to use a T-piece resuscitator... and usually the T-piece resuscitator was so that the blood flow to the lungs was smooth, he has to use CPAP so that the airway opens properly".

FGD BEmONC Deli Serdang

Similar to BEmONC Deli Serdang, at BEmONC TTS, if a baby has severe asphyxia, an emergency CPAP consisting of a hose and plastic bottle will be fitted.

"...CPAP was for babies with severe asphyxia and respiratory emergencies, well we (use) CPAP emergencies immediately refer, according to the doctor's advice".

FGD BEMONC TTS

Furthermore, according to the explanation of the BEmONC Garut resource person, CPAP was reserved for infants with a condition of "respiratory shock".

"So we have the sequence of keeping warm, suctioning the electric mucus, drying it, adjusting the position again, then using the ambubag... CPAP was used when the baby ... has respiratory failure in the upper tract .... CPAP for patients in respiratory shock".

FGD BEmONC Garut

Based on the 2018 National Guidelines for Medical Services for Resuscitation, Stabilization and Transport of Low Birth Weight Infants, shock was only divided into 3 types, namely hypovolemic shock, cardiogenic shock and septic shock, so there was no respiratory shock.

An interesting finding from this study shows that the Puskesmas' understanding of the use of CPAP was to wait for the baby to experience severe respiratory distress. Supposedly, the correct indication for CPAP was that CPAP was intended for all newborns with breathing difficulties who still have spontaneous breathing, with a heart rate >100 beats/minute or in the category of mild and moderate respiratory distress, while in infants with severe respiratory distress (including severe asphyxia) intubation should be carried out immediately before the baby was referred (Kepmenkes, 2019).

# Kangaroo Mother Care (KMC) Implementation In Primary Health Care

Most BEmONCs and non-BEmONCs admitted that when teaching KMC to patients, they not only verbally but also directly practice. However, the practice of implementing KMC in health centers in this study was quite diverse.

Non BEmONC Pamekasan health workers felt that KMC was not practical because in addition to having to buy KMC equipment, KMC also caused people to be unable to work, so it would be better if LBW were placed in a baby box.

"... we (Puskesmas) also lack the motivation for LBW to be implemented like that. It's not practical for me because, you don't have to buy equipment, right. But they (the community) can't work, it's not practical hehe. So it's better to use a box and put it...".

### FGD Non BEmONC Pamekasan

In Non BEmONC TTS and Non BEmONC Nagan Raya, KMC education for actively moving LBW was not directly practiced, but only explained verbally. The existence of the Little Baby Book was felt to help Non BEmONC TTS to explain the steps of KMC to mothers.

"We don't practice KMC too often, if we see that the baby was active, we don't (practice KMC), we (Puskesmas) only provide IEC. Direct practice was rare, with the Little Baby Book, we were helped. We show it to the community or to mothers, the steps were there, it's more helpful."

#### FGD Non BEMONC TTS

Based on information from Non BEMONC TTS health workers, community acceptance of KMC was still not good, so there were still people who believe that the Sei tradition will warm the LBW better than KMC.

"I was once on duty, it happened (there was a LBW) 1.8 kilos active, I said: Mum, Dad, do you have a big shirt? ... we wear a shirt to cover the warm sonde, give us a hat, hand shirt. (LBW) Put it here to keep ade warm, if there was breastfeeding we looks for stomach contraction, if that was good so as not to bleed. Our simple language, they don't want to. They (the community) say, we go home, we roast (LBW)".

The findings of the Non BEmONC TTS on the roast tradition are supported by the findings of the TTS study hospital which proves that this tradition is still practiced in TTS.

"...because they were still baked, even though here we (health workers) have advised not to do that... Sometimes their parents (LBW) want to follow the doctor's recommendations, but their grandparents (do not want to follow the doctor's recommendations)... then they (parents of LBW) say: let me (health workers) explain to their grandparents... Especially if they live with their mother-in-law".

FGD Rumah Sakit TTS

The tradition of roasting (*Sei*) was the tradition of heating or smoking new mothers and their babies by sitting and sleeping on a bed with a fire underneath for 40 days. Some people in TTS district believe that roasting the mother and baby can speed up postnatal health recovery and strengthen the baby's condition.<sup>56</sup>.

Similar to TTS, community acceptance of KMC in Pamekasan district was also poor because KMC was considered dangerous and troublesome for parents of LBW, especially for manual laborers who have to work such as hoeing under the hot sun every day.

"If the baby was taped, in my opinion, it seems that they (the community) have not accepted it as a good enough strategy for LBW. If the baby was small, just leave it alone. Don't carry them, they will fall even more. Especially if you have to wear taped clothes. ...Maybe if you work abroad, you don't hoe, ma'am hehe. If here, it's a girl who does the labor... If abroad, the culture was different. Here, for example, if you carry a baby in a hoe, it's already exposed to the heat of the sun, you can't wrap it in the sun either, hehe. At 12 o'clock it burns. Wear the father's jarik. Keringete gobyos iku. The kangaroo method was still not accepted. If you teach it here (Puskesmas), you will, ma'am. .... It's only the aftercare that we can't guarantee. I was told not to bathe them, but to bathe them anyway..."

FGD Non BEmONC Pamekasan

In Garut BEmONC, KMC was considered to reduce the mother's mobilization ability, so instead of performing KMC, people prefer to place the LBW under an incandescent lamp to warm the baby.

"During the home visit, ... the mother did not practice KMC with various excuses, it was difficult to go here and there, water was difficult when I visited. Just use the lamp"

FGD BEMONC Garut

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<sup>&</sup>lt;sup>56</sup> Anwar, A., & Soerachman, R. (2014). Kesehatan ibu dan bayi yang melakukan tradisi sei dan gambaran kesehatan lingkungan rumah bulat (ume 'kbubu) di Kabupaten Timor Tengah Selatan Provinsi Nusa Tenggara Timur (NTT). *Indonesian Journal of Reproductive Health*, *5*(1), 105952.

In Deli Serdang District, the community felt that the air temperature in the area was already hot so LBW did not need to be kept warm.

"Sometimes Deli Serdang was hot, we make the kangaroo method complain to them (the community), finally they don't do it because it's already hot at home"

FGD BEmONC Deli Serdang

In BEmONC North Lombok, mothers were asked to stand while performing KMC for 30 minutes until they feel tired, then the LBW will be monitored.

"If my own recommendation was 3 times (a day), keep it on her chest. (At the Puskesmas) We ask (mothers) to stand while holding the baby in the postpartum room. Sometimes the mother reports, "Mum, I'm tired" and then we monitor the baby's condition. (Each time PMK for) 30 minutes actually, but it's not yet time to complain about being tired, because the room was hot too."

FGD BEmONC Lombok Utara

In non BEmONC North Lombok, KMC will be carried out if the mother was in the hospital with her baby. KMC was carried out for 1 hour per day during the co-patient period. KMC was carried out by sitting on a plastic without a backrest in the postpartum room.

"For example, if she (the mother) was admitted to the Puskesmas, (KMC) was applied until the admission process was complete, ... (KMC a day was carried out in) 1 hour, for example, the baby was sleeping, let it go ... immediately monitored, usually we (Puskesmas) monitor whether the baby's position has changed or not, then the position of the head, body temperature."

FGD Non BEmONC Lombok Utara

In some cases, if the mother refuses to perform KMC due to discomfort and fear that the baby was too small, the baby will be placed in a warmer. Non BEmONC North Lombok interviewees admitted that it was rare for mothers to ensure that the KMC taught at the health center was actually carried out at home.

# Breast Milk Feeding

In general, based on the explanation of BEmONC and non-BEmONC in this study, Puskesmas have tried to educate the community on various things related to breast milk, including the nutritional content of breast milk, breast care, how to breastfeed and exclusive breastfeeding, especially for LBW.

"With good nutrition for the mother, the breast milk will have a high quality and the baby's weight increases quickly... we also teach young mothers how to breastfeed and the correct breastfeeding techniques."

"...give breast milk as often as possible, so every 1-2 hours even though the baby's suction power was weak, we give advice to give breast milk every 2 hours, ... the more often the baby suckles the more breast milk production".

FGD Non BEMONC TTS

However, some health workers highlighted poor LBW feeding practices, including pre-lacteal feeding using formula milk and solid food. Non BEmONC Pamekasan and BEmONC Deli Serdang explained that usually breast milk was only released 2-3 days after delivery, therefore while waiting for breast milk to come out, some mothers choose to give formula milk.

"They (the patients) used formula milk, it's probably because the breast milk hasn't come out yet. It usually comes out after three days. That (formula milk) helps. But after the milk comes out, they stop using formula."

FGD Non BEmONC Pamekasan

"... In the beginning, because the mother's milk didn't come out, she had to give formula milk. It was forced, because it was impossible for the baby (to be) dehydrated. It was only for a few days. After knowing breastmilk, I didn't want formula milk anymore"

FGD BEmONC Deli Serdang

Not only formula milk, in Pamekasan District, early complementary feeding was often done by the community.

"It's actually a cultural factor. The provision of nutrition that was given before the time was given, it's early complementary food... Cornflour (mixed with hot water and made into porridge), banana, then young coconut, cassava tape. Maybe because the texture was soft so it was considered easy to digest... Yes, spooned. Scooped. More extreme, maybe not using a spoon ma'am, so sorry, food ingredients were inserted and then forced to press with the thumb. So the baby cries and then continues... That mindset, my parents were like that and in the family nothing happens".

FGD Pamekasan Hospital

Health workers were concerned that LBW were given solids immediately after birth, so Non BEmONC Pamekasan health workers try to explain to the community to wait at least until the baby was 4 months old before giving solids.

"Instead of just being born immediately, it's better for four months, Mum. Ask me to choose (Puskesmas).... If I can't wait long (to give early complementary foods), I give it at least four months. I can't wait for six months, four months...".

FGD Non BEmONC Pamekasan

Furthermore, the Non BEmONC Pamekasan health worker explained that some mothers prefer practical ways to keep their babies from fussing, so mothers and families choose to give MP-ASI with the assumption that the baby will be full and not fussy for a long time.

"So the baby does not cry in the middle of the night and mum can sleep. Actually, the counseling was already done... But the community wants something practical, something easy... (mum and family would like to) stuffing a banana (for the baby)... the baby will be full for two days and not fussy... the baby's stomach was big... Cornflour, formula milk mix with cornflour, ... use unripe coconut and honey. They (patients) want the baby to grow up fast"

FGD Non BEmONC Pamekasan

At BEmONC North Lombok, if a mother complains that she has little milk supply, the advice given was for her to increase her food portion.

"We (Puskesmas) ask how much did the mother's food portion is, if it's not enough we tell them to add more"

FGD BEmONC Lombok Utara

## Post Discharge

According to BEmONC Garut's explanation, if a LBW born at BEmONC Garut requests forcefully to go home, the public primary health care will collaborate with the village midwife to be monitored.

"... from the hospital there was a notification of a referral letter, the village midwife will be informed, ... the first 2 days the baby was recommended here (Puskesmas), then the first and second week the village midwife visits the house. The first 2 days the baby was recommended to come here (Puskesmas), then the first and second week the village midwife visits the house."

FGD BEmONC Garut

Based on the Regulation of the Minister of Health of the Republic of Indonesia Number 53 of 2014 concerning Essential Neonatal Health Services, it was stated that the timing of newborn examinations was carried out as follows, when the baby was 6-48 hours old (neonatal visit/KN 1), when the baby was 3-7 days old (neonatal visit/KN 2), and when the baby was 8-28 days old (neonatal visit/KN 3), so based on the explanation of the Garut BEmONC resource person above, KN 1 was carried out by the mother coming to the Puskesmas, while KN 2 and 3 were carried out by the village midwife coming/visiting the patient's house. This condition shows that both for non LBW babies and LBW babies, the number of neonatal visits carried out was the same, which was enough 3 times.

Ideally for LBW with a weight of <1800 grams after the first control 3 days after discharge, recheck every 1-2 weeks until the baby's weight reaches 3000 grams. In addition to the immunization schedule, the baby's growth and development also needs to be monitored at the age of correction at 3, 6, 9, 12 and 18 months and then every 6 months.<sup>57</sup>.

Based on the explanation of Non BEmONC North Lombok informants, when the Non BEmONC North Lombok Puskesmas referred LBW to the hospital, there was no further explanation from the hospital regarding the baby's condition, either during treatment or after the baby returned home.

"...sometimes when referring a patient to the hospital, we don't get a referral back from the hospital to the health center... regarding the development of the baby, ... the extent of treatment at the hospital ... Patients who were discharged from the hospital we don't know what their development was like, ... when referred to the hospital there should be a referral back to the Puskesmas, sometimes there was no feedback to us (Puskesmas), meaning (we don't know) what the baby's condition was like..."

#### FGD Non BEmONC Lombok Utara

Similar to the condition in North Lombok, in Pamekasan District, Puskesmas also did not feel that they received adequate information regarding the condition of the referred patients, including when the patients were discharged from the hospital.

"So we only know that the patient was discharged ... The patient shows us (the referral sheet). Not from the hospital, the patient. So yes, we have surrendered the patient's condition (to the hospital) ... When the patients went home, hospital didn't tell me anything unless there was something special... I consult privately to the doctor usually. ... But there's no notification from the hospital to us"

### FGD Non BEmONC Pamekasan

Regarding the monitoring of babies after returning from the hospital, Non BEmONC Nagan Raya explained that they work closely with cadres, so that if there were LBW who have just returned home, the cadres will report to the village midwife. In Deli Serdang District, visits for infants were conducted by the village midwife.

#### MANAGEMENT OF LBW IN HOSPITAL

At the Pamekasan study hospital, LBW born in the hospital in a stable condition will be cared for together with their mothers, but if they were not stable, they will be admitted to the NICU.

<sup>&</sup>lt;sup>57</sup> Nakatudde, I., Rujumba, J., Namiiro, F., Sam, A., Mugalu, J., & Musoke, P. (2019). Vaccination timeliness and associated factors among preterm infants at a tertiary hospital in Uganda. *PloS one*, *14*(9), e0221902.

Based on the results of FGDs with the resource person from the Perinatology Room of the Garut District study hospital, for monitoring sick babies, Downe score calculation was used. If the Downe score was above 5, intensive monitoring will be conducted. Downe score was used to assess the level of respiratory distress in neonates. The Downe score calculation table was presented as follows:

Table 11. Evaluation of Respiratory Distress: Downe's Score

Examination	Score			
	0	1	2	
Breathing frequency	< 60/minutes	60-80/minutes	>80/minutes	
Retractions	No retraction	Mild retraction	Severe retraction	
Cyanosis	No cyanosis	Cyanosis resolves with O2 administration	Cyanosis persists despite O <sub>2</sub> administration	
Breathing Sound	Breathing sounds in both lungs were good	Breathing sounds in both lungs decreased	No breathing sounds in both lungs	
Whimpering	No whimpering	Can be heard with a stethoscope	Can be heard without an instrument	

The evaluation of respiratory distress with Downe's score was as follows:

- Score 1-3: mild respiratory distress: level II B treatment
- Score 3-6: moderate airway distress: Level II B treatment
- Score >6: severe respiratory distress
- Next, plan the management of respiratory distress that requires treatment up to Level II B.

The Downe score should not be used as a basis for performing respiratory support in infants. Downe's score was required when health workers were about to pass with the aim of ensuring an objective "common understanding" to determine further care for the infant (the consensus from Neonatology Working Group of IDAI (Indonesia Pediatric Society)).

Regarding recording, health workers at the Garut study hospital felt that recording was limited because the form used was the CPPT (Integrated Patient Development Record) which

only contained oxygen levels, heart rate, and temperature. Meanwhile, LBW babies treated at the North Lombok study hospital will be monitored at least every 2 hours using a long sheet. The monitoring includes the fulfillment of nutrition, medicines, and the use of equipment. In infants with respiratory distress, routine monitoring will be carried out then the baby's condition will be reported to the paediatrician.

Monitoring of LBW in the NICU (level 3) of Deli Serdang Study Hospital was done once every 1 hour. However, if the LBW problem was quite severe/serious, monitoring can be done every 30 minutes. Oxygen Saturation monitoring in the NICU was carried out continuously using a pulse oximeter with a probe where the device was installed continuously, not removable. Whereas in infants at level 2, oxygen saturation will only be checked when the baby was going home.

# Management of Respiratory Distress at Hospital

Based on the results of FGDs with health workers at the Deli Serdang Study Hospital, if a baby suddenly had difficulty breathing, what would be seen was the oxygen saturation. If the saturation was good, it was confirmed whether the baby was crying or not. If the baby was not crying, the duty doctor will attach oxygen and then be monitored at the hospital by a nurse. The doctor and nurse then ascertained whether it was only the muscles that were weak or whether the LBW's heart rate was also weak. If the baby's heart rate was below 100, VTP (positive pressure ventilation) should be done and if the baby's heart rate was below 60, intubation should be done. This explanation was in accordance with the flow of resuscitation in Newborns by the American Heart Association, 2010.

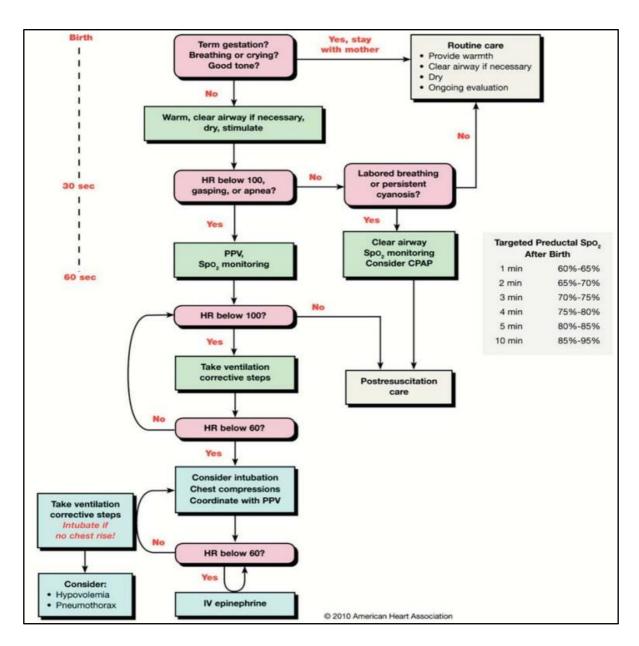


Figure 7. Newborn Resuscitation Flow Chart

Regarding the use of CPAP, in the Deli Serdang District several Puskesmas already have CPAP equipment, but there were no personnel trained to use CPAP. This condition was different from the Puskesmas of Nagan Raya region, most of which do not have CPAP. CPAP (Continuous Positive Airway Pressure) was a device to maintain positive pressure in the airway of neonates who can breathe spontaneously.<sup>58</sup>. CPAP requires a pressurized gas source, administered through a nasal cannula and used in all infants with respiratory distress but LDJ > 100x/min. CPAP must be available in every hospital that handles LBW cases.<sup>59</sup>.

58 Portal, M. R. Continuous Positive Airway Pressure (CPAP)-Care in the Newborn Intensive Care Unit (Butterfly Ward).

<sup>&</sup>lt;sup>59</sup> Smithhart, W., Wyckoff, M. H., Kapadia, V., Jaleel, M., Kakkilaya, V., Brown, L. S., ... & Brion, L. P. (2019). Delivery room continuous positive airway pressure and pneumothorax. *Pediatrics*, *144*(3).

There were differences in the availability of CPAP equipment in Nagan Raya, Garut and Deli Serdang District Hospitals. At the Garut study hospital, there were 4 CPAPs and all of them could still be used. Whereas in the Nagan Raya study hospital there were only 2 of the 4 CPAPs that could be used because the other 2 were damaged. Based on the FGD results with Deli Serdang Hospital, the use of CPAP in the room depends on the baby's indication and the doctor's direction. When installing CPAP, make sure the disposible circuit was attached to the central oxygen and then the nasal prong was attached to the baby. The installation of CPAP has conditions. The paediatrician determines the amount of PEEP CPAP and then delegates the authority to the duty nurse, but sometimes the duty doctor himself directly measures the PEEP CPAP needs. PEEP (Positive end-expiratory Pressure) was the remaining air that fills the airway to the alveoli at the end of the first expiration which makes it easier for the alveoli to expand in the next breath. Through the installation of CPAP, it was expected that the baby's oxygen saturation could reach the target of 90-95%.<sup>60</sup>.

While the LBW received oxygen therapy in the hospital, vital signs such as HR (Heart Rate), RR (Respiratory Rate) and Temperature will be monitored.

Slightly different from the management of the Deli Serdang study hospital, at the Garut study hospital, if the baby whimpers or there was retraction (moderate respiratory distress), it would be referred to the DPJP (Doctor in Charge of Services) who was a paediatrician, then the CPAP installation action was carried out by the nurse. The Perinatology Room health workers feel trained to install CPAP because they have attended a CPAP installation workshop.

In the Deli Serdang and Pamekasan study hospitals, there was one ventilator and if needed, it would be installed, but the setting and installation was done by paediatricians. Furthermore, post-installation monitoring of the ventilator was carried out by nurses.

# KMC implementation in referral health care

Based on information from sources at the Garut Study Hospital, before the COVID-19 pandemic, KMC (Kangaroo Mother Care) was implemented, but since the COVID-19 pandemic, KMC was no longer carried out.

"KMC was not done immediately..., after Covid we kind of ignore it...if bonding has been done. But pure skin to skin KMC has not been done for a long time."

FGD Garut Hospital

The resource person from Pamekasan Study Hospital explained that KMC will be carried out if the baby's condition allows for KMC. If there were medical contraindications, then KMC will not be performed.

"If there was a contra-indication, we will not do it. For example, if a ventilator was installed and the LBW was not stable, we will not do it. But if the baby was stable and

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<sup>60</sup> Sola, A., Golombek, S. G., Montes Bueno, M. T., Lemus-Varela, L., Zuluaga, C., Domínguez, F., ... & Van Bel, F. (2014). Safe oxygen saturation targeting and monitoring in preterm infants: can we avoid hypoxia and hyperoxia?. *Acta paediatrica*, 103(10), 1009-1018.

it was possible to do KMC, then it will be done. So some were full and some were partial. But most of them were partial. So at any time, that was also when the baby was stable until they go home with KMC"

FGD Pamekasan Hospital

In the study hospitals of TTS, Deli Serdang, Nagan Raya, and Pamekasan, KMC as a measure to prevent heat loss of LBW had been and was still being implemented. However, the results of the assessment related to the implementation of KMC in this study were quite diverse. Based on the results of FGDs with health workers in the Perinatology Room of the TTS study hospital, the implementation of KMC was not mandatory for all LBW, but only for LBW less than 1800 grams, especially before the baby went home.

"For us in Perinatology, before discharge, for stable babies, it was mandatory to inform the kangaroo method before discharge, for babies who weigh below 1800, PMK was mandatory before discharge."

**FGD TTS Hospital** 

KMC was also not yet a mandatory management for LBW in the Nagan Raya study hospital, because KMC will only be taught to patients / LBW with long hospitalization, while in the Deli Serdang study hospital, KMC was a mandatory management for all LBW.

"It (PMK) was for all LBWs because the doctor advised that PMK was mandatory"

FGD Deli Serdang Hospital

The availability of facilities for KMC also varied in each of the study hospitals. At the Garut study hospital, in addition to no special room, there were also no supporting facilities for KMC.

"We have never done (KMC) in Ibu's inpatient room, (in the past) we did (KMC) in the Perinatology room. There was one room that was not ideal for KMC, because there were documents, medical equipment, ... ordinary household sofas ... not adequate for KMC"

**FGD Garut Hospital** 

Similar to the Garut study hospital, the Pamekasan study hospital also did not have an KMC room. However, the hospital provides a selamper or long cloth to facilitate mothers who will perform KMC.

"...but we don't have that (KMC room), so the KMC is next to the bed, next to the incubator. The mother just sits there while we educate ..., until the mother (says) "my hands are tired already"".

FGD Pamekasan Hospital

In contrast to the Deli Serdang Study Hospital, in addition to the available KMC room, which

was located in the NICU, which was intended mainly for LBW with breathing apparatus such as nasal cannula, the room has also provided various facilities such as a long bendable kuRumah Sakiti so that mothers can perform KMC in a sitting, prostrate or standing position so that mothers and families can perform KMC as comfortably as possible. The KMC room was also always ensured to have a warm temperature. KMC for infants who have been released from oxygen can be carried out in a different room.

To support the implementation of KMC, Deli Serdang Study Hospital has prepared a KMC sling, and kimono robes that can be used by mothers and families. TTV checks were conducted before and after KMC. Before performing KMC, health workers also explained to mothers/families how to perform KMC, and the danger signs of infants during KMC, such as hypoxia and cyanosis. In infants with a stable condition, and can suckle directly (good suction reflex), KMC can last for more than 4 hours. Usually, if the person performing KMC was a companion (grandmother or father), the duration of KMC was about 2-3 hours. After that, nutrition was given to the baby. The principle was that the more often KMC was performed, the faster the baby's recovery will be.

Meanwhile, at the Nagan Raya, Garut and Pamekasan study hospitals, mothers or companions who will perform KMC were asked to bring large clothes with front buttons. If during the implementation of KMC there was a baby who turns blue or had cyanosis, the baby will be immediately put into the incubator and given oxygen while looking for the main cause of cyanosis and also consulted to the doctor in charge. Stabilization measures were carried out while the baby was in the incubator while still monitoring the baby's oxygen saturation (FGD Deli Serdang Hospital).

Barriers in the implementation of KMC also varied, such as the father/family did not want to be taught KMC so that only the mother of the baby was usually taught KMC (Nagan Raya), the distance from the mother's/family's house to the health facility was far so that sometimes there were no family members to help perform KMC while the mother was still recovering from the post-copy (Deli Serdang, Pamekasan), and even if there were family members who wanted to perform KMC, for example the father, it turned out to be smoking (Deli Serdang). In addition, it was also common to find mothers who forget how to do KMC, and were even reluctant to do it even though they have been taught the method by hospital health workers (TTS).

"The baby was 1800 grams, I had to go back and forth with KMC 5 or 6 times because they (the baby's mother) didn't want to (learn). We just went out to tell the doctor, when we came back the baby had already dropped from the mother's arms ... so we have to monitor, we have to take care ... if the mother does not want to, (the PMK sling) was also thrown away, released and angry".

FGD TTS Hospital

### Care of LBW using Incubator

In all study hospitals, one of the ways to keep LBW warm was by using incubators. However, the availability of incubators in the Nagan Raya study hospital was still limited, so the hospital was sometimes forced to refer LBW baby without using an incubator.

If the LBW must be fitted with an IV, the baby was first moved to the infant warmer then after the IV has been installed, the baby can be put back into the incubator. Regarding incubator temperature settings, the Deli Serdang and Lombok Utara study hospitals have a reference table for infant weight and temperature requirements. Infants in the incubator will then be monitored for vital signs every 1 hour.

In some study hospitals, it was found that one incubator was used for more than one baby, namely in the TTS and Garut study hospitals. This practice was certainly dangerous because it can increase the risk of babies being switched and does not respect the privacy or safety rights of babies.

"... (babies) who were premature enter the incubator even if there was an overload of 1 incubator for 2 babies. That was not allowed for the safety of the patient, if the patient was different, it makes us anxious, afraid of being mixed up ... small babies were loose bracelets, (bracelets suitable for the size of LBW babies) we don't have, so the patient's risk was very high ... we hope the baby was not hypothermic. ...."

FGD Garut Hospital

"The incubators happen to be good now there were 8, so usually if there was an increase in cases, we were forced to give other babies who have stabilised the damaged incubators, ... sometimes twin (babies) were combined in one place. Because usually the case is... situational"

FGD TTS Hospital

In the Pamekasan study hospital, a conventional incubator in the form of a homemade incubator could be lended to LBW patients if needed, although health workers realize there were some risks to be aware of.

"Yes, the light box, still a glass box, will have a dop lamp, ... at least 25 watts, end to end, it was enough to warm. But if the baby was there because there was no detector, the body temperature was very risky (unstable), the baby was dehydrated or maybe overheated. For example, the family does not routinely make a habit of controlling the baby. When people used to use it, they felt safe, even though the baby's needs were not only warm".

FGD Pamekasan Hospital

A baby with a birth weight of less than 1000 grams was considered to have an extremely low birth weight. Babies with low birth weight, including those with extremely low birth weight, often require special care in the neonatal intensive care unit (NICU) until they gain weight and are well enough to go home. This care might include being placed in a temperature-controlled incubator. Additionally, babies with serious infections might also require care in the NICU and might need to be placed in an incubator. Therefore, it was recommended that babies with an extremely low birth weight and/or serious infections be placed inside an incubator.<sup>61</sup>.

# Nutrition/Breastfeeding

Based on FGD information from health workers at the TTS Study Hospital, if the LBW's

61 Lin, C. W., Ko, H. Y., Huang, C. C., Yeh, C. Y., Chiu, Y. C., & Chen, H. L. (2022). Body Weight Gain Status during the Incubator Weaning Process in Very Low Birth Weight Premature Infants. *Children*, *9*(7), 985.

condition was stable, IMD can be done, but if there were danger signs in the LBW's condition, stabilization measures will be taken on the infant warmer first. Based on the experience of health workers at the TTS Study Hospital, if there was plenty of breast milk, the LBW can be breastfed immediately. However, most of the postnatal milk has not been released so the LBW was given formula milk first on the first and second day, then continued with breast milk. Usually the doctor also asks that the LBW be given additional formula milk so that it becomes a combination of breast milk and formula milk. Formula milk has also been provided at the hospital.

Ideally, in full-term LBWs, there was no need to delay breastfeeding including IMD because the suction and swallowing reflexes of full-term LBWs were good. Breast milk needs to be given immediately because if nipple stimulation was weak and breast emptying was inhibited, breast milk production will decrease, and even run out over time.<sup>62</sup>. Health workers also need to be aware of hypoglycemic conditions in the first 24 hours of a baby's life. Monitoring GDS levels can be done after the LBW was 2 hours old and not yet breastfeeding. If the GDS value was rather low (less than 2.31mmol/L), the GDS examination can be repeated according to the protocol.<sup>63</sup>.

Table 12. Evaluation of Respiratory Distress: Downe's Score 64

Age (hours)	Mean ± SD of blood glucose level (mmol/L)
At birth	$4.05 \pm 0.61$
2 h	
	$2.31 \pm 0.34$
4 h	$2.95 \pm 0.36$
12 to 24 h	$3.13 \pm 0.50$
24 to 48 h	$3.42 \pm 0.57$

In the meantime, if the baby appear weak, expressed breast milk (if available) or formula milk can be given with a spoon. After breastfeeding was sufficient and the LBW's blood sugar was stable, exclusive breastfeeding can be continued.<sup>65</sup>

In infants with a gestational age of 32-34 weeks, the swallowing reflex was quite good, but the sucking reflex was not yet strong, so breast milk can be expressed and given using a spoon, cup or pipette. Whereas in infants with gestational age <32 weeks whose suction and

<sup>&</sup>lt;sup>62</sup> Krüger, E. E., Kritzinger, A. A., & Pottas, L. L. (2019). Breastfeeding skills of full-term newborns and associated factors in a low-and-middle-income setting. *African Health Sciences*, 19(3), 2670-2678.

<sup>&</sup>lt;sup>63</sup> Ayas, N. T., Jeklin, A. T., Tholin, H., Rogers, A. E., Dodek, P., Hirsh-Allen, A. J., ... & Wong, H. (2020). Consecutive nursing shifts and the risk of hypoglycemia in critically ill patients who are receiving intravenous insulin: a multicenter study. *Journal of Clinical Sleep Medicine*, *16*(6), 949-953.

<sup>64</sup> Khairuzzaman, M., Sarker, N. R., Sarker, M. M. A., Matin, A., Rakshit, S. C., Mojumder, B., & Absar, M. N. (2018). Blood Glucose Level in Low Birth Weight Babies in First 48 hours of Life. *Journal of Current and Advance Medical Research*, *5*(1), 33-38

<sup>&</sup>lt;sup>65</sup> Pillai, S. K., & Fhausiya, V. K. (2022). A cross-sectional study on the frequency and risk factors for neonatal hypoglycemia in babies born in rural Kerala. *Journal of Family Medicine and Primary Care*, *11*(11), 6949.

swallowing reflexes were not yet good, breast milk can be given with an orogastric tube.66

Based on information from all study hospitals, if the suction and swallowing ability of LBW was not yet strong, nutrition will be provided through OGT (Orogastric Tube) with the target formula needs determined by the paediatrician. Meanwhile, if the paediatrician advises breastfeeding, the mother of the baby can come directly to breastfeed her baby or with expressed breast milk. In the TTS and Garut study hospitals, if the LBW was already in a stable condition and has good sucking and swallowing reflexes, after releasing the OGT, the doctor will usually give instructions to drink every 2 or 3 hours, and if the mother experiences breastfeeding arrest, the LBW will be given formula milk.

In the North Lombok Study Hospital, breastfeeding for LBW was gradually increased. Supporting facilities from the hospital for mothers in providing breast milk were counseling from health workers for mothers and if the mother experiences breast milk arrest, the hospital will ask the family to find a breast milk donor. At the Garut District Study Hospital, counseling related to breastfeeding, especially for mothers with infants who were still being treated at the hospital, was related to how to pump breast milk, how to store the pumped breast milk at home, and how to bring the pumped breast milk to the hospital. Furthermore, the pumped breast milk will be stored by health workers in the breast milk refrigerator at the hospital. At the Nagan Raya Study Hospital, the pumped breast milk stored in bottles will be labeled with the name and date of pumping. When the baby was admitted to the NICU room of Nagan Raya Study Hospital, the baby's mother will also be counseled on breastfeeding, including teaching breastfeeding techniques and positions, food consumption and nutrition for the mother during breastfeeding, and lactation massage.

The availability of breast milk storage refrigerators in the study hospitals also varied. In the Pamekasan, the breastmilk storage refrigerator was a special freezer for breastmilk storage, while in the Deli Serdang study hospital, although the breastmilk storage refrigerator was separate from the room refrigerator, the refrigerator was only a regular refrigerator, not a special refrigerator such as a freezer for breastmilk and there was also a sterilizer available. In the Nagan Raya study hospital, the refrigerator for storing breastmilk used an ordinary refrigerator and was mixed with the storage of drugs and vaccines.

Based on the explanation of the health worker at the Pamekasan study hospital, the expressed breast milk that has been stored in the freezer and frozen, will be thawed first before being given to the baby in the following way.

"The expressed breast milk (is thawed) using the mother's body temperature, for example at home you can hold it... The temperature of the breast milk will be equal to the mother's temperature. But if you were in a hurry, for example while working, just soak it in room temperature water, it will melt itself slowly..., if you need it quickly, then use warm water".

FGD Pamekasan Hospital

## Pre Discharged

Some aspects that were considered by Pamekasan Hospital to discharge LBW include the ability of the baby to suckle and the implementation of KMC.

"If the KMC and breastfeeding were both adequate, (the baby) was then advised to go home. Going home was also in a KMC position. So (the hospital) prepares the support system as well (the companion) ... So if there was a husband, parent or relative in the same house, we also educate them about it..."

FGD Pamekasan Hospital

As for what examinations need to be carried out before LBW admitted to the hospital can be discharged, there was no policy that regulates this at the Garut study hospital.

"...screening of babies when they want to go home, it must be ascertained what the screening is. It was not yet a hospital policy, babies (must be) screened (for anything) before going home".

FGD Garut Hospital

# Post Discharge

In the Deli Serdang study hospital, in the case of healthy newborns, only outpatient treatment and re-control to the poly 3 - 5 days after discharge were recommended and there was no re-referral programme for LBW. This condition was different from the provision of re-control in the TTS, Nagan Raya and Pamekasan study hospitals, where the re-control schedule for LBW was determined by (depending on) the doctor's decision, so that if re-control was needed, it will be explained when the first re-control time was and the time was uncertain.

In the Deli Serdang study hospital, in the case of healthy newborns, only outpatient treatment and re-control to the poly 3 - 5 days after discharge were recommended and there was no re-referral programme for LBW. This condition was different from the provision of re-control in the TTS, Nagan Raya and Pamekasan study hospitals, where the re-control schedule for LBW was determined by (depending on) the doctor's decision, so that if re-control was needed, it will be explained when the first re-control time was and the time was uncertain.

"Sometimes the village midwife doesn't know (if there was a LBW case), she knows the baby has died".

FGD Deli Serdang Hospital

Whereas in the Pamekasan study hospital, there was no post-discharge communication at all with primary health facilities or village midwives in the area where the LBW lived.

"There was no direct communication (with the Puskesmas or Village Midwife), but we have a KIA book that contains the referral. That seems to be enough of an introduction to go back to the local health worker... (patients) go to Posyandu more for immunization and weight monitoring".

FGD Pamekasan Hospital

Five of the six study hospitals had no communication with primary health facilities in the area of LBW discharged. Only North Lombok Hospital had communication with Puskesmas regarding the condition of LBW discharged from the hospital.

"We (the hospital) usually communicate with the Puskesmas or the village midwife. Later from there who confirm to us"

FGD Lombok Utara Hospital

In the Pamekasan study hospital, there were several cases of LBW who were asked by the family to return home and ended up dying.

"Actually, it was not time to be discharged, the lactation observation was not yet adequate, KMC has not been carried out, but taken home. ... most of them die at home. There were many like that".

FGD Pamekasan Hospital

Evidence-based care for LBW babies in Indonesia included health education, identifying maternal risk factors, Kangaroo Mother Care, Breastfeeding and NICU treatment, but the implementation varied between health facilities in this study. In general, health facilities that have implemented evidence-based practice adequately are type B referral health facilities, namely Deli Serdang Hospital. In other health facilities, both hospitals and community health centers, the implementation of EVB is still not optimal. Though most of the health facility stated that they done the health education and identifying maternal risk factors well, but the health workers' understanding of the importance of KMC still inadequate, also lack of motivation from the facility for mothers to breastfeed LBW.

The results of this study indicated that the integration of health services between primary and referral levels was seen in the management of pregnant women with complications, but the integration of services for LBW after discharge was still not established due to the lack of communication between referral and primary facilities and the lack of monitoring of LBW after discharge.

Based on the medical record data collected, several things were not written completely in the medical records, both in the medical records collected by the hospital and the puskesmas. In the medical records from the hospital, there were 4 referral cases reported, but only 1 case had a referral letter recorded, while the other 3 cases did not mention the existence of a referral letter including the treatment obtained at the referring health facility. It was very important to know what to do before referring for the sake of patient safety and determining further medical action. Apart from that, in cases of babies who received resuscitation measures, there were medical records which noted that post-resuscitation stabilization measures were not carried out according to the SOP.

Meanwhile, medical records recorded at the puskesmas contain basic information regarding the services and care of newborns born at the puskesmas. Based on medical records reported, there were puskesmas that issued regulations that LBW babies of 1900 grams had

to be treated at the puskesmas, but in reality the mother and family refused and asked the baby to go home with the mother because they considered the baby's condition to be fine.

# Actionable Information system

The Ministry of Health did not have a specific routine reporting system for LBW cases since LBW was not a part of the national indicators that were made mandatory to be reported by district back to the central level. This has created impediment for the Ministry to plan for specific intervention or adjust policy and guideline, specifically about the pre-term LBW, since pre-term LBW might need a different approach to monitor their progress/development. At the moment, routine data on neonates are collected through several different mechanisms and kept in different datasets; but, since LBW is not part of national indicators the Ministry of Health needs to use survey data to gather information about LBW. The Ministry of Health hoped with the newly launched health transformation initiative, there will be more integrated routine data that they can use.

"So for LBW data, we could get it from the nutrition survey, SSGI (note: SSGI = survey of national nutrition status). It was an annual survey because it's used for stunting reports. LBW is recorded as one of the risk factors for stunting. Previously we also used Riskesdas data (note: Riskesdas = basic health survey) ..... This year we have SKI (note: SKI = Indonesia Health Survey) so we hope SKI could produce LBW data as well .... We hope." (GKIA, Ministry of Health)

On the other hand, there was a death reporting system, using MPDN (Maternal, Perinatal, Death Notification) which lists causes of death, such as LBW and asphyxia.

"So, we report the cause of death in the MPDN; Maternal, Prenatal and Notification, which already exist, also include the cause of death. The cause of death of LBW babies and asphyxia is indeed from the MPDN report." (Dit GKIA, Kemenkes)

Maternal and Perinatal deaths were supposedly discussed in the AMP (Audit Maternal Perinatal) SR (Surveillance) process. AMP-SR process conducted at different levels: at the facilities where death occurs, at the district level, province level and national level. However, the study observed that there was no common practice of conducting a regular monitoring of neonatal death cases, only maternal death. For instance, the district health office conducted a maternal death audit every six months in Lombok Utara, but not (or rarely) on perinatal death. Although since 1994 the Ministry of Health has urged AMP-SR to avoid preventable deaths, previous studies have shown that AMP-SR was not used effectively due to several reasons. AMP was seen as a "judgment" and verbal autopsy were not done or the form were not filled according to standard.<sup>67</sup> resulting in limited information and inaccurate results, moreover there were rarely notes from the AMP process and thus recommendations were not followed up.<sup>68</sup>. A scoping review study in Indonesia also found that the dissemination of the results of the AMP has not been carried out, efforts to address problem according to the

<sup>67</sup> Satria Wibawa, "Otopsi Verbal Kematian Maternal-Perinatal Studi Kasus Menindaklanjuti Temuan-Temuan Lapangan Di Pesisir Selatan Sumatera Barat", Program Magister Kebijakan dan Manajemen Pelayanan Kesehatan, Universitas Gadjah Mada, Yogyakarta, 2008

<sup>&</sup>lt;sup>68</sup> Feronica Masila, "Audit Maternal Perinatal Kabupaten Parigi-Moutong Propinsi Sulawesi Tengah", Universitas Gadjah Mada, 2007

recommendations have not been prepared, monitoring and evaluation are not intense, and lack of socialization of the latest guidelines for the implementation of AMP-SR.<sup>69</sup>.

On the other hand, the used of data was in fact deemed to be very crucial by IDAI. IDAI initiated collecting register data as evidence in hope for influencing policy and also as a basis for research purposes.

"We also collect registry data. We played an active role in trying to collect data. Because this register will be used as material for determining future policies, we have this register in collaboration with the Ministry of Health. However, we also made a special register that can be used via mobile phones by individual medical personnel so that later we can get data on what the death rate is in a particular place and what the problem is. We also do research, by our members. These will be shown and presented at the neonatology annual meeting." (IDAI)

# The Implementation of Information System in District Level

The implementation of the information system at the district level varied between the 6 districts in our study area. A case in point was in TTS district. TTS, with the help of MOMENTUM (an international donor NGO concerned with MCH issues) assisted the DHO in monitoring MCH status, which they started in 5 sub-districts. The DHO initiated what they called *Supervisi Fasilitatif* (Sufas - Facilitative Supervision) where every week each Puskesmas reported to them the expected delivery in their area in the 14 days and also reported the number of babies until they are 28 days . The report included the due date, the mother's and baby's condition, and the health insurance they used. This also will be used for LBW babies monitoring.

"Supervision of MCH services, we look at MCH services at the puskesmas, we see from the patient arriving until the service until they go home. Until now, the Weekly report, we have developed it from the P2P reporting, we have duplicated it. In essence, the health center reports to us, from the 14 before giving birth, we can know how many mothers will give birth in the next 2 weeks. And also until the baby is 28 days old." DHO TTS

In addition, the DHO will also report using SIKDA (Sistem Informasi Kesehatan Daerah - District Health Information System), where the maternal and child health, including stunting, reported regularly toward the SIKDA. However, there were some challenges regarding the information system, because not all Puskesmas are capable to report to DHO. Some complained about the lack of human resources to run the reporting system in puskesmas level.

In North Lombok, acknowledging the limitation of the existing information system, the District Office was planning to develop an app (to be used in mobile phone) that helped the Puskesmas and village midwives identify pregnant women with high risk (including those with risk of having LBW) in their areas. This was hoped to enable them to intensify effort in prevention and promotion tailored to each area, as well as help prepare the health facilities to handle the cases.

<sup>69</sup> Ninik Dwi Ambarwati et. al. Implementation of Maternal Perinatal Surveillance and Response (AMP-SR) Audit in Indonesia: Scoping Review. Scientific Periodical of Public Health and Coastal 5(1),2023 , halaman 87-101 97

Meanwhile in Nagan Raya, apart from using the reporting system issued by the Ministry of Health, it also used a reporting system created by the DHO. Every birth, pregnancy reported every month through the *Ureung Mumeu* information system application. The purpose of this application, if the midwife in the village found a pregnant woman, the pregnant woman's data immediately entered into the form. This data then can be summarized to select which included as high risk pregnant women including pregnant women whose pregnancies were too close, children's health, nutritional status including stunting which always be monitored by the DHO. Then a month before giving birth, the DHO and Puskesmas will contact the pregnant women to ask where she will give birth, whether there is consumption of Fe tablets and so on. This reporting system runs side by side with applications issued by the Ministry of Health such as EPPGBM.

#### Information based on medical records

Medical records can be a useful source of information. There were 2 sources of medical records that we collected in this study, from hospitals and puskesmas.

## Hospital

There were 10 medical records collected from the hospitals involved in this study. 4 out of 10 existing medical records were cases referred to hospitals. The weight range of babies being cared for was between 1100 grams and 2300 grams with the gestational age of the mother giving birth between 27 weeks and 38 weeks. Of the 10 cases collected, there were 4 cases of babies who died while receiving treatment at the hospital.

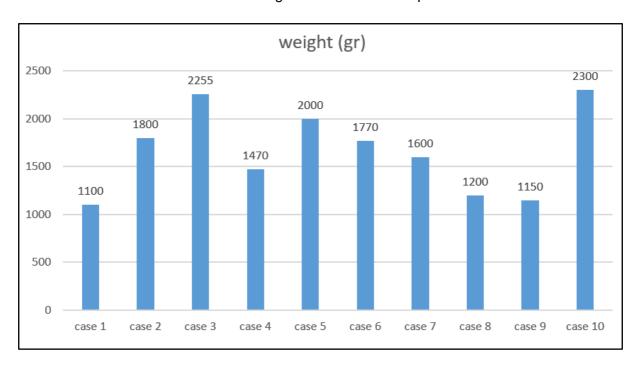


Figure 8. The weight of Baby from Medical Record in Hospital

Meanwhile, the mother's age when giving birth was in the range of 24 to 36 years and most of them were pregnant with their second child. Only 2 cases included maternal risk factors during

pregnancy, namely breech and anemia. For the risk factors for babies, most listed prematurity (6 cases) but only 2 cases recorded administration of antenatal steroids. Not all medical records collected were filled in completely by hospital staff. Birth attendants were only written in 7 medical records, most of them were assisted by midwives (5 cases were spontaneous) and 2 cases were assisted by obstetricians, one of whom assisted with vacuum extraction.

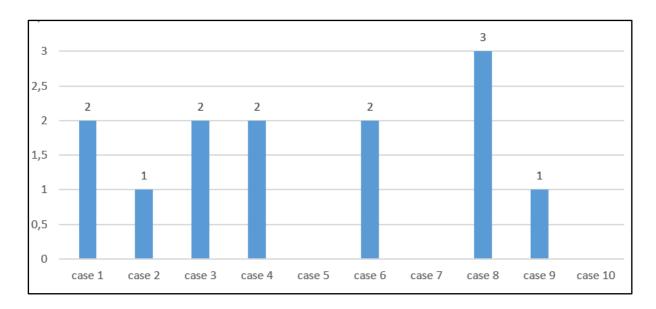


Figure 9. The parity among pregnant women from medical record in hospital

When carried out resuscitation, of the 8 cases undergoing resuscitation, there was 1 case that did not record resuscitation step in the medical record. For hospitals that carry out resuscitation, it has been carried out according to the SOP. Only 2 cases of resuscitation were carried out by paediatricians, while the rest were carried out by midwives. It was recorded that there were 8 hospitals that carried out baby stabilization, but there was 1 hospital that did not carry out stabilization according to the SOP. There were 2 cases of babies experiencing delayed clamping of the umbilical cord for 30 and 6 minutes because they were referral cases.

Regarding early initiation of breastfeeding, only 1 hospital reported doing this. Meanwhile, umbilical cord care, administration of eye antibiotics and vitamin K were carried out immediately after the baby was born, but for administration of the HB 0 vaccine, only 1 hospital reported administering it within 24 hours after birth.

There were only 4 cases that included information related to providing nutrition to babies. Babies were fasted for 2 days before being given nutrition in the form of breast milk (2 cases) and special formula milk (2 cases). In some cases, the staff filled out the medical records did not write down the type of nutrition provided. This applied to both enteral and parenteral nutrition. The efforts made by the hospital to keep the baby warm are using Radiant warmers, Incubators, KMC, delaying bathing the baby, and early initiation of breastfeeding. There were 5 cases that stated that breathing assistance was provided via CPAP (2 cases) and Nasal IMV (3 cases) with a duration of 2-4 days. CPAP is used by type B hospitals

Babies who died while receiving treatment were in the age range of 4 days to 22 days due to asphyxia, LBW, prematurity, sepsis. Based on medical records, the reports regarding neonatal deaths were quite well documented. There was information regarding time of death, age and place of death, main cause of death, detection and treatment of emergencies while in hospital. Meanwhile for referral cases:

- a. A baby born in a midwife's clinic, there was no referral letter, only information via telephone. When in the ER, an IV was immediately installed and the baby received emergency treatment according to the SOP because the baby's condition when he arrived at the hospital was critical. The baby was diagnosed as asphyxia, LBW, premature, RDS after consulting with a paediatrician (Garut).
- b. There was no statement from where the baby was born, it was only written that the helper was a specialist obstetrician and midwife, when referring there was no referral letter and it was handled according to the SOP (Deli Serdang).
- c. A baby referred from a type C private hospital, referred by a paediatrician and brings a referral letter. Referral process via SISRUTE. Referred because of asphyxiation and LBW. Pre-referral therapy includes vitamin K injection, dexamethasone and cefotaxime. In the emergency room, he received an IV, gastric tube and breathing assistance via CPAP and antibiotics. When he arrived at the ER, the baby was in critical condition. When in ER, the baby is fasted and then given enteral drinking, breast milk via OGT. The baby returned home alive on the 72nd day and when he returned home the family was given counselling regarding education on home care and how to administer medication (Deli Serdang).
- d. A baby weighing 2300 came to the emergency room accompanied by his parents and was given an IV drip in the emergency room and received emergency treatment according to the SOP. Health workers in the emergency room consulted with a paediatrician, the baby was diagnosed with sepsis and LBW. Babies receive special formula milk after fasting and also receive parenteral fluids (intravenous fluids) (Nagan Raya).

Based on data in medical records, only 1 hospital used SISRUTE while others used telephone and even came in person. There were no complete records regarding the treatment the baby had received from the referring health facility. This was very unfortunate because if it is filled in completely, this could be a good source of information regarding neonatal services. This documentation indicated the efforts of the health facilities to monitor the emergency LBD babies who were referred to them.

#### Puskesmas

There were 10 medical records collected from the Puskesmas involved in this study. However, not all Puskesmas can fill in medical records because there were no cases handled by the Puskesmas. The weight range of babies cared for by Puskesmas is between 1400 grams and 2485 grams with the gestational age of mothers giving birth between 31 weeks and 41 weeks. Of the 10 cases, there were 2 cases of IUFD.

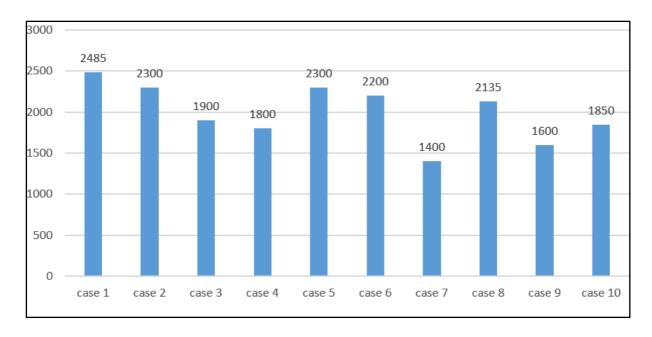


Figure 10. The weight of Baby from Medical Record in Hospital

Meanwhile, based on notes in the medical record, the mother's age when she gave birth was in the range of 21 to 44 years. 4 cases were the first pregnancy, 3 cases were the second pregnancy, 1 case was the 3rd pregnancy and 1 case was recorded as the 6th pregnancy. There were 5 cases that included maternal risk factors during pregnancy, namely unwanted pregnancy, hyperthyroidism, hypertension, syphilis and TB. For risk factors for babies, only 3 cases included premature and 1 case was preterm and breech. However, there was no provision of antenatal steroids at Puskesmas for babies at risk of premature birth. All cases recorded were births at Puskesmas assisted by midwives and delivered spontaneously and only 1 case was assisted by a physician.

Regarding resuscitation, there were only 2 Puskesmas (Garut) that carried out resuscitation by midwives according to the SOP. All Puskesmas carried out initially breastfeeding, administer vitamin K and eye antibiotics according to SOP. However, there was 1 case where umbilical cord care was not carried out according to the SOP (Pamekasan). In Pamekasan, all cases of LBW babies consulted with a paediatrician and babies born weighing less than 2500 grams should be referred, but considered at the baby's condition. There were 3 cases from Puskesmas in Pamekasan that allowed LBW babies to go home, where 2 babies who were allowed to go home weighed > 2200 grams and 1 baby weighed 1900 grams. Even though according to Puskesmas regulations, LBW babies 1900 grams should be treated at the Puskesmas, the family refused. The mother and family wanted to go home immediately and felt that the baby was fine. The mother and baby went home after 6 hours, got treatment and were given education in the form of not bathing the baby until the weight was normal, exclusive breastfeeding, maternal nutrition and a repeat control schedule.

Medical records at the Puskesmas contained basic information on services and care for newborns such as birth attendants, delivery methods, early initiation of breastfeeding, umbilical cord care, administration of eye antibiotics and Vitamin K because in general babies go straight home after 6 hours of receiving treatment at the Puskesmas even if the baby is

admitted in the LBW category. However, there were several considerations made by the puskesmas to allow the baby to go home with the mother.

The use of medical records as a source of information was still not optimal by health facilities. Medical records should be filled out completely according to standard and contain ongoing records, for example information regarding the mother's risk factors during pregnancy, childbirth, and the condition of the baby born. Likewise, actions carried out on babies, for example resuscitation actions, who carried them out, resuscitation steps, post-resuscitation actions, stabilization should be recorded completely in the medical record. Including if the case was a referral case, the medical record must contain information about who made the referral, the system used for the referral, whether there was a referral letter, what actions have been taken previously so that the baby gets the right nurse. Therefore, filling out medical records must be done optimally because they were the basis for patient care and treatment, evidentiary material in legal cases, could also be used as research and educational material, as well as for compiling health statistics.

Findings of this study explained that based on the FGD results, medical personnel felt that the current computerized recording and reporting system was still a challenge.

"Computerisation was indeed the difficulty there. There were so many patients, so when I worked on one, then there was a patient struggling, and we kept working on the computer, he thought we were playing. Even though we were working on the previous patient's actions, the patient doesn't want to know. For example, there was a mother who came in in partum, there was also a patient in the condition of chirping, well the baby after being treated in the emergency room, stable, directly to the NICU for example. But we haven't filled in the system yet... we change shifts at 2 o'clock, but even at 2 o'clock we always start at 3 o'clock because we have to fill it in".

FGD Deli Serdang Hospital

In addition, every time a baby or mother dies, within 1x24 hours the data must be inputted into the MPDN application and then reported to the Health Office. However, the utilization of this application had not been implemented in all regions in Indonesia.

"But MPDN was not done in all districts, depending on the activity of the Department and Hospital. Here, MPDN was quite active. I don't know who was working on it before, I started holding the report in 2021, and I just learned that there were a lot of indicators".

FGD Deli Serdang Hospital

After the MPDN was reported, in Nagan Raya and North Lombok there had been no feedback from the Health Office regarding the high LBW rate, only an audit, while in Deli Serdang, the Health Office's feedback was limited to socializing so that the Puskesmas can inform the community so that the same cases of death do not occur again. In addition to MPDN, there were several other maternal-neonatal recording applications that must be completed and reported.

"... mostly applications, e-cohort, Simatneo,... Now we have "1 Sehat", so we were integrating the hospital SIMs into that. Our IT was in the process of going there. So it's a hassle for the doctor, but it's even more hassle for me to fill out the application, and it requires manual data that I'm working on".

FGD Deli Serdang Hospital

In conclusion, the actionable information from the medical records were limited. The medical records mainly noted the treatment and services that were given to the babies prior to its death. It can be argued that current medical record systems in Indonesia may not be used for the actionable information. This was also consistent with studies in other countries that showed the lack of documentation surrounding the use of non-pharmacologic interventions related to neonatal deaths is common. Fortney and Steward (2015).<sup>70</sup> argued that the lack of documentation of the interventions is due to the organized chart for every case in the hospital and might not reflect what the health workers performed to the babies. In Indonesia context, as well as in our study sites, the complete history of the neonatal death might be recorded in the Audit report. The audit system for maternal and neonatal death was a must to conduct by the health facilities. However, in most cases, the audit results were rarely used for the actionable information to prevent the avoidable neonatal death.

Medical records could actually be used as a means of information if they are filled in optimally. From medical records, we could find out various types of history of conditions and complications of pregnancy and childbirth for the mother and baby. Apart from that, it could also be studied regarding the various actions and treatments that the baby has received. If the baby was to be referred to another health facility, information regarding the care that had been carried out on the baby while being treated at the referring health facility should be clearly written. Because this was also useful for taking action to save the baby. Apart from that, from medical records we could also find out about the referral system used, including who referred, how they referred and the reasons for referring. However, the medical records collected in this study showed that this was not done optimally. For example, we found medical records that were filled in that did not mention who was referring and what the referral system wass. Apart from that, there was still information regarding the gestational age, gender, and treatment of the baby that had not been filled in in the hospital medical record.

Meanwhile, for medical records at the Puskesmas contained basic information on services and care for newborns such as birth attendants, delivery methods, early initiation of breastfeeding, umbilical cord care, administration of eye antibiotics and Vitamin K because in general, babies went home after 6 hours of received treatment at the Puskesmas even if the baby admitted in the LBW category. However, there were several considerations made by the puskesmas to allow the baby to go home with the mother. In fact, medical records played a very important role if, for example, an audit of a baby's death is held because all actions regarding the baby should be written in it. Therefore, filling out medical records must be done optimally because they are the basis for patient care and treatment, evidentiary material in

<sup>70</sup> Fortney, C. A., & Steward, D. K. (2015). Medical record documentation and symptom management at the end of life in the NICU. Advances in neonatal care: official journal of the National Association of Neonatal Nurses, 15(1), 48–55. https://doi.org/10.1097/ANC.0000000000000132

legal cases, can also be used as material for research and education, as well as for preparing health statistics.

## Functioning referral system

An ideal referral system for low birth weight babies should ensure that these infants receive appropriate care and support promptly to improve their chances of survival and healthy development. At the end of 2016, The Indonesian Ministry of Health implemented The SISRUTE application nationally. SISRUTE is an acronym for *Sistem Informasi Rujukan Terintegrasi*, which is the Indonesian national integrated referral information system. It is a health information system that facilitates referrals between healthcare providers and hospitals, both horizontally and vertically. SISRUTE is managed by the Indonesian government and is used to assign duties and responsibilities for health services. The system is designed to help address delays in reaching a health facility that can provide the necessary care. But there is a need to improve the referral system for maternal and newborn care facilities because the implementation of referrals, especially for LBW, is still constrained in some areas.

In Pamekasan and TTS areas, referrals will be smooth if before referring the Puskesmas reports the condition of the patient to be referred through the Whatsapp group.

"For example, if we have a LBW baby, we consult in the group that we have a LBW baby in this condition, how to do it. So this (Whatsapp group) does make it easier for us to make referrals because there it is, oh yes, the doctor has consulted, (please) go in, ma'am".

FGD Non BEmONC Pamekasan

According to Non BEmONC Pamekasan, in high-risk pregnancy cases that require referral, pregnant women will be accompanied by the village midwife during the referral process.

"Those who were referred were usually if there was malnutrition or if the ultrasound was not normal, they were referred to the Sp.OG doctor. They usually do not go alone, under the escort of the village midwife ... After the referral, they were still monitored by the midwife".

FGD Non BEmONC Pamekasan

While in North Lombok District the referral system was done via telephone by the Puskesmas doctor only, the problem was that the North Lombok BEmONC doctor lives in a city that was far from North Lombok BEmONC, so if there was a case of emergency, the health worker must call the Puskesmas doctor, then the Puskesmas doctor calls the hospital.

<sup>&</sup>lt;sup>71</sup> Handayani, P. W., Saladdin, I. R., Pinem, A. A., Azzahro, F., Hidayanto, A. N., & Ayuningtyas, D. (2018). Health referral system user acceptance model in Indonesia. *Heliyon*, *4*(12).

In contrast to Pamekasan Regency, in Garut Regency there were challenges encountered by Puskesmas when making referrals. Based on information from BEmONC Garut, the main obstacle when making a referral was the difficulty in accessing Sisrute.

"... the availability of baby beds or incubators at the hospital was often a waiting list, and then the patient initially wants to (be referred), waiting a long time so it doesn't happen (even doesn't want to be referred). The problem was always that, it takes a long time... Every time we refresh (the application) there was an update on the latest (hospital conditions), ... updating beds or incubators was (the job of) the local ER, so slow or fast (updates) was (determined by) the local ER. The problem is, the speed of updating depends ... on the operator. ... We will not go if there (hospital) was not ready. We don't get nagged, but coordination takes a long time. Once (Puskesmas) went around the hospital looking for an incubator and there was none available".

FGD BEmONC Garut

The second obstacle was that even if a health facility was available, the patient's family does not allow the patient to be referred. This usually happens to patients who do not have health insurance.

"Initially the plan was to be referred but it turned out to be in Sisrute for a long time, there was an option to go to a private (hospital) but the family refused because of the cost, so they were forced to go home"

FGD BEmONC Garut

Based on the experience of the resource person at the Garut Regency Study Hospital, with SISRUTE, the patient referral process to the hospital often experienced delays in response. To mitigate this, the hospital used a WhatsApp group. The WhatsApp group included all Puskesmas, private clinics, private midwives, and hospitals in Garut. The hospital hoped that if a case was referred to an expert, there would be at least some management at the Puskesmas before the patient was taken to the hospital. This finding in the Garut District study hospital was similar to the TTS study hospital, which explained that the SISRUTE system had just started to be activated and was still not optimal.

The FGD results of the Garut Regency Study Hospital explained that every referral is made through the SISRUTE application. However, more patients or families come directly to the Hospital, without going through the Puskesmas first because currently, each village in the Garut area already has a village ambulance from the village fund whose operations are also funded by the village fund. In practice, any case is brought directly to the hospital, although there are cases that can be brought to the primary health care facility.

"... "This is critical" they said (people who refer to the hospital directly), actually there is no need for a referral hospital, but we cannot ignore and we cannot refuse them, SISRUTE system will stated the bed is full..."

FGD Garut Hospital

In Pamekasan District, every time a referral was made to the hospital, the Puskesmas would first consult a cluster doctor consisting of obstetricians and paediatricians to decide whether the mother would deliver at the Puskesmas or needed to be referred. The same process applied to LBW cases, determining whether they needed to be referred to the hospital or could be handled at the Puskesmas.

Based on the experience of the study hospitals in both Nagan Raya and Deli Serdang Regencies, when receiving referral patients from primary care, there were still many and even frequent cases of LBW handling that did not align with the referral standards for maternal-neonatal emergencies. For example, babies did not receive adequate stabilization measures before referral, warming methods were inappropriate, and even babies with breathing difficulties were referred with empty oxygen cylinders.

The findings of the focus group discussions at the TTS District Study Hospital showed that there were several cases of LBW that had just arrived at the emergency room in an unstable condition, so that when they entered the perinatology room to receive treatment, within a few days there were babies who died. This was thought to have occurred, in part, because before and during the referral journey, efforts to overcome respiratory distress and prevent infant heat loss were inadequate.

Things that need to be considered in referring include LBW must be accompanied by health workers who were trained in resuscitation and stabilization, all necessary equipment must be available and functioning properly and if the LBW has breathing problems such as severe shortness of breath, then take intubation measures first at the Primary Health Facility. Intubation management will be better done at the facility rather than during the referral process. Therefore, it was better for primary health care facilities to refer pregnant women than to refer LBW.<sup>72</sup>. Before referral, LBW should first stabilise their condition. If the condition has not stabilized, they should not be rushed to be referred.

Based on the experience of the Deli Serdang Study Hospital, referral distance was quite a challenge because often the golden hour (the first 60 minutes) of referral was not optimal. Golden hour was a crucial period for neonates to obtain the care needed for stabilization. The Golden Hour concept has been shown to reduce neonatal morbidity such as hypothermia, ROP, and BPD, thus having a positive impact on LBW survival (Sharma, 2017). In addition, the findings of the Deli Serdang Study Hospital regarding oxygenation were that not all primary care facilities used mixed oxygen for stabilization or referral of LBW.

Flow of Services at the Hospital after LBW was Referred

The service flow of LBW cases at the Deli Serdang Study Hospital (Type B) was as followed:

 Patient Referral (referral from within Deli Serdang or referral from outside Deli Serdang)

<sup>72</sup> Govender, I., Nzaumvila, D. K., & Maphasha, O. M. (2022). Failed tracheal intubation in primary health care. South African Family Practice, 64(1), 5532

Before deciding whether the patient's referral request will be accepted, the Hospital first inquired about the condition of the mother and the fetus or baby. For pregnant patients, if the mother's condition was severe, usually the fetus would also be at risk when born. Therefore, the Hospital contacted the NICU first to ensure that the necessary equipment for the referred patient was available, and then the referral request could be accepted. If the necessary equipment was in use, the hospital also explained to the referring health facility. If the referral request was accepted, the referring health facility arrived with the referral team.

When the patient arrived, an assessment was carried out, and the condition of the pregnancy was examined. If there were signs of in partu, it was confirmed whether she could deliver normally or had to undergo surgery. Additionally, the condition of the fetus was also confirmed, and laboratory examinations were performed if necessary. After that, specialists related to the case were contacted, such as an Obstetrician Gynaecologist. If a problem with the fetus had been identified based on the initial assessment, a paediatrician was also contacted, even though the mother had not yet given birth. The results of the specialist's examination then determined whether the fetus would be born normally or through surgery. If surgery was necessary, it was confirmed whether the operation would be carried out immediately (emergency / cito) or could wait. If immediate surgery was required, the operating room was prepared, and the anesthetist was contacted. If the baby had been born, resuscitation was carried out until the baby was stabilized, and then the baby was evacuated. Every action was always coordinated with a specialist doctor.

#### Patient without Referral

If If the patient came in with a stable condition, the same steps were taken as for the referral patient upon arrival at the hospital. Cases of self-presented mothers were usually related to pre-eclampsia and eclampsia. The challenge faced by the hospital when the patient came alone was that the hospital had not yet obtained a clear picture of the patient's condition, so the room and equipment needed for both the mother and baby had not been prepared.

If the mother's condition upon arrival at the hospital was of an emergency nature, stabilization was carried out in the ER while a specialist was consulted regarding the condition of the mother and fetus.

Furthermore, if the hospital was unable to accept the patient, a plan was made to refer the patient to another hospital. There were two alternative hospitals in the Medan area that had a Perinatology Room and NICU. If the patient refused to be referred, then the Hospital explained the current condition, indicating that although the Hospital was still attempting to provide maximum treatment, there were many limitations.

The service flow for LBW cases at the TTS District Study Hospital (Type C) was as followed:

If a patient wanted to be referred, usually the Puskesmas sent a WhatsApp message
to the WhatsApp group containing the Puskesmas, Hospital, and Health Office, to
confirm whether the Hospital would accept the referral. The information reached the
central emergency room, where the duty doctor in the emergency room communicated
with the specialist. The patient's condition to be sent was explained, and then the

specialist was asked for advice on whether to wait first or refer immediately, depending on the patient's condition and the distance from the Puskesmas. Usually, the specialist recommended stabilization measures first. Communication continued until the patient was stabilized. Once the patient had stabilized, they were referred to the hospital, and the hospital was ready to receive them. Unless the patient came with an emergency condition without consultation with a specialist, the patient still had to be accepted. Furthermore, patients (mothers) who entered through the emergency room had to undergo a COVID-19 swab first. After swabbing, the patient was asked to register for administrative purposes at the counter. After the patient's status was determined, the patient was anesthetized, and the duty doctor in the emergency room consulted with a specialist. If it was approved by the specialist, the patient was moved to the room for further observation or was given further action.

For neonates with postnatal problems such as LBW cases, they were referred to the
paediatrician first, and then the mother was provided with Information, Communication,
and Education (IEC) about her child being transferred to the Perinatology Room. If the
baby to be born was in distress and required actions such as vacuum extraction or
experienced post-birth distress like asphyxia and needed immediate help, the duty
doctor would call the perinatology team to take action together. The perinatology team
consisted of doctors (pediatric/general/internship Hospital specialists) and nurses on
duty.

## Service flow of North Lombok Hospital (Type C):

- Before the referral, the Puskesmas would call the Hospital's maternity ward and explain the type of patient they were referring, such as referring a patient with a pregnancy under 36 weeks. The hospital would then provide the necessary examination results and instructions for the referral process
- Upon arrival at the emergency room, the hospital staff would conduct a re-examination. The results of the examination from the emergency room would be shared with the doctor in charge and referred to two specialists, namely obstetricians and paediatricians. Subsequently, the emergency room would await approval from both obstetricians and paediatricians. If both doctors agreed, then the patient could be transferred to the delivery room for further action and to give birth at the North Lombok Study Hospital. If the mother was already in the delivery room, the condition of the mother and fetus would still be monitored, and if the mother was already in labor, the baby's condition would be communicated to the specialist again. However, if only one of the specialists agreed, the hospital would plan to refer the patient to another hospital or to an advanced hospital, typically a city hospital (horizontal referral) or a provincial hospital (vertical referral). When making the decision to admit a patient, the obstacles often encountered at the North Lombok Study Hospital were the absence of the equipment needed by the patient and fully occupied treatment rooms. Furthermore, before accepting LBW cases, the NICU would first receive information from the maternity ward or emergency room. This ensured that when the LBW baby entered the NICU room, the necessary tools were ready, and immediate action could be taken.

INTER-HOSPITAL REFERRALS

Based on information from health workers at type C hospitals in this study (North Lombok, Nagan Raya, and TTS), the limited space and equipment meant that, in some cases, hospitals had to make vertical referrals to other hospitals with higher types. However, based on information from the FGD results, the North Lombok study hospital admitted to facing difficulties in making referrals to the provincial hospital because the process took a long time.

"It was difficult to get a referral to the provincial hospital. Usually, we had to wait first, and the waiting process was lengthy, sometimes taking days, until the patient passed away before they could be referred... yes, we still accommodated them here; this was for LBW cases"

FGD Lombok Utara Hospital

Meanwhile, at the Nagan Raya Study Hospital, referrals for LBW cases were made if the baby's condition did not improve after being treated with CPAP for an extended period.

"This month (July, 2023), there were 6 LBWs referred with asphyxia cases. Despite CPAP treatment, there was no improvement, so we coordinated with a paediatrician for the referral. Usually, during the journey, the baby's condition deteriorates, especially when traveling in hilly areas".

FGD Nagan Raya Hospital

There was a risk of the baby's condition deteriorating during the referral journey, which prompted the referral hospital to require video documentation of the baby's condition during the journey. During the referral journey, LBW babies were accompanied by 2 health workers. In addition, other challenges faced by the Nagan Raya study hospital in making LBW referrals included the unavailability of the referring team at the time of the baby's referral and the need for close monitoring during the LBW referral journey, which included the installation of monitors and VTP measures along the way if necessary (FGD Nagan Raya).

The Ministry of Health recognized that there are several challenges regarding referral for LBW babies. One being the financial barrier. LBW babies that are referred to hospital usually need a relatively longer length of stay, and therefore there might be reluctance for the family to refer. For instance, in Lombok Utara, although Universal Health Coverage has been achieved, for a majority portion of the community are still reluctant to be referred to hospital due to the necessary out-of-pocket expenditure (to cover the transport, accommodation and meal cost of the accompanying family members) and opportunity cost (of losing revenue from their daily work especially if they are farmers, tending cattles, or daily labor). To reduce the financial burden for the family, Puskesmas could actually help pay for these costs and then asked to be reimbursed by BAZNAS (the religious-affiliated body that pool and manage *infaq and shadaqah*).

According to the Ministry of Health, the second reason might be due to limited availability of NICU facilities at district hospitals.

Table 13. NICU Capacity in District Hospital

District Hospital In Study Area	"NICU" Capacity*
RSU dr Slamet (Garut)	6 beds
RSU Sultan Iskandar Muda (Nagan Raya)	10 beds
RSU Soe (TTS)	6 funcitioned incubators, 2 infant warmers, 2 broken incubators
RSU Tanjung (North Lombok)	6 incubators and 3 infant warmers
RSUD Dr. H. Slamet (Pamekasan)	13 beds
RSUD Drs H. Amri Tambunan (Deli Serdang)	5 beds

\*Notes: We are not really confident with the term NICU here. All facilities might have different standards for NICU. For instance, in Lombok Utara, they used the term NICU room to refer to all beds in the perinatology room. Meanwhile in TTS they did not have the NICU term, they used the 'Perinatology' ward. But when we asked how many NICU capacity they have, they referred to the numbers of incubators and infant warmers in the perinatology ward. From the observation, not all the perinatology or the NICU beds here necessarily have the ventilator for the neonates.

Anecdotal comments suggested that lower level facilities tend to refer cases as quickly as possible. This might be due to avoiding perceived low/bad achievement in performance indicators reports, fear of being held responsible, lack of competency, or even legal consequences that might entail. Unfortunately, the quick referral practice was not always accompanied by adequate equipment and competency to handle pre-referral and during referral situations.

"In short, referral is about transferring death ... 'don't die here, you should go there, and if you die there, oh well .... ' " (IDAI)

"Like it or not, we as health professionals, our work always involve risk, and we cannot predict risk. So in providing services we need to stick to the SOP, the process ... however, our client/community only sees the result .... We have been involved in several legal cases, not all cases got to the court but one that did usually took time, almost two years, and it was a painful experience for us." (IBI)

In the referral process from Puskesmas to hospitals, several Puskesmas have used SISRUTE, but the long follow-up period results in patients refusing to be referred. At the same time, SISRUTE itself is not without problem. Some still perceived SISRUTE as difficult to operate.

"The name of the application is sisrute, for every patient who comes in, we can see the availability of beds or baby incubators and in hospitals there is often a waiting list, then the patient wants to refer, but because they wait a long time, they end up not being referred." (Puskesmas Garut)

"Initially the plan was to refer but it turned out that the long respond in SISRUTE, there was an option to go to the private hospital, but the family refused because of the costs and ended up having to go home" (Puskesmas, Garut)

"We have not conducted a formal evaluation, but when we go to district we often hear from the staff in the facilities complaining about the long respond when using SISRUTE .... in other area, the connection is slow or troubled, hence difficult to use SISRUTE ..... .Sometimes the hurdle is actually the use of SISRUTE although SISRUTE was initially created to ease the referral process" (GKIA, Ministry of Health).

As a solution, some districts use other mechanisms, for instance WhatsApp, phone call or develop their own command center for referral. For instance, in Pamekasan, they use whatsapp group that consists of paediatricians, obsgyn, general practitioners, nurses, and midwives. Meanwhile, telephone calls are the most used mechanism for referral in Lombok Utara. If a pregnant mother with risk of pre-term LBW or LBW infants need to be referred from Puskesmas, the doctor (himself, cannot be substituted by a nurse/midwife) in the Puskesmas has to call the hospital. The Obgyn and the paediatrician in the hospital have to agree (both) to accept the referral before the pregnant woman/LBW infants can be taken to the hospital. From the medical perspective, the specialists see this step as necessary in order to transfer knowledge to the Puskesmas doctor about how to handle the pregnant woman/mother/LBW infants pre-referral. However, from the nurse/midwife perspective, this step prolongs the process as most of the times the labor cases happen in the evening when the doctor is not in the Puskesmas, which means that they need to contact the doctor first and it is not always easy to reach them. SISRUTE is only used by the hospital to refer patients to provincial hospital. According to the hospital, referral to Provincial hospitals take time and sometimes it is too late for the patient.

Even when babies are being referred, it seems to be that lack of competency is one of the major suspected problems in referral. In some cases, the babies that are referred are not handled and monitored properly or worse, not being stabilized first. A puskesmas in North Lombok stated that they did not have a portable incubator and portable CPAP.

"In the curriculum we were taught about clinical ethics, and one of them is the ethic of life saving actions: when we are faced with a situation where there is no one else available then we have to take action .... It's Good Samaritan Law ... if a baby is having seizures, for instance, although there is a paediatricians in that town but s/he cannot be there in an instance, so the general practitioners or the nurse must take action, without any excuse such as, 'I am not a paediatrician, I am not allowed to do such and such' ... in a life saving situation, do the life saving action first, and then consult with the paediatricians afterward .. This is something that we always stressed in our neonatal resuscitation training ..... I suspect that those who proclaim 'I am not allowed to do this or that' are usually because they are incompetent." (IDAI)

On the other hand, there was a concern from other professions, notably midwives, about the limitation of what competency they are allowed and prohibited from.

"Trainings are necessary, and this is investment, but we need to be clear about whether we allowed to do it (a certain care) or not ... and we are law abiding people. So, even if we are competent to do something, but we were not given authority to do it, we won't do it .... We are trying to avoid a situation where we were forced to do something because there is no one there, but when there is a problem we are not protected." (IBI)

Discussion with mothers and caregivers also revealed some information about the referral process from their perspectives. A mother who gave birth to a surviving LBW baby in a private midwife clinic in Garut told us her story. After being born, the baby had seizure and was referred to a type D private hospital, the family went to the hospital by themselves, used their own car, without the midwife accompanied them. The baby was wrapped in a blanket (dibedong) on the way to the hospital.

In another district, a mother of surviving LBW baby in Deli Serdang was referred to the hospital from the Puskesmas by motorbike. She went to the midwife clinic first, where she was suggested to go straight to the Puskesmas because of her short breath, and she was told to directly go (with the motorbike). In Garut, a midwife properly accompanied her patients (a mother and the LBW newborn) during the referral process. The mother explained that when taking the baby to the hospital from home, the village midwife --who taught her how to do KMC-- kept the baby under her clothes to keep the baby warm in the village ambulance with no incubator.

These practices were probably not unknown to professional organizations. To address this challenge, IDAI had conducted a workshop on stabilization and transportation during referral, however this was not yet a routine workshop. To improve the situation, IDAI was working on developing a National Guideline on referral which includes the necessary skills to stabilize babies pre-referral. IDAI also envisioned that a functioning referral should mean that there was a transparent communication between the team that are referring, the transport team and the team at the hospital that receive the referral case.

For districts with health facilities near the bordering other districts or districts with specific local culture, referral system and how it was paid could also become problematic. In North Lombok there was a culture of giving birth in their hometown. Therefore, it was not uncommon

for puskesmas and hospitals in North Lombok to treat a pregnant woman in giving birth although the woman actually was a resident in another district. Although this was covered by BPJS-K, the matter would be complicated if the baby happened to be LBW with complications as the baby might need to stay in the hospital for a few more days or even weeks. The NTB Province needed to handle the situation by coordinating between Lombok Utara and the district where the mother resides. Besides, sharing the record of such mothers and LBW infants to another district could be challenging.

In TTS, the use of SISRUTE was not popular. The facilities, both from Puskesmas dan hospitals, faced challenges when using the system. Therefore, they preferred to use phone calls instead. For them, it was easier and quicker.

"The system is from Ministry of Health, SISRUTE. It's just that the hospitals are not ready .. so we just call them (as long) as we have all the requirement (to refer) " (Dinkes TTS)

A referral system is an essential component of the health system to improve outcomes of Low Birth Weight Babies, an ideal referral system should have a clearly defined referral criteria to identify low birth weight babies who require specialized care and monitoring. Protocols should outline the steps and processes for making referrals, including the responsible healthcare professionals and facilities; Implement a triage system to prioritize referrals based on the severity of the baby's condition. This ensures that the most at-risk infants receive immediate attention and care; Ensure efficient communication channels between healthcare providers, including those at the primary care level and referral facilities. Quick and accurate transfer of medical information is crucial for making informed decisions: Responsive Transportation to establish a reliable and timely transportation system to transfer low birth weight babies to higher-level healthcare facilities when necessary. This ensures that babies in need of advanced care can access it quickly; Quality Care at Referral Facilities which well-equipped and staffed with trained healthcare professionals capable of providing high-quality care to low birth weight infants: Specialized Follow-Up Healthcare Programs for Low birth weight babies to monitor their growth and development. These programs should include regular check-ups, nutritional support, and developmental assessments; Monitoring and Auditing of the performance of the referral system. Regular audits and evaluations can identify weaknesses and areas for improvement, allowing for continuous enhancement of the system.<sup>73,74</sup>.

Competent, motivated, empathetic and multidisciplinary HRH

Having guidelines developed from evidence-based practices, being trained and supported by professional organizations, were fundamental to lay a solid foundation for ensuring basic competency to care for LBW. However, those might not guarantee skilful staff in the real life setting. To assess the capacity of health workers in providing essential and emergency newborn care, as well as handling complications and performing KMC, we conducted field visits in two districts (one in western Indonesia and one in eastern Indonesia). In each district, our

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<sup>73</sup> Teklu, A. M., Litch, J. A., Tesfahun, A., Wolka, E., Tuamay, B. D., Gidey, H., ... & Every Preemie—SCALE Ethiopia Implementation Research Collaboration Group Tedros Hailu Solomie Jebessa Amaha Kahsay Kemal A. Kuti Gillian Levine Judith Robb-McCord Yared Tadesse Abraham Tariku Abubeker Kedir Usman Abate Yeshidinber Weldetsadik. (2020). Referral systems for preterm, low birth weight, and sick newborns in Ethiopia: a qualitative assessment. *BMC pediatrics*, 20, 1-12.

 $<sup>^{74}\ \</sup>text{https://newbornfieldguide.com/en/chapters/5/2-developing-a-referral-system/}$ 

neonatologist consultant facilitated a clinical simulation and discussions with health workers in one BEmONC Puskesmas and one referral hospital in each district. The participants in Puskesmas were mostly midwives. At one Puskesmas, the simulation included not only midwives but also a general practitioner and several village midwives, while at the other Puskesmas, neonatology ward nurses also took part in the simulation. In the hospital setting, the participants were primarily perinatology nurses, although delivery room midwives were also involved in one of the hospitals. Additionally, we conducted site visits to the Puskesmas and hospitals rooms/unit to gain further insights on the capacity of the human resources. Findings from the clinical simulation were triangulated with those from FGDs with health care providers and document review.

In general, our study identified issues around the availability, capacity, and interdisciplinarity of human resources for health, particularly the health workers, in the provision of neonatal and LBW care.

# Availability

Table 14. shows the density of physicians, midwives, nurses, and paediatricians in the study districts based on the Indonesian Health Profile 2021.

Table 14. The availability and density (ratio) of health workers in each district

		Availability of practicing health workers			Ratio per 1,000 population*				Ratio per 100,000 populatio n	
District	Population	GP	Midwiv es	Nurse s	Pedia - tricia ns	GP	Midwi ves	Nurse s	GPs + Midwiv es + Nurses	Paediatri cians
Nagan Raya	173,510	76	778	596	3	0.44	4.48	3.43	8.36	1.73
Deli Serdang	2,415,031	370	1776	1588	38	0.15	0.74	0.66	1.55	1.6
Garut	2,759,490	422	1569	2736	4	0.15	0.57	0.99	1.71	0.14
Pamekasa n	914,700	254	1487	1410	3	0.28	1.63	1.54	3.44	0,1
Lombok Utara	231,278	26	45	192	3	0.11	0.19	0.83	1.14	1.4

Timor Tengah Selatan (TTS)	462,135	68	623	563	2	0.15	1.35	1.22	2.71	0.4	
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\*WHO recommendations for the density of health workers include a) 1 doctor per 1,000 population or b) 2.5 health workers (nurses, and midwives) per 1,000 population and 1 obgyne and paeditrician: 100,000 population.

Among the six study locations, only Nagan Raya, Pamekasan, and Timor Tengah Selatan (TTS) had sufficient ratios of health workers (doctors, midwives, and nurses) per 1,000 population, based on the WHO recommendation. However, none of the districts had sufficient density of doctors (1 per 1,000 population). When it comes to paediatricians, the densities were even lower, ranging from 0.1 -1.7 per 100,000 population. Although in some regions, the ratio meets the WHO standard. These findings showed that the studied districts were still dealing with scarcity of health workers, particularly doctors and paediatricians.

## Capacity

With regards to health workers capacity, as laid out in the Evidence-Based Practice section (see 3.1.A), the study found the need for improving health workers' skills in providing LBW care. Based on the clinical simulation, at the primary-level (Puskesmas), midwives and nurses demonstrated insufficient skills in resuscitation, assessing risk factors for asphyxia, assessment of conditions at birth, performing appropriate anthropometric measurement, lactation/breastfeeding management and counselling, hypoglycemia and hypothermia management, alternative feeding, and KMC. At the referral level (hospital), while the nurses displayed better skills, some practices require improvement, namely alternative feeding, lactation/breastfeeding management and counselling, and KMC. With particular emphasis on KMC, we found that some nurses and midwives were not familiar with the goals and procedures on KMC, resulting in inappropriate KMC practices among the patients. Through FGDs with mothers and family members of LBW babies who survived, we found that most of them were not able to provide further explanation about KMC other than "hugging the babies close to the chest" and "wrapping the baby with a clean cloth".

#### Interdisciplinarity

Another issue regarding the lack of interdisciplinary approach in the decision-making process. Through our clinical simulation, we have identified that decisions pertaining to therapy and interventions at Puskesmas and hospitals are typically made by general practitioners (GPs) or paediatricians, especially in cases where no improvement is observed during resuscitation or when the cases necessitate a referral. When we asked questions about antibiotic regimens during the simulation, for instance, some participating nurses and midwives were not able to provide information on the specific antibiotic regimens used within the facility because the decision to provide antibiotics is made by the doctors.

In a discussion with the association of community nurses, they suggested that their role has not been optimized yet. IPANI and PPNI had put effort in strengthening the community nurses

by advocating to Bappenas, Ministry of Home Affairs, Ministry of Health, Ministry of Villages to acknowledge the role of community nurses and provide remuneration of community nurses. From their point of view, there should be more involvement of nurses, and particularly the community nurse, in caring and monitoring babies with special needs since they are also equipped to provide care, and since they could also play a bigger role in educating women and families with regards to risk factors of LBW.

"... please give nurses a chance to implement their skills, so that they could also play a role ... LBW is also a matter of what happens in the family, about the roles, values and functions in the family, and community nurses could play a bigger role in educating the community, promoting health, ... please give us a room to serve." (IPANI).

However, our informant from the Indonesian Paediatrician Association (IDAI) emphasized the importance of interdisciplinarity, and hoped that by involving multidisciplinary health professions, there would be a more integrated approach and increased competency to handle LBW cases at sub-national or even sub-district level.

"Therefore, even though we are the Indonesian Paediatrician Association, actually every time we conduct training, we always focus not only on paediatricians, but also the other three health professions: midwives, nurses and general practitioners. So every year we have an annual neonatology meeting and PICU/NICU update, yes, it's actually open for doctors, nurses, and midwives, general practitioners...... In addition, we also do routine training for resuscitation and stabilization, the main target is actually the general practitioner. Paediatricians can participate, but actually we hope for more general practitioners participants, ..... we want these knowledge and skills actually be trickled down to health workers who are more peripheral." (IDAI)

As such, IDAI as a professional organization played a role in strengthening the capacity of health workers, not only for fellow paediatricians but for other health professions as well.

"We are also, from the professional side, trying independently, improving training for these human resources, not only through universities or through the Ministry of Health, but we also hold events, various routine events, such as neonatal resuscitation, neonatal stabilization, LBW emergency services, then there is non-invasive mechanical ventilation, etc. Yes, a lot. That's our routine, some are periodic routines every month, some are annual, so yes, depending on the needs .... These workshops are not only attended by paediatricians but also midwives, general practitioners and nurses." (IDAI)

Factors contributing to human resource issues

Our FGDs with the management and health workers in Puskesmas and hospitals as well as document review identified several factors that contributed to human resource issues in the context of LBW management.

a. Poor human resource management system

Both at the facility and district-level, we identified room for improvement in the human resource management system. For one, the human resource unit or department for health works put a lot of emphasis on the administrative sides, but little on the workforce development and retainment sides.

In terms of retainment, staff rotation was a common problem, particularly in public facilities. Rotation could occur within the facility itself (transferred to another position and roles) but, worse, between facilities. The risk of staff rotation threatened the availability and sustainability of competent and adequately trained health workers to handle neonatal emergency cases, especially the LBW infants. Rotation could also result in a waste of investment for capacity development, as some staff who had been trained in specific skills suddenly got transferred to a different department, potentially underutilizing their expertise.

"The staff often does not stay for long in one Puskesmas .. although we and the Ministry of Health conduct capacity building training, but often not long after that the staff is being transferred elsewhere, leaving the Puskesmas with no competent and properly trained staff." (IDAI)

Acknowledging this challenge, IDAI recently initiated a coaching program, where a paediatrician was assigned to support a Puskesmas in the area, in which the Puskesmas could consult with the paediatrician free-of-charge through call or online/video call and the paediatrician would also come to the Puskesmas to conduct skill-building session.

#### b. Insufficient implementation and support in capacity development

Through our discussion with the nurses and midwives during case simulation in two districts, we identified insufficient implementation and opportunity for training and refresher courses related to neonatal and LBW management, both for midwives and nurses at Puskesmas, as well as for nurses in the hospital perinatology department. Furthermore, there was an insufficient knowledge transfer from healthcare professionals who have received training to colleagues within the same facility/unit. For those who had been trained, they stated that the training lacked insufficient practical components. These findings are evidenced in the following statements from FGD participants.

"...in terms of skills for handling LBW cases, most of us in the NICU have not been trained, perhaps around 30% have been trained in managing LBW cases...so all the actions are delegated to the doctor..." (FGD participant in Lombok Utara)

"I was indeed trained in maternal-neonatal emergencies. So, if it's just a one-week training without practical experience, it's insufficient. When it happens, I get confused. Last time, I had maternal-neonatal emergency training, and the practical part was at the RSUD (public hospital), but the coordination with the RSUD was lacking. In the end, I was there and was not informed. When I'm there, I need to have a clear goal. I would go through medical records, but the first time I went, I

went twice. The first time, my certificate was lost. The first time, there was a connection between [a learning institute] and the hospital, so at the first time, we were given an opportunity to help. But not at the RSUD. I only reviewed medical records. If asked about skills, maybe I'm good at filling out medical records (giggles)... So, when I encounter cases involving babies, I feel a bit challenged, especially with LBW. And then, when it comes to setting up a D5 infusion, my skill in that area is not optimal." (FGD participant in non-BEmONC Puskesmas in Pamekasan)

It is important to strengthen capacity development, not only for the doctors and specialists, but also for the allied health workers (in this case nurses and midwives) because there were times when the doctors or specialists were not available or could not provide answers immediately.

Another issues that hindered capacity development was insufficient financial support, lack of information about training and knowledge refreshment events, and lack of collaboration with the private sector in the system. While one study site (Timor Tengah Selatan/TTS) acknowledged receiving support from a donor (USAID MOMENTUM) for a training and refresher course, transfer knowledge to health workers in the same facility was still "being planned".

Furthermore, health workers in private facilities (such as clinics) were often not included in the government program of BEmONC training, as identified in North Lombok. BEmoNC training is usually targeted mainly to cover the public sector staff. There are eight Puskesmas in Lombok Utara and all Puskesmas have at least one team of staff (doctor, nurse and midwife) who have been trained in BEmoNC, but not all Puskesmas has an adequate number of staff trained in BEmoNC skills and therefore some Puskesmas have not yet received their legal BEmoNC status since they do not have adequate number of BEmoNC trained staff to be ready 24 hours.

Following their training, healthcare professionals often faced challenges in promptly applying their newly acquired skills due to insufficient equipment within their units. In Deli Serdang and Pamekasan, for instance, FGD participants acknowledged the difficulty in utilizing CPAP techniques due to the unavailability of the necessary equipment. By the time the equipment was eventually supplied, they had already lost proficiency in the skills due to the extended delay in equipment procurement.

"There is no support, if I may say. For example, like that time, I said that after completing the training, I knew how to use the CPAP machine for babies like this, but when I got to the Puskesmas, there was no CPAP. It was for over two months. When I got it again, I was confused. I forgot it again. I have already forgotten. For specialized training in LBW cases, we really want that training, at least with practical experience. We are hindered because, yes, we have been practicing for two months, but there was no CPAP at the hospital at that time. It's like...it's useless." (FGD participant in non-BEmONC Puskesmas in Pamekasan)

## Availability of Essential physical resources for small newborn

As stated in the previous sections, the availability of equipment is important for the implementation of evidence-based neonatal and LBW care practices, as well as in developing the skills of health workers. Our findings from the facility checklist showed that both Puskesmas and hospitals lacked several essential tools for providing maternal and neonatal emergency and essential services.

#### **Puskesmas**

## Maternal-Neonatal Emergency Sets

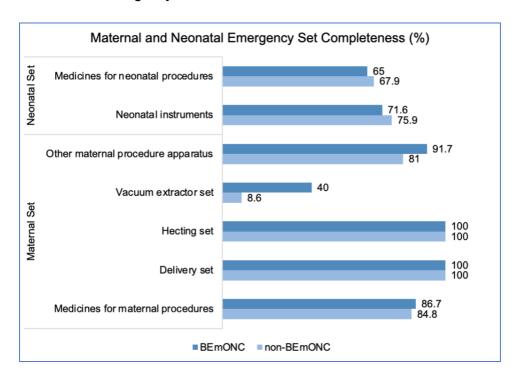


Figure 11. Completeness of maternal-neonatal emergency sets

The completeness of maternal and neonatal emergency set supplies in Non-BEMONC and BEMONC Puskesmas was almost similar. Complete sets of vacuum extractor were only available in 2 Puskesmas (BEMONC), while 1 non-BEMONC Puskesmas had an incomplete set (without the bottle with a manometer and the extractor) and thus, cannot be used. Three BEMONC Puskemas had no vacuum extractor set at all.

The completeness of medicine supplies for maternal procedures was slightly better in the BEmONC Puskesmas. Drugs that were lacking in both the BEmONC and non-BEmONC Puskesmas included Gentamicin (IV) and Metronidazole (IV/per oral). Some non-BEmONC Puskesmas also lacked 0.9% NaCl infusion, adrenaline injection, ampicillin/amoxicillin (IV/per oral), and 10% calcium gluconate—all of which were considered essential medicines for Puskesmas in Indonesia.

BEmONC Puskemas also had higher completeness scores for maternal procedure apparatus. Instruments that were lacking in both types of Puskesmas included ovum forceps, uterine forceps, and bag valve masks. One non-BEmONC puskesmas also lacked basic apparatus such as a stethoscope, a tensimeter, and 5 mL syringes.

In terms of neonatal instruments and medicines, non-BEmONC Puskemas had slightly higher completeness scores. More BEmONC than non-BEmONC Puskesmas lacked neonatal instruments such as neonatal stethoscopes, suction, spatula, 10 mL and no. 23 syringes, IV catheter, as well as blanket and diaper. Furthermore, both BEmONC and non-BEmONC Puskesmas lacked instruments for vital sign measurement (pulse oximeter), body temperature maintenance (radiant warmer and incubator), as well as feeding and resuscitation (nasogastric feeding tube and bag valve masks). As for neonatal medicines, two BEmONC Puskesmas reported the unavailability of sterile double-distilled water and 10% dextrose, and one BEmONC Puskesmas reported the unavailability of epinephrine. Both non-BEmONC and BEmONC Puskesmas in this study reported the lack of 7.5% and 8.4% sodium bicarbonate injection, while two non-BEmONC Puskesmas (in the same district) reported the availability of cefotaxime injection for neonates instead of ampicillin/procaine penicillin and gentamicin injection.

Both the BEmONC and non-BEmONC Puskesmas showed better readiness in maternal instruments and medicines compared to the neonatal counterparts. Most Puskesmas particularly lacked instruments for feeding (nasogastric feeding tube) and body temperature maintenance (radiant warmer and incubator); both of which are important for the management of LBW newborns. Based on the clinical simulation in Puskesmas in two sampled districts, we found that the use of the feeding tube as an alternative feeding method was not well-implemented. Furthermore, many Puskesmas also lacked radiant warmers and incubators, citing inadequate mechanisms to repair broken incubators as one of the reasons.

"Yes, we do have [an incubator], but we found some defects during the monitoring. The calibration has been scheduled, but we have not implemented it. This year, we have to calibrate it because [the activity] has been budgeted, and also because there will be a [Puskesmas] re-accreditation process." (BEmONC Puskesmas staff, Garut)

"We have an incubator, but it's never been used ever since we received it." (Non-BEmONC Puskesmas staff, Nagan Raya

Despite the absence of incubators or radiant warmers, it is essential to ensure thermal management for low birth weight (LBW) infants, as not all LBW infants necessarily require these devices. The 2017 WHO Guideline on Newborn Care and the 2022 WHO Recommendations for Care of Preterm or LBW Infants both advocate for Kangaroo Mother Care (KMC) as the standard care for newborns weighing 2000 grams or less at birth, to be initiated in healthcare facilities as soon as clinical stability is achieved. However, in cases where newborns weighing 2000 grams or less are unstable or unable to receive KMC, it is imperative to provide a thermoneutral environment for these infants, either through radiant warmers or incubators. This underscores the importance of more effectively implementing KMC across all healthcare facilities to address the shortage of incubators or radiant warmers.

Inappropriate calibration and maintenance processes also sometimes happened and resulted in damaging the devices. Furthermore, some facilities also reported that devices (such as T-piece resuscitator) often went missing.

"After the calibration process, the cables were entangled, so there was a high risk of getting electric shock. Sometimes [the apparatus] were switched, that's why I'm not carrying mine. Even once my tensimeter was broken due to the calibration process. I suggest that during the calibration process, instead of fully relying to the technician, we need to monitor [the process] because we do not know whose devices are being treated." (Non-BEmONC Puskesmas staff, Pamekasan)

"When I inspected the storeroom, I could find T-piece resuscitators. But now they were all gone. Perhaps when they gave [the devices] to us, we did not know what item they were. When I found out that these devices could be used for mixing oxygen, the supporting apparatus have all been gone. So I found the T-piece resuscitators when it was no longer complete." (Non-BEmONC Puskesmas staff, Pamekasan

Overall, our study found that the completeness of maternal-neonatal emergency sets in BEmONC and non-BEmONC Puskesmas were similar. It insinuates that the BEmONC status did not necessarily result in better supply-side readiness. Our finding resonated with that of Stein et al. in 2020.<sup>75</sup> who reported poor performance of BEmONC signal functions among the 15 sampled BEmONC Puskesmas.

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<sup>75</sup> Stein, D., M.F. Rakhmadi, J. Ugaz, and A. Dutta. 2020. Does Better Financing Enable Delivery of Higher Quality Maternal Health Services in Indonesia? Evidence from Providers and Local Governments. Washington, DC: Palladium, Health Policy Plus.

## Maternal-Neonatal Emergency Referral

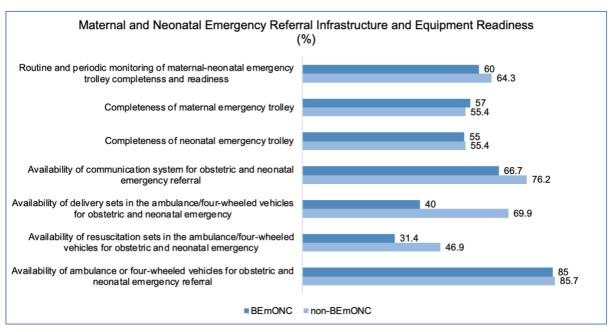


Figure 12. Maternal-neonatal emergency referral infrastructures and equipment readiness

Figure 12 shows that the non-BEmONC Puskesmas demonstrated slightly better preparedness in maternal and neonatal emergency referral procedures, infrastructures, and equipment than the BEmONC Puskesmas, as demonstrated by the average completeness scores for the transport and communication system, as well as the availability of delivery and resuscitation sets in the ambulance/referral vehicles. However, in general, both types of Puskesmas lacked the preparedness for maternal and neonatal emergency referral. For instance, some Puskesmas kept the delivery and resuscitation sets in the maternal room instead of the ambulance. Most Puskesmas also did not have directories for the list of blood donors and blood banks in their area. Both types of Puskesmas also lacked resuscitation sets, oximeter, suction, gastric tube, endotracheal tube, stylet, 4.25% sodium bicarbonate, 10% dextrose, orogastric tube, umbilical catheter, scalpel, iodine solution, and three way stopcock in the neonatal emergency trolleys. As for the maternal emergency trolleys, both Puskesmas types lacked most of the required equipment, particularly suction catheter, or opharyngeal airway, laryngoscope, endotracheal tube, nasogastric tube, stylet, tourniquet, atropine sulfate, 40% dextrose, 8.4% sodium bicarbonate, labetalol/hydralazine injection, and xylocaine jelly for intubation. Only 7 out of the 12 Puskesmas in the study reported having the list and schedules for maternal-neonatal emergency trolleys routine monitoring.

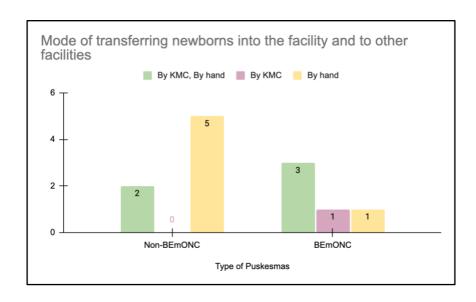


Figure 13. Mode of transferring newborns from and to other facilities

Figure 9 showed that the most common method for carrying newborns during the referral (both from and to the participating Puskesmas) was by hand. Five Puskesmas reported doing KMC when transporting the newborns, in addition to carrying them by hand. None of the Puskesmas reported using incubators when transporting newborns to other facilities, most probably due to the lack of incubators in Puskesmas as stated in 2.3.1.1.

Table 15. Communication modes and infrastructures in the participating Puskesmas

Type of	District	Communication	Internet	Phone	Number of
Puskesmas		methods (available and	reception	reception	room with a
		functioning)			computer
Non-	Deli	No landline phone and	Always	Always	1 (KMC Unit)
BEmONC	Serdang	cellphone was available	reliable,	reliable	
			available		
			in the		
			maternal		
			room,		
			neonatal .		
			room, and		
			other		
			places in		
			the facility		
Non-	Garut	No landline phone was	Somewhat	Always	1 (Maternal
BEmONC		available, Cellphones	reliable,	reliable	and child
		were available (owned	available		room)
		by the facility and the	in the		
		staff)	facility, but		
			not in the		
			maternal		

			and neonatal rooms		
Non- BEMONC	Nagan Raya 1	Landline phones were available in the maternal and neonatal rooms, cellphones were available (owned by the facility and the staff)	Always reliable, available in the maternal room, neonatal room, and other places in the facility	Always reliable	1 (Administrative room)
Non- BEMONC	Nagan Raya 2	No landline phone was available, Cellphones were available (facilityowned)	Not available anywhere in the facility	Always reliable	1 (Administrative room)
Non- BEMONC	Pamekasan 1	No landline phone is available, Cellphones are available (facility and staff-owned)	Always reliable, available in the maternal room, neonatal room, and other places in the facility	Always reliable	1 (Emergency room)
Non- BEMONC	Pamekasan 2	No landline phone is available, Cellphones are available (facility and staff-owned)	Always reliable, available in the maternal room, neonatal room, and other places in the facility	Always reliable	3 (Maternal room, neonatal room, inpatient ward)
Non- BEmONC	Timor Tengah Selatan	No landline phone is available, Cellphones are available (staff- owned)	Always reliable, available in the maternal room,	Always reliable	1 (postpartum room)

BEMONC	Deli Serdang	No landline phone and cellphone is available	neonatal room, and other places in the facility Always reliable, available in the maternal room, neonatal room, and other places in the facility	Always reliable	1 (Administrative unit)
BEMONC	Garut	Landline phone is available in the maternal room and other places in the facility, Cellphones are available (facility and staff-owned), Two-way radio is available	Always reliable, available in the maternal room, neonatal room, and other places in the facility	Always reliable	1 (Maternal room)
BEMONC	Lombok Utara 1	No landline phone is available, Cell phones are available (staffowned)	Always reliable, available in the maternal room, neonatal room, and other places in the facility	Always reliable	1 (Neonatal room)
BEMONC	Lombok Utara 2	No landline phone is available, Cellphones are available (facility and staff-owned)	Somewhat reliable, available in the maternal room and other places in the facility,	Somewhat reliable	1 (Maternal room)

			but not in the neonatal		
			room		
BEmONC	Timor	Landline phone is	Not	Always	1 (Postpartum
	Tengah	available, but not	available	reliable	room)
	Selatan	functioning,	anywhere		
		Cellphones are	in the		
		available (staff-owned)	facility		

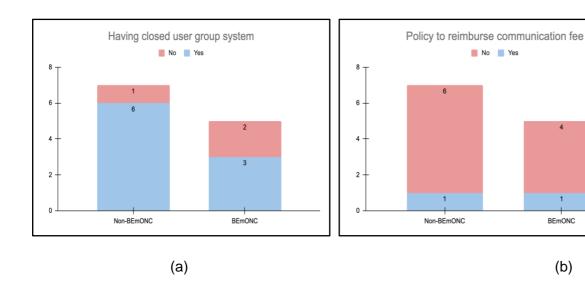


Figure 14. Distribution of Puskesmas with (a) a closed-user group system and (b) a policy to reimburse communication fee

BEmONC

(b)

All participating Puskesmas in this study had adequate communication infrastructure to assist emergency referrals. While well-functioning landline phones were only available in 2 Puskesmas, cell phones were available in most Puskesmas. However, 2 Puskesmas reported relying on staff-owned (rather than facility-owned) cellphones. One Puskesmas in Deli Serdang District reported the unavailability of both landline and cell phones, although phone reception worked well in the facility. All Puskesmas had at least one room with a computer in the facility, with one Puskesmas had 3 rooms with a computer. Most Puskesmas in this study (75%) had a closed-user group system to assist referral communication. Three Puskesmas (2 BEMONC and 1 non-BEMONC), however, did not have access to such a system. Almost all Puskesmas did not have the policy to reimburse communication fees, except for two Puskesmas that provided the reimbursement for all staff/staff on duty.

Table 16. Availability of referral transportation in the participating Puskesmas

Type of Puskesmas	District	Availability of Referral Transportation
Non-BEmONC	Deli Serdang	1 four-wheeled ambulance
Non-BEmONC	Garut	<ul><li>2 four-wheeled ambulance</li><li>1 motorcycle</li></ul>
Non-BEmONC	Nagan Raya 1	3 four-wheeled ambulance
Non-BEmONC	Nagan Raya 2	1 four-wheeled ambulance
Non-BEmONC	Pamekasan 1	<ul><li>1 four-wheeled ambulance</li><li>1 motorcycles</li><li>1 stretcher</li></ul>
Non-BEmONC	Pamekasan 2	<ul><li>1 four-wheeled ambulance</li><li>6 motorcycles</li><li>2 stretchers</li></ul>
Non-BEmONC	Timor Tengah Selatan	<ul><li>1 four-wheeled ambulance</li><li>4 motorcycles</li><li>1 stretcher</li></ul>
BEMONC	Deli Serdang	1 four-wheeled ambulance
BEmONC	Garut	<ul><li>2 four-wheeled ambulance</li><li>2 stretchers</li></ul>
BEmONC	Lombok Utara 1	2 four-wheeled ambulance
BEmONC	Lombok Utara 2	2 four-wheeled ambulance
BEmONC	Timor Tengah Selatan	2 four-wheeled ambulance

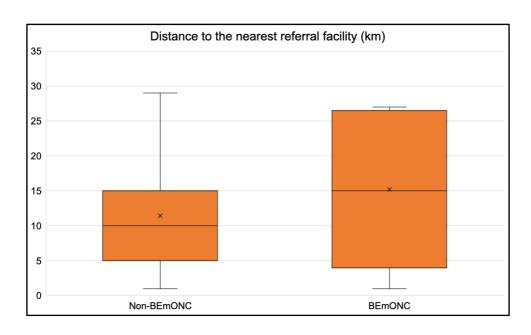


Figure 15. Access to the nearest referral facility among the participating Puskesmas

The data showed that all participating Puskesmas used four-wheeled ambulances for maternal and neonatal emergency referral. Six Puskesmas even reported having more than one ambulance. Four Puskesmas also had at least one motorcycle to assist in the referral if needed, although four-wheeled ambulances were the primary mode of referral transportation. Figure .. also showed the similarity in the average distance from Puskesmas to the nearest referral facility between the BEmONC and non-BEmONC Puskesmas. Two Puskesmas in Garut and one Puskesmas in Timor Tengah Selatan (TTS) reported the longest distance to the nearest referral facility (26-29 km). Two Puskesmas (one in Timor Tengah Selatan and one in Deli Serdang) were located in a very close proximity with the referral hospital (around 1 km).

Table 17. Referral transport preparedness among the participating Puskesmas

Component				Non-BEmONC Puskesmas
	no	n	0	2
Availability of routine maintenance schedule		%	0	28.6
Scriedule	yes	n	5	5
		%	100	71.4

	no	n	0	1
Availability of repair or maintenance		%	0	14.3
personnel	yes	n	5	6
		%	100	85.7
	no	n	0	1
Availability of repair or maintenance budget		%	0	14.3
budget	yes	n	5	6
		%	100	85.7
	don't	n	0	1
	know	%	0	14.3
Availability of fuel management plan	no	n	0	1
		%	0	14.3
	yes	n	5	5
		%	100	71.4
Fuel was sufficient*	yes	n	5	7
		%	100	100
Driver was available*	yes	n	5	7
2 3 3 3 3 3 3 3 3		%	100	100

	no	n	0	3
Nurse or other paramedics were available for referral transport*		%	0	42.9
available for relevant transpers	yes	n	5	4
		%	100	57.1

<sup>\*</sup>On the day of data collection

BEmONC Puskesmas in the study showed a better preparedness in terms of referral transport management than the non-BEmONC counterparts (Table 11). All BEmONC Puskesmas reported the availability of routine maintenance schedule, as well as maintenance/repair personnel and budget. However, both types of Puskesmas reported the sufficiency and availability of fuel and driver on the day of data collection. Furthermore, only 57% of non-BEmONC Puskesmas reported the availability of referral nurses or paramedics on the day of data collection

**Infection Prevention and Control** 

Table 18. Infection prevention and control in the study Puskesmas

	Performance Score			
Items	(0-100; 0=Not achieved, 100=Completely achieved)			
	Non-BEmONC	BEmONC		
Cleanliness	100	100		
Availability of equipments and materials for infection prevention and control in the emergency room	95.5	87.5		
Availability of equipments and materials for infection prevention and control in the delivery room	90.5	98.1		

	Performance Score  (0-100; 0=Not achieved, 100=Completely achieved)	
Items		
	Non-BEmONC	BEmONC
Availability of equipments and materials for		
infection prevention and control in the postpartum room	58.2	64.3
Availability of clean water	100	100
Sharp disposal	88.6	100.0
Availability of antiseptic and disinfectant in the storeroom	85.7	66.7
Cleaning materials are available and ready to use	87.8	94.3
Proper washing preparation (for equipment in the delivery room)	53.6	60
Decontamination of equipments and other materials	80	84
Availability of room for processing equipments in the correct flow to avoid cross-contamination	70.5	77.3
Proper washing of equipments and materials	96.1	96.4
Correct high-level disinfection: with boiling	100ª	87.5 <sup>b</sup>
Correct high-level disinfection: with steam	75ª	100°
Shelf-life system for storing high-level disinfection/sterile materials/equipment	86.7	60

	Performance Score  (0-100; 0=Not achieved, 100=Completely achieved)	
Items		
	Non-BEmONC	BEmONC
Correct waste disposal to avoid injury or contamination	NA*	NA*
Availability of designated places to store equipment for cleaning floor, toilet, and window	100	100

<sup>&</sup>lt;sup>a</sup>Only 5 facilities were included in the calculation. Two facilities used sterilisation for decontamination, but did not provide the exact steps for sterilisation

<sup>c</sup>Only 1 facility was included in the calculation. Three facilities used sterilisation for decontamination, but did not provide the exact steps for sterilisation. One facility did not implement high-level disinfection with steam.

Performance achievement for infection prevention and control was similar between the BEmONC and non-BEmONC Puskesmas. Both types of Puskesmas excelled in terms of cleanliness, clean water availability, availability of infection prevention and control equipment and material in the emergency and delivery rooms, sharp disposal (except for one Puskesmas), availability of cleaning materials, and washing of equipment and materials. Designated places to store equipment for cleaning the floor, toilet, and window were also available in all Puskesmas. However, both types of Puskesmas were lacking in terms of the availability of infection prevention and control equipment and material in the postpartum room, and washing preparation for equipment in the delivery room. Some Puskesmas used sterilization (instead of high-level disinfection) for decontamination, but not all Puskesmas had a shelf-life system for storing high-level disinfection/sterile materials/equipment. As for waste disposal, all Puskesmas reported partnering with a third party (a medical waste management company).

#### 1.1.1.1. *Hospitals*

In this section, we calculated the average score of physical resource readiness across 5 rooms/units, namely emergency unit, delivery unit, operation unit/theater room, perinatology unit, standard care neonatal unit, and NICU. The results will be presented based on the

<sup>&</sup>lt;sup>b</sup>Only 2 facilities were included in the calculation. Three facilities used sterilisation for decontamination, but did not provide the exact steps for sterilisation

<sup>\*</sup>Waste disposal was managed by a third party

type/class of the hospital, namely C (3 hospitals) and B (3 hospitals); the latter are higher-level referral hospitals.

# Neonatal Emergency Response in Hospital

In this part we assessed the performance standards of neonatal emergency response in hospitals. These included the availability of an emergency team who was ready to be called to treat neonates in life-threatening conditions due to complications, availability and readiness to use of equipment and supplies for handling neonatal emergencies, equipment on the neonatal emergency trolley and readiness to handle emergencies being checked regularly, algorithm/assistive media regarding the management of neonatal emergencies being visible for health workers, the unit/room scheduling and conducting routine neonatal emergency management simulations or exercises, balloon and hood equipment, mucus suction equipment, intubation equipment, medicine and fluid equipment, and other equipment. We examined these categories in 5 rooms/units, namely: emergency unit, delivery unit, operation unit/theater room, perinatology unit, standard care neonatal unit, and NICU unit. We made an average score to do the description calculation of each dependent variable. After that, we divided the 6 hospitals into 2 categories, public hospital class B (n=3), hospital class C (n=3).

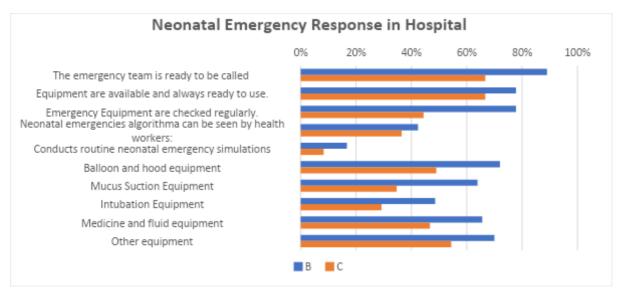


Figure 16. Neonatal Emergency Response at Hospital

Overall, district hospitals class B performed better in all categories compared to district hospital class C. We could see from the readiness of the hospital to provide emergency management to neonates. In hospital class B, 89% of the emergency team in the 6 rooms examined in the hospital were ready to treat the neonates in life-threatening conditions, compared to 67% of the teams in the rooms in class C hospital. Similarly with regards to equipment, in type B hospitals, 78% of rooms had available equipment and supplies for managing neonatal emergencies, and they underwent regular checks. In contrast, within

hospital class C, even though 67% of rooms had emergency equipment, only 44% of these rooms received regular inspections. The rooms primarily equipped with emergency teams and the necessary equipment were located in the emergency room, delivery room, perinatology room, and NICU room.

Additionally, when it came to the management of neonatal emergency algorithms and assistive media visible to health workers, only 42% of rooms in hospital class B and 36% of rooms in hospital class C had access to such resources. Typically, these algorithms were available only to health workers in the delivery room, perinatology unit, and the NICU unit. Similarly, only 17% of rooms in hospital class B and 8% in hospital class C scheduled and conducted routine neonatal emergency management simulations or exercises.

Regarding the types of equipment, approximately two-thirds of the six rooms in hospital class B were equipped with balloon and hood equipment, mucus suction equipment, medicine and fluid equipment, and other essential tools. In contrast, in hospital class C, fewer than half of the rooms were equipped with these essential items. Unfortunately, when it came to intubation equipment, only 49% of rooms in hospital class B and 29% of rooms in hospital class C had access to it. Rooms most commonly lacking this equipment were the standard care neonatal unit, perinatology room, and theater room.

Maternal and Neonatal Emergency Referral

Table 19. Communication Method

No.		Type of hospital		
	Communication methods (available and	D	С	
	functioning)	В	C	
	Telephone in the maternal room (delivery			
1	room)	100%	33,3%	
2	Telephone in the neonate's room	100%	33,3%	
3	Telephone in any room in the facility	100%	33,3%	
4	Mobile phone owned by the facility	100%	66,7%	
5a	Mobile phones are provided for staff	33,3%	66,7%	
5b	Staff owned mobile phone	100%	100%	
6	Public telephone nearby	33,3%	0	
7	Two way radio	66,7%	0	
8	Internet connection in maternal room	100%	100%	
9	Internet connection in neonate room	100%	100%	
10	Internet connection in any area of the facility	100%	100%	
11	Telephone signal condition	100%	100%	
12	Internet signal condition	100%	100%	
13	Access to closed group user systems	100%	100%	
	Reimbursement policy for staff who use their			
14	credit for work-related calls	33,3%	0	

15	An area in the facility that has a working	Unit neonates,	one hospital
	computer	Unit KMC,	stated that
		maternal room,	computers were
		postpartum room,	only available in
		children ward, and	the medical
		other	records room

Type B hospitals were equipped with more landline telephones in various areas, including the maternal room, neonate room, and other rooms within the facility, when compared to type C hospitals. However, it's worth noting that one of the type B hospitals had a non-functioning telephone in the maternal room tl. In contrast, among the type C hospitals, only one hospital had functioning landline telephones in all rooms.

Every staff member within the hospitals had access to mobile phones, with some hospitals additionally supplying mobile phones to their employees. Notably, only one type B hospital had a public telephone available nearby, a feature not found in type C hospitals. Both type B and C hospitals enjoyed sufficient internet and telephone signal coverage throughout their respective premises. Remarkably, among all the hospitals participating in this study, only one hospital offered credit reimbursement for telephone usage related to work.

# Transportation

Table 20. Availability of Referral Transportation

Type of hospital	Availability of Referral Transportation
В	four-wheeled ambulance, motorcycles (2 hospitals), 3 four-wheeled ambulance (1 hospital), stretcher (2 hospitals)
С	four-wheeled ambulance, motorcycles (1 hospital)

There were variations in the number of ambulances with each hospital having between 4 and 12 ambulances. Almost all hospitals had a regular schedule for the maintenance of these vehicles. Furthermore, each hospital had designated individuals responsible for vehicle repairs in the event of a breakdown.

Additionally, all hospitals had allocated funds to cover expenses related to vehicle repairs, fuel, and the employment of drivers and paramedics, ensuring that these resources were readily available when needed.

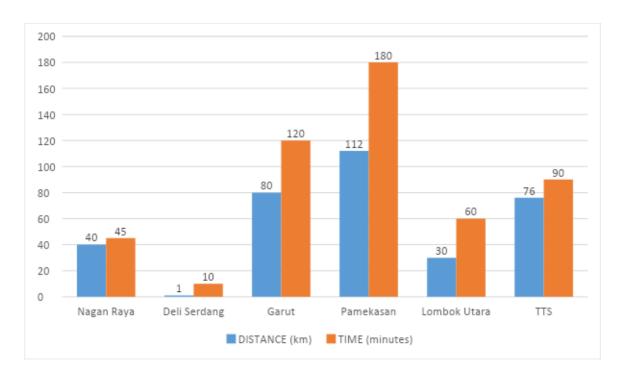


Figure 17. Average of distance to the nearest referral facility

Figure 17 showed that study hospitals in Pamekasan, Garut, and Timor Tengah Selatan, reported the highest average of distance to the nearest referral facility. In Garut, particularly, the nearest referral hospital was in the adjacent district, that is Bandung. In contrast, the study hospital in Deli Serdang reported the lowest average of distance to the nearest referral hospital. This figure emphasized that access to other referral facilities varied among hospitals in the study districts.

### Neonatal Resuscitation

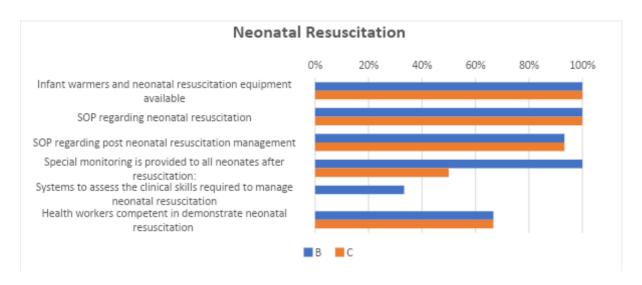


Figure 18. Readiness for neonatal resuscitation among the study hospitals

In part 2, we assessed the neonatal resuscitation performance standards, which include, adequate infant warmers and neonatal resuscitation equipment available near the Maternity Room and operating theater, Standard Operating Procedures (SOP) regarding special monitoring is provided to all neonates after resuscitation regarding neonatal resuscitation, special monitoring is provided to all neonates after resuscitation, systems in place to assess the clinical skills required to manage neonatal resuscitation, health workers are competent to demonstrate neonatal resuscitation management to clients or models.

The result showed that 100% district hospitals, both class B and C, had infant warmers and neonatal resuscitation equipment available near the maternity room and operating theater, and have the SOP for neonatal resuscitation. As many as 93% of all hospitals had the SOP for post neonatal resuscitation management. All hospital class B provided special monitoring to all neonates after resuscitation, but only half of the hospital class C provided the treatment. A third of the hospital class B had systems in place to assess the clinical skills required to manage neonatal resuscitation. Meanwhile none of class C hospitals had the clinical assessment system to monitor the skills of their health workers. Since this was a self-assessment questionnaire, two third of all hospitals stated that they had competent health workers to conduct the neonatal resuscitation management. In some hospitals, they mentioned in the instrument that the health workers in their facility were rarely getting trained to update the knowledge regarding the neonatal resuscitation.

The insufficient resuscitation equipment frequently posed challenges for healthcare professionals in the hospital, impeding their ability to deliver optimal care, as evidenced in the following quote.

"...these tools, what is it called, ambu-bag? We only have one. So, when the ER has borrowed our equipment when we need to perform emergency procedures, we have to run around searching for them, while the patient is already asphyxiating or in critical condition. We rush to retrieve them, but by the time we return, the patient is already gasping for air. We haven't even had the chance to call the perinatology specialist. Automatically, we have to act on our own, and when the doctor gets angry, we're already in a panic wondering where to run to. Our equipment is also limited..." (FGD participant in Timor Tengah Selatan)

To address this issue, certain facilities crafted makeshift equipment, such as a simple CPAP tool using a nasal cannula and plastic bottle. Some hospitals were also still using oxygen tanks, instead of centralized ones.

Management of Neonatal Sepsis and Antenatal Steroid Administration to Prevent Early Complications in the Hospitals

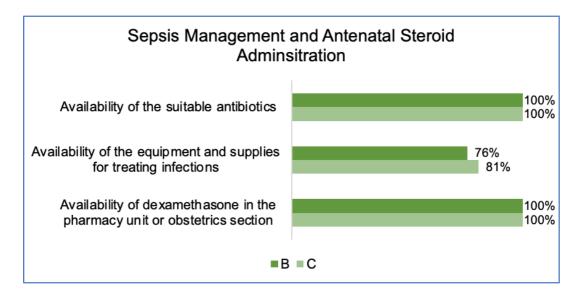


Figure 19. Logistic preparedness for the management of neonatal sepsis and the administration of antenatal steroid

All of the participating hospitals reported having suitable antibiotics for neonates (along with the SOP for administering first-line antibiotics). Our interview with nurses from a class B hospital revealed the following SOPs of antibiotic regimens for neonates.

- a. First line: ampicillin, amikacin + gentamicin (if neonates showed good renal function)
- b. Second line: cefotaximec. Third line: meropenem
- d. Fourth line: ampicillin + sulbactam (only if resistant to meropenem)

Furthermore, 76% of hospital class B and 81% of hospital class C had the equipment and supplies for treating infections in neonates. All class B hospitals and 2 out of 3 class C had the SOP for administering first like antibiotics including antibiotic protocols. Our qualitative findings showed that nurses in the hospitals consulted all decisions regarding suspected infection in neonates were made by paediatricians. Some hospitals also partnered with laboratories outside the hospitals to conduct sepsis screening and IT ratio assessment.

In terms of antenatal steroids, all hospitals reported having dexamethasone available in the pharmacy unit or obstetrics section to prevent early neonatal complications.

### Fluid and Oxygen Management for LBW Babies

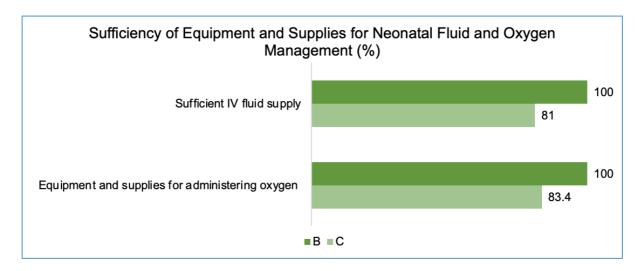


Figure 20. Logistic preparedness for fluid and oxygen management for LBW babies

The class B hospitals were more prepared to provide nutritional and fluid for LBW babies. Readiness in fluid supply was reported by all type B hospitals. Some class C hospitals lacked designated refrigerators for storing breast milk, teaspoons, and scales. In terms of equipment for administering oxygen, both type B and C hospitals reported the availability of ambu-bags, oxygen central, oxygen concentrate, and oxygen cylinders.

Our FGDs with health care providers also showed the availability of medical devices for fluid and oxygen management. As an example, in Garut, there are only three infusion pumps and six patient monitors available. In Timor Tengah Selatan, they faced a situation where pulse oximetry is utilized without a probe, and it must be shared among multiple infants. In Nagan Raya, they used oxygen regulators for adults when treating LBW babies weighing less than 1000 grams due to the limited equipment available.

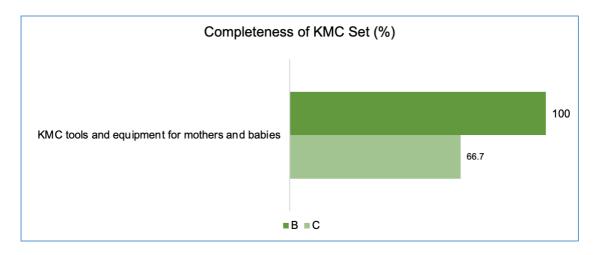


Figure 21. Logistic readiness for KMC in the hospitals

All class B hospitals reported the adequacy of KMC tools and equipment for the mothers and the babies. On the other hand, only 2 out of 3 class C hospitals had adequate tools and equipment for KMC, which included rooms with a temperature between 22-24°C sufficient for 2 to 4 beds. However, our field visit to the hospital showed that some of the KMC rooms did not meet the standard. For instance, one hospital used the KMC room for storing documents and unused equipment also. The room was also not air-conditioned and the temperature was not monitored.

In 2009, the Ministry of Health in collaboration with PERINASIA (The Indonesian Society of Perinatology), IBI dan PPNI produced a guideline on the implementation of KMC in hospitals and its network, and they are quite certain that all staff are familiar with KMC and how to educate the mothers (and caregivers) about KMC. However, the Ministry of Health acknowledges that there might be challenges in whether mothers (and caregivers) would actually do KMC. The collected data showed that some study facilities (particularly Puskesmas) did not record the number of babies receiving KMC. While these facilities acknowledged the practice of KMC in some mothers, the omission of recording these cases was attributed to its non-inclusion in the mandatory reporting.

Table 21. Proportion of LBW babies receiving KMC

District	Facility	Year	Number of LBW babies treated	Number of LBW babies receiving KMC	Percentage of LBW babies receiving KMC (%)
Nagan	Non-BEmONC	2020	0	0	0
Raya	Puskesmas 1	2021	0	0	0

		2022	0	0	0
	55 0.10	2020	0	0	0
	Non-BEMONC	2021	0	0	0
	Puskesmas 2	2022	0	0	0
		2020	123	47	38.2
	Hospital	2021	199	53	26.6
		2022	155	61	39.4
	55 000	2020	0	0	0
	BEMONC	2021	1	0	0
	Puskesmas	2022	1	0	0
	55 0.10	2020	0	0	0
Deli	Non-BEMONC	2021	0	0	0
Serdang	Puskesmas	2022	15	15	100
		2020	23	23	100
	Hospital	2021	106	106	100
		2022	122	122	100
	DE 0110	2020	0	0	0
	BEmONC Puskesmas	2021	2	1	50
		2022	2	1	50
	Non-BEmONC Puskesmas	2020	0	0	0
Garut		2021	0	0	0
		2022	0	0	0
	Hospital	2020	1330	705	53
		2021	1009	NA*	NA*
		2022	1101	NA*	NA*
	Non-BEmONC Puskesmas 1	2020	NA*	NA*	NA*
		2021	NA*	NA*	NA*
	i uskesiilas i	2022	NA*	NA*	NA*
	Non DEmONO	2020	NA*	NA*	NA*
Pamekasan	Non-BEmONC Puskesmas 2	2021	NA*	NA*	NA*
	i uskesiilas z	2022	NA*	NA*	NA*
		2020	135	86	63.7
	Hospital	2021	111	81	73
		2022	145	92	63.4
	DEONG	2020	5	0	0
	BEMONC	2021	5	0	0
	Puskesmas 1	2022	7	0	0
Lombok Utara	DE ON O	2020	0	0	0
Utara	BEmONC Puskesmas 2	2021	0	0	0
	i uskosilias z	2022	18	0	0
	Hospital	2020	NA*	NA*	NA*

		2021	205	180	87.8
		2022	NA**	NA**	NA**
	BEmONC Puskesmas	2020	23	23	100
		2021	38	38	100
		2022	47	47	100
Timor	Non-BEmONC Puskesmas	2020	82	82	100
Tengah		2021	84	84	100
Selatan		2022	111	111	100
	Hospital	2020	NA*	NA*	NA*
		2021	NA*	NA*	NA*
		2022	200	NA*	NA*

<sup>\*</sup>The facility did not record the number

Infection Prevention and Control

Table 22. Infection prevention and control in the study hospitals

Items	Performance Score (0-100; 0=Not achieved, 100=Completely achieved)		
	Type B	Type C	
Cleanliness	96.3	100	
Labor observation room, delivery room and postpartum room have sharps disposal containers and use them properly	100	100	
Use of antiseptics in the first stage of labor observation room, delivery room and postpartum room	80	66.7	
Preparation of washing equipment in the stage I labor observation room, delivery room and postpartum room	55.6	37.1	
Processing used equipment in the stage I labor observation room, delivery room and postpartum room	90.5	38.1	
Washing of equipment in the stage I labor observation room, delivery room and postpartum room	66.7	66.7	
Availability of sharp disposal container in the perinatology room	100	100	
Antiseptic prepared the perinatology room	80	100	

<sup>\*\*</sup>Requires further clarification from the facility

Preparation of washing equipment in the perinatology room	66.7	75
Processing of reusable equipment in the perinatology room	79.2	58.4
Washing tools in the perinatology room	66.7	33.3
Availability of sharp disposal container in the operating rooms and post-operative rooms (High Care)	100	100
Antiseptic prepared in the operating room and post-operative room (High Care)	93.3	93.3
Preparation for washing equipment in the Operating Room and Operating Room and Post-Operation Room (High Care)	100	100
Processing of reusable equipment in the operating room and post-operative room	62.4	41.7
Washing of equipment in the operating room and the post-operative room	66.7	33.3
Availability of sharp disposal container in the Emergency Room (ER)	100	100
Antiseptic prepared in the ER	100	93.3
Preparation of washing equipment in the ER	66.7	41.5
Provision of reusable equipment in the ER is carried out correctly and washing is carried out as recommended	33.3	61.7

Our study revealed that Class B hospitals exhibited better overall performance in infection control and prevention. However, it is worth noting that both hospital classes displayed room for improvement in certain areas. Generally, both Class B and Class C hospitals maintained a visibly clean environment. Nevertheless, there was one Class B hospital that combined a delivery room with a first-stage observation room. Beyond this, all facilities, irrespective of their class, have implemented stringent sharps disposal procedures by utilizing safety boxes.

The utilization of antiseptics in the First Stage Labor Observation Rooms, Delivery Rooms, and Postpartum Rooms adhered to regulatory guidelines in all hospitals. Notably, one Class B hospital properly stored cornangs in dry containers that had undergone High-Level Disinfection, while one Class C hospital labeled its containers with the antiseptic solution's name and the date of refill.

Furthermore, the preparation of washing equipment in the First Stage Labor Observation Rooms, Delivery Rooms, Postpartum Rooms, Perina Rooms, Operating Rooms, and Post-Operative Rooms was in line with recommendations in nearly all hospitals. The only exception was the direct preparation of chlorine in the Central Sterile Supply Department (CSSD) rooms. Most Class C hospitals processed used equipment in the CSSD rooms.

The correct processing of reusable equipment in the Perinatology Room was nearly universally implemented in Class B hospitals, but some Class C hospitals failed to provide labels, types, and processing dates for their equipment. Lastly, for the washing of equipment in the Perinatology Rooms, Operating Rooms, and Post-Operative Rooms, a few hospitals, particularly Class C, delegated this responsibility to the CSSD.

Factors contributing to physical resources availability issues

Financing issues in procurement and maintenance

Management and care for LBW did not rely solely on the availability of competent human resources but also availability of appropriate equipment. The assumption was that even a highly competent and skillful health worker would not be functioning optimally without the necessary tool. In most cases, competent human resources and availability of the appropriate equipment went hand-in-hand.

"It depends on the facilities and infrastructure, right? In terms of competence, I'm sure the midwife can do it because of the same education, but because there aren't any tools, they can't operate it, right? That is how it depends." (IBI)

Equipment required heavy investment, and the responsibility for ensuring equipment availability in health facilities should not rest solely on the Ministry of Health. Local governments could actually spend the budget on investment. The challenge was to advocate for the necessary budget for it. This proved to be a challenge since it required the local government to see LBW as a health priority, and the study observed that this had not been a priority yet. In addition, the already limited budget at the local government level is sometimes burdened even more with other priorities, including non-health issues, for example in election year most of the funding will be concentrated for election. In addition to competing interests, our FGD participants from a district hospital also stated about the difficulty in the procurement process due to the rigid requirement. It could take more than 1 year to procure certain devices.

"...the equipment must be of good quality, must be domestically produced, must be included in the e-catalog, so when we open this (e-catalog) for the first time, we want to see that it is already controlled from there. We're confused about why they control this, why they look at these prices, why there are these prices, but they choose those prices; all of this is controlled by the KPK (Corruption Eradication Commission). So those working in equipment procurement are very cautious because any administrative errors will lead to their dismissal..." (FGD participant in Timor Tengah Selatan)

In terms of maintenance, we found there was a varying degree of medical device maintenance system among the participating hospitals. In Deli Serdang and Nagan Raya, there was an inhouse maintenance personnel, while in Pamekasan, they relied on external technicians to repair the devices whenever necessary. In Deli Serdang, calibration and maintenance is conducted by the in-house technician on a monthly basis, and by an external body (BPFK/Agency for the Security of Health Care Facilities) on an annual basis. On the contrary, in the other districts, there was little evidence about such a mechanism. Participants in Nagan

Raya and Lombok Utara also reported that medical device maintenance required lengthy bureaucratic processes which could take months.

#### Distribution issues

The Ministry of Health had a centralized procurement system for certain devices, based on the national priorities. This system had a benefit, i.e. the ability to negotiate lower prices due to heavy volume (and continuous) demand. The Ministry of Health had a plan in place to gradually complete the health facilities especially at primary care level due to the recent initiative of Integrated Primary Care (KMK 2015/2023). For instance, to increase the capacity for primary care to improve early detection, ultrasound equipment is one of the priorities in the Ministry of Health procurement.

"The Ministry of Health is distributing ultrasound equipment to each area so they can diagnose in more detail and provide first-hand treatment." (IDAI)

Even though the Ministry of Health often made some equipment available at primary care facilities, it appears that the distribution did not always match the availability of human resource competency in that facility. Moreover, the question of ability to budget for maintenance and to find a maintenance service in the area was problematic.

"We received information through WhatsApp ... 'Doc, the equipment in Puskesmas A is complete, however it is still wrapped in plastic.' How come? 'Because we don't know how to use it' .... So, there seems to be unsynchronized planning. One district might want to complete the necessary equipment, but there is no staff there that could operate let alone do maintenance, so that equipment is left unwrapped and unused. This is not a rare case." (IDAI).

"Sometimes there is no technical people there ... for instance ventilator, for instance incubator, we often see incubators in Puskesmas already became a 'garbage': they're there, but cannot be use ... nobody there understand how maintain it .. or, sometimes when there is someone who is competent to operate it, the person was not assigned to do it instead s/he is assigned to keep the (accounting) book." (PPNI)

Another challenge was the administrative hurdle. In cases where the MInistry of Health dropped new equipment, oftentimes the equipment (e.g. USG) was delivered by courier service without sufficient documentation for instance the Record of Transfer document (*Berita Acara*) or the letter stating that the equipment had passed the functional test. Without the functional test, Puskesmas usually would not dare to operate the machine. And without the Record of Transfer document, Puskesmas also could not allocate budget to conduct functional tests or to allocate budget for maintenance. When they tried to reach the Ministry of Health to clarify this matter, the calls were usually diverted several times without any solution. In contrast, when Lombok Utara also received equipment from philanthropy groups (Rotary Club), the Rotary Club also provided technical support for the equipment use and maintenance.

# Experience of care

Understanding quality of care from the perspective of patients has been pivotal in the discussion of quality of care. While medical profession has traditionally focussed on technical aspects of medical service provision. Patients typically focus on functional aspects as a proxy in evaluating the quality of the medical service received. In other words, patients used functional quality assessment to judge the service overall; while in contrast, medical professionals focus on technical quality. Recognizing this difference, our study explored how mothers and caregivers of LBW babies experience care in the health facility (puskesmas and hospital) and sometimes beyond that (post-dicharge). There were three standards related to the experience of care in the framework that we used, namely: (1) effective communication and meaningful participation, (2) respect, protection and fulfillment of newborn rights and preservation of dignity; and (3) emotional, psychological and development support. Effective

# Communication and meaningful participation

WHO recommends a communication with small and sick newborns and their families is effective, with meaningful participation, and responds to their needs and preferences, and parental involvement is encouraged and supported throughout the care pathway.

To equip health workers in providing correct information to mothers and families with LBW infants, the Ministry of Health also provides several tools. For instance, in 2021, the Ministry of Health produced a video (translating Global Health Media video) on neonatal care as a tool of IEC for health workers on LBW infants' care. However, the study found a variety of the health worker skills in communication and engagement of parents (and future caregivers) in communicating about the LBW situation.

### ANC to prevent LBW

Antenatal Care (ANC) represents the initial engagement involving communication and involvement of pregnant women and their families in relation to the pregnancy. ANC plays a crucial role in potentially preventing Low Birth Weight (LBW) by identifying and addressing risks associated with pregnancy. However, our study revealed that, despite the mothers' diligence in adhering to ANC protocols, challenges exist that impede effective communication between mothers and health workers during the ANC process that caused disappointment of mothers and the families.

The ANC process was consistent across Kabupaten, involving assessments of pregnant women's body weight, blood pressure, and heart rate, as mentioned elsewhere in this report. Ultrasound was used to determine the fetal position. If chronic energy deficiency was identified, supplementary meals are provided by Puskesmas or village administration.

<sup>76</sup> Donabedian A. Evaluating the quality of medical care. Milbank Mem Fund Q 1966; 44: 166–206. doi:10.2307/3348969 StewartM.Patient-centered medicine: transforming the clinical method. Oxon: Radcliffe Publishing; 2003.

Health CA. The patient as a pivot point for quality in health care delivery. Hosp Health Serv Adm 1995; 40: 25–39. Babakus E, Mangold WG. Adapting the SERVQUAL scale to hospital services: an empirical investigation. Health Serv Res 1992; 26: 767–86

Additionally, pregnant women receive 90-day courses of Fe tablets during check-ups at posyandu/Puskesmas.

Health workers who served as our key informants expressed their confidence in guiding mothers for a healthy pregnancy, relying on *kaders* and village midwives. Regular posyandu visits were encouraged. Our key informants, however, admitted that their works did not always successful; there were mothers who resist for various reason from none could take her there, the equipment was damaged, to the need to wait for the husband.

WhatsApp was chosen as a primary communication method between pregnant mothers and health workers throughout Kabupaten as it was more practical with a wider outreach level. The use of whatsapp was also consistent across Kabupaten and activities that involved communication with pregnant mothers.

"If she has any complaint, we provide a counselling through Whatsapp." (North Lombok, IDI Puskesmas)

Despite health workers' efforts to promote essential behaviours via Whatsapp, some mothers remain indifferent.

"The problems were more of awareness, or willingness. Because the health workers have already maximized their efforts in providing education. From the WhatsApp group, if the patient doesn't want to, there's nothing we can do. We have already visited their homes; if the patient still refuses, it's challenging." (Garut, IDI Puskesmas)

In Garut, the DHO's Melani program collaborates with OBGYNs to visit and examine high-risk pregnant women at Puskesmas at least twice during pregnancy. However, as portrayed later, we still found inaccuracy in ultrasound interpretation there.

Thus, regardless the health workers' efforts and confident level in communicating with mothers, many mothers of low birth weight (LBW) babies expressed dissatisfaction with the precision of examinations during antenatal care (ANC), leading to feelings of shock and surprise among them.

Experiences during the delivery and beyond

The norms that allowed (or in a stronger term, demanded) extended families (or even close neighbours) to help or get involved in issues faced by nuclear families provide a wide range of potential caregivers for healthcare providers to (1) choose to participate in the care, and (2) give information regarding the baby's and the mother's conditions, and treatments needed. Although mothers who delivered the LBW baby were the ones who almost always with the baby, not all were informed about the baby's conditions and treatments given, due to various reasons, as portrayed in this section.

The array of caregivers' experiences reflected different practices performed by the health workers, either because of too many situational circumstances to consider or diverse perceptions about the standard or quality statements. In general, participants in this study reported to be at least moderately satisfied. Parents of deceased LBW babies varied in their responses, with some feeling deeply disappointed while others were more accepting of the unfortunate circumstances. Some believed that most healthcare providers had made sufficient efforts to save the baby.

### Experiences at Puskesmas

### -Who gets the information?

The mother and father usually are the ones who get information about the baby's conditions, treatments, and results. However, our study indicated that staff of healthcare providers might choose any family members or even close neighbours to talk with. For example, a mother of twins, who both have LBW, said that health workers at the puskesmas only communicated with a kader --that was acknowledged as the mother's niece-- about her and her babies' conditions. The information given through the niece ranged from the mother's hypertension in the antenatal check-up to the twin babies she had during the labour. Instead of telling the father of the baby, the health workers preferred informing the niece about the conditions of the newborns since the ANC, because

"Her husband gets shocked easily; the one who was strong was their niece. Her husband couldn't do it and was often confused and scared." (mother of a surviving LBW baby, Puskesmas, Garut)

While decisions regarding information giving may align with the family's preferences, our key informant did not explicitly clarify whether the choices to withhold information from the parents originated from the mother, the niece, the extended family, or the healthcare provider's staff. These decisions left the mother uninformed; for instance, she only learned about having twins with Low Birth Weight (LBW) after the babies were born, despite the niece having received this information during the Antenatal Care (ANC) and after the ultrasound, which made her shocked and sad.

### -Information given

Mothers participating in the study commonly reported two issues with health workers at the Puskesmas. The first issue, also observed at the hospital, pertained to inquiries about how to maintain the baby's warmth and exclusive breastfeeding. The second issue, specific to the Puskesmas context, revolved around challenges associated with the referral processes.

### -Keeping the baby warm

As health workers continued to remind parents to keep the LBW baby/ies warm at home, the information given and the way it was given were different from one health facility to another.

Mothers in TTS who gave birth to surviving LBW babies at a Puskesmas knew that the LBW babies should be wrapped and put on the chests skin-to-skin to keep them warm. The midwife was the one who informed them about that. They knew "cara kangguru" or "kangaroo method" to keep them warm and increase their weight. In Garut, one mother proudly told us about her experience of having a midwife that provided her with information and guided her in practising KMC.

In Pamekasan, a mother who gave birth in the Puskesmas network (polindes) told us that she was instructed,

"... to still bathe the baby but not to rub, because this [baby] is sensitive, but I was not told to warm [the baby], or to avoid chilling. Or if possible, swaddle them skin-to-skin." (Mother of a surviving LBW baby, Polindes, Pamekasan)

The last sentence (*dibedong dari kulit ke kulit*) might be a piece of advice from the midwife to do a KMC that the mother missed. The mother acknowledged receiving instructions on the procedure but was not encouraged to practice it while in the health facilities.

## -Informed consent in referral processes

We have mentioned that Puskesmas at times served as a transit place for mothers and babies with complications, thus a lot of patients went through referral processes to the hospitals. In that process, usually health workers in Puskesmas gave alternatives to parents so they could choose based on urgency, familiarity, or other considerations.

"I asked here at the Puskesmas, where should I be referred to? There were two options: DRS [name of a hospital] is an option, MD [name of a hospital] is also an option, they're the closest. If we go to DRS, it's further away, and we're afraid the baby won't make it. So, we chose the closest one and brought the baby to MD, it's about an hour from here." (Mother of surviving LBW, Garut)

"Actually, I was given a choice, whether to go to G hospital or the other... So, I chose G hospital because it's closer to home. Their mom also had a C-section there, so they know what it's like there." (Mother of surviving LBW, Puskesmas, Deli Serdang)

Mothers and other caregivers did not provide information regarding whether healthcare providers adequately communicated details about referral hospitals, including service availability and potential out-of-pocket expenses.

A health worker in Pamekasan cared to ask the father to let the whole family members know about the plan to refer the baby to the hospital

"When they were about to refer the baby from the Puskesmas to the hospital, the midwife told them to inform everyone, the whole family." (Father of a deceased LBW baby, Puskesmas Pamekasan)

This good intention of the health worker somehow might make the process complicated, as will be explained in the next section, due to the lengthy family discussions on the referral processes.

Mothers discharged before their infants encountered challenges in comprehending health workers' information during the referral process. For instance, in Pamekasan, a mother of a low birth weight (LBW) baby, who had delivered at a Puskesmas and was discharged before the infant, expressed confusion. She was requested to provide consent over the phone for the Puskesmas to refer the baby to a type B hospital. The midwife communicating with her appeared to obfuscate the actual situation.

"I was also confused. Why was the baby suddenly taken to the hospital? Why not bring him home first? I feel regretful, ma'am. I asked the midwife at the Puskesmas, 'Why was the baby taken to the hospital?' Then the midwife said, 'It's okay, ma'am. It's to help him gain weight. He'll be brought back in a few days, maybe two or three days,' like that, ma'am." (Mother of a deceased LBW, Type B hospital, Pamekasan)

The midwife was perceived as lacking empathy, as well. She harboured remorse for allowing the situation to unfold, as ultimately, her baby passed away in the hospital.

-Satisfaction level or perceived treatment from healthcare providers

In general, mothers who delivered LBW babies in Puskesmas felt quite satisfied with the service, mainly because of the staff of healthcare providers' kind and friendly manners in treating the patients. In Pamekasan, mothers said that the health workers were empathetic and caring for telling them that the baby/ies had LBW,

"I was immediately informed by the midwife, 'Ma'am, your baby is small, only 2 kg, please be patient,' like that." (Mother of a surviving LBW baby, Puskesmas, Pamekasan)

The inability to demonstrate empathy and encouragement, as highlighted earlier, resulted in negative evaluations of health workers by mothers and their families. Additionally, within the contextual framework, the lack of trust in health workers significantly contributed to this issue.

### -Parents' active participation in caring for the newborn

Being in the same room with the baby/ies created a bigger opportunity for mothers and/or other caregivers to get involved in caring for the baby/ies. Mothers who delivered the baby/ies in Puskesmas had a better chance of it, in comparison to hospitals. Most probably because the baby/ies had no complications when staying in the Puskesmas. A mother of a surviving LBW who gave birth in a Puskesmas in Garut said that the twins (one of the twins was LBW, the other one was normal) stayed with her during their stay in the Puskesmas. In one Puskesmas in North Lombok, instead of putting the twin babies with their mother, the healthcare provider let the grandmother take care of the babies while the mother was resting in a separate room. They only stayed half a day in the Puskesmas. Some LBW babies with complications were directly referred to the hospitals without the mothers. The mothers either stayed at the Puskesmas, or were discharged if they were in good condition.

### • 4.3.2.2 Experiences at Hospital

# -Who gets the information?

Similar to Puskesmas, although mothers are the ones who are usually present at the hospital, health workers do not always inform them about what happened because of the health or psychological condition of the mothers. In that case, they talked to other family members or caregivers, such as the mother of the LBW baby's mother, or the father of the LBW baby.

"No, they told my mother. Because I had just had surgery." (Mother, hospital, Deli Serdang)

"Yes, but through my husband because I couldn't get up and go to the NICU room." (Mother of a surviving LBW baby, hospital, Nagan Raya)

In Puskesmas, patients typically encountered midwives and nurses, occasionally general practitioners (GPs), whereas in hospitals, they interacted with specialty doctors, regarded for their higher level of expertise. The communication can be more complicated, particularly with mothers from lower socioeconomic status. In their study on family planning, Kim, Heerey, & Kols (7860) emphasises the importance of making a client feel comfortable and

<sup>&</sup>lt;sup>78</sup> Kim, Y. M., Heerey, M., & Kols, A. (2008). Factors that enable nurse-patient communication in a family planning context: A positive deviance study. *International Journal of Nursing Studies*, *45*(10), 1411–1421. <a href="https://doi.org/10.1016/j.ijnurstu.2008.01.002">https://doi.org/10.1016/j.ijnurstu.2008.01.002</a>

empowered to encourage them to ask questions and clarify. Asking questions and clarifications oftentimes is perceived as challenging the authority, such as health workers, as exemplified in the following section. The 'good' manners norms amongst mothers also led to less challenging of authority in both proffering of information and decisions on contraceptives by the health providers. Lastly, they also identified that profound social distance separates clients, commonly from lower socio-economic backgrounds, from relatively better-off and better-educated providers in Indonesia. This is related with the compliance of the health workers to standard 5, which will be explained later.

Fathers, who are believed to have higher self-confidence, can play an active role in getting information about the baby. A mother of a surviving LBW baby from Garut explained that her husband who works in Jakarta, came home when she delivered the baby and asked detailed questions when talking with the health workers so that they didn't experience any confusion at home. Nevertheless, the fathers usually were left out of participating in caring for the baby at the facility. For example, a father whose baby was admitted to the NICU in the hospital in North Lombok, stayed outside of NICU every day for a few days and was not allowed to enter the NICU room. There appears to be a gender-based policy, either implemented by the hospital or enforced by individual health workers, regarding entry into the NICU, as evidenced by the fact that the baby's aunt —but not the father-- was permitted to visit.

### -Information given

In general, health workers in hospitals informed parents or caregivers about the conditions of the newborn. The three most communicated issues are the newborn's weight, prematurity (gestational age), and complications, such as lung and heart problems, and intracranial bleeding. Some –particularly to parents whose baby did not survive-- included detailed information about the conditions,

"On the 15 [date] at 10 in the morning, the baby passed away. He was born crying and briefly lived, but there was a delay in his lung's blood circulation, so a C-section was performed, which is why they didn't survive. The baby's weight was 1.8 kilograms because they were born prematurely." (Mother of a deceased LBW, type C hospital, TTS)

Regarding treatments received when hospitalized, health workers often told the parents or caregivers that the baby was admitted to the NICU, due to the LBW or prematurity. Incubator.<sup>79</sup>, and breathing support.<sup>80</sup> for LBW with complications are equipment used to help the newborns that some parents were aware of.

"The baby was placed in an incubator. The doctor said, 'We're using a small amount of oxygen, and if it doesn't work, we'll use a larger amount. If the condition doesn't

 $<sup>^{79}</sup>$  Mentioned in various terms such as oven, a box with a lamp, tube.

<sup>80</sup> Terms used: Oxygen therapy, breathing support

improve and remains poor, we'll refer to Banda Aceh." (mother of a surviving LBW baby, hospital, Nagan Raya)

Another example from Nagan Raya, the mother seemed to be knowledgeable,

"The platelet count dropped at one point, and the baby had to receive six pockets of blood transfusions. Then the doctor said, 'It seems like there might be a hole in the heart.' So, we went for a follow-up at ZA Hospital. The doctor said that because the baby's body was small, it could be that the heart valve hadn't closed yet, so it was not a problem. But if their body weight doesn't increase for two months, we were told to come back for another check-up when they are 6 months old." (mother of a surviving LBW baby, hospital, Nagan Raya)

A mother of a deceased LBW baby explained that she was shown the results of a glucose test of her baby that indicated the baby's high glucose level.<sup>81</sup>.

"What surprised me was that their blood sugar level was 517. The baby was just born two nights ago. The doctor asked me, 'During pregnancy, did you consume any sugary drinks?' So, I said, 'In the morning, instead of tea or coffee, I just had plain sugary water."" (Mother of a deceased LBW baby, Puskesmas, TTS).

There are times when –according to parents-- the healthcare providers' staff only told them about the care they did for the baby without explaining the reasons.

"The baby spent a month in the incubator, was told she was not well, and we were told to buy medication. They had a blood transfusion with four pouches, but they did not tell us the reason for being placed in the incubator." (Mother of surviving LBW, type C hospital, North Lombok)

Those differences seemed to indicate different treatments given to the parents and caregivers that is yet to be explored. Another mother who delivered a surviving LBW baby in a type C hospital in North Lombok elucidated that she was not told about the baby's condition, but suggested "no bathing, just put some *minyak telon*, that's all. Lay the baby down when the baby's sleeping, when she's awake breastfeed her." She was also taught how to breastfeed the baby and practiced it in the health facility, although when she got home she forgot everything.

Communicating with parents of hospitalized infants

Giving information about the condition of the LBW baby when hospitalized separately from the parents can be complicated. Parents might feel healthcare providers ignore their feelings, and requests or try to conceal the condition when it's worsening.

<sup>81</sup> The baby was born at a private hospital in TTS and then referred to the District Hospital due to jaundice.

A mother of a deceased LBW baby in Pamekasan remembered when the baby was hospitalized in the type B hospital,

"My mother-in-law also asked, 'When can the baby be taken home?' They said, 'Be patient, ma'am, when their breathing is better...'. And then, 'When?' The answer was the same, like that, over and over. No, they said the condition is good. 'When can we bring the baby home, ma'am?' They said, 'Not yet,' like that. No, they never provided any information from there." (Mother of a deceased LBW baby, type B hospital, Pamekasan)

Nevertheless, all phone calls from the family members, grandparents, and father in particular were responded to.

"Yes, because I called this doctor. I always asked. And every time I called, they always picked up."(Father of a deceased LBW baby, type B hospital, Pamekasan)

-Satisfaction level or perceived treatment from healthcare providers

Overall, even among parents who experienced remorse and profound disappointment with treatment outcomes, including those with Low Birth Weight (LBW) babies that did not survive, there was no perception that medical staff had not exerted effort to save the infants. Some parents chose to emphasize the positive aspects of the situation, and highlight the positive aspects of the situation, guided by their cultural and religious beliefs, attributing the mortality of the baby to God's will or fate.

"I am speechless. The service at the hospital was good, so what could I say, Doctor? This is indeed God's will. The doctor once asked me: 'Mom, do you want to ask why the baby passed away?'" (Mother of a deceased LBW baby, hospital, TTS)

A mother of a deceased LBW baby in North Lombok remembered that when the doctor informed her that they could not save the baby, the doctor (who was a male doctor) cried with her. This showed that empathy and emotional support so far were more important for parents, in comparison to accurate information about the cause of mortality cause.

A mother of a deceased LBW baby in Deli Serdang was satisfied with the service, although she lost the baby. She mentioned that during the emergency condition, the team worked fast.

"The speed of their works. Maybe if it wasn't fast, this wouldn't be possible. Because I was bleeding. Yesterday, it was photographed by the doctor, and the doctor said that even the intestines were affected. There was also heavy vaginal bleeding." (Mother of a deceased LBW baby, hospital, Deli Serdang)

Parents of deceased LBW babies may have used their responses as coping strategies, in addition to the fact that they did not need information about caring for LBW babies at home. In contrast, parents with surviving LBW babies expressed a desire for more information to better prepare them for baby care.

"I don't think it's enough. Especially regarding breastfeeding and baby care. Besides the midwife, I get information from family members, especially from my mother." (A mother of a surviving LBW baby, hospital, Deli Serdang)

### -Active participation in caring for the newborn

In Pamekasan (type B hospital), parents –particularly of the deceased LBW-complained about not being allowed to visit the baby, moreover, to participate actively in the care.

"I did not breastfeed the baby directly. They took the baby to a different room and then asked me for a bottle [of breastmilk]. Well, if [the father] cannot enter the room, at least the mother should be allowed in to breastfeed. But even the mother is not allowed to enter like that. Yes, I come here on Tuesday, Wednesday, Thursday, Friday, and Sunday, bringing clothes for change. I want to breastfeed my baby, but the nurse said I'm not allowed, she said, 'Ma'am.' I felt like crying, Ma'am, because the baby doesn't look normal... but I'm the mother; it should be easier for me to see." (Mother of a deceased LBW baby, Type B hospital, Pamekasan)

Unlike the experience of the mother in Pamekasan, a surviving LBW mother in a type C hospital in North Lombok felt well-supported by the midwife who patiently assisted with breastfeeding the baby.

"Yes, the midwife accompanied me, showing how to breastfeed my baby, the midwife didn't leave the room until the breastfeeding was done." (Mother of surviving LBW, laboured in type C hospital, North Lombok)

One mother who delivered the baby in another type D private hospital in Garut was allowed to carry the baby, even when her husband visited them, he was also allowed to carry the baby. Another mother who had twins stayed with one of the babies who was not LBW. The LBW baby stayed separately.

"Because one of the twin babies is small, [the other one has a sufficient body weight], that's why they are separated. [Only one of them is separated?] Yes, the older one." (Mother of a surviving LBW, Type C hospital, Garut)

Other mothers of surviving LBW baby who gave birth in private hospitals in Garut appreciated the friendliness of the healthcare providers' staff, but was not happy with the regulation to keep the babies separated from them.

"They are friendly, but we were not allowed wait inside. My experience was just like that, the baby was immediately separated, they only checked the baby's sex. I met the baby when I was about to go home" (Mother of a surviving LBW baby, type D hospital, Garut)

Another mother stayed in the hospital for a month to tend to the baby who needed to be hospitalized,

"We were informed that the baby was not in good health and were told to redeem medicine. The baby had a four-bag blood transfusion. They said that the cost of the blood transfusion was covered by the doctor because we are using BPJS (a national health insurance program)." (mother of a surviving LBW baby, type C hospital, North Lombok)

When the baby was allowed to go home, the family was only told,

"They just told to go home, without any information. We were told that the baby was already healthy, and we were asked to come back to the hospital for a check-up in one week; they said everything was normal." (a mother of a surviving LBW baby, type C hospital, North Lombok)

Another instance, the hospital seemed not to provide facilities for parents and caregivers who tend the babies at the hospital to stay healthy and fit. A surviving LBW baby in North Lombok with jaundice was referred to a type C hospital from Puskesmas. The mother was asked to stay in the hospital, slept in a porch outside the baby's room:

"[I had to stay] outside the room, they said I must not leave because when the baby needed to be breastfed, we would have to enter only at the appropriate time. We could enter but had to leave afterward, not allowed to stay inside. Outside, we brought all the sleeping mats and bedding for two days." (Mother of a surviving LBW, gave birth in Puskesmas, the baby was admitted to a type C hospital, North Lombok)

A mother of a deceased LBW baby delivered in Polindes in North Lombok, and the baby was referred to a hospital without the mother, because she had Covid-19. The father was not allowed to get in the room (possibly a NICU room), only the aunt to visit the baby. After day 5, the mother came to provide breastmilk for the baby, yet when she came she was not allowed to see the baby. When finally the mother was allowed to come and see the baby, she was told to recite Qur'an, and soon after, the baby died.

There seemed to be lack of information given to parents about the reasons of them not allowed to participate in caring for their baby. However, sometimes mothers felt uncomfortable in caring for their baby/ies, due to assorted reasons, such as a mother in Nagan Raya:

"I kept pumping, and they were given breast milk through a tube. Three days after birth, they were given breast milk. Yes, because my breast milk supply was insufficient, I myself asked the midwife to give them formula milk (sufor)."

# -Incongruent information

Parents involved in this study seldom expressed concerns about receiving conflicting information from multiple health workers, especially those employed within the same health facilities.

Komunikasi satu pintu or appointing one person to provide information to the patients seemed to be one of the keys to avoiding confusion, as a mother of a surviving LBW baby elucidated. She was referred from one hospital to another due to the complication of her LBW newborn. When moved to the referral hospital, she realized that the hospital enacted several limitations, including from whom the parents can get the information about the baby:

"The baby had difficulty breathing. While in SIM Hospital, there was no improvement in their condition. There were times when they were not moving at all. In the NICU at ZA Hospital in Banda Aceh, we were not allowed to visit the child, and we could only see the doctor every two days, and if we had any questions, we had to go directly to the doctor." (Nagan Raya)

Having more than one source of information with more or less similar expertise might help parents in decision-making. But when those health workers consulted gave different suggestions, parents had to choose which one to follow. Mothers of surviving babies reported that information given by health workers at time was against one another.

A mother of a surviving full-term LBW baby in Deli Serdang described the differences between a doctor and a midwife that she consulted with:

"Yes, I was referred by Dr. J and given a referral letter for the operation at the hospital. After that, I returned to the midwife, and I told her about this. The midwife said, 'Just wait, usually the first child takes a long time [to be born].' We waited for a week, ma'am. We didn't go to the hospital because of the midwife's suggestion, so I walked more and moved around. When we checked on the second day, the cervix was dilated to 3 centimeters. But even after waiting for a week, there was no progress, and no contractions. The cervix remained at 3 centimeters. After that, there was no further dilation, and I didn't feel any pain. Finally, we went to the hospital with the referral letter from Dr. J, even though it had been a week, it was still valid." (Mother of a surviving LBW baby, hospital, Deli Serdang).

A mother in Nagan Raya described the inconsistencies of advice given by hospital doctor and the midwife she consulted.

"I told them I have diabetes, but during my pregnancy with Am [the LBW baby], my blood sugar was never high, so I didn't need insulin injections. Then the doctor asked, 'If it's not because of high sugar levels, why did you have excessive amniotic fluid? And who told you not to use insulin injections?' I replied, 'Midwife, because my blood sugar wasn't high,' that's how I answered." (Mother of a surviving LBW baby, hospital, Nagan Raya)

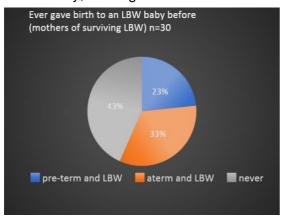
Or between the hospital midwife and the private practice midwife. For example, the hospital midwife did not allow the baby to be bathed, but when the baby came home, the village midwife bathed her although she was just five days old and hadn't gained weight velocity.

Regardless of the conditions informed, not everyone followed medical advice from health workers, like a mother of a surviving LBW in a Puskesmas in Deli Serdang,

"Yes, on the ultrasound, the doctor said that the foetal heart rate was no longer beating, and it had to be delivered immediately. The doctor recommended a caesarean section, but I did not want that. The labour process was fast, maybe because the baby was small."

Challenges Surrounding Low Birth Weight Babies from the Mother's Perspective

Mothers of LBW babies listed perceived causes of having LBW babies. Most mentioned pregnancy malnourishment, loss of appetite caused by certain conditions or sickness (hyperemesis, thyroid), and genetics (the families have small postures). None mentioned "4Ts" as the cause of low birthweight. Some of them nevertheless thought that they had tried their best in taking care of the baby during the pregnancy and did not really understand why the baby was LBW. Most mothers stated that LBW or small babies are not typical in their community, although health workers said otherwise.



Our participant data also showed that 34% of the mothers of surviving LBW ever delivered full term babies with LBW, 23% preterm with LBW. Only one mother in TTS and two in North Lombok had these surviving LBW babies as the first child.

Meanwhile, the majority of mothers of deceased LBW babies (73% out of 15 mothers) never delivered an LBW baby prior to this one. A quarter of the mothers had this deceased LBW baby as their first child. Among 15 mothers of deceased LBW baby participated in the study,

Ever gave birth to an LBW baby before (deceased LBW babies) n=15

20%
73%

pre-term and LBW

aterm and LBW

never

40% stated they did not have any health problems during the pregnancy.

Asthma, diabetes mellitus, and hypertension were often mentioned as complications the mothers had before and during labour, which caused them to have caesarean section, such as the two mothers of surviving LBW babies in Nagan Raya.

"Yes, because of my short breath, I was treated first, and then the C-section was performed. The

doctor said there was no other way; the operation had to be done." (mother of a surviving LBW baby, hospital, Nagan Raya)

"Yes, I had a C-section because I have asthma. I also had a C-section with my first child." (mother of a surviving LBW baby, Puskesmas, Nagan Raya)

When the ultrasound indicated the baby was small, mothers in Garut and Pamekasan were told by the midwives and doctors to have sweet food like ice cream, along with the normal nutritious food, such as vegetables, and fruit to improve the weight of the baby.

In TTS, mothers associated this LBW with stunting, because

"They told me that at the integrated health post (Posyandu), 'If the weight is not sufficient, it's stunting'"(mothers of surviving LBW babies, Puskesmas, TTS)

On some occasions, health workers seemed to mix common knowledge and traditional customs with information about evidence-based practices. Common advice given by the health workers across health facilities during the antenatal was for mothers to consume milk, vegetables, and fruits, or to pay attention to the diet. A health worker from Pamekasan advised a mother of a surviving LBW baby whose skin was scaly when we visited the mother.

"If you don't have money to buy baby oil, you can use homemade coconut oil, but not the commercial one. Coconut oil made from fresh coconut gratings is also good. In case sometimes you're worried that the store selling baby oil is closed, it's okay to use coconut oil, but make sure it's the real one, not cooking oil."

A doctor that assisted a mother of a surviving LBW baby in Deli Serdang said she needed to eat *ikan gabus* (Channa striata) to get the stitch wound dry faster.

In summary, the study revealed a diverse range of interactions and communications between parents of low birth weight (LBW) babies and health workers. The key attributes in these communications were empathy and friendliness, followed by the information provided. However, certain factors influencing communication styles and information delivery from the health workers' perspective still require exploration, including: (1) perceived power relations, contingent on factors such as the socioeconomic status of patients; and (2) health workers' assessments of conditions, encompassing the psychological state of the mother or caregivers and the baby's health.

In general, parents demonstrated a willingness to actively participate in caring for their babies and engage in decisions regarding referral processes, or at the very least, be informed about impending procedures for their infants. In Puskesmas, active participation in baby care was more feasible due to uncomplicated baby conditions, enabling them to stay in the same room as the mother. Conversely, at the hospital, various factors discouraged parental involvement in baby care, including the lack of facilities to accommodate caregiver at the hospital and perceived gender-based norms that hindered fathers from entering the NICU.

# Respect, protection, and fulfilment of newborn rights

Newborns' rights are respected, protected and fulfilled without discrimination, with preservation of dignity at all times and in all settings during care, transport and follow-up.

One of the immediate rights of a newborn is indiscriminate access to health care. With the universal health coverage readily imposed in some districts, there was an effort to ensure that newborn children can immediately access health care without financial barriers. BPJS-K has a policy in place to cover newborn care for free up until 28 days after birth, while the parents are processing the necessary documents to include the newborn in their family coverage. In Lombok, there was staff from the Civil Register Office stationed at the Puskesmas (and hospital) to ease the process of producing a birth certificate. The birth certificate could then be used to update the family card so that the newborn would be covered in JKN. The study observed that no newborn had been denied access to health care or that the parents were hurdled with administrative requirements prior to care.

However, oftentimes, parents and caregivers questioned the commitment of healthcare providers to protect and fulfill the newborn rights to survival and health. A father of a deceased LBW in Pamekasan saw the baby was not put in an incubator, but only on a bed, without any explanation. The mother was so sad, asking about it all the time.

"And then the baby passed away on Tuesday, Ma'am. What's sad is, Ma'am, if the baby's condition was already serious, why was the baby placed in the regular area? If she/he a real doctor, she/he must know, Ma'am..." (Mother of a deceased LBW baby, type C hospital, Pamekasan)

A TTS family worried about their struggling LBW baby in a hospital, while there were no health workers available to help although they had tried to find them for hours. The baby stayed for more or less six hours in the ER, and there was still no room available for him.

"Hospitals have many patients, right, Doctor? One patient enters, and then there's another one. But at that time, I don't remember what time it was, from when the baby cried until there was no sound. No staff noticed it. I told my husband to go report to the front. He went several times, and it was only in the evening that there was an operating room staff. My husband was running around, saying, 'Please, the baby was crying, and now there's no sound." (Mother of a deceased LBW baby, type C hospital, TTS)

"The baby's breathing stopped in the Emergency Room (IGD) because there was no room that we could move to. When the time reached 3 p.m., they said we would be moved to a room at 5 p.m. At 5 p.m., they said it would be at 7 p.m., and at 7 p.m., they said the room would be available at 9 p.m. But the baby didn't make it." (Mother of a deceased LBW baby, type C hospital, TTS)

The abovementioned experiences showed that equal access to care did not automatically mean that the parents and caregivers felt there was sufficient information or explanation given to them while accessing care, in other words, rights to information. There's also a chance of healthcare providers breaching parents' right to privacy and confidentiality. Eg and Jensen explored the challenges healthcare providers in Denmark faced in maintaining patients' confidentiality and privacy, and identified where, with whom, and how much information they communicate as one of the challenges.

The case of a niece who got the information that was supposed to be for the parents in Garut in the previous section is one example that we need to scrutinize. Who decided to inform the niece, instead of the father, or who judged the father as too weak to hear the news were yet to explore.

A mother of surviving LBW who gave birth in a type C hospital in Garut said that although the healthcare providers' staff were commonly friendly and polite, they never gave her any advice regarding how to care for the baby at home directly. It was the *kader* that the doctor talked with.

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<sup>82</sup> Eg, M., & Jensen, C. S. (2023). The challenges of maintaining patient confidentiality in pediatric settings. *Journal of Pediatric Nursing*, 69, 18–23. https://doi.org/10.1016/j.pedn.2022.12.022

"No, the doctor told the community health worker (kader)." (Mother of a surviving LBW, Type C hospital, Garut)

Limited studies on privacy and confidentiality in healthcare service were found in Indonesia. Kim et al. who studied communication patterns between Family Planning providers and clients fifteen years ago identified that privacy was not a top priority among FP clients. They are concerned more about making other patients queue longer. The latest study by Pratiwi et al..<sup>83</sup>, on the other hand, found that for Puskesmas patients, privacy means secrets not to be told to other people, including information in the medical records. This is mainly to avoid shame and judgment on certain medical conditions seen as breaching the community norms. Pratiwi emphasized that the need for privacy is mainly toward neighbours, family, and people who are close to the patient. Choosing health workers of the same gender is also considered as an intuition about having a secure feeling of the patient's privacy.

Another issue in health worker-patient relations was their power over the patient, which seemed to be based on their expertise. A mother of a surviving newborn LBW referred to a hospital told us about her conversation with a doctor, which the doctor's harsh comments made *her feel awkward*.

"At that time, I had a high fever and was referred to the hospital after visiting the community health center. Then, the doctor examined me with an ultrasound and recommended surgery. I was worried because it was not yet full-term, so I asked the doctor again. Instead, the doctor said, 'Do you understand, even if I say it needs to be removed, it will be removed, even if it's [the baby] only 1 month [old]. Otherwise, it will affect the baby later,' that's what the doctor told me." (Mother of surviving LBW, Puskesmas, Nagan Raya)

Another mother described her conversation with a doctor when she wanted to get discharge against medical advice.

"And the doctor said, 'If you want to take Ameena home, are you sure you can take care of her? There are many things to consider. In the hospital, we bathe her once or twice a day, you must keep her warm, no exposure to cold, and avoid cigarette smoke, and so on.' At first, I had doubts, but in the end, I was sure I could do it. Thank God, I was able to." (Nagan Raya)

Without hearing the intonations and facial expressions of both the doctor and the mother involved in this conversation, it is difficult to judge manners and ethics. But because this section discusses the experience of care, we relied on parents' and other caregivers' judgment on the healthcare providers' treatment.

a qualitative study in Indonesia. Frontiers in Medicine, 9(October), 1–12. https://doi.org/10.3389/fmed.2022.915237

Pratiwi, A. B., Padmawati, R. S., & Willems, D. L. (2022). Behind open doors: Patient privacy and the impact of design in primary health care,

Another newborn right is to have access to exclusive breastfeeding, when possible. Unfortunately, this was not something that is recorded appropriately. The study found that although this was recorded quite regularly at the hospital level, this was not the case at the primary care level.

Table 23. Coverage of Exclusive Breastfeeding

				strict				
Coverage	Year	Nagan Raya	Deli Serdang	Garut	Pamekasan	North Lombok	TTS	
% Early	2020	79	69,6	95,8	65,6	N/A	87,1	
Initiation of	2021	87	68,5	88,9	66,3	N/A	85,4	
Breastfeeding	2022	70	65,4	91,1	74,2	N/A	83,5	
0/ Evelueive	2020	57	39,9	45	68,7	N/A	79,1	
% Exclusive	2021	52	40	74	86,6	N/A	78,3	
Breastfeeding	2022	15	37,2	68,5	57,3	N/A	82	
LBW neonates	2020	123	23	1330	135	N/A	N/A	
admitted in the	2021	199	106	1009	111	205	N/A	
hospital	2022	155	122	1101	145	16	200	
% LBW with	2020	52,8	100	N/A	41,5	N/A	N/A	
exclusive	2021	35,2	100	N/A	38,7	65,4	N/A	
breastfeeding when discharged from hospital	2022	36,8	100	N/A	46,2	N/A	N/A	
LBW neonates	2020	0	0	0	0	5	105	
admitted in the	2021	0	1	2	0	5	128	
Puskesmas	2022	0	16	2	0	32	158	
% LBW with	2020	N/A	0	0	N/A	0	100	
exclusive	2021	N/A	100	0	N/A	0	100	
breastfeeding when discharged from Puskesmas	2022	N/A	100	0	N/A	0	100	

N/A - data not available or unable to calculate

In summary, the study suggested that no LBW baby was denied in the fulfilment of their rights to access healthcare. However, with regards to breastfeeding, apparently not all LBW baby received this right or at least not exclusively. This was consistent with studies that found that there were many barriers for exclusive breastfeeding for LBW babies, despite evidence of the

positive result of exclusive breastfeeding for growth of LBW babies (including preterms).<sup>84</sup>. Further descriptions on the practices of exclusive breastfeeding would be provided in the next sections. Protection over confidentiality and privacy was also lacking, although a further exploratory study might be needed in this aspect. This underscores a deficiency in providing information to parents concerning the rights of newborns. Uninformed health workers and parents may inadvertently violate these rights by adopting methods perceived as practical.

### Emotional, psychological, and development support

All small and sick newborns are provided with family-centred developmental supportive care and follow-up, and their families receive emotional and psychosocial support that is sensitive to their needs and strengthens their capability

Where were the LBW babies born?

Significant attention was devoted to comprehending the maternal care experiences during childbirth, encompassing not only material aspects but also emotional and psychological support needed by mothers. Our investigation revealed that, despite endeavours to meet the specified criteria aimed at mitigating maternal and neonatal mortality rates, there persisted instances where mothers opted for assistance from traditional birth attendants or a health worker. The decisions in such cases were largely influenced by the perceived support and comfort experienced by both mothers and their families, with some actively choosing traditional birth attendants, or *Polindes* for this reason.

# Childbirth assisted by a traditional birth attendant

Permenkes 97/2014 required childbirth to be done in a health facility. An authorized midwife, however, was still allowed to assist labour outside health facilities, in case the health facility was inaccessible to pregnant mothers. The latest Permenkes 853/2021 restated those regulations in article 16, that childbirth should be done in a health facility, assisted by one medical doctor and two health workers (midwife and/or nurse).

In the early 2000s the GoI had started to shift the role of traditional birth attendance (TBA) from the primary childbirth assistant into a midwife's partner in providing care to mothers and babies through *Kemitraan Dukun Beranak dan Bidan* program. Studies conducted a decade

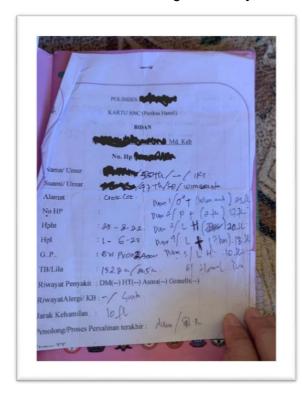
<sup>&</sup>lt;sup>84</sup> D Singh, N Devi, TSR Raman , Exclusive breast feeding in low birth weight babies, *Medical Journal Armed Forces India*, Volume 65, Issue 3, July 2009, Pages 208-212. <a href="https://doi.org/10.1016/S0377-1237(09)80004-X">https://doi.org/10.1016/S0377-1237(09)80004-X</a>

Juharji H, Albalawi K, Aldwaighri M, et al. (December 24, 2022) Impact of Breastfeeding on Low Birthweight Infants, Weight Disorders in Infants, and Child Development. Cureus 14(12): e32894. doi:10.7759/cureus.32894

ago showed variations in the results of the Kemitraan Dukun Beranak dan Bidan (e.g., Budiyono, et al., 2011.85, Nanur et al., 2016.86).

We identified one mother in North Lombok who delivered an LBW baby with help from a *belian* (TBA in North Lombok's local language). Her assertion reflected the respected position of TBA in the community, in line with the findings of Febriana (2018).<sup>87</sup>.

"At 10 o'clock, I felt unwell and immediately called a traditional healer. [Has the healer been trained?] He often performs deliveries. Traditional healers have been around for a long time, even before there were doctors. The healer has a lot of experience." (A mother of a surviving LBW baby, Puskesmas, North Lombok)



In accordance with that, we also met an LBW baby in Pamekasan who was the sixth child of the family, but the first one whose birth was assisted by a midwife.<sup>88</sup>. The same story was also found in TTS. This finding reemphasized the trust people still have to TBA.

Another story about the involvement of a paraji (TBA in Sundanese) was found in Garut. Different from North Lombok, the paraji did not directly assist the mother's childbirth in delivering the baby,

"Indeed, the [traditional healer] just comes to the [midwife's place], already knowing that someone is about to give birth. In our [region], it's said that the [traditional healer] has already been to the midwife. 'It's about this far along,' they say, and only then do

they go to the midwife." (Mother of a deceased LBW baby, Polindes/PMB, Garut)

The *paraji* usually helped care for the baby and mother: massaging the mother and bathing the baby. She mentioned that the entire body of the mother, with a special emphasis on the uterus, should also be massaged as it plays a crucial role in supporting the baby.Likewise, a mother in Deli Serdang received massages from a dukun, not only for her baby but also for

<sup>85</sup> Budiyono, Suparwati, A., Syamsulhuda, Nikita, Adrian. Kemitraan bidan dan dukun dalam mendukung penurunan angka kematian ibu di puskesmas Mranggen I Kabupaten Demak. Media Kesehatan Masyarakat Indonesia. 2011; 11(1).

<sup>&</sup>lt;sup>86</sup> Nanur, F. N., Widarini, N. P., & Karmaya, I. N. M. (2016). Kemitraan Dukun dengan Bidan dalam Pertolongan Persalinan: Studi Kualitatif di Kabupaten Manggarai Timur. Public Health and Preventive Medicine Archive, 4(1), 23–28. https://doi.org/10.15562/phpma.v4i1.52

<sup>87</sup> Febriana, L. L. R. (2018). Kajian Perawatan Bayi Suku Sasak Di Dusun Sade Lombok Tengah. 1–141. http://lib.unnes.ac.id/32424/1/1601414105.pdf

<sup>&</sup>lt;sup>88</sup> The LBW baby's five older brothers-sisters were born with help from a *dukon rembik* (TBA). This supports health workers' assertion that people are still reluctant to come to health facilities. Our team also met one village midwife whose practice was suspended for 7-month as a punishment for assisting partum at her Polindes/private clinic from IBI. According to the midwife, the mothers who came were in the last stage of labour and urged to give birth, therefore she helped the delivery at her place, instead of referring them to Puskesmas as required. She repeatedly said she rejected a number of pregnant mothers who came to her for help because she felt afraid of getting another punishment from the association. In Pamekasan, mothers admitted that they gave birth at the Private Midwife Clinic in the neighbouring village, after being rejected by their own village midwife to give birth at the Polindes.

herself after giving birth to her first child. She reported feeling her stomach settling and experiencing overall improvement after these massages. This role of *paraji* as an assistant of midwife remained the same from the partnership promoted two decades ago.

However, the majority of our informants had childbirth in some type of health facility: Polindes or private midwife practice/clinic, Puskesmas and hospital. Depending on the local government policy and capacity, some might have an initiative to have maternity waiting homes readily available to support those who live far away from the health facility to ensure access, as the expecting mothers and their family could stay in the maternity waiting homes when it is nearing the due date. Lombok Utara had three maternity waiting homes: in Tanjung (near the hospital), in Gangga and in Kayangan (both near the Puskesmas). Though, except in Kayangan, according to the health office the utility rate was low.

#### Childbirth at Private Midwife Clinic or Polindes

Mothers delivered the LBW baby at private midwife clinics and/or Polindes in four out of six Kabupaten where we did our study (Pamekasan, Garut, North Lombok, and Deli Serdang). Most of mothers and caregivers depicted the urgent situation faced, usually a sudden and fast (precipitous) labour process, that disabled them from traveling far to Puskesmas or private maternity clinics.

One of the surviving LBW babies we visited in Pamekasan was reported to be born in a nearby private midwife clinic, due to precipitous labour. Nevertheless, as suspected by some health workers, the delivery at the Polindes may have resulted from a combination of the mother or family's hesitancy to seek hospital referral and the health worker's potential financial gain from facilitating the delivery.

A few mothers openly said that they chose to give birth in private midwife clinics because of their familiarity with the midwife. However, apart from parents' and caregivers' positive experiences with private midwife practice/clinics, staff of healthcare providers complained about the lack of attention on data from private midwife clinics that made it difficult for them to refer a patient:

"In Midwife's private practices sometimes, there were no recorded data, so it was difficult for us to determine: which trimester was this woman already in?" (Midwife Coordinator, Puskesmas, Pamekasan)

#### **Childbirth at Puskesmas**

In TTS, all mothers of surviving LBW babies gave birth in Puskesmas. They chose Puskesmas because the village midwife who has been caring for them during the pregnancy works there. Being assisted by health workers who are already familiar with them makes them feel comfortable. A mother who used to give birth with help from TBA and just delivered an LBW

baby in a modern facility (Puskesmas) for the first time said that it brought a different feeling for her because there were "many people helped, many people observed".<sup>89</sup>.

Many surviving LBW babies in North Lombok were also born in Puskesmas, as advised by village midwives, to anticipate problems that might happen in the process of childbirth. Related to this suggestion, for some labouring mothers Puskesmas was like a transit place between Puskesmas network (Polindes or private midwife clinics) and the hospital. Whenever possible, they would still be referred to the hospital. For example, a mother of an LBW baby in Garut clarified that since she was pregnant with a twin, the midwife told her to give birth in Puskesmas.

"Because they're twins, if you go to a midwife, she can't handle it." (Mother of surviving LBW, Puskesmas, Garut)

She further explained that she was about to get referred to the hospital, but one of the twins' heads had come out already, so that was the real reason for her to deliver in the Puskesmas. In Pamekasan, two mothers of surviving LBW babies gave birth at two different Puskesmas, and they were already in the last stage of labour when arrived.

"It wasn't like that... [Initially], they motivated me to be referred to the hospital because the baby's weight was low, but when I arrived at the Puskesmas, I was already dilated to 8 cm, so there was no time for the referral." (Mother of a surviving LBW baby, Puskesmas, Pamekasan)

The other mother who worked as a fish seller got PROM when she was in the market, and was immediately taken to the Puskesmas where she gave birth to the baby. The Puskesmas staff in Pamekasan emphasized that –related to mothers' preference to give birth at the Polindes/private midwife clinics-- a lot of mothers were anxious to deliver the baby at the Puskesmas, because of the over-the-top likelihood of being referred to the hospital.

Mothers whose childbirths were done in Puskesmas tended to get discharged shortly, some even within a day. Some went home without the baby/ies, because the baby/ies had complications and thus got referred to the hospital. There was also an example that the LBW baby was discharged immediately along with the mother in North Lombok, but then the baby got jaundice and hospitalised two days later for phototherapy.

## **Childbirth at Hospital**

Overall, the LBW baby's mothers (both deceased and surviving) gave birth in hospitals, from type D (usually private hospitals in a Kabupaten) to type B (the highest referral public hospital at the city level). They were formally referred or informally suggested to give birth at the hospital by health workers at the lower-level health facilities (Puskesmas and its network), where they initially consulted during the antenatal.

 $<sup>^{89}</sup>$  In Puskesmas, delivery should be helped by three health workers to meet the six-hand regulation.

Mothers of low birth weight (LBW) infants in Nagan Raya predominantly delivered in hospitals, specifically in SIM (Nagan Raya) or ZA (Banda Aceh), without the need for a formal referral. Some reported that the midwives overseeing their antenatal care advised direct hospital visits instead of utilizing Puskesmas services. This practice was influenced by the Provincial government's policy, which incorporates Jaminan Kesehatan Aceh (JKA) alongside the national coverage provided by *Jaminan Kesehatan Nasional* (BPJS K). The accessibility of hospitals without a referral letter is facilitated by the presence of JKA, thereby bypassing the constraints imposed by the zoning system.

#### Parents' first reactions to LBW infant

As previously mentioned, most of the parents knew that the baby had low birthweight after the baby was born. Only some of them knew it during the pregnancy from the Ultrasound. However, either because the healthcare facilities' staff inaccurately read the Ultrasound images (due to their capacity) or the low quality of the images, the prediction was found inaccurate,

"At the time of the ultrasound with the doctor, the baby was estimated to be around 3.3 kilograms, but when born, the baby weighed 2.3 kilograms, so the baby was placed in the NICU. He went in there right after his birth. Just one day later, he joined the other babies." (Mother of surviving LBW, Puskesmas, Deli Serdang)

This inaccuracy brought problems to some mothers across Kabupaten:

"Yes, disappointed and sad because before, the baby looked perfectly fine in the ultrasound." (Mother of a deceased LBW baby, hospital, Deli Serdang)

"When we had the first ultrasound, we didn't know that there were two babies. It was only when I was about to give birth that they did another ultrasound. The midwife said, 'There are two babies, ma,' and my blood pressure immediately went up." (Mother of surviving LBW, Type C hospital, Garut].

"[Did you tell your mother or husband that the baby was small?] I didn't dare to tell them because my body was carrying large, but the baby was small. During the ultrasound, only one was visible, but when they were born, it turned out to be twins. The doctor and the integrated health post (Posyandu) also said it was only one."(Mother of a surviving LBW baby, Puskesmas, North Lombok).

One mother of a surviving LBW baby was even forced to deliver the baby (by induction) in a type B hospital in Pamekasan because the baby was diagnosed as stillbirth based on the ultrasound result, but it turned out the baby was alive with LBW when born.

90 Ultrasound is not a pre-requirement in Puskesmas in all districts, thus having (or not having) an Ultrasound exam, or having it in the Puskesmas or other healthcare facilities is a matter of personal choice, with a plethora of reasons, such as the availability of fund and KIS/BPJS ownership. "[saya] tidak USG. Disuruh USG, karena faktor keuangan, BPJS tidak ada jadi harus bayar", said a mother from TTS. Some of the mothers in TTS owned KIS (Kartu Indonesia Sehat), and they did not have to pay if they had ultrasound in a Puskesmas. However, the service was not available in Puskesmas because even if the Ultrasound equipment was there, there was no staff to operate it. In some districts, including TTS, mothers went

In other cases, there was some regret about trying to quickly refer the mother to give birth in the health facility. Mother of a deceased LBW baby in Pamekasan told us that sometimes they regret having the baby directly referred to hospital because the grandparents might not have the chance to see their newborn until it was too late (i.e., the baby died).

"Had we known, we should have just brought the baby home right away. My mother-in-law is so sad because this is her long-awaited first grandchild." (Mother of a deceased LBW baby, Type C hospital, Pamekasan)

Our study found that giving birth to a baby with low birthweight caused mixed emotions among mothers. Parents (mothers and fathers) felt shocked, and sad to find out their baby had low birth weight. Some of the mothers cried, feeling worried and scared because the baby was taken away from them to stay in NICU, and not seeing them for days. And yet they were still rejoicing, as a part of religious belief, people tend to be thankful even for disastrous experiences.

"I'm happy, even though [the baby] is small, it's okay, what's important is the baby was born safely." (Mother of a surviving LBW baby, Puskesmas, North Lombok)

Some of them reported to feel sad, not only because of the baby's low birthweight, but on top of that they were not able to see the baby right away.

"I'm sad, you know, when I had just given birth, I wasn't allowed to see [the baby] right away; they were placed in the NICU." (Mother of surviving LBW, type B hospital, Pamekasan)

## Parents' mourning and grief for losing their babies

Parents experienced profound mourning and grief upon losing their baby or babies. In some instances, mothers never had the opportunity to see their infants again after giving birth, as the newborns succumbed to mortality when the mothers were unable to visit them. The mother of a deceased LBW baby in Pamekasan told us that sometimes they regret having the baby directly referred to the hospital because the grandparents might not have the chance to see their newborn until it was too late (i.e. the baby died) and blamed the mother, instead of providing emotional and psychological support to the mourning parents,

"Some of my family members blamed me for this. If we had known [that the baby was in a serious condition], why didn't we just bring the baby home right away? We hadn't even held the baby yet. My mother-in-law was really sad about it, Ma'am, because this was her first grandchild, the one she had been eagerly waiting for." (Mother of a deceased LBW baby, type C hospital, Pamekasan)

In contrast, a mother in TTS remained by her baby's side throughout his struggle until his eventual passing. She openly expressed her grief while earnestly attempting to come to terms with the situation.

"We didn't have a premonition. At that time, the doctor asked, and I said, 'Doctor, I have come to term with it (ikhlas)." (Mother of a deceased LBW baby, type C hospital, TTS)

Family support usually had a positive impact on the parents, especially the mothers. For example, in Deli Serdang, the extended families came to support the mother who was about to give birth. But there were times when support from family (and relatives) potentially inhibited the process, as reported by a health worker:

"When it was time for childbirth, and we informed them about the likelihood of the baby being Low Birth Weight, how should we guide them educationally? Numerous family discussions ensued, involving everyone, Ma'am." (Staff of a Puskesmas, Pamekasan)

### Readiness to care for the LBW infants at home

Asked if they were ready to take care of the LBW at home, parents' responses varied. Some said they were ready, some said they were still confused. When coming home, one of the mothers in North Lombok felt afraid if anything bad happened. Another felt anxious and worried about the baby having another seizure. But she has already been told if there's a seizure problem with the baby, she needs to go to the Puskesmas and the Puskesmas will refer them to the hospital, in addition to the medicine for the seizure.

"I was just confused, not knowing how to take care of them. The older one was bigger, so it was a bit simpler. I didn't know what it's called, whether it's premature or something, and I was afraid." (Mother of a surviving LBW baby, type B hospital, Deli Serdang)

In Pamekasan, both fathers and mothers that participate in this study reported that the most important and popular advice from health workers across health facilities in taking care of the LBW babies at home was <u>not to bathe them</u> until their weight reached 2.5 kgs. The same message was also found here and there across health facilities and district, but unlike in Pamekasan, not all healthcare providers warned parents and caregivers not to bathe the baby.

Controversies arose between the recommended and actual home care practices in Pamekasan, potentially causing confusion for parents who may opt for easier and more practical approaches. The first one is on exclusive breastfeeding. The LBW newborns consumed formula since they were in the health facilities. Parents were told that breastmilk was not sufficient to increase baby's weight so formula was needed. Two fathers interviewed chose different formula brands for their babies, depending on the budget and purchasing access. One of them gave SGM 06 formula that actually is not for babies under 6 months old, moreover an LBW. But working as a fisherman he could not make a lot of money so they could only buy formula at a lower price. The other father gave Lacto BBLR to his LBW baby.

The second one was the use of an incubator for LBW babies at home. Puskesmas staff mentioned that the majority of village midwives bought a quite cheap incubator (more or less 750 thousand rupiahs, in local medical supplies and equipment stores) and they lent the incubator to each other when mothers in their areas gave birth prematurely or to a LBW baby.



One Puskesmas' data showed that in 2023 almost 90% of the LBW babies are twins, therefore the families need at least two incubators. The village midwife usually helped by borrowing an incubator from her colleagues. Fathers said that they were told to put the LBW baby in a room with bright lights without knowing the reason and the specifications of the lights. One of them used 5 watt (dop lamp) and the other used 30 watt (LED

lamp). Some mothers reported that KMC was practiced a day before the discharge, and only one of them practiced in the car on the way home from the hospital. The rest have never done KMC at home. In our discussion with the mothers, almost none mentioned that the village midwives asked whether they practiced KMC at home or not.

In a casual conversation, the fathers strongly advised us to: "Remember, we don't only need to save money, but we need to earn money" implying that there is little opportunity to practice KMC at home. This actually highlighted lack of information given to parents regarding newborns' rights.

### Supports received following discharge from health facilities

The capacity of mothers and families to care for low birth weight (LBW) babies is crucial, as it hinges on the knowledge, mental preparedness, and proficiency in baby care skills they possess. Family and environmental support was also very important to increase the ability and confidence of mothers in caring for babies, especially <sup>91</sup> . Therefore, the role of health workers in providing sufficient knowledge and support to the parents and family with LBW babies were crucial, starting from the time when the baby is still in the hospital, discharged and post- discharged. This responsibility should not lie on the midwives alone. Experience in other country has shown that multidisciplinary approach in promoting lactation <sup>92</sup> should be encouraged. <sup>93</sup>Correct information about LBW care both during childbirth and on their return to the hospital from a health worker in charge of the community would increase the level of maternal knowledge. Visits by community health workers had been shown to increase the interaction and communication of mothers and health workers so then they are able to solve

<sup>&</sup>lt;sup>91</sup> Sisk, PM. , Lovelady, CA., Dillard, RG., Gruber, KJ. Lactation counseling for mothers of very low birth weight infants: effect on maternal anxiety and infant intake of human milk, Pediatrics, 2006;117 (1). Available at: www.pediatrics.org/cgi/content/full/117/1/e67

<sup>92</sup> Bixby, C., Baker-Fox, C., Deming, C., Dhar, V., Steele, C., A multidisciplinary quality improvement approach increases breastmilk availability at discharge from the neonatal intensive care unit for the very-low-birth weight infant. *Breastfeed Med*, 2016;11(2):75-79

<sup>93</sup> Horowitz, J. A. et al. (2013). 'Nurse home visits improve maternal/infant interaction and decrease severity of postpartum depression'. JOGNN - Journal of Obstetric, Gynecologic, and Neonatal Nursing, 42(3), pp. 287–300. doi: 10.1111/1552-6909.12038

any baby health problems well, especially in the first month. Home visits enabled the mother to adapt more quickly to the situation after childbir. Home visits enabled the mother to adapt more quickly to the situation after childbir.

Home visit for neonates was mandated through *Peraturan Menteri Kesehatan Republik Indonesia Nomor 25 tahun 2014 pasal 10 ayat 1 dan 2* regarding essential neonatal care, and specific to LBW infants one of the mandated function of essential neonatal care is to ensure the use of KMC. Home visits were mandated at least once when the baby is between 3-7 days old, and another time is when the baby is between 8-28 days. The result of the home visits monitoring was supposed to be recorded in the KIA book (in LBW infants case, the KIA book for small babies). However during conversation with mothers with LBW infants in our study, not all parents and caregivers mentioned the home visit.

Our study found a variety of information regarding home visits. The Puskesmas relied on village midwives to do the home visit. In Pamekasan, village midwives we met in one Puskesmas said that they visited LBW babies every day until at least they reached weight velocity. However, not all mothers supported the statement. Some said they were visited only on the 5<sup>th</sup> day or a week after coming home. Some were checked through WhatsApp messaging.

In North Lombok, for LBW babies, the village midwife regularly visited the mother and the infant throughout the period of 28 days to monitor the weight and growth, or until the infant reached a normal weight. In Garut, the timing of a village midwife's home visit varied, starting from 3 days post-discharged, and then 1 week after that, or 2 weeks post-discharged.

"One time, the day after I came home..." (mother of surviving LBW, Type C hospital, Garut)

The treatments administered by village midwives typically involved monitoring the baby's conditions, but some mothers could not provide detailed elaboration.

"[the midwife] Check whether [the umbilical cord] it's already dry or wet, whether the body is swollen, check the blood pressure, and see if there's any pain at the stitches." (mothers of surviving LBW baby, Garut)

"The baby was visited three times by the midwife. She was weighed and checked." (a mother of surviving LBW baby, hospital, Nagan Raya)

A mother in Nagan Raya counted the number of home visits a village midwife did, as well as what she did during the visit: how to care for cuts from caesarean section, KMC, how to breastfeed, how to take care of the baby's umbilical cords. In North Lombok, mothers

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<sup>94</sup> Schönbauerová, A., & Boledovičová, M. (2015). The role of paediatric nurse in home visiting of newborns and infants in the past - Literary survey. Kontakt, 17(4), e211–e218.

acknowledged that there was a village midwife who came once every three days, she taught the mother to do KMC, and practice KMC on the way to the referral hospital.

Similar to the ANC setting, the use of WhatsApp as a communication method is prevalent throughout Kabupaten, especially in more urbanized areas. Mothers frequently consult with midwives via WhatsApp to discuss various issues concerning the baby.

"Almost everyone has it. Those who have babies or toddlers join the group and [they have] the midwife's number. You can consult and join the group. For the first time, sometimes if the baby had a fever [you can ask] what's the first aid?"

"The midwife, when she knows you're pregnant, immediately adds you to the group. In that group, you mostly get information about the yandu (integrated health post) schedule, and you get the most information."

A mother in Nagan Raya said,

"I want to be visited frequently, but the midwife is really close, so if there's anything, I can just message her on WhatsApp." (a mother of surviving LBW baby, hospital, Nagan Raya)

• Community support and responses to LBW babies and mothers

In some communities, having an LBW baby is not seen as a shameful condition or a taboo. A mother of a surviving LBW baby in TTS said LBW babies are common in her area. Similarly, in Pamekasan,

"In my village, Ma'am, if a baby is born with Low Birth Weight, it's not considered a dangerous thing. In our village, it's quite common, across generations, many of them are premature and small. So, LBW babies are not considered taboo or dangerous in my village." (Village midwife, Pamekasan)

Indonesians are known to pay a visit to show their care and respect for others, including visiting newborns. A mother in North Lombok told us:

"Many relatives came to visit, but the baby was not allowed to be seen while sleeping in the room, and they couldn't be exposed to the wind because the baby was small." (mother of a surviving LBW baby, Puskesmas, North Lombok)

In Garut, when arrived home, the baby was usually put at the centre of the house waiting for relatives and friends to pay for a visit.

Mothers who came home without the baby were asked by people who paid a visit at home, which made them feel a little discouraged.

"I wanted to go home together with the baby, but it wasn't possible, you know...

Some relatives that came, asking where the baby was." (Mother of a surviving LBW baby, hospital, Garut)

As mothers interacted in the communities, they started to receive information about traditional customs in caring for babies. In Deli Serdang, a mother of a surviving LBW baby got information from:

"For example, if someone comes to visit, they would tell us how to take care of the baby, 'If the baby cries, let her/him cry for a bit to strengthen their lungs.' But sometimes, you know, I feel sorry when the baby cry, so I sometimes just pick them up." (Mother of a surviving LBW baby, Puskesmas, Deli Serdang)

Our study participants in Garut and Nagan Raya mentioned at least two major traditions to follow: (1) not to go out before reaching 40 days, and (2) the baby must be wrapped in a cloth before reaching a certain number of months (*dibedong*)

A coordinator midwife explained that in Nagan Raya people have a certain belief that:

"The community here has a myth that if you're pregnant and it's not yet past 7 months, you shouldn't prepare things like diapers, clothes, and others." (coordinator midwife, Puskesmas, Nagan Raya)

Therefore, parents of premature babies typically had not prepared anything for the baby, not even a *popok* (diaper). Another mother in Nagan Raya said she was also told not to drink much, in addition to the 40-day restriction to go out. She also reported that her baby was wrapped for almost two months.

Nutrition intake: formula vs. breastfeeding

Exclusive breastfeeding emerged as a prominent topic in this study, other than KMC to keep the baby warm, encompassing all three standards in the experience of care.

Other than in Pamekasan, information about formula consumption to increase the baby's weight was also found in all Kabupaten, from parents and other caregivers, be it the mothers who delivered the baby in private or public health facilities, primary or referral. Formula consumption started when the baby was still in the health facility, and usually was continued to be given at home. Brands mentioned includes Lacto BBLR, SGM, BMT, and Chil-go.

Some mothers said that they brought the formula from the health facility home. A mother in Deli Serdang explained that her breastmilk was only produced the first three days.

"Yes, I produced a lot of breastmilk. But I do not know why it stopped. The baby refused to be breastfed because the nipples were inverted so it was difficult for him to suck, and then when he's thirsty he becomes impatient." (Mother of a surviving LBW, hospital, Deli Serdang)

A mother from Deli Serdang suspected that the doctor's gender might be the reason why she was not told about how to breastfeed and KMC:

"He didn't provide information like that, because the doctor was a man. He just told me that for follow-up appointments, I could go to the hospital or his private practice."

Slightly different from other parents, a mother in North Lombok was not advised to give the baby formula, but

"I was told to breastfeed, and it had to be a lot. I was also told to take pills to stimulate breast milk production, and to eat a lot. They told me to sunbathe the baby for 10-15 minutes." (mother of a surviving LBW baby, Puskesmas, hospitalized, North Lombok)

A mother who gave birth to a surviving LBW baby in a private midwife clinic in Deli Serdang told us that she was not counselled at all:

"They didn't give any information because when I went home, the midwife wasn't there. Only her assistant was there, but she didn't provide any instructions for breastfeeding."

Breastfeeding practices vary among mothers. Some breastfeed every two hours, 1.5 hours, and the length of the breastfeeding session depends on the baby. Mothers reported various ways to improve breastmilk production: *kelor* (*moringa* leaves) North Lombok, or peanuts from TTS.

Mothers of twins usually found it difficult to breastfeed the two babies simultaneously if both were hungry. A caregiver/family member of a surviving LBW baby said:

"Just take turns, it is easy. One of them is usually given formula milk (sufor) first, and sometimes she breastfeeds the twins together."" (caregiver/family member of a surviving LBW baby, Puskesmas, Garut)

Or when both babies cried.

On the other hand, in North Lombok, the mother was encouraged to supply the baby (who stayed in the hospital) with daily breastmilk, "to strengthen the baby, that's why we send [pouches of breastmilk] every day."

### Keeping the baby warm

There are several ways to keep the baby warm as described by study participants, from soaking the baby under the sun as a natural phototherapy, using a lamp when the baby is inside, bathing the baby when the air temperature gets warm, *dibedong* (wrapped tightly in a clothe), to lastly, being held by an adult, which some said must be done by the parents. In North Lombok, the use of *minyak* (ointment) is very common. One mother was told to put *minyak telon*, the other put rempah kelapa parut before bathing.

While we found many mothers not receiving appropriate counselling and guidance in KMC and breastfeeding, one mother who gave birth in a type D private hospital in Garut reported receiving a full explanation about KMC and had an opportunity to practice it with a carrying cloth or wrap, while the others did not. She was also told to be cautious when using a lamp to warm the baby because it might damage the skin.

We also found various sources of information for mothers after they came home, from the mother's mother, mother-in-law, neighbour, to traditional birth attendant. A mother of a surviving LBW baby said she was not counselled about how to care for the baby at home at all. So, her source of information was her mother-in-law:

"[The one who taught] was my mother-in-law. If the baby pees, change the diaper; if they poop, change it; bathe them, sometimes bathe them two or three times with regular water, and they were told to be sun-dried. When it comes to breastfeeding, my mother-in-law taught me." (mother of a surviving LBW, Puskesmas G, North Lombok)

In Garut surviving LBW mothers who gave birth in Puskesmas dan type D/C hospital were told to hold the baby for an hour when he/she feels cold, yet they have never practiced it at home. They were not taught how to breastfeed the baby. One of the mothers already fed the baby before she reached six months old.

"[Marie] biscuits. They asked for milk, and if they were still crying, they weren't given any food, which made it hard for them to sleep. It was advice from a neighbour." (Mother of a surviving LBW, type C hospital, Garut).

Paraji hired to assist the mother in taking care of the baby (such as bathing the baby) after being discharged from the health facility had her way of keeping the baby warm.

"The one who takes care of and bathes the baby is the traditional midwife (paraji), for 40 days. When bathing on the second day, she used oil, and on the third day, she used warm water." (Mother of a surviving LBW, Type C hospital, Garut)

Once again, as previously highlighted, conflicting advice provided by midwives regarding effective methods to keep the baby warm resulted in hesitancy among mothers and caregivers at home to practice KMC. Almost all mothers never practiced KMC at home. In Garut they tended to use lamps.

"To keep the baby warm, not having jaundice, many people advised to use a lamp and don't forget to sunbathe." (Mother of a surviving LBW, type C Hospital, Garut)

When asked about KMC by our researcher, a mother in Deli Serdang explained about the way she burps the baby to release gas pocket after breastfeeding the baby.

"This baby is placed on the shoulder. You can wear a t-shirt."

A mother of a surviving LBW baby in Nagan Raya (who gave birth in a hospital) said that she practiced KMC twice after the baby was home. Each session was 30 minutes.

[You were told to hold the baby for 1 hour if they were cold, did any of you practice it?] "I held the baby, but not for 1 hour. When they were bathed, they were held because they were cold, and the other twin had a continuous yellow lamp. A yellow study lamp, for 5 minutes." (mother of a surviving LBW, Puskesmas, Garut)

A mother in Deli Serdang was told by the family that *bengle* (Zingiber Montanum) to keep the baby warm and harden the baby's skull.

"Spices like ginger and turmeric are ground and then placed on the baby's forehead to keep them warm. It also helps in strengthening the skull. Oh yes, to prevent a chill, they say. If the ground spices are placed on the mother's body, the mother's body also becomes warm."

In Pamekasan, when babies with LBW returned home, midwives who had small incubators would lend them to the family. Some village midwives and Puskesmas staff said using an incubator at home to keep the baby warm is a common practice in Pamekasan.

"Yes, when we got home, the baby was put in an incubator, for one month and one week." (A mother of a surviving LBW baby, hospital, Pamekasan)

As a result, when asked if the mothers practiced KMC, those mothers admitted they did not, or at least just once or twice only.

"No, only sometimes. Because the baby was already warm in the incubator."

"Yes. When we returned home from the hospital, they told us to use the kangaroo care method. But when we arrived at home, there was already an incubator, so we didn't need it."

#### Information sources

After being discharged from the health facility, mothers of surviving and deceased LBW babies listed their sources of information, from mothers (grandmothers of the LBW babies), mothers-in-law, midwives, TBA, relatives (especially those who already have children), neighbour, *kader*, Pink (KIA) book, *posyandu*, Google, and last but not least, for mothers who previously had LBW babies, their own experiences.

Mothers who participated in this study commonly had the pink book (buku KIA) from posyandu, or Puskesmas. When asked if they check the KIA book to get information about taking care of the baby, we received various responses:

"I didn't have time to read it, it's easier to listen than to read." (mother of a surviving LBW, hospital, Nagan Raya)

"Yes, I read it when I was pregnant." (mother of a surviving LBW, hospital, Nagan Raya)

"I wasn't taught; I just enjoy reading KIA books." (mother of a surviving LBW, Puskesmas, Garut)

Another 'non-human' resource of information is Google. A mother of a surviving LBW baby in Garut learned from Google that increasing a baby's weight can be done by giving yoghurt and avocadoes. But the mother had not tried it yet, due to her worries about the accuracy of the information. So, she chose those in line with the advice from the midwife: Breastmilk, fruits and vegetables.

A mother from Deli Serdang reported that she did not consume certain fruits such as melon and pineapple. She found on Google that melon caused complications or birth defects.

In North Lombok, the perceived reliable source of information was mother-in-law and mother. One of the most common pieces of advice in North Lombok was for the mother to consume moringa leaves. In Nagan Raya, most reliable and support came from their mother and village midwife.

### Help from family members

Women-help-women was the main theme in caring for LBW babies. Exhibiting gendered norms across Kabupaten, from TTS to Nagan Raya, numerous mothers of LBW babies leaned on women of extended families. Mother (or grandmother of the LBW babies), of course, was on the top list of the helping persons mentioned by mothers of LBW babies.

### A mother in Nagan Raya depicted:

"Not too difficult because my mother helps me. When the baby was born, yes, it was my mother who bathed him. But now, I can bathe the baby myself."

The second position on the list was the mother-in-law. In North Lombok, mother-in-law helped a mother of a surviving LBW baby,

"But most mothers-in-law have been holding him since he was a baby because I wasn't allowed to move much and they bathed him until he was 3 months old. I did not dare to watch when he was being bathed. He was still so small."

This is similar to the one in Nagan Raya, and other Kabupaten. A mother is culturally discouraged from doing anything during the post-partum period.

"Bathing, carrying, everything was done by my mother-in-law. In our culture, during the postpartum period, we are not allowed to do anything, and we are not allowed to cook either."

In Pamekasan, mothers asserted their husbands' help in various household chores, as well as baby cares. The husbands, on the other hand, felt they had not done much.

Meanwhile, Garut mothers got help from their mothers or mothers-in-law because many fathers of LBW babies (deceased or surviving) work out of town, usually in bigger cities such as Bandung and Jakarta. Some of the families live with or close by the extended families so it's quite easy for them to get help. There is no particular arrangement of who does household chores and baby care. Help can be given anytime, except at night, because nobody wakes up to help when the baby cries.

Mothers/grandmothers of the baby usually lent their hands to take care of the baby. Fathers when they are at home help with house cleaning/tidying, wash laundry, and tend the baby when the mother needs to take a shower, for instance. Some mothers hired a *paraji* or midwife to assist them in taking care of the baby, especially during the first days after they came back from health facility.

### Husband's roles

The involvement of husbands in caring for the babies or helping with chores varies, as well. Husbands from Garut were not available at any time because they predominantly worked in major surrounding cities, such as Bandung and Jakarta. However, some of them managed to accompany their wife when in the health facilities and engaged in discussions with health workers. A mother reported that husband's involvement talking with medical staff helped her a lot in understanding LBW babies caring issues, "He asked a lot of questions to clarify information given by the health workers".

Some mothers were fortunate enough to have a husband who was keen to do their parenting role. A mother of a surviving LBW baby in North Lombok received much-needed psychological support from her husband, by comforting her and taking her and the baby to the

Posyandu every month. The caring husband also made a wooden baby box just before the baby arrived home. The husbands of LBW babies' mothers in TTS were reported to take turns with the mothers undertaking KMC.

An LBW baby's father from North Lombok said that he did not get any information directly from any healthcare provider' staff, but overheard when the midwife explained to the wife.

"Not taught. [did you wear a t-shirt?] No, I did not wear t-shirt. [I overheard] when Midwife Am came to the house [and told my wife about how to do it]. We took turns carrying the baby [doing KMC] every day. From morning till night, we weren't allowed to take him outside. Because he was too small, and we also used a lamp. Midwife Am taught us too." (Father of a surviving LBW baby, Puskesmas, hospitalized, North Lombok)

However, the majority of mothers in North Lombok did not receive the same level of support from their husband. One of them complained:

"If the baby is fussy when he's sleeping, he's supposed to help calming her, instead of getting angry." (Mother of surviving LBW baby, Puskesmas, North Lombok)

A story of a mother who lost her LBW baby below describes how essential supports were for a mother.

### BOX 1

### A mother's dilemma, a mother's agony

Ibu NL gave birth to a baby at 5 months and a week, weighed 900 grams. She was examined with an ultrasound and the doctor told her to stay at the Puskesmas, because the baby was only 900 grams. She refused and immediately went home.

"I am frustrated because there's none taking care of my children".

Her husband works in Jakarta and comes home once every three months. She has hypertension but regularly went to posyandu for antenatal care. Though the baby was seven months, the midwife advised an ultrasound, but it turned out the baby was only five months and a week when s/he was born, indicating a miscalculation of gestational age. Previously, Ibu NL had relied on a *paraji* for assistance during the childbirth of her older children. However, she was advised to seek assistance from a healthcare facility, which she promptly did.

The Ultrasound image showed she had twins and within a few hours, she delivered the babies. She stayed at the Puskesmas from 10:30 in the morning until evening, lying on the bed, doing nothing but waiting for the report of the doctor on duty. That's why she insisted on going home. She left the Puskesmas in the evening.

At 1 a.m. she decided to go back to the Puskesmas due to her painful labour. There's only her 16-year-old son to take her to the Puskesmas by motorbike from their house, which is located on the other side of the mountain. She did not go by the village ambulance because she had to pay 300 thousand rupiah for using it. And then she was left in the Puskesmas with the midwife on duty, her son went back home right after they arrived. Then the twins were born.

The midwife told her that the baby passed away because s/he's not strong enough to be born yet, and the organs had not yet developed well.

Mothers in Nagan Raya seemed to dismiss their expectation of getting help from the fathers (their husbands). One of them was so pessimistic when asked about her husband's help:

"Yes, whether I'm ready or not, I have to be sure that I can do it. I can't expect the father [to help caring for the baby], I have to rely on myself. I don't trust the father to carry or bathe the baby, either."

While another mother already received support from the matriarch, so she does not expect the husband's support.

"No, I'm not sure, because he smokes. It's not possible to quickly change clothes and wash hands all the time." (Mother of a surviving LBW baby, Nagan Raya)

Some of the family members smoke around the baby so they often have runny nose and asthma. In Garut, the hospital's midwife apparently told the caregiver about the danger of smoking around babies so that the father stayed away from the babies when he was smoking.

Knowledge and practices on developmental aspect

While the exploration of parents' and caregivers' knowledge about the developmental aspects of the low birth weight (LBW) baby was limited, certain situations provided insights. For instance, during a visit to a surviving LBW baby, a general practitioner from a Puskesmas in Pamekasan posed questions about the baby's development based on their behavior.

"Ma'am, compared to his sibling, can Ik [the baby] turn over and roll to her stomach at the same speed or is she slower? And can she be comforted, greeted..." (conversation between a GP and a mother of surviving LBW, Polindes/Puskesmas network, Pamekasan)

When we arrived, the baby was lying down on the floor with a toy hung above her. However, we did not extend to an examination whether the families recognize and use the baby's behaviours and cues to determine the care.

Figure 23. Hand-made hanging toy for the baby to play with placed on top of the baby's mat

### • Growth Monitoring in Posyandu

LBW babies' mothers were keen to routinely join Posyandu to monitor the baby's growth, particularly their weight. Some of them mentioned the information from Posyandu about caring for the baby, although not necessarily an LBW baby:



"Now, at the integrated health post (posyandu), there are counselling sessions on how to care for the baby, their eating patterns, and what they can eat at this age. There are also counselling sessions from the village midwife on such topics." (a mother of surviving LBW, Puskesmas, Garut)

Unfortunately, there was no further information from the health workers regarding preterm babies with regards to details on chronological age, length and weight according to a certain growth curve.

Simultaneously, the Posyandu appeared not to address the specific needs of mothers with low birth weight (LBW) babies. Some mothers were instructed to increase their baby's weight without receiving guidance on the 'how to' aspect. Two mothers of LBW babies mentioned that their infants had not achieved the expected weight velocity, with one of them emphasizing,

"The sister [kader] never mentioned it." (Mother of surviving LBW, Type C hospital, Garut)

The posyandu focused more on stunting, as it was the President's instruction. One of the LBW babies in Garut was categorised as stunting so that he gets egg and milk. According to the mother, the assistance was not from Posyandu, but from the village administration for stunting elimination.

"They weren't given [the assistance was only for children with stunting]. If there's stunting assistance, they provide eggs and milk." (Mother of surviving LBW, Type C hospital, Garut)

The other mother who gave birth at the Puskesmas was not yet listed in DTKS as someone who meets the criteria to get assistance from the village administration.

Although the queue was usually long and took some time to get weighed, a caregiver of a surviving LBW baby in Garut had nothing that made her dissatisfied with the service of Posyandu.

in contrast to what happened in Garut, a mother in North Lombok elucidated that in the Posyandu she was told:

"Don't bathe the baby, just wipe them; breastfeed them frequently, and when they're sleeping, don't keep them at a distance; that's why they stay close to their mother.". (Mother, Puskesmas, hospitalized, North Lombok)

In summary, mothers commonly experienced emotional and psychological support from their husbands, family members, the community, and health workers in various ways. The prevalence of trans local families in Garut, however, might contribute to mothers feeling isolated and frustrated due to a lack of available support. Mothers of surviving low birth weight (LBW) babies expressed a heightened need for information to care for the babyfrom health workers. In cases where the provided information was deemed insufficient, they sought alternative sources such as their mothers-in-law, neighbors, or the internet, but they predominantly followed advice from health workers. A limited number of mothers also consulted the KIA book. Occasionally, individuals and family members shared information without being prompted, which may not align with contemporary issues in maternal and neonatal health, particularly in caring for LBW babies. Additionally, information provided by health workers was noted to be occasionally inconsistent, prompting parents and caregivers to adopt practical approaches. For instance, parents in Pamekasan opted to use an incubator instead of practicing Kangaroo Mother Care (KMC) for keeping the baby warm. Posyandu appeared to provide limited attention to low birth weight (LBW) babies. While the use of technology, specifically WhatsApp messaging, facilitated rapid information dissemination to a broader audience, its effectiveness in mentoring parents of LBW babies in caring for their infants was not conclusively evident.

### Conclusions and Recommendations

The study had described the situation of care for LBW babies in different settings and contexts in Indonesia. Although the study result was not meant to be generalized, there were some important conclusions with regards to care for LBW babies in these study districts.

In general, the study found that readiness to care for LBW babies according to ENAP seems to be more happening at the referral care level rather than at primary care level. Although all health facilities reported to have standards for LBW care, the implementation of such standards varied. Lack of necessary training and incomplete equipment were mostly churned up during the discussion about evidence based practices. In addition, LBW was not seen as a top priority with regards to maternal and neonatal health in some of the districts.

Care for LBW infant with weight between 2000-2500 grams were manageable at the primary care level. However, this was not the case for readiness to provide emergency care. LBW cases in these study districts were exacerbated with perceived high unintended pregnancy, teenage childbirth, and inadequate prevention care due to socio-culture-gender issues.

With regard to essential evidence-based care practices for LBW infants at the primary and referral level facilities, noticeably the utilization of effective and low-cost care such as KMC and breastfeeding were not on par with the standard. Reflecting from the discussion with health workers, there was an impression that the health workers tend to undermine the role of KMC to bring positive impact to the LBW babies. Health workers also often lack enthusiasm to encourage exclusive breastfeeding and tend to quickly revert to formula milk whenever the mother experiences difficulty with breastfeeding.

The completeness of equipment and medical devices as well as the competency of the health staff at the referral care were better than at primary care level. This, in turn, also reflects in the tendency for primary care level to refer LBW babies to hospital than keeping the care at the primary level. As the study also conducted a review over the medical record, the study also found that in general medical records were not completed properly, both in the medical records collected by the hospital and the puskesmas. In the medical records from the hospital, there were 4 referral cases reported, but only 1 case had a referral letter recorded, while the other 3 cases did not mention the existence of a referral letter including the treatment obtained at the referring health facility. It was very important to know what to do before referring for the sake of patient safety and determining further medical action. Apart from that, in cases of babies who received resuscitation measures, there were medical records which noted that post-resuscitation stabilization measures were not carried out according to the SOP. The medical records at primary care level that were collected also showed that in general healthy LBW babies were discharged after 6 hours, after given breastfeeding initiation, umbilical cord care, antibiotic for eyes and vitamin K.

Specifically with regards to the capacity of health workers and families in providing care to small newborns, the study found that most health workers, especially those that were observed during case simulation in the two districts, showed enthusiasm and were motivated enough to give their best care. However, reflecting upon the case simulation, the study also found that there were rooms for improvement in terms of skills related to resuscitation, lactation and initiation of breastfeeding, KMC, alternative feeding, monitoring and discharge criteria for LBW babies. Notably, the composition of available health workers at referral level was still not ideal, most specifically on the number of paediatricians and general doctors. The study also found that, despite claims about the numerous training that were already conducted, the health workers in these districts still needed updating skills training and transfer of skills, and investment around this capacity building effort was not adequate.

The study also identified the enablers to provision of essential newborn care for small newborns at primary and referral level. We found that some districts, namely Nagan raya, Pamekasan and TTS, had the adequate ration of doctor, midwives and nurses according to WHO standard. The health workers in all districts were also found to be motivated, both at the primary and referral care level.

As expected, the availability of equipment, medical devices and medicines were more complete in the referral care than in the primary care level, but surprisingly there was almost no significant difference between BEmONC and non BEmONC facilities. All hospitals reported to have infant warmers and neonatal resuscitation equipment available near the maternity room and operating theater, but not available in the emergency room, perinatology room. Few hospitals reported to have the clinical assessment system to monitor the skills of their health workers. All hospitals reported having suitable antibiotics for neonates (along with the SOP for administering first-line antibiotics). 76% of hospital class B and 81% of hospital class C had the equipment and supplies for treating infections in neonates. The class B hospitals were more prepared to provide nutritional and fluid for LBW babies. In terms of equipment for administering oxygen, both type B and C hospitals reported the availability of ambu-bags, oxygen central, oxygen concentrate, and oxygen cylinders. All class B hospitals reported the adequacy of KMC tools and equipment for the mothers and the babies. On the other hand, only 2 out of 3 class C hospitals had adequate tools and equipment for KMC, which included rooms with a temperature between 22-24°C sufficient for 2 to 4 beds. However, our field visit to the hospital showed that some of the KMC rooms did not meet the standard. Health facilities received infrastructure support from the Ministry of Health although not without challenges, whether in the use or maintenance aspect of it. Health workers tried to educate the mothers with KMC although limited. In terms of communication facility and transportation for referring cases however they are not ideal.

The study further looked into the pathway of referring LBW infants with complications, in order to try to understand its barriers and enablers. In general, SISRUTE is still not the first mechanism of choice in all study districts. Capacity of health workers to provide (and record) sufficient information for referral and their ability to provide standard care during referral (for babies with complications) were also limited. The study also concluded that there were still rooms for improvement in terms of the skills of health workers to identify dangerous sign and also provide (and record) stabilization care pre-referral and during referral (in transport). Puskesmas' ambulance was not equipped with mobile incubator.

In addition, the capacity of families to provide care to small newborns also varied. Their ability to provide the correct care for LBW babies were influenced by: (1) the effectiveness of communication by the health workers and (2) the information that they received while the baby was still at the health facility. Consistent and proper examples were often not given to parents (and other caregivers) with regards to the correct way of practicing KMC, breastfeeding, thermal care, and noticing danger signs. In general, parents and caregivers tend to perceive that enough information were given as long as the health workers were nice and friendly, and they were hesitant to ask too many questions or ask for clarifications. Parents and caregivers were supported by family members and community, as well as by health workers through home visits and messaging communication (whatsapp).

Based on these conclusions, the study recommended:

On prevention of LBW, to:

- Improve the capacity of village midwife to conduct active surveillance and early detection at the community level according to standard. Most particularly on the education to pregnant women and adolescent girls to keep an eye on their nutrition intake pre and during pregnancy (including addressing certain taboo and local superstition), as well as learning the skills of persuasive communication to educate girls and women to avoid the 4Ts (too young, too old, too often and too many pregnancy). Village midwives might collaborate with community nurses in this regard. With the new GOI initiative of integrated primary care, active surveillance and early detection must be happening not only at the Puskesmas but also to the lower levels of care.
- Practicing quality ANC according to standard is also key. Most particularly, paying more attention on the third semester pregnancy weight, and pregnant women with gemelli status, and women of certain age group as well as other risk factors. ANCit needs to be accompanied by contextualized education to adolescent girls, women and pregnant women, as well as other member of the family. Health workers need to be aware of the local social and cultural phenomena related to LBW regarding family and children value, pregnancy value, and customary dietary 'taboo' in pregnant women, and a local social structure that might exacerbate risks of LBW.

While on management of care for LBW babies at primary and referral level, the recommendations were arranged according to the WHO building blocks.

On service delivery, the study recommended to:

- Encourage and ensure more utilization of basic and low-cost effective evidence based care for LBW babies, including correct KMC and breastfeeding at health facility. This might include infrastructure and institutional support that enable mothers and caregivers to practice KMC and breastfeeding comfortably at the facility under observation of the health workers. Investment should be made to aim for family-centered care for neonates especially for LBW babies.
- Practice KMC during transport to referral hospital and provide complete information regarding the LBW baby condition and record about the stabilization care that was already given pre-referral.
- Develop individualized pre-discharged plan for every mother with LBW babies with comprehensive education about lactation management to mothers and caregivers are equipped and prepared to practice breastfeeding and KMC at home
- Tailor impactful communication strategies with parents and other caregivers by considering contextual aspects, including specific cultural and religious norms, as well as the individual characteristics of parents.

On *health workforce*, the study recommended to:

- Strengthen mechanism of post-training mentoring and invest more in more mentorship/coaching of health workers at primary care level by specialist doctors, supplementary to investment in infrastructure, equipment, medical devices and medicines.
- Revisit training package to include skill-based curriculum. Any kind of trainings must be followed up by the District Health Office (and in collaboration with professional organization) with frequent and regular on-the-job drilling session
- Establish or assign a team/unit that is in charge of Human Resource for Health (HRH) Management more comprehensively. This means that there is a complete HRH planning with regards to numbers (and what strategy in place to meet the number and proportion according to standard), identify and record capacity building need for each HRH (doctors, midwives, village midwife and nurses), and keep track of the whereabout of the already trained and skilled HRH most typically that were already skillful and experienced in essential care and emergency care (including resuscitation, breastfeeding initiation and lactation management, KMC and alternative feeding).
- Policy on staff rotation must be heavily reconsidered for these group of already trained staff, in order to avoid the situation where a facility is lacking these skills and potentially risking patient' safety.

On *information*, the study recommended to:

- Impose on complete medical record, especially in referral LBW babies with complications, and take immediate action on recommendation results of AMP-SR. Medical record should be reviewed randomly and regularly by Medical Committee in the hospital, and noncomplete medical record should be discouraged.
- Start to record KMC and breastfeeding practice at the primary and referral care.
   Coordinating midwifes also need to start asking village midwives to actively record KMC and breastfeeding practices (especially for LBW babies) at the community level.

On *medical products and technology*, the study recommended to:

- Plan for phasing of government investment in necessary equipment at primary care for maternal and neonatal health, including any equipment that enable early detection of LBW and essential care for newborn, as well as capability to provide stabilization care pre and during transport to referral facility.
- Ensure that the government invest in necessary equipment at referral facility which include adequate number of NICU facilities at referral facilities
- District Health Office needs to have ensure availability of trained team of medical equipment technicians that able to provide scheduled and timely maintenance to medical equipment in their district (Unit Pemeliharaan Alat Kesehatan – UPAK) to avoid dependence on third parties. More importantly, ensuring optimal utility, safe and accurate medical equipment is crucial to ensure patient' safety.

On *financing*, the study recommended to:

- Establish a fool-proof mechanism between health facility with Office of Civil Registry and local/regional BPJS-K to warrant that every living newborn immediately receives their birth certificate and be a member of JKN to avoid financial hardship and catastrophic health spending related to the health of the newborn.

On *leadership/governance*, the study recommended to:

- Update existing STPs and SOPs with the most updated government regulation and follow WHO recommendations and evidence. In LBW cases, the leadership of neonatal paediatricians and paediatricians nurse are crucial; and therefore, they both were the ones that need to ensure that all STPs and SOPs in the health facility are up to date and implemented. However, a multidisciplinary approach is needed and thus SOPs must also extend to other health professionals at the facilities to equip them in supporting mothers and caregivers of LBW babies at the facility
- Encourage parents (not only mothers) and caregivers' participatory and active involvement in providing care for LBW babies at the facility and at the community level. Health workers, especially those in perinatal ward, must provide information and education to parents (not only mothers) and caregivers prior to discharge. Coordinating midwives need to require village midwives to provide information and education to parents (not only mothers) and caregivers at home at least during the first 28 days of monitoring LBW newborn.
- Strengthen the role of District Health Office to utilize AMP-SR (including for neonatal deaths) and provide necessary feedback. This might involve the ability of District Health Office to address issues such as additional workload and support that are needed to follow up feedback of AMP-SR result. This role can also be supported by the existing mechanisms of mentorship program of the IDAI (I.e. one pediatrican for a number of Puskesmas in the district)

### Annex 1. Key Informants and FGD Participant Information

Table 24. Actual number of informants in each district

Kabupaten	Types of study participants	Types of data collection method	# of study participants	Total
Nagan Raya	Hospital staff	1 FGD, 1 IDI	12	38
J .	Puskesmas staff	2 FGDs, 2 IDIs	13	
	Mothers of surviving LBW babies	1 FGD, 4 IDIs	6	
	Mothers of deceased LBW babies	2 IDIs	2	
	Fathers/caregivers of LBW babies	3 IDI	3	
	DHO staff	1 IDI	2	
Deli	Hospital staff	1 FGD	9	42
Serdang	Puskesmas staff	2 FGD	12	
	Mothers of surviving LBW babies	4 IDI's	4	
	Mothers of deceased LBW babies	1 IDI	1	
	Fathers/caregivers of LBW babies	4 IDI's	4	
	DHO staff	1 FGD	12	
Garut	Hospital staff	2 IDIs	2	34
Garut	Puskesmas staff	2 FGD	14	34
	Community health workers (kader)	1 IDI	1	
	Mothers of surviving LBW babies	2 FGD	8	
	Mothers of deceased LBW babies	4 IDIs,	4	
	Fathers/caregivers of LBW babies	3 IDIs	3	
	DHO staff	2 IDIs	2	
Pamekasan	Hospital staff	1 FGD	5	32
	Puskesmas staff	2 FGDs	10	
	Mothers of surviving LBW babies	1 FGD, 2 IDIs	8	

	Mothers of deceased LBW babies	2 IDIs	2	
	Fathers/other caregivers of LBW babies	2 group interviews, 2 IDIs	6	
	DHO staff	1 IDI	1	
North	Hospital staff	FGD	9	40
Lombok	Puskesmas staff	2 FGD	18	10
	Mothers of surviving LBW babies	IDI	2	
	Mothers of deceased LBW babies	IDI	4	
	Fathers/other caregivers of LBW babies	IDI	3	
	DHO staff	FGD	4	
TTS	Hospital staff	1 FGD, 1 IDI	8	32
	Puskesmas staff	2 FGDs	12	
	Mothers of surviving LBW babies	1 FGD	6	
	Mothers of deceased LBW babies	2 IDIs	2	
	Fathers/caregivers of LBW babies	1 IDI	1	
	DHO staff	3 IDIs	3	

Table 25. Actual Number of KII Informant

KII Informant	Number of informants	Total
Indonesian Midwives Association (IBI)	4 persons	1 group interview
Indonesian Pediatric Nurse Society (IPANI)	2 persons	1 group interview

Indonesian Pediatric Society, in particular the UKK Neonate	1 person	1 KII
Ministry of Health (Directorate of Maternal and Child Health and Nutrition)	2 persons	1 group interview

### Annex 2: Clinical simulation report

# REPORT (1) FIRST LEVEL HEALTH FACILITY OBSERVATION RESULTS PUSKESMAS A

- Time: 10am-1pm, August 26, 2023.
- Place: Delivery room, resuscitation room.
- Method: Direct observation of case management skills based on a checklist prepared.
- Subjects: Delivery room midwives and neonatal ward nurses.
- · Observer: Setya Wandita.

### 1. PRETERM INFANTS/LOW BIRTH WEIGHT (LBW) BABIES THAT DO NOT REQUIRE RESUSCITATION

### 1.1. Preparation before the baby is born.

Observation. Nurses prepare resuscitation equipment and place it in the delivery room. The preparation of equipment is carried out thoroughly. What needs to be done adequately is the readiness of tools that may need to be used. The resuscitation site is close to delivery. An algorithm of the neonatal resuscitation mounted near the resuscitation table. There has not been a review regarding the risk factors for asphyxia.

Impression. The preparation of equipment and place and the vigilance of officers are carried out adequately. Improvements needed are anticipating or reviewing risk factors and ensuring the tool is ready for use.

### 1.2. Initial step.

Observation. Assessment of conditions at birth could have been carried out more thoroughly. The initial steps were carried out sequentially well. The time to take the initial steps still seems slow, more than 1 minute. Evaluation after the initial steps are carried out correctly and completely.

Impression. The officers took the initial steps quite well. Improvement is a complete assessment of the condition at birth, namely whether it appears full term, whether breathing is spontaneous, and whether muscle tone is good. The time to take the initial steps is accelerated.

### 1.3. Early initiation of breastfeeding

Observation. Nurses can initiate early breastfeeding for LBW infants who do not require resuscitation. The early breastfeeding initiation procedure lasts 60 minutes without intervention or invasive procedures. Monitoring the baby's condition during early breastfeeding initiation is done only sometimes.

Impression. Officers can carry out early breastfeeding initiation procedures correctly. Improvement is monitoring the baby's condition every 15 minutes, namely general condition, vital signs, and danger signs.

### 2. NEONATAL RESUSCITATION.

### 2.1. Preparation before the baby is born.

Preparations before the baby is born, as in 1.1.

### 2.2. Initial step.

Preparations before the baby is born, as in 1.2.

### 2.3. Positive pressure ventilation.

Observation. The nurses can perform positive pressure ventilation (PPV), which expands the chest at the correct frequency (20-30 x/30 seconds). Corrective action techniques mask, repositioning, suction, open mouth, pressure increased, and alternative airway (MRSOPA) have not been carried out adequately. After correction, PPV was 15 seconds; it should be 30 seconds. Evaluation after 30 seconds of PPV that expands the chest is the heart rate. Chest compressions are performed in coordination with PPV.

Impression. Officers carry out good PPV. The improvement is that the MRSOPA correction is carried out sequentially, and after that, the PPV is carried out for 30 seconds.

### 2.4. The next step.

Observation. After PPV, if the baby is breathing spontaneously and the heart rate is  $\geq$ 100 x/minute, an assessment is carried out to see if there is difficulty breathing and cyanosis. If respiratory distress continues, a referral is made.

Impression. Officers can take adequate action after PPV. See the REFERRALS section for babies who need to be referred.

### 3. POST-RESUSCITATION STABILIZATION AND TRANSPORTATION

Observation. Stabilization is carried out for babies who do not need to be referred and those who need to be referred. Stabilization is carried out respiration by providing nasal oxygen or continuous positive airway pressure (CPAP) and temperature measurement. Nurses do not check blood sugar levels.

Impression. Post-resuscitation and prereferral stabilization were not carried out adequately. The improvement is a complete stabilization action by measuring random blood glucose level.

### 4. ESSENTIAL CARE FOR SMALL BABIES.

Observation. Essential care for small baby include identity, vitamin K, hepatitis B-0, eye ointment, and umbilical cord care. A doctor carries out the physical examination. The anthropometry performed was birth weight, head circumference, and body length. Measure body length with a measuring tape. Bathing the baby is postponed for up to 24 hours.

Impression. Essential neonatal services are provided well. Improvement is measuring body length using standard measuring instruments.

### 5. BREASTMILK

Observation. Breast milk (BM) is given to premature/LBW babies. Breastfeeding counselling is not provided to mothers. Nurses counsel mothers on breastfeeding their babies, but the way mother breastfeed the baby is still incorrect.

Impression. The skills of staff providing counselling need to be improved so that mothers can breastfeed their babies properly.

### **6. LACTATION MANAGEMENT**

Observation. Lactation management is not carried out.

Impression. Staff needs to be trained in lactation management and breastfeeding counselling.

### 7. ALTERNATIVE FEEDING

Observation. The nurses were unable to examine the sucking and swallowing reflex. The officer demonstrated giving a drink with a cup, not a feeding tube. The officers did not teach how to give drinks using a cup.

Impression. Staff must learn to identify alternatives to breastfeeding, whether by the cup or feeding tube, and counsel mothers on these methods.

#### 8. KANGAROO MOTHER CARE

Observation. Nurses know the benefits of kangaroo mother care (KMC), preventing hypothermia. The ability of officers to carry out counselling and preparation before KMC is carried out and monitoring is limited. Meanwhile, skills regarding the criteria for babies that can be carried out and how to carry out PMK are well mastered.

Impression. The officers' skills in carrying out PMK are good—improvements in monitoring while the baby is undergoing PMK.

### 9. KANGAROO MOTHER CARE PROCEDURE

Observation. Officers can demonstrate KMC skills. The procedure begins with preparing, placing, and positioning the baby on the mother's chest. However, counseling for the baby's mother was not carried out.

Impression. Officers need to prepare mothers before carrying out KMC.

### 10. MONITORING DURING KANGAROO METHER CARE

Observation. While the baby is undergoing KMC, vital signs and emergency monitoring are not carried out.

Impression. Officers were unable to carry out baby monitoring carried out by PMK. Officers need to practice monitoring babies carried out by PMK.

### 11. DISCHARGE OF LOW BIRTH WEIGHT INFANTS

Observation. The nurse can explain the criteria for discharge for LBW. It was explained that the discharge criteria were sometimes unmet, but the baby was still sent home. The discharge procedure depends on the doctor's decision.

Impression. The nurse knows when to send the baby home.

### 12. RESPIRATORY DISTRESS

Observation. Nurses can determine the severity of respiratory distress by assessing the Downes score. Downes' score charts are in the delivery room and action room. Babies with respiratory distress are treated with nasal oxygen or CPAP. If it does not improve, a referral is made. Those treated for LBW were not monitored for signs of respiratory distress. Impression. Nurses know how to assess signs of respiratory distress and provide respiratory support. Stable LBWs who are treated require regular monitoring for signs of respiratory distress.

### 13. HYPOGLYCEMIA

Observation. For LBW, no blood glucose examination is carried out. If hypoglycaemia occurs, management is based on the doctor's instructions. Signs of hypoglycaemia are unknown to the nurse.

Impression. Nurses need to know the signs of hypoglycaemia and which babies need to be screened for GDS.

### 14. HYPOTHERMIA

Observation. Nurses' skills in managing LBW who experience hypothermia are up to standard. LBW temperature monitoring is carried out infrequently.

Impression. Treatment for hypothermia is adequate, but monitoring is not carried out routinely. Blood glucose examination is not performed on hypothermic babies.

### 15. INFECTION

Observation. A doctor diagnoses an infection. The supporting examination carried out is a complete blood count without blood culture. First-line antibiotics are ampicillin and gentamicin. Impression. Infection management is adequate.

### 16. SEIZURES

Observation. Seizure management is based on the doctor's instructions. The nursing action for babies having seizures is only to be given nasal oxygen.

Impression. Nursing actions for babies with seizures need to be improved.

### 17. NUTRITION

Observation. The doctor determines the nutrition program. There is no monitoring of calorie intake and daily evaluation.

Impression. Nutrition is only given enterally, by breastfeeding, or by cup feeding.

### 18. REFERRALS.

Observation. Post-resuscitation or seriously ill patients who cannot be treated at the Community Health Centre are referred to RSUD Soe—communication using the telephone. Pre-referral stabilization measures needed to be implemented adequately. Transportation uses an ambulance and is accompanied by a nurse.

Impression. Pre-referral and stabilization measures needed to be implemented adequately.

### RESUME

The Niki-Niki Health Centre is suitable for treating stable LBW or those with non-severe morbidity. Handling of pre-referral and stabilization needs to be improved. Improvements need to be made: preparation before the baby is born (anticipating asphyxia in the form of detecting risk factors), preparing equipment to be ready to use, quicker initial steps, and SRIBTA correction. Improvement of monitoring of babies carried out by IMD. Post-resuscitation and pre-referral stabilization need to be improved by conducting a GDS examination.

Breastfeeding and KMC counselling need to be done well. Nurses need to be able to teach alternative feeding and monitor nutrition intake. A breastfeeding counsellor or officer who can carry out lactation management is needed. During initial breastfeeding, vital signs, danger signs, hypothermia, infections, and seizures must be monitored periodically. Blood glucose screening for babies with risk factors for hypoglycemia.

### REPORT (2) PUSKESMAS B

• Time: 4 September 2023 (9.00-15.00 WIB)

Place: Delivery room

• Method: Direct observation of case management skills based on a checklist prepared.

• Subjects: Midwives and a GP

Observer: dr. Ekawaty Lutfia Haksari, SpA

### 1. PRETERM INFANTS/LOW BIRTH WEIGHT (LBW) BABIES THAT DO NOT REQUIRE RESUSCITATION

### 1.1. Preparation before the baby is born.

Observation. There were insufficient skills in the delivery preparation. The midwives did not assess risk factors for asphyxia, and preparation for resuscitation place and equipment. Staff and self-preparation were not performed by the participants.

Impression. The preparation of equipment and place and the vigilance of officers were not carried out adequately.

### 1.2. Initial step.

Observation. Assessment of conditions at birth could have been carried out more thoroughly. Evaluation after the initial steps were not carried out correctly and completely. When asked about suction catheters, no participant was able to mention the sizes.

Impression. Improvement is needed.

### 1.3. Early initiation of breastfeeding

Observation. Some steps in the early initiation of breastfeeding could be performed appropriately, such as positioning the baby on top of the mother's body and enabling skin-to-skin contact. The participants answered correctly about the frequency of early breastfeeding initiation (60 minutes). However, monitoring of the baby's condition (general condition, vital signs, and danger signs) were not performed and answered correctly.

Impression. Need improvement in monitoring the baby's condition during early initiation of breastfeeding

### 2. NEONATAL RESUSCITATION.

### 2.1. Preparation before the baby is born.

Observation. There were insufficient skills in the delivery preparation. The midwives did not assess risk factors for asphyxia, and preparation for resuscitation place and equipment. Staff and self preparation were not performed by the participants.

Impression. The preparation of equipment and place and the vigilance of officers were not carried out adequately.

### 2.2. Initial step.

Observation. Assessment of conditions at birth could have been carried out more thoroughly. Evaluation after the initial steps were not carried out correctly and completely. When asked about suction catheters, no participant was able to mention the sizes.

Impression. Improvement is needed.

### 2.3. Positive pressure ventilation (PPV)

Observation. Participants demonstrated insufficient skills in PPV. Participants were not able to explain the initial duration of PPV (15 seconds), the use of laryngeal mask, repositioning, suction, breathing and heart rate improvement. Participants said that if there was no sign of improvement, they usually immediately sought advice from the GP.

Impression. PPV skills were insufficient

### 2.4. The next step.

Observation. Participants demonstrated insufficient skills in performing follow-up actions after PPV, including airway and heart rate evaluation, oxygen saturation, signs of cyanosis, and post-resuscitation care. It seemed that the participants had never performed resuscitation before.

Impression. Post-PPV skills were inadequate.

### 3. POST-RESUSCITATION STABILIZATION AND TRANSPORTATION

Observation. Stabilization skills were insufficient, particularly in terms of measuring oxygen saturation, respiratory distress signs, and heart rate measurement. No CPAP was available in the facility. Participants could not explain thoroughly what measure was taken to stabilize the infants prior to referral.

Impression. Post-resuscitation and prereferral stabilization were not carried out adequately.

### 4. ESSENTIAL CARE FOR SMALL BABIES.

Observation. Essential care for small babies including identification, vitamin K administration, hepatitis B-0, eye ointment, and umbilical cord care were performed adequately. For umbilical cord care, it was performed only when the observer asked to do so. Measurement of birth weight was not using digital scales. Bathing the baby was postponed for up to 24 hours.

Impression. Essential neonatal services were provided well. Measurement of body weight should use digital scales.

### 5. BREASTFEEDING

Observation. Breastfeeding was the primary feeding method for premature/LBW babies. However, skills in breastfeeding counselling were not adequate among the participants. During the simulation, participants seemed doubtful about what to do next and had to seek advice from the colleagues.

Impression. The skills of staff providing breastfeeding counselling need to be improved so that mothers can breastfeed their babies properly.

### 6. LACTATION MANAGEMENT

Observation. Lactation management was not simulated, but was discussed with participants. From the discussion, it seemed that the implementation of lactation management on LBW babies was still lacking. Some participants mentioned cleaning the areola with wet wipes, while it should have been with plain and clean water instead.

Impression. Staff needs to be trained in lactation management and breastfeeding counselling.

### 7. ALTERNATIVE FEEDING

Observation. Midwives said that the provision of breastmilk to babies with sucking problems was performed with a pipette. None of the participants seemed to ever use feeding tube because they could not explain and perform it correctly. They also lacked knowledge in other alternative feeding methods (using cups or spoon), including the amount of breastmilk given to the baby. Only one participant provided a correct answer to "how many times should a baby urinate in a day?" (6 times).

Impression. Staff must learn to identify alternatives to breastfeeding, whether by the cup or feeding tube, and counsel mothers on these methods.

### 8. KANGAROO MOTHER CARE

Observation. Insufficient skills and knowledge about the purpose, goals, and procedures of KMC (including what to monitor during KMC).

Impression. Insufficient skills and knowledge

### 9. KANGAROO MOTHER CARE PROCEDURE

Observation. Insufficient skills and knowledge about the purpose and goals of KMC (including what to monitor during KMC).

Impression. Insufficient skills and knowledge

### 10. MONITORING DURING KANGAROO MOTHER CARE

Observation. Sufficient KMC skills, but it seemed that KMC was not implemented well in the facility. Lack of skills regarding breastfeeding during KMC.

Impression. Need to improve skills about breastfeeding during KMC

### 11. DISCHARGE OF LOW BIRTH WEIGHT INFANTS

Observation. Insufficient knowledge about discharge criteria (including body weight). After being discharged, the babies were usually monitored by village midwives. Knowledge on danger signs was still lacking.

Impression. The midwives lacked the knowledge about discharge criteria.

### 12. RESPIRATORY DISTRESS

Observation. Very insufficient knowledge. Many did not know about Downes score. Impression. More training should be provided.

### 13. HYPOGLYCEMIA

Observation. For LBW, no blood glucose examination is carried out. If hypoglycemia occurs, management is based on the doctor's instructions. Signs of hypoglycemia are unknown to the midwives

Impression. Nurses need to know the signs of hypoglycemia and which babies need to be screened for GDS.

### 14. HYPOTHERMIA

Observation. Nurses' skills and knowledge in managing LBW who experience hypothermia were insufficient. LBW temperature monitoring was not explained thoroughly. Impression. Insufficient knowledge

### 15. INFECTION

Observation. Not observed/discussed. A stray cat was observed in the maternal room and the surroundings.

Impression. Not observed/discussed

### 16. SEIZURES

Observation. Not observed/discussed.

Impression. Not observed/discussed.

### 17. NUTRITION

Observation. Lack of knowledge about feeding (by breastfeeding, enteral feeding, or alternative feeding method other than pipettes)

Impression. Lack of knowledge about feeding (by breastfeeding, enteral feeding, or alternative feeding method other than pipettes)

### 18. REFERRALS.

Observation. Lack of pre-referral stabilisation knowledge. Meanwhile, all LBW cases were usually referred to the hospital despite weighing over 2000 grams. Participants said that to keep the babies warm, the babies were wrapped in plastic during the referral process since no incubator was available in the ambulance. Participants could mention most items that had to be prepared before referral (staff, resuscitation kit, family, documents, and vehicles), but they forgot to mention oxygen and KMC.

Impression. Pre-referral and stabilization measures needed to be implemented adequately.

### RESUME

Many aspects about the PHC should be improved – from the skills of human resources, the availability of other human resources such as physicians and nurses, the availability of devices and equipment, as well as routine training for the HRH. For referrals, skills in stabilisation and

resuscitation also required attention. Breastfeeding and KMC skills needed to be improved and the implementation should be encouraged too.

### RECOMMENDATIONS

- Enabling refresher training/drill regarding LBW cases and resuscitation at the hospitalsetting for all staff in charge. Transfer of knowledge should also be ensured.
- Ensuring the availability of equipment such as CPAP/T-piece

### REPORT (3)

### OBSERVATION OF LOW-BIRTH-WEIGHT INFANTS MANAGEMENT HOSPITAL A

- Time: 11am-3pm, August 25, 2023.
- Place: Delivery room, neonatal ward.
- Method: Direct observation of case management skills based on a checklist prepared.
- Subjects: Delivery room midwives and perinatology room nurses.
- · Observer: Setya Wandita.

### 1. PREMATURE BABIES/LOW BIRTH WEIGHT INFANTS THAT DO NOT REQUIRE RESUSCITATION

### 1.1. Preparation before the baby is born.

Observation. Before the birth of a premature baby, the preparations made include preparing the equipment, place and staff. Equipment is available in the delivery room, but its function and usability are not checked. The resuscitation table is located near the birthing area and preparations are made by covering it with linen and warming the resuscitation table. There is no action to review the condition of the fetus and look for risk factors for asphyxia. The officer who carried out the action was a midwife on duty in the Maternity Room using personal protective equipment in the form of sterile gloves.

Impression. It is necessary to improve the review before the baby is born to look for risk factors for asphyxia and prepare equipment.

### 1.2. Initial step

Observation. An assessment of the condition at birth is carried out and the initial steps are continued. The initial steps are carried out non-sequentially. After that, breathing effort and heart frequency are assessed.

Impression. Needs improvement initial steps.

### 1.3. Early breastfeeding initiation

Observation. Early breastfeeding initiation is carried out in LBW infants who do not require resuscitation. The baby is placed on top of the mother's body, in skin-to-skin contact with a head covering and a blanket. The early breastfeeding initiation is performed in around 60 minutes and invasive procedures such as injections are performed. Monitoring the baby's

condition during early breastfeeding initiation is not carried out. The staff (midwives) seemed skilled at performing IMD on premature babies.

Impression. Babies with IMD are not monitored for their clinical condition and invasive procedures are carried out.

### 2. NEONATAL RESUSCITATION

### 2.1. Preparation before the baby is born.

Observation. Preparations before the baby is born as in 1.1. If the baby requires resuscitation, the team from the neonatal ward is called to carry out this action. It is not clear how the staff from the neonate ward prepared themselves.

Impression. It is necessary to clarify the officers who carry out resuscitation on babies with risk factors for asphyxia.

### 2.2. Initial step.

Observation. The neonatal nurse properly assesses the condition at birth, namely whether he appears full term, whether he is breathing spontaneously, and whether his muscle tone is good. When carrying out the first steps, they are not in sequence and there are things that are not done. The initial steps take a long time (more than 1 minute). The assessment after the initial step is only breathing effort, without calculating the heart rate.

Impression. Need to improve skills in taking initial steps.

### 2.3. Positive pressure ventilation.

Observation. Staff skills in performing positive pressure ventilation (PPV) are very limited. PPV techniques that expand the chest, frequency, duration are inadequate. The corrective actions of masking, repositioning, suctioning fluid, opening the mouth, increasing pressure, and alternative airway (MRSOPA) in carrying out the initial steps were not understood by the nurse. The PPV cycle carried out is 60 seconds, not every 30 seconds.

Skills in performing coordinated chest compressions with VTP are minimal. In the chest compression stage, oxygen is not increased to 100%.

Impression. The skills of officers performing PPV resuscitation and chest compressions are lacking.

### 2.4. The next step.

Observation. When the baby is breathing spontaneously and the heart rate is >100 x/minute, an assessment is carried out to see if there is difficulty breathing and cyanosis. Monitor oxygen saturation using a pulse oximeter probe that is clamped, not tied according to neonate standards. Post-resuscitation care is inadequate. There are no facilities and staff skills for emergency umbilical catheter installation.

Impression. Monitoring oxygen saturation is carried out with inadequate equipment.

### 3. POST-RESUSCITATION STABILIZATION AND TRANSPORTATION

Observation. Post-resuscitation stabilization is carried out by measuring temperature and signs of respiratory distress. Blood glucose level, heart rate monitoring, and capillary refill time were not carried out. The baby is transported to the neonatal ward without using transportation equipment. Oxygen saturation monitoring is carried out using an adult probe (clamped).

Impression. Post-resuscitation stabilization and transportation were inadequate.

### 4. ESSENTIAL NEONATAL CARE FOR SMALL BABY

Observation. The baby was not given identification. The anthropometry carried out by the nurse is birth weight and head circumference. Measure body length with a measuring tape, not a standard measuring board. Doctors also carry out other physical examinations.

Vitamin K is given in the delivery room before being transferred to the neonatal ward, while the hepatitis B-0 vaccine is given 1 hour after the vitamin K injection. Umbilical cord care is carried out in an open, clean, and dry manner. Povidone iodine is applied topically if there is local omphalitis. Delay bathing the baby for 6 hours.

Impression. Essential neonatal services for small babies are adequate.

#### 5. BREASTFEEDING

Observation. Mother's milk is given to LBW infants, but no counseling regarding breast milk is provided. Schedule breastfeeding every 3 hours, namely 10.00, 13.00, 16.00 and so on. At Soe hospital, there are no breastfeeding counselor. The baby's mother is taught how to breastfeed correctly, but the positioning, attachment, and sucking are not appropriate.

Impression. Mothers are not given breastfeeding counseling, and breastfeeding is not done correctly.

### **6. LACTATION MANAGEMENT**

Observation. Lactation management is not carried out. Impression. Lactation management is not carried out.

### 7. ALTERNATIVE FEEDING

Observation. The nurse can check the sucking and swallowing reflexes. Alternatives feeding is by a spoon/cup or gastric tube. Nurses can identify how to provide alternative feeding to LBW infants and can teach the baby's mother how to give breastmilk with a spoon/cup by the nurse. The paediatrician determines daily fluid requirements and their increase. The breast milk given is from the baby's mother; there is no donor breast milk.

Impression. Providing breast milk with an alternative form of drinking is good.

### 8. KANGAROO MOTHER CARE

Observation. Nurses' knowledge about problems in care and complications of LBW infants is lacking, such as hypothermia; and kangaroo mother care (KMC), namely goals, preparation, criteria, monitoring, and family counseling.

Impression. KMC knowledge is good.

### 9. KANGAROO METHOD CARE PROCEDURE

Observation. Nurses' skills in carrying out KMC are good. The procedure begins with preparing, placing and positioning the baby on the mother's chest. KMC is carried out once a day, in the morning, afternoon or evening shift with a duration of around 2-4 hours. Impression. Skills in carrying out KMC procedures are good.

### 10. MONITORING DURING KANGAROO MOTHER CARE

Observation. During KMC, monitoring of the baby's condition is not carried out, namely vital signs and emergencies. The nurse did not explain to the mother how to stimulate and the normal condition of the baby.

Impression. There is no monitoring of the baby's condition during KMC.

### 11. DISCHRAGE OF LOW BIRTH WEIGHT INFANTS

Observation. Decision to discharge of LBW infants by paediatrician. The nurse can explain the criteria for discharge for LBW. The criteria are good general condition, being able to feed, gaining weight and reaching birth weight, stable vital signs, and the mother being able to care for the baby.

Impression. LBW discharge is good.

### 12. RESPIRATORY DISTRESS

Observation. Nurses can determine the severity of respiratory distress by assessing the Downes score. Regarding the respiratory frequency parameter, the nurse did not calculate the frequency correctly. Monitoring the development of respiratory distress is not carried out adequately every 3 hours, namely the Downes score and oxygen saturation. Nurses can operate continuous positive airway pressure (CPAP) devices. In respiratory emergencies (apnea), nursing management and initial emergency response actions are inadequate.

Impression. The way to assess respiratory frequency is incorrect. Nursing actions for respiratory emergencies are inadequate.

### 13. HYPOGLYCEMIA

Observation. Not all babies are at risk of hypoglycemia and are screened for blood glucose tests. Hypoglycemia management is based on paediatrician instructions, namely 10% dextrose bolus, glucose infusion rate, and fluid requirements. Post-correction of hypoglycemia monitoring cannot be explained correctly.

Impression. Hypoglycemia screening is inadequate. Management of hypoglycemia is inadequate.

### 14. HYPOTHERMIA

Observation. Nurses' skills in managing LBW who experience hypothermia are up to standard. Monitoring of hypothermic infants is inadequate. Blood glucose test is not performed on hypothermic babies.

Impression. Nursing skills for hypothermic babies are adequate, but monitoring is lacking.

### 15. INFECTION

Observation. The diagnosis of infection is made by paediatrician based on clinical symptoms. Laboratory examinations and antibiotic therapy are also based on paediatrician instructions. Monitoring is not carried out adequately.

Impression. Infection management is good. Need to improve monitoring of infected LBW infant.

### 16. HYPERBILIRUBINEMIA

Observation. The nurse's ability to carry out nursing actions for babies undergoing phototherapy is adequate. A paediatrician carries out the diagnosis and determination of phototherapy.

Impression. Management of hyperbilirubinemia babies is good.

### 17. SEIZURES

Observation. Nurses only know that seizures in neonates are of the tonic or clonic type. If the baby has a seizure, the nurse reports it to a paediatrician to administer medication. Drugs for treating seizures are phenobarbital and phenytoin. Supportive care for infants with seizures is the administration of nasal oxygen alone.

Impression. Nurses' ability to identify seizures and support the management of infants with seizures is lacking.

### 18. NUTRITION

Observation. The paediatrician determines the nutritional program. Monitoring of fluid intake, fluid balance, and calorie intake are insufficient.

Impression. Daily nutritional monitoring needs to be improved.

### RESUME

In general, LBW services at RSUD Soe need much improvement. The skills of nurses or midwives who handle LBW infants need to be improved. Babies undergoing early breastfeeding initiation should not be disturbed by invasive measures such as vitamin K injections. Monitoring during early breastfeeding initiation needs to be done periodically. Identification needs to be placed on all babies. Measuring body length must be done with adequate tools.

Before birth, it is necessary to anticipate the occurrence of asphyxia by reviewing the risk factors. Tool preparation needs to be improved. Nurses' skills in resuscitation, from the initial steps to chest compressions, could be better. Oxygen saturation device with tools according to neonate needs. Nurses still need to be skilled in post-resuscitation stabilization and LBW transportation.

All mothers of LBW infants need breastfeeding counseling. Therefore, there needs to be competent staff who provide breastfeeding counseling so that mothers can breastfeed their babies properly and carry out lactation management. Alternatives to drinking are good.

LBW infants undergoing KMC need to have their clinical condition monitored. The management of KMC and the return of LBW is good. Monitoring the baby's condition for respiratory distress, hypoglycemia, hypothermia, infection, and seizures needs to be improved, likewise with nutritional intake. Nursing actions for babies with respiratory distress, hypothermia, infections, and seizures must be improved.

### REPORT (4)

### OBSERVATION OF LOW BIRTH WEIGHT INFANTS MANAGEMENT HOSPITAL B

• Time: 5 September 2023 (9.00-15.00 WIB)

Place: Perinatology room

• Method: Direct observation of case management skills based on a checklist prepared.

• Subjects: Perinatology room nurses

Observer: dr. Ekawaty Lutfia Haksari, SpA

## 1. PREMATURE BABIES/LOW BIRTH WEIGHT INFANTS THAT DO NOT REQUIRE RESUSCITATION

### 1.1. Preparation before the baby is born.

Observation. Before the birth of a premature baby, the preparations made include preparing the equipment, place and staff. Participants showed sufficient skills in the preparation, but were still lacking in reviewing the condition of the fetus and finding the risk factor of asphyxia. Impression. It is necessary to improve the review before the baby is born to look for risk factors for asphyxia.

### 1.2. Initial step

Observation. An assessment of the condition at birth was carried out and the initial steps were continued. Participants demonstrated sufficient skills in performing the initial steps (that included body temperature management, clearing the airway, and repositioning). Skills in assessing breathing effort and heart frequency were also appropriate.

Impression. Sufficient skills in the initial steps

### 1.3. Early breastfeeding initiation

Observation. Early breastfeeding initiation was not performed, but was discussed with the participants. From the discussion, it seemed that early breastfeeding initiation was not performed appropriately (or even not performed at all) to LBW infants.

Impression. Insufficient skills in early breastfeeding initiation

### 2. NEONATAL RESUSCITATION

### 2.1. Preparation before the baby is born.

Observation. Before the birth of a premature baby, the preparations made include preparing the equipment, place and staff. Participants showed sufficient skills in the preparation, but were still lacking in reviewing the condition of the fetus and finding the risk factor of asphyxia. Impression. It is necessary to improve the review before the baby is born to look for risk factors for asphyxia.

### 2.2. Initial step.

Observation. An assessment of the condition at birth was carried out and the initial steps were continued. Participants demonstrated sufficient skills in performing the initial steps (that included body temperature management, clearing the airway, and repositioning). Skills in assessing breathing effort and heart frequency were also appropriate.

Impression. Sufficient skills in the initial steps

### 2.3. Positive pressure ventilation.

Observation. Staff skills in performing positive pressure ventilation (PPV) were very limited. PPV techniques that included expanding the chest were not adequate, the duration (15 seconds) was not mentioned correctly. The corrective actions of masking, repositioning,

suctioning fluid, opening the mouth, increasing pressure, and alternative airway (MRSOPA) in carrying out the initial steps were not understood by the nurse.

Impression. Insufficient skills in PPV resuscitation and chest compressions

### 2.4. The next step.

Observation. When the baby is breathing spontaneously and the heart rate is >100 x/minute, an assessment is carried out to see if there is difficulty breathing and cyanosis. If there was no improvement in the heart rate and oxygen saturation, nurses would seek advice from the doctor. Post-resuscitation care was performed appropriately. If the heart rate was <60x/minute after ventilation for 30 seconds, endotracheal intubation would be performed, and oxygenation would be increased to 100%. Chest compression was performed appropriately.

Impression. Sufficient skills in airway and heart rate assessment, as well as post-resuscitation care, endotracheal intubation, and chest compression.

### 2.5. Medicament

Observation. The provision of medicament was not simulated, but participants were able to provide correct answers related to the provision of adrenaline/epinephrine, including the concentration (1:10,000).

Impression. Possibly sufficient skills in the provision of medicament (adrenaline/epinephrine).

### 3. POST-RESUSCITATION STABILIZATION AND TRANSPORTATION

Observation. Insufficient knowledge about post-resuscitation stabilisation and transportation because the participants were not used to implementing it.

Impression. Post-resuscitation stabilisation and transportation were inadequate.

### 4. ESSENTIAL NEONATAL CARE FOR SMALL BABY

Observation. Sufficient knowledge was demonstrated. Babies were given identification. However, the facility did not use a digital scale for measuring babies' weight.

Impression. Anthropometric measurement could be improved by using digital scale

### 5. BREASTFEEDING

Observation. Insufficient skills were observed due to lack of training in assisting breastfeeding. No nurses were trained for breastfeeding counselling. Breastfeeding counselling was not provided to mothers.

Impression. Mothers were not given breastfeeding counselling.

### 6. LACTATION MANAGEMENT

Observation. Insufficient knowledge and implementation was observed. Only 2 nurses in the Perinatology room had been trained for lactation management.

Impression. Insufficient knowledge and implementation of lactation management

### 7. ALTERNATIVE FEEDING

Observation. Pacifiers might sometimes be used as one of the alternative feeding methods. Impression. Alternative feeding methods should be improved (not using pacifiers)

### 8. KANGAROO MOTHER CARE

Observation. Nurses demonstrated sufficient knowledge about KMC, namely goals, preparation, criteria, monitoring, and family counselling. However, no records about the number of infants receiving KMC were available in the facility. Posters on the algorithm of KMC were visible in the KMC room. However, the KMC room was not used often since the COVID-19 pandemic. Routine internal refresher drill about KMC was conducted before the COVID-19 pandemic, but it had not been conducted again since the pandemic occurred.

Impression. Sufficient knowledge about KMC

### 9. KANGAROO METHOD CARE PROCEDURE

Observation. Nurses' skills in carrying out KMC were inadequate. There was a mistake in tying the cloth for KMC. KMC was usually carried out for at least 1 hour, and then the mother was advised to continue practising to their heart's content. Some mothers were able to do KMC throughout the day.

Impression. Skills in KMC should be improved

### 10. MONITORING DURING KANGAROO MOTHER CARE

Observation. Sufficient knowledge about what to monitor and the frequency, but the real-life implementation was still lacking

Impression. Monitoring during KMC should be improved.

### 11. DISCHARGE OF LOW BIRTH WEIGHT INFANTS

Observation. Decisions to discharge LBW infants were made by the paediatrician. The nurse could explain criteria for discharging LBW infants, including good general condition, ability to feed, and good vital signs. Weight, SpO2, sight, hearing, and icteric were not among the criteria. If the babies were treated in NICU, they would be transported to the Perinatology room first before being discharged, as long as they had good feeding reflect and breathing. Thus, discharge screening was performed by Perinatology staff.

Impression. LBW discharge skills could be improved by including other screening criteria.

### 12. RESPIRATORY DISTRESS

Observation. Respiratory distress management was not performed, but questions were asked to the participants. Nurses were able to determine the severity of respiratory distress by assessing the Downes score, as well as the respiratory frequency parameter. Nurses used continuous positive airway pressure (CPAP) devices in their daily practices, but there was a limited number of CPAP in the unit. According to the head of the Perinatology room, they usually use Neopuff CPAP due to the limited availability of mixsafe CPAP. They used 100% oxygen for the Neopuff CPAP because they do not have the device to adjust/blend the Oxygen airflow. Other participants were not able to tell the difference between Neopuff and Mixsafe CPAP. All participants (except for the head of the Perinatal room) demonstrated insufficient knowledge regarding the cut-off of Downes score for the provision of PPV with intubation, prereferral stabilisation, and the use of infant pulse oximeter. Through our interview with ER nurses, the nurses were not able to tell the adult/child oximeter and the infant oximeter apart. Further discussions with the participants revealed that the provision of surfactant to infants with RDS had not been performed due to the unavailability of surfactant. If the infants had apnoea, they will be treated in the incubator. When the infants got stabilised, they would then be transported to the infant warmer.

Impression. Inadequate knowledge in assessing respiratory distress parameters, CPAP utilisation, pre-referral stabilisation, and assessing oxygen-level.

### 13. HYPOGLYCEMIA

Observation. Hypoglycaemia management was not simulated, but was asked to the participants. Participants showed sufficient knowledge in assessing the risk of hypoglycaemia (including the symptoms), the cut-off for blood glucose level to provide 10% dextrose. However, they could not explain post-correction of hypoglycaemia (fluid replacement within 4 hours after the infants were born and blood glucose level monitoring) correctly.

Further discussions with the participants revealed that lipid was not provided to infants in the perinatology room, only in the NICU. NICU nurses said that the supply of lipids was limited. TPN was provided in the NICU, prepared by the nurses instead of the pharmacists.

Impression. Sufficient knowledge in hypoglycaemia screening, insufficient knowledge in post-correction of hypoglycaemia.

#### 14. HYPOTHERMIA

Observation. Participants showed appropriate knowledge in hypothermia management–including measuring body temperature for 5 minutes from the axilla, ensuring the cloth is dry and warm, and putting on a blanket and a hat. However, skills and knowledge in repeated temperature measurement (after 15 minutes), KMC, breastfeeding counselling, and checking for any signs of infection were inadequate. Regarding signs of infection, participants only mentioned the measurement of leucocytes.

Impression. Insufficient knowledge in hypothermia monitoring, KMC, breastfeeding counselling, and checking of any signs of infection

### 15. INFECTION

Observation. The diagnosis of infection is made by a paediatrician based on clinical symptoms. Laboratory examinations and antibiotic therapy are also based on paediatrician instructions.

Impression. Insufficient knowledge in infection signs and symptoms, as well as antibiotic regimens

### 16. HYPERBILIRUBINEMIA

Observation. Based on discussions with participants, clinical signs were monitored from day one. If signs of hyperbilirubinemia were present, nurses would seek advice from the paediatricians. Laboratory test included bilirubin serum. If positive, nurses would give intensive phototherapy 3x6 hours. However, oftentimes phototherapy was given 1-2 x 6 hours due to the limited number of phototherapy, while demand for phototherapy was high. During phototherapy, infants were fed using pacifiers or tube feeding. Babies with hyperbilirubinemia would be transported to the NICU if breathing was not improved with CPAP. However, if the NICU was fully-occupied, the babies would be treated in the Perinatology room using double phototherapy (above and below the infants). Both in the NICU and the perinatology room the bili blanket was not available.

The nurse's ability to carry out nursing actions for babies undergoing phototherapy is adequate. A paediatrician carries out the diagnosis and determination of phototherapy.

Impression. Management of hyperbilirubinemia need improvement due to the limited stock of phototherapy

### 17. SEIZURES

Observation. Nurses showed sufficient knowledge of clearing airway and provision of oxygen, fluid correction, and provision of slow phenobarbital injection. However, there was insufficient knowledge regarding follow-up actions if seizures did not stop, including electrolyte and fluid correction.

Impression. Lacking knowledge on follow-up actions if seizures did not stop

### 18. SHOCK

Observation. Shock management was not simulated/performed, but was discussed with participants. There was overall inadequate knowledge about shock management among participants, particularly regarding assessing the type of shock (hypovolemic, cardiogenic, or septic). Participants were able to answer questions regarding hypovolemic shock without acute blood loss and septic shock, but answers regarding hypovolemic shock with acute blood loss and cardiogenic shock were inadequate. Vital signs assessment on infants with shock were answered appropriately, laboratory assessment could not be explained comprehensively.

Impression. Insufficient knowledge about shock management

### 19. SEPSIS

Observation. Sepsis management was conducted if the paediatrician instructed it. There was overall sufficient knowledge about sepsis management (physical assessment, laboratory results interpretation based on the number of leucocytes, fluid correction, antibiotic regimens, and patient monitoring). Nurses were not aware of any SOPs about antibiotic regimens, but were able to mention as follows.

- a. First line: ampicillin, amikacin + gentamicin if renal function was good
- b. Second line: cefotaxime
- c. Third line: meropenem
- d. Fourth line: ampicillin + sulbactam (only if resistant to meropenem)

Impression. Adequate knowledge about sepsis management, although the nurses did as instructed by the paediatricians.

### 20. ENTERAL FEEDING

Observation. The skill was not simulated, but discussed with participants. Enteral feeding in the unit was performed with an orogastric method. Participants were able to explain the orogastric method appropriately. Supplementary feeding (using tube while breastfeeding) had never been conducted in the facility. Participants showed insufficient knowledge in enteral feeding, including the requirement for enteral feeding, early initiation of enteral feeding, scheduled feeding for LBW babies, and alternative feeding method. Participants mentioned the use of formula milk whenever breastfeeding was not feasible.

Impression. While participants were able to explain the orogastric method, there was a general lack of knowledge regarding enteral feeding probably because: a) most decisions were made by paediatricians and/or b) the use of formula milk was still permitted

### SUMMARY AND ADDITIONAL NOTES

In addition to performing simulation and discussions with the perinatology room nurses, we observed the delivery room, the post-partum room, the NICU, and infant ER. No doctors or

paediatricians participated in the simulation. All participating staff and the staff we met in other rooms were very welcoming and eager to learn. In every activity, nurses would always seek advice from doctors. The doctors could be GPs or paediatricians. In general, the number of doctors in the hospital was not sufficient. In every shift, only one GP would be on duty and he/she had to oversee all units in the hospital, whereas there were only 3 paediatricians who were active in the hospital (plus 1 inactive paediatrician who was doing a sub-specialisation in neonatology). The doctors would be rotated in the NICU and perinatology on a monthly basis. All paediatricians graduated from the same university.

Besides insufficient human resources, the hospital's layout made it difficult to transport babies from the Perinatology room to the NICU. To reach the NICU, the staff had to walk up a very steep path and no elevator was available to the NICU.

The availability of medical devices and equipment necessary for LBW management was also not sufficient. In the NICU, there were only 6 incubators and all infants—LBW or not—were put in the incubator. There was no family centre in the perinatology room. Pulse oximeters, CPAP, and ventilators were also limited. In the ER, ambu-bags and resuscitation masks for neonates were not kept in the emergency trolley, but in the staff room because it had been missing a couple of times. Electricity was also unstable at times and there was no UPS. An infant warmer had been impaired due to the unstable electricity. However, if the incubator was full, nesting was implemented. When we came to the perinatology room, some babies were nested.

There were not many cases requiring referral to higher-level hospitals. However, some complicated cases (such as diaphragm hernia) might need to be referred to other hospitals in the adjacent district. During the referral process, a perinatology nurse would assist the patients in the ambulance. As of August 2023, an ER team had been established to assist referrals. The ambulance had also been equipped with an incubator.

In summary, the staff' skills and medical device supplies in the facility should be improved. There was insufficient knowledge and skills about shock and seizure management, enteral feeding, KMC, early breastfeeding initiation, as well as breastfeeding counselling.

### **RECOMMENDATIONS**

- Enabling refresher training/drill regarding LBW cases and resuscitation at the hospitalsetting for all staff in charge. Transfer of knowledge should also be ensured.
- Ensuring the availability of equipment such as CPAP and phototherapy in each unit