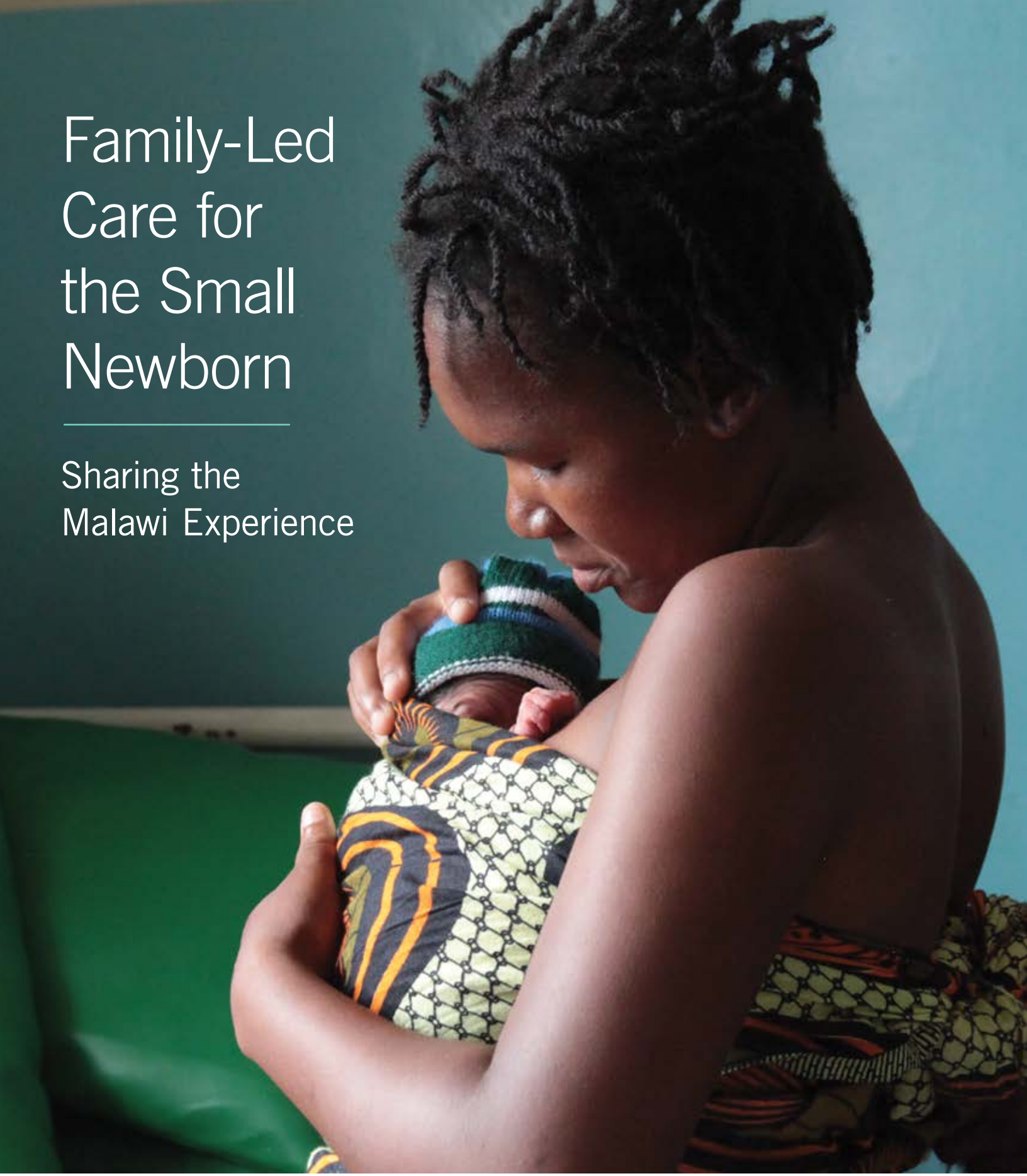

Family-Led Care for the Small Newborn

Sharing the Malawi Experience

EVERY PREEMIE SCALE

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Contents

A mother rests while holding her baby skin-to-skin at a health facility in Balaka district, Malawi.

Introduction

Globally, nearly 46% of all deaths in children under five occur during the first 28 days of life (the neonatal period), and preterm birth complications are the leading cause of under-five and neonatal deaths.[1] Studies show that preterm babies often die because they receive inadequate care during those crucial early days of life, particularly in low- and middle-income countries.

Given the global prominence of preterm birth and low birth weight, Every Preemie—SCALE (Every Preemie), a five-year USAID/Washington supported project (2014 – 2019), was designed to expand the uptake of interventions for early/small newborns in USAID's 24 priority countries in Asia and Africa. As one of the high priority countries, Malawi has a long history of commitment to improving its maternal, newborn and child health services. Malawi is one of a few countries that achieved Millennium Development Goal four to reduce under-five mortality by two-thirds by 2015.

While Malawi is making great strides in its efforts to improve maternal and child health, preterm birth and low birth weight remain high with rates of 10.5%, and 14%, respectively.[2,3] The Ministry of Health has demonstrated its commitment to improved preterm outcomes with the development of country-wide Kangaroo Mother Care (KMC) units in 122 hospitals and the launch of its national Every Newborn Action Plan (ENAP) in June 2015. Malawi's ENAP included a strategy to improve community health services and referral systems for families with preterm/low birth weight newborns discharged from the KMC units, and a robust community

Our Most Vulnerable Babies

- **Premature babies are born before 37 weeks of gestation.**
- **Of all small newborn deaths, two-thirds are born preterm.**
- **Babies that weigh less than 2500g are considered low birth weight.**
- **Low birth weight is considered an important predictor of mortality.**
- **Small newborns account for up to 80% of all neonatal deaths.[4]**

education program to prevent preterm birth and low birth weight by promoting antenatal care, screening for risk factors, birth preparation, recognition of preterm labor, as well as postnatal visits that focus on recognition of complications for mothers, and early management and referral of preterm and low birth weight newborns.

Within this environment and in response to findings from clinical assessments, Every Preemie developed the Family-Led Care model in collaboration with Malawi's Balaka District Health Management Team (DHMT). The country's unique situation – expressed need combined with demonstrated commitment and desire to improve – made Malawi an excellent partner to design and implement an innovative model of care for preterm babies.

The Family-Led Care model was designed to improve facility- and home-based care of small newborns. Here, we share the story of how the model was developed and implemented in Malawi's Balaka district and its promising results.

What do Preemies Need?

In Malawi, Every Preemie sought to bridge the gap between what preemies need and the care they were receiving. Even when babies are born too soon, the vast majority can survive with essential newborn care, including drying, warming, immediate breastfeeding, hygiene and handwashing, and basic care for breathing difficulties.

KMC is a globally recognized best practice and an effective, low-cost way to care for early and small babies by providing warmth, breastfeeding support, infection prevention and prompt discharge from the facility when the baby is stable and has shown adequate weight gain. KMC involves placing a small newborn on a mother or other caregiver's chest – skin-to-skin – for as long as possible each day.[5] This skin-to-skin care is effective regardless of where it is done, be it in a facility or at home.

Evidence shows family involvement in care of preterm babies is associated with better development outcomes.[6] It is also a better experience of care for all involved.

Every Preemie's goal was to use the evidence around "what works" to design appropriate and effective interventions that, when implemented, would improve the care of preterm and low birth weight babies – and, ultimately, save their lives.

Top: A mother carries her baby skin-to-skin.

Bottom: Sellina Mwenyedini (right), a hospital attendant, helps a preemie mother position her baby properly.

Caring for Small Babies in Health Facilities—What Did We Learn?

In its first 18 months, Every Preemie conducted clinical assessments of KMC in six facilities in Balaka district.[7] The clinical assessments were designed to evaluate:

- The adequacy of care preterm and small babies in Malawi were receiving; and
- The health services resources available at those facilities.

Lucy Mlangali, a hospital attendant, stands outside Chiendausiku Health Centre, one of nine facilities implementing Family-Led Care in Balaka district.

While KMC was introduced in Malawi in 1999 and in Balaka district in 2013, it was practiced inconsistently, potentially due to the same issues found in Every Preemie's health facility assessments. These included staff shortages; the lack of clear admission and discharge criteria; absent care standards and protocols within KMC units; and no patient follow-up after discharge. Additionally, some facilities had space constraints and lacked basic equipment and supplies needed for care of small babies.

The health facility assessments found that documentation of KMC was erratic or often missing altogether. There were no specified forms for recording daily progress, and often vital signs or chart notes were recorded on scraps of paper which were later misplaced. Typically, staff did not document frequency, volume, or mode of feeding, nor was there documentation of whether the weights recorded represented adequate or inadequate growth. Weight gain was sporadically recorded, and the scales being used were not accurate for weighing preterm babies.

Staff shortages were a critical issue identified in the assessments. In the postpartum and newborn patient care area at Balaka District Hospital, which includes preterm and low birth weight newborns as well as postpartum mothers with serious medical issues, the assessment observed a ratio of one professional staff for every 25–26 beds. When including support staff, the ratio ranged from 1:6 during the day and 1:17 during the night shift. Based on these ratios, it was apparent that not enough professional staff were available to adequately care for preterm and low birth weight newborns, who need more frequent attention than healthy babies. Mothers of preterm and low birth weight babies were also given the same discharge instructions as mothers with healthy newborns, so they were not adequately prepared to continue KMC at home and monitor their baby for danger signs.

Little was known about what happened to these early and small babies after discharge, since many did not return for more than one follow-up visit (if any). It was clear from these facility assessments that Balaka district needed a model of care that actively engaged the family while in the KMC unit, utilized support staff to encourage these families in their care, and built families' confidence and knowledge to continue providing the care their baby needed after returning home.

"They [mothers of premature babies] are kind of victimized, because they believe that if a woman gives birth to a preterm baby, it means the husband was promiscuous. So when they see the woman, they might say, 'Oh, you had a small baby because your husband is promiscuous.'

Lucy Mlangali *(pictured above)*,
Hospital Attendant, Chiendausiku Health Centre

Caring for Preemies within Communities

In Malawi, Health Surveillance Assistants (HSAs) are a link between communities and health care facilities. Yet Every Preemie's assessments found that not all HSAs received training in community-based maternal and newborn care, and none received training in how to support the care of small babies at the community or household level.

Through the formative assessment of community, family and health care provider knowledge, attitudes, beliefs and practices, family members were also found to have limited knowledge of preterm or small babies prior to their own experiences. Most families reported practicing KMC at home; yet, while

fathers were reported to be the greatest influence over a baby's care, they were not active participants in providing skin-to-skin care.[8]

Community attitudes towards preterm and small babies were mostly negative. Prevailing beliefs included the ideas that these babies were malnourished, unattractive, unintelligent, and unable to grow or survive. When a family practiced skin-to-skin care, community members were able to easily identify the baby as premature and shun or insult the family.

Armed with insights from these assessments, the Every Preemie team together with the Balaka DHMT sought to answer such questions as: How can we strengthen clinical care for the small newborn? How can we engage families more actively in that care? How can we prepare families to care for their newborns when they are home post-discharge? And finally, what are the necessary linkages at the community level with HSAs, for example, that will ensure continued care of the early/small baby?

> **"When others ask why they are putting the baby on skin-to-skin…the mothers are able to explain what they were taught. Because of their counseling and experience, mothers are able to tell other mothers who have given birth to preterm babies that they should come here. They know we can help.**
>
> **Sevelina Chikanda, Patient Attendant, Balaka District Hospital**

Introducing the Family-Led Care Model

In early 2017, Every Preemie in consultation with the DHMT developed and launched the Family-Led Care model. The model is designed to improve the quality of care in facilities and empower families to participate in the care of their small babies. It envisions families as active, confident participants in the care of their preterm and low birth weight newborns, while they are in the health facility and after they return home. The model leverages the use of support staff – including hospital attendants – by providing them with standardized educational materials to teach proper positioning, skin-to-skin contact, feeding, and how to recognize danger signs. Using standardized materials, support staff and attendants can counsel and coach families, alleviating the burden of professional staff shortages without sacrificing quality of care.

FIGURE 1. Family-Led Care model

In the Facility

Family-Led Care enhances provider skills and quality of care within KMC units and empowers families to directly participate in the care of their early/small newborn

- Quality improvement enhances and supports service delivery
- Builds clinical capacity for all health cadres responsible for care of early/small newborns
- Strengthens provider-family counseling with standardized messages using pictorial counseling flipbook
- Provides newborn monitoring forms for both staff and family members

Referral System

The Family-Led Care model links to existing community structures and referral systems and strengthens care of early/small newborns by empowering families to:

1) continue care at home;
2) recognize and seek immediate care for danger signs; and
3) return to the facility for follow up care.

In the Home and Community

Family-Led Care builds family confidence and skills to care for their early/small newborn at home and ensures an active link to the health system

- Care Groups and HSAs encourage families to return for facility-based follow up care
- Provides guidance for families on care of their early/small newborn at home
- Provides monitoring forms for families to track number of feedings, monitor temperature and breathing, and check for danger signs
- Promotes male involvement in newborn care

> **The good thing is the program did not only train health care workers. It also includes support staff. For example, we have hospital attendants here that are trained. Which means that in my absence, they can also take care of these babies. Where they feel they cannot manage them, they can call me to come in and assist them. Everyone working in this maternity unit is trained in Family-Led Care.**
>
> **Gift Kunimba, Nurse Midwife, Mbera Health Centre**

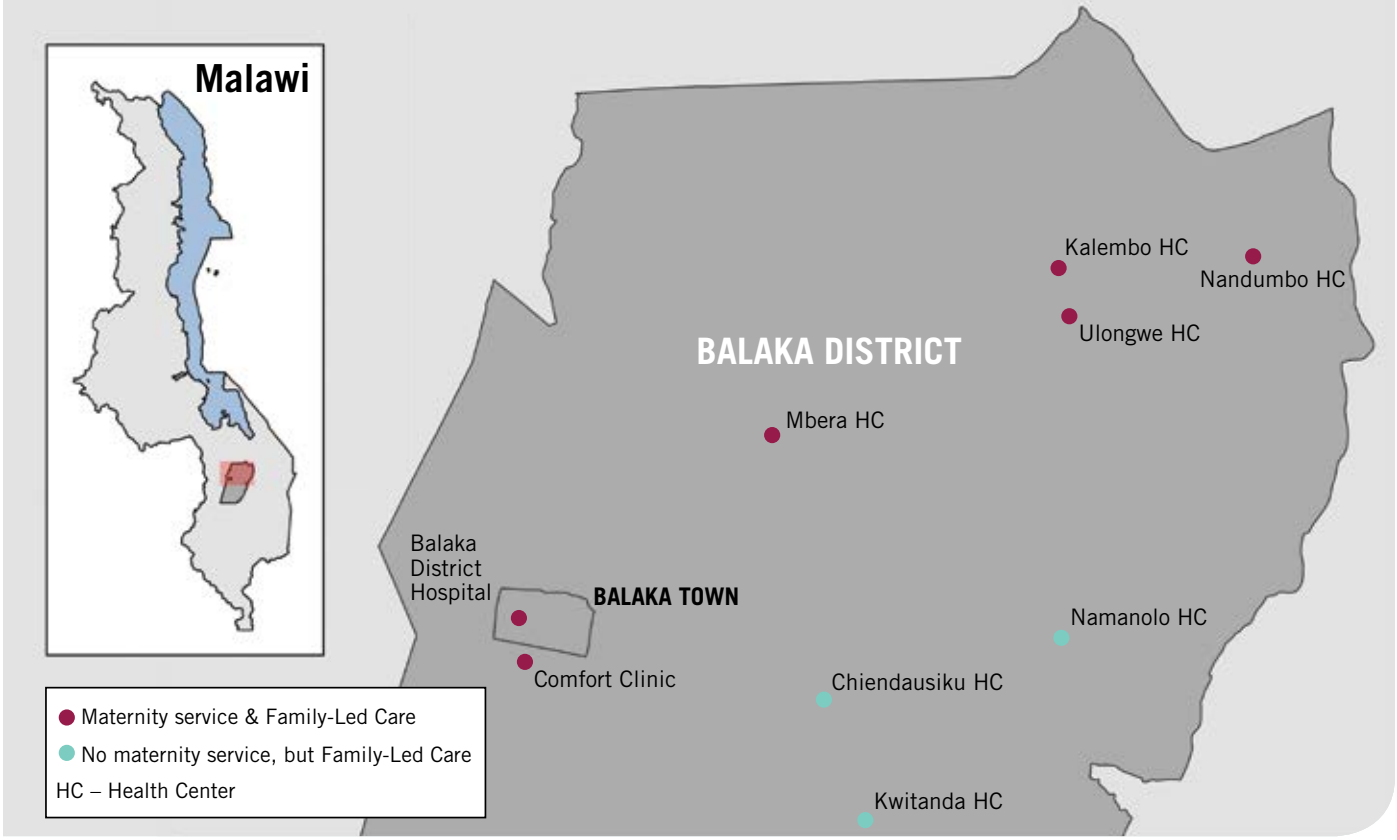
The Family-Led Care model:

- Educates and involves care providers and support staff in a facility to reinforce KMC practices and the quality of care provided;
- Increases family involvement in KMC and the baby's overall care, further compensating for staff shortages, building family confidence in caring for their baby, and improving quality of care;
- Provides a variety of resource materials for use in facilities, communities and homes to support monitoring and tracking the baby's care and progress;
- Dispels myths and negative perceptions about small babies within families and communities to help these babies thrive; and
- Links families to community structures and referral systems, so they feel confident in continuing care at home, recognizing and seeking immediate care for danger signs, and returning to a facility for follow-up care.

Family-Led Care in Malawi

Family-Led Care was implemented in nine health facilities: six facilities were able to support in-patient KMC and three health centres without maternity services provided follow-up care. The facilities were located in northern Balaka district, as shown in Figure 2.

FIGURE 2. Family-Led Care health facilities in Balaka district, Malawi



While it is important to ensure that the number of providers in a KMC unit is adequate, Family-Led Care does not require additional staff. It is integrated into the existing health system structure, takes advantage of all available staff members and resources in a facility, and places great importance on preparing parents and family members to be able to care for their small babies. Health care providers are trained in Essential Care for Every Baby[9] and Essential Care for Small Babies[10] and receive two days of training in the specific content and clinical elements of Family-Led Care. As a result, Family-Led Care has a foundation in evidence-based clinical care and is designed to be sustainable over time, readily adopted in new facilities, and feasibly scaled—in Malawi and elsewhere.

"We start chatting with the mothers and checking on the babies. We take the temperatures of the babies, we weigh the babies and tell the mother the amount of breast milk the baby should take for that particular day. The calculation is based on the weight.

Sevelina Chikanda, Patient Attendant, Balaka District Hospital

Family-Led Care Resources

The Every Preemie team developed a set of materials for both families and providers. Some tools help families learn what and how to observe their newborn. Other tools provide a place for documentation of the baby's care including mode and volume of feeding required.

The Family-Led Care Package was designed to be easy-to-understand for all audiences and literacy levels, and was produced in English and Chichewa, a national language of Malawi. The package includes a flip chart, feeding charts, and facility monitoring forms for staff use, plus a monitoring form and brochure for family use. The flipchart, brochure and family monitoring form include illustrations and simple instructions. Flipcharts support key messages when the baby is born or admitted to a KMC unit or space and when the baby is discharged from the health facility.

While in a health facility, care providers and support staff use these materials, particularly the flipchart, to counsel and guide families on caring for their preterm or low birth weight newborn. Families also receive instructions on how to care for their baby once they return home. Parents and family members learn how to complete the family monitoring form twice each day and look for danger signs that warrant urgent care. Prior to being discharged from inpatient care, families are instructed to return for a follow-up visit at a health facility. They take a copy of the family monitoring form home with them as a tool to help them continue to monitor their baby, and they bring the forms to follow-up visits to review with the health provider. Upon discharge they are also given a take-home leaflet with pictorial messages about the care of their baby at home, which they can share with other family members and use as a reminder to help them monitor their baby at home. HSAs and community care group members may also reference this brochure in their work.

Prior to the Every Preemie project, many facilities lacked accurate weight scales and other important equipment for the quality care of premature and low birth weight babies. Initially, the project provided an inventory of basic supplies such as a newborn weighing scale for each facility, locally procured calibrated feeding cups, digital thermometers, electric space heaters, and assorted plastic buckets to decontaminate feeding cups and to promote hand washing in KMC units. After a donation from a group of private donors, the project was able to support some simple upgrades to the KMC units and spaces. This included procuring local fabric, bed wedges, and baby hats and socks. Fabric was hung in units to provide greater privacy, tailored into gowns and infant wrappers, and fashioned into drapes, bed sheets and curtains. By project end, Every Preemie was able to purchase additional weighing scales with the ability to measure small fluctuations in weight.

Sevelina Chikanda, a patient attendant, helps a new mother wrap her baby skin-to-skin.

Contents of Family-Led Care Package (Malawi)

TOOL 1. Facility 2 Hour Feeding Chart (babies less than 1500g)

TOOL 2. Facility 3 Hour Feeding Chart (babies more than 1500g)

TOOL 3: Facility Monitoring Form for KMC Babies

TOOL 4. Family Monitoring Form

TOOL 5. Flipchart – Basic Care of Preterm and Low Birth Weight Babies

TOOL 6. Brochure – Basic Care of Preterm and Low Birth Weight Babies

Families at Home and in the Community

To support families once they returned home and to their communities, HSAs and care groups were oriented to the Family-Led Care model and resource materials. Their role is to visit families of preterm or low birth weight babies after they have returned home in order to provide support and encourage them to return to the health facility for their scheduled follow-up visit; go to a facility immediately if the baby develops danger signs; and continue with breastfeeding and skin-to-skin care. They also support the continued use of the family monitoring form and encourage fathers' participation in care.

Ongoing Quality Improvement

With the rollout of Family-Led Care, it was important to develop a solid quality improvement (QI) program. Working with MaiKhanda Trust, a non-governmental organization specializing in quality improvement, Every Preemie and the DHMT built a QI mentorship program to support the ongoing mentoring and supervision of clinical work, and to ensure a standard level of knowledge among care providers.

Twelve *QI mentors* were nominated by the Balaka DHMT to serve the nine health facilities including Balaka district hospital. Mentors were trained in facilitating QI skills, using data for decision-making, and scaling up Family-Led Care activities.

In addition to quality improvement measures, the DHMT, QI mentors and facility personnel made a series of commitments to support and sustain the Family-Led Care model as Every Preemie transitioned out of the district described in Table 1.

TABLE 1. Local stakeholder commitments to sustain Family-Led Care model

Stakeholder	Family-Led Care model commitments
DHMT	• Allocate ambulances with adequate fuel and ensure that vehicles are routinely serviced and available to serve the community, including preterm and low birth weight babies • Formally integrate KMC supervision into monthly DHMT supervision schedule • Supply essential resources, such as thermometers, by including in implementation plans and budgets
Health facility	• Conduct monthly/quarterly in-facility meetings with all maternity staff to review data quality and identify necessary changes/issues • Provide health talks about KMC and Family-Led Care during mobile clinics to sensitize community and improve support
QI mentor	• Plan QI visits and delegate to another mentor when not available • Lobby District Health Office for support • Educate new staff and students who arrive at facilities about KMC and the Family-Led Care model o KMC district focal lead to share QI gains from intervention sites to non-intervention sites in Balaka district • Utilize social networks like WhatsApp to keep in touch with their teams to be able to get and provide additional support

Making a Measurable Difference

To determine the project's success, Every Preemie enlisted the University of Malawi, College of Medicine and MaiKhanda Trust[11] to conduct phased implementation research. Both efforts revealed that providers and support staff had embraced the Family-Led Care model. Evidence also showed there was improvement in the adherence to clinical care standards. Providers indicated high satisfaction levels with the Family-Led Care model, noting that it improved communication with parents and other family members and eased their workload.

With data regularly collected from a variety of Ministry of Health sources (including facility registers and patient forms), the Every Preemie team identified performance indicators to measure over time, including:

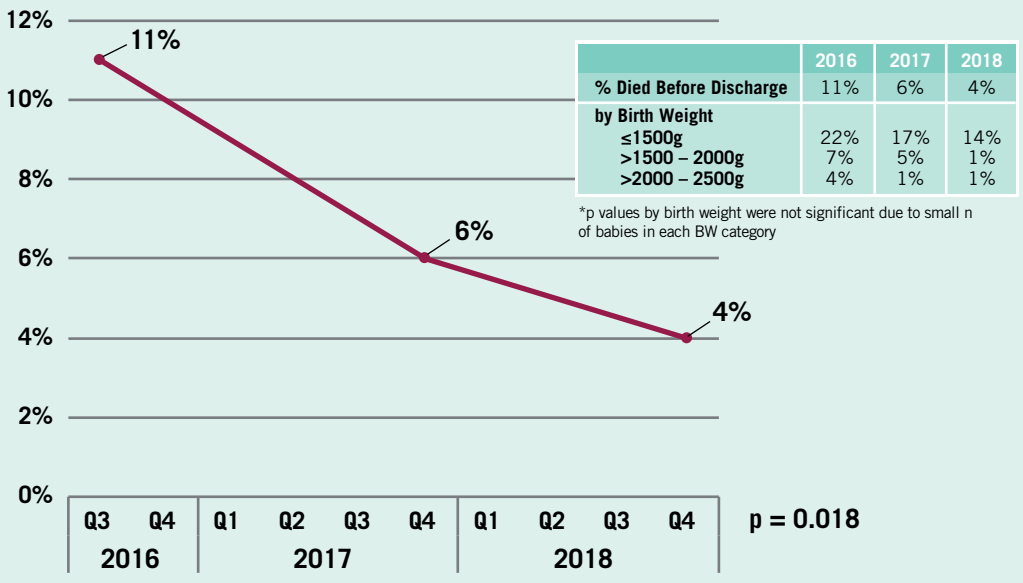
- Percent of eligible preterm and small newborns (<2500 g) initiated on KMC
- Percent of newborns in KMC who died before discharge

Assessing these indicators over a three-year period showed a significant decrease in the percentage of preterm and low birth weight newborns who died in KMC before discharge from the health facility (shown in Figure 3), and an increase in the percent of eligible preterm and low birth weight newborns initiated on KMC at the facility.[12] Anecdotally, care providers reported seeing higher survival rates of preterm and low birth weight newborns since the model started.

Top: Sevelina Chikanda, a patient attendant at Balaka District Hospital, leads a counseling session on basic care of preterm and low birth weight babies.

Bottom: A new mother looks at the Family-Led Care brochure.

FIGURE 3. Observed newborn deaths in KMC before discharge



	2016	2017	2018
% Died Before Discharge	11%	6%	4%
by Birth Weight			
≤1500g	22%	17%	14%
>1500 – 2000g	7%	5%	1%
>2000 – 2500g	4%	1%	1%

*p values by birth weight were not significant due to small n of babies in each BW category

Sellina Mwenyedini (center), a hospital attendant, counsels a mother on how much breast milk her preemie needs to take by cup.

Shifting Perspectives

In addition to data showing that more preterm and small babies survived, there was strong evidence that perspectives were shifting about these babies and such Family-Led Care principles as father participation, family engagement and skin-to-skin contact.

The College of Medicine found that at both the national and district levels, managers and other stakeholders were positive about the introduction of Family-Led Care and considered Balaka to be a benchmark district. Managers appreciated the ways in which the model involved and promoted the family's ownership of care for their newborn. One of the biggest achievements attributed to the implementation was the strengthening of facility-based follow-up care for preterm and small babies.

For families, revelations came from the fact that despite being surprised at having a preemie, their baby could survive if they followed the care guidance. Mothers, in particular, appreciated the encouragement and support they received from care providers regarding the importance of skin-to-skin contact, breastfeeding, and regularly checking the baby for danger signs.

"I get satisfied when I see that I've helped a mother with a baby and the baby has grown well and they are discharged. When we meet at gatherings in the community, mothers will come to show their babies to me and say, 'See your child now! She is growing well. She is big.' I feel good about that; satisfied that I have done something valuable here.

Sellina Mwenyedini *(pictured above)*, Hospital Attendant, Balaka District Hospital

Beyond Balaka District

The success of Family-Led Care in Balaka district led to the Ministry of Health's request to expand use of the model to sixteen other districts in the country and is inspiring other countries to consider adapting the model for

Lukia Julius (right) and her husband Osward Mphepo, proud parents of Vincent, a KMC graduate, and Shedrick (left to right).

their own use. With the Malawi project nearing its end, Every Preemie has provided the national Ministry of Health and Balaka district with training tools and resources to support the expansion of Family-Led Care throughout the country.

Based on the Malawi experience and in anticipation of the model's expansion beyond Balaka, the Every Preemie team updated the Family-Led Care Package of resource materials for wider application.

For more information about Every Preemie and the Family-Led Care model, or to view and download the global Family-Led Care package, go to: **www.everypreemie.org**

"To others, if they have a baby who is born prematurely or with low birth weight, they should follow the advice given to them by the health workers. If they follow the advice, the baby will grow just like any other baby. There might be some challenges whereby the baby cries, but that shouldn't make you remove the baby from KMC. If you do that, the baby will lose weight.

Lukia Julius *(pictured above)*, Mother of Vincent (a KMC graduate), Kalembo Health Centre

CASE STUDY

Family-Led Care Leads to Bright and Healthy Future

Samalani Katiye, his wife, Enipha Elisha, and their daughter Martha.

When Martha was born, her mother Enipha says she was barely the size of her own slender forearm. The nurse on duty at Balaka District Hospital recorded her weight at just over 1.5 pounds. She arrived eight weeks early and was immediately placed on oxygen to regulate her breathing. The odds did not look good for her survival.

To see Martha now—six months later, smiling up at her father with chubby cheeks and bright, dark brown eyes—is to witness a miracle in motion. Samalani, the proud bambo who carried his laboring wife to the hospital in the middle of the night, says he had faith in his baby girl all along.

"I was just hoping God would take care of her," Samalani recalls of first learning Martha was born prematurely. "I was not sure what to expect, but when I saw her, I knew that she would make it."

In the days following Martha's birth, she was transferred to the hospital's KMC ward, where Enipha learned how to place her fragile newborn skin-to-skin on her chest, keep her tiny body clean, and ensure she received enough milk through breastfeeding and by cup.

While Samalani was unable to visit Enipha and Martha in the KMC ward, he stopped by the hospital every day. His dedication as a father was an unusual but welcome sight for staff members.

"He was very involved and always there during visiting time," Sevelina Chikanda, a patient attendant at the hospital, says. "That continued with follow-up visits. He always accompanied the wife and baby to the hospital and participated in the sessions. They were learning together. Usually fathers don't do that. They think, 'This is woman's work. It is not my job.' This was a special father."

Samalani acknowledges that he, too, had never seen male examples in his own life who actively participated in caring for their children. When he and Enipha returned home with Martha, several people in their village even questioned some of the techniques the hospital had taught them.

"Some community members were discouraging us," he says. "But [my wife and I] encouraged each other. We said, 'Let's just focus on what we have been told on how we should take care of the baby.'"

Through Enipha and Samalani's dedication to practicing Family-Led Care, Martha graduated from the KMC program three months after her birth. At 6 months old, she weighed 11.2 pounds and is now happy, healthy and thriving.

"I just wanted to do what I was told to save my baby," Samalani says. "I hope she will continue to grow, start school and become a doctor for preterm babies."

Case study by Maureen Simpson

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[11] MaiKhanda Trust evaluated an aspect of the project unrelated to their implementation.

[12] Every Preemie does not have data on whether other facilities in Malawi observed similar changes during this time period.