

The Paediatric Development Clinic: A model to improve outcomes for high-risk children aged under-five in Rural Rwanda



Mothers playing with their babies in the Rwinkwavu Hospital PDC

By Kathryn Beck, Catherine M Kirk, Jessica Bradford, Christine Mutaganzwa, Evrard Nahimana and Olivier Bigirimwami



Kathryn Beck is the Nutrition Specialist at Partners In Health/Inshuti Mu Buzima, Rwanda. She is a registered dietitian with over seven years' experience of clinical nutrition practice and three years working internationally on paediatric nutrition programming, with a specific focus on improving the quality of programmes to detect and manage acute

malnutrition in infants and children.



Catherine M Kirk is the Director of Maternal and Child Health at Partners In Health/Inshuti Mu Buzima, Rwanda. She has over six years' experience in child health programming and evaluation and is Principle Investigator of a Saving Lives at Birth grant evaluating scale-up of a neonatal quality improvement programme with the Ministry of Health and advisor on and development evaluations with UNICEF Rwanda.

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Christine Mutaganzwa is a general practitioner and was the Paediatric Development Clinic lead from 2015 to 2018. She has seven years' experience of paediatric clinical care provision and programme implementation and three years' research experience in chronic diseases and child health.



Jessica Bradford is the Pediatrician Specialist at Partners In Health/Inshuti Mu Buzima, Rwanda. She is a pediatrician and internist with over eight years' experience working in East Africa. In her current role she is a clinical advisor in district hospital neonatal and paediatric units, as well as the Paediatric Development Clinic.



Evrard Nahimana, the Deputy Chief Medical Officer in charge of primary healthcare at Partners In Health/Inshuti Mu Buzima, is a clinician and public health researcher with over ten years' experience. His research has focused on how to strengthen capacity for delivering high-quality neonatal services across the continuum of care in rural Rwanda.



Olivier Bigirimwami is a non-communicable disease trained nurse at Rwinkwavu District Hospital in eastern Rwanda. He has been working in the Paediatric Development Clinic (PDC) for the past four years and is a mentor in the Kayonza District catchment area to other PDC nurses.

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Location: Rwanda

What we know: In Rwanda 9.5% of newborns are born prematurely and 6% are born low birth weight (LBW). Identifying and managing growth failure in LBW infants is challenging.

What this article adds: Preterm and LBW survival is increasing in Rwanda, partly due to opening of neonatal care units (NCUs) in district hospitals. Review of progress of a cross-section of infants aged 1-3 years post-discharge found prevalent feeding difficulties, anaemia and stunting and wasting rates well above that of the general infant/child population. In response Paediatric Development Clinics (PDCs) were developed by Ministry of Health/UNICEF/Partners in Health (PIH) to provide more comprehensive and specific medical/nutritional follow-up. Subsequent review of a cohort of 316 enrolled infants less than six months old indicated ongoing poor nutritional status (25% severely underweight, 5% severely malnourished). Implementation challenges included difficulties calculating corrected age and gaps in capacity to assess and support feeding difficulties. Actions taken include specialist training for staff on managing infant feeding difficulties in low-resource settings, identification and training of expert mothers, strengthened breastfeeding support in the NCUs, adaptation of the C-MAMI tool to manage malnourished cases, and development of a mobile app to help anthropometric/growth assessment. Further experiences will be documented. Research is examining contributing factors to malnutrition in this age group.

Background

Postnatal medical, nutritional and developmental needs of infants born preterm, low birth weight (LBW), with hypoxic ischemic encephalopathy (HIE) (a brain injury following asphyxia), central nervous system (CNS) infections and other disabilities, including trisomy 21, are different from those of normal weight, full-term infants without developmental disabilities and have a higher risk of respiratory, hematologic, infectious, sensory and neurologic complications and require regular monitoring and early intervention. Optimal nutrition and growth requires monitoring growth velocity over time, including weight, length and head circumference, and adequate interpretation of z-scores to assess for malnutrition. Identifying growth failure in LBW infants is particularly challenging as this group includes a mix of preterm infants, small for gestational age (SGA) infants, and infants who are both preterm and

SGA. Current World Health Organization (WHO) growth charts to assess nutritional status (weight-for-length) exclude infants <45 cm. Intergrowth 21 has recently published international growth standards based on appropriate gestational age (AGA) for preterm infants, yet detailed information on gestational age and birth weight is often lacking in low- and middle-income countries (LMICs).

Infants born preterm may also have difficulties breastfeeding due to potential for an immature suck pattern, difficulties coordinating breathing and vomiting during or after feeding, and have reduced milk intake. This requires strategies to regulate the infant, including providing Kangaroo Mother Care (KMC) for thermoregulation and bonding and strategies to improve suck and reduce vomiting. Infants born with syndromes such as trisomy 21 may have low muscle tone or exhibit “floppiness,” causing the infant to be less alert and have decreased tone and sensation in the mouth and throat, resulting in difficulty swallowing. Infants born with HIE may demonstrate high muscle tone, causing stiffness and resulting in difficulty in positioning for breastfeeding, and “tight” jaws, causing difficulty in latching.

To address these challenges, specialised feeding support by trained personnel is needed to ensure adequate breastfeeding and therefore appropriate growth. In addition, higher risk of developmental delay in these newborns requires early stimulation and developmental monitoring over time.

Country context

In Rwanda 9.5% of newborns are born prematurely and 6% are born LBW (Every Preemie Scale, 2017). Preterm and LBW survival is increasing in Rwanda, in part due to the opening of neonatal care units (NCUs) in district hospitals. Postnatal follow-up of healthy newborns is performed at the community level by Agent de Santé Maternelle et Infantile de Santé (ASM), who are Community Health Workers (CHWs) in charge of maternal and newborn health. After facility discharge following delivery, ASMs conduct postnatal home visits that include identification of danger signs, with referral to health facilities if needed, breastfeeding education, encouragement of KMC for LBW infants, and weighing newborns. However, no national system is in place for targeted postnatal follow-up of high-risk newborns including preterm, LBW, or infants with other vulnerable medical conditions. In a study conducted in Kayanza district in eastern Rwanda, LBW and preterm infants discharged from the hospital NCU were followed up at one to three years post-discharge to determine their nutritional, medical and developmental status in the absence of routine follow-up (Kirk et al, 2017). Caregivers reported 47% of children had feeding difficulties and 40% reported signs of anaemia; 67% had an abnormal development screening on the Ages and Stages Questionnaire-3 (ASQ-3). Notably, malnutrition parameters were more than double or triple the 2014/2015 Demographic Health Survey (RDHS, 2014/15) national averages: 79% stunted, 9% wasted and 38% underweight, vs. 38%, 2%, and 9% nationally, respectively. Lack

of comprehensive and consistent follow-up can have detrimental impacts on the health and well-being of high-risk newborns, which has lasting implications beyond the neonatal and infant periods.

Paediatric Development Clinics

In 2014 Partners In Health (PIH), in collaboration with the Rwanda Ministry of Health (MoH) and UNICEF, implemented Paediatric Developmental Clinics (PDCs) to provide integrated early-intervention clinical, nutritional, social and developmental services to infants born with perinatal complications in rural Rwanda. Currently there are eight PDCs across two districts in the eastern province of Rwanda. To our knowledge, this is the only clinic of its kind in sub-Saharan Africa. PDC provides integrated care to at-risk infants and children under-five years old in a medical-home model, using a comprehensive and continuous team-based approach. Nearly 90% of infants admitted to the PDCs are neonates discharged post-NCU admission for prematurity, birth weight <2000 grams, HIE, cleft lip/palate, or trisomy 21. Other reasons for admission include developmental delay, hydrocephalus and those <12 months old who had required hospitalisation for complicated severe acute malnutrition. PDCs are funded by the MoH with support from PIH. A costing study is underway to assess the cost of providing PDC care.

PDC interventions

At each PDC visit caregivers participate in a group education session followed by individual consultation, where the nurse screens the patient for danger signs following Integrated Management of Childhood Illness (IMCI) guidelines (and refers to IMCI if needed), weighs the patient, measures the length/height and head circumference, and calculates corrected age up to two years in infants born premature, interval growth in children <2 years (targets include ≥ 20 grams/day <3 months and ≥ 15 grams/day 3-6 months) and z-scores using WHO growth charts. A feeding assessment is conducted to assess appropriateness of the diet at home and the child's appetite. Certain conditions require medical management; for example, providing iron to premature infants up to 12 months old or provision of anticonvulsants to infants with seizures. Referrals are made to specialists where needed, including physiotherapy, cardiology and optometry to address medical complications. Children are screened for developmental problems at specific ages (including 6, 12 and 18 months), using the ASQ-3. Counselling is provided to the caregiver by the nurse and/or social worker regarding medical conditions, growth assessment, nutrition and feeding, and/or developmental status. Social workers may conduct home visits to those most vulnerable patients.

Food supplementation is provided to mothers of infants with growth faltering and counselling to breastfeeding mothers where needed. Those with medical complications are referred to district hospitals.

PDC staff training and mentorship

Nurses in PDCs are usually general nurses with a post-secondary diploma in nursing. Social workers typically also have a post-secondary diploma.

Both nurses and social workers have been trained in the PDC protocol annually since 2014, with new PDC staff trained as new clinics open.

PDC has adopted the Mentoring and Enhanced Supervision for Healthcare (MESH) model (Anatole et al, 2013), developed by PIH and MoH, and utilises one-on-one provider mentorship as a method for continuous quality improvement. PDC mentors are district hospital-based nurses in charge of hospital PDCs who have demonstrated exceptional provision of quality care. They are trained in mentorship methods and are facilitators during annual PDC trainings. Mentors utilise checklists to assess quality of care during mentorship visits, which inform targeted feedback to the mentee.

Additionally, the PDC receives mentorship support from the PDC Manager (who is a clinician), a pediatrician/internist doctor trained in the United States and nutritionists from PIH and district hospitals.

Nutrition outcomes in the PDCs

Nutritional status of infants under six months old was assessed over the period January 2015 to December 2016. During this period, 316 infants under six months old completed follow-up (52% female) and had 2,117 individual PDC visits. They were enrolled with the following diagnoses: prematurity or LBW (70%), HIE (28%) and other conditions (9%). About half (43%) were born <37 weeks (32% with missing gestational age data), 53% had a low weight at birth (14% VLBW (very low birth weight)), and 32% were SGA (36% with missing data).

Prevalence of weight-for-age (WAZ) and weight-for-length (WHZ) were used to assess nutritional status at 3 and 6 months old. When a gestational age was available, corrected age was used. Prevalence data show that, at three months, 9% had moderate acute malnutrition (MAM: WHZ <-2) and 5% had severe acute malnutrition (SAM: WHZ <-3). Seventeen per cent were moderately underweight (WAZ <-2) and 25% were severely underweight (WAZ <-3). By six months, SAM increased slightly to 6% and MAM almost doubled (16%). By six months, WAZ <-2 increased to 22% and WAZ <-3 decreased to 23%. WAZ <-2 at six months is more than five times the national prevalence (4.3%), while WHZ <-2 at six months is three times the national prevalence (5.4%). The same infants were not used to assess growth trajectory over time in these data, which only show prevalence of malnutrition at three and six months of age.

Nutrition-related challenges and solutions developed in PDCs

Although the PDC has provided a much-needed service in the absence of high-level postnatal follow-up for high-risk infants, some challenges remain.

Nutrition assessment

Identification of accurate gestational age at birth remains a challenge in many low and middle-income countries (LMICs). This prevents differentiating prematurity, SGA and LBW, which has implications for growth trajectory and achieving optimal growth targets.

For infants with a known gestational age, nurses calculate corrected age up to two years old, which is used to determine z-scores and (ideally) in counselling on timing for introduction of complementary feeding. Calculation of corrected age and interval growth, or growth velocity, is a challenge in the PDCs. Corrected age requires calculation of chronological age and subtracting weeks premature from the chronological age. For interval growth, nurses determine the number of days since the last PDC visit and divide this by the difference between the child's current weight and previous weight. Errors in calculations lead to discrepancies in both corrected age and interval growth. Initial data showed that corrected age was not calculated for around three quarters of infant visits and interval growth was missing for one quarter (Ngabireyimana et al, 2018).

Plotting WHO z-scores has also remained a challenge for nurses, particularly with those infants who fall on the lower end of the growth curve, where distinguishing between one growth centile and another is challenging.

For those infants whose gestational age is known, an mHealth application has been developed through a collaboration with Dtree International. This tool assists PDC nurses in the calculation of corrected age and chronological age. Additionally, it calculates interval growth and z-scores for all children, regardless of availability of gestational age. The decision-support tool links nutritional calculations to further nutritional assessments and/or counselling through messages to the provider. Staff in one of the PDC catchment areas have been trained and effectiveness of the tool will be assessed before scaling up to the remaining PDCs. The hope is that this tool will aid PDC nurses with earlier recognition of growth faltering/failure and appropriate guidance on how to manage it.

Infant feeding assessment and breastfeeding support

Adequate and safe exclusive breastfeeding starts in neonatology and continues in the home and outpatient setting. In the two district hospitals from where PDC patients are referred, at baseline (October–December 2017), only 6% of infants born VLBW, 60% of infants born LBW, 72% of infants with HIE, and 65% of neonates overall were exclusively breastfed from the breast at time of discharge (compared to a national breastfeeding prevalence of 87%). Adequate growth in these infants during admission was also a challenge: average interval growth during admission was 0.6 grams/day for VLBW infants, 5.0 grams/day for LBW infants, and 15.4 grams/day for infants with HIE, compared to the recommended 15 grams/day.

Knowledge and practice in addressing feeding challenges in this population is a challenge in PDCs and the challenges often increase after hospital discharge, when there are fewer opportunities to receive counselling and support at home. Accurately and comprehensively assessing feeding difficulties requires expertise (often lacking at community level), as does the provision of counselling to mothers in this population, which also requires time to 'trial and error' positioning and

other interventions. Often infant formula was provided in PDCs to mothers experiencing difficulties with breastfeeding; however, provision of artificial milk, particularly in rural, LMIC settings, may pose risks to the infant that outweigh any benefit, including use of unclean water, expense of infant formula and the burden of preparing artificial milk feedings, in addition to missing the well established benefits of exclusive breastfeeding.

To address these issues a partnership was formed with MAITS, a UK-based non-governmental organisation (NGO) that aims to improve the lives of individuals living with disabilities through access to family support, quality healthcare and education. MAITS teams of healthcare and education experts travel to low-resource settings to share their skills with other health providers. In February 2018 two speech and language therapists, who are international MAITS trainers, travelled to Rwanda to train 24 nutritionists, neonatal nurses and midwives working in maternity and post-partum wards and PDC nurses and social workers on their self-developed two-day training, Working with Infants with Feeding Difficulties in Low Resource Settings. The purpose of the training is to improve the knowledge and skills of healthcare providers working with infants with feeding difficulties, and their caregivers, to support breastfeeding and nutrition. Through a training-of-trainers model, three local 'Master Trainers' were trained to be able to continue delivery of this training in Rwanda and continue to be supported by MAITS trainers through ongoing phone calls and case studies. To date, the three Master Trainers have gone on to train 36 additional healthcare providers from seven district hospitals in Rwanda.

In addition, a new position has been created in both district hospital NCUs in the PDC catchment areas called, 'Umujejanama mu konsa' or 'Expert Mothers'. These are women who had a baby discharged from the hospital NCU who is now enrolled in PDC and serve as peer counsellors to other mothers, helping them learn how to breastfeed and promoting early and exclusive breastfeeding through counselling, education and emotional support. The Expert Mothers have been trained by the Master Trainers in a three-day version of the MAITS training and components of the WHO Breastfeeding Counselling training course. They continue to receive on-going mentorship from the Master Trainers.

Other strategies to promote early and exclusive breastfeeding include availability of refrigerators in the hospital NCUs for breastmilk storage, KMC chairs and breastfeeding u-shaped pillows to support comfortable breastfeeding positions, privacy screens for mothers who do not want to breastfeed or express breastmilk in an open ward, and education materials, including tablets and projectors to play Global Health Media Videos for mothers. The impact of these measures will be assessed through ongoing and continuous monitoring and evaluation.

Addressing both the issue of accurate nutritional assessment and feeding assessment, in Au-

gust 2017 the PDC protocol was revised to include more clear and comprehensive guidance on assessing and managing malnutrition in infants <6m old and their caregivers through integration of the Community Management of Malnutrition in Infants and At-Risk Mothers (C-MAMI) tool into the PDC protocol. This shifted treatment of uncomplicated acute malnutrition in infants <6m old to PDC, instead of referring these infants to the district hospital. A complementary algorithm was developed to guide nurses and social workers in growth failure and malnutrition assessment and management. The C-MAMI counselling tool was translated into the local language, Kinyarwanda, and staff were trained in September 2017. Ongoing facility-based mentorship has continued since that time by PDC mentors and nutritionists.

Conclusion and way forward

This experience demonstrates that LBW/premature/disabled infants are at high-risk of malnutrition, and that active follow-up and intervention is necessary to address this. In this rural Rwandan context, PDCs are a medical-home model that are being implemented in the Ministry of Health system with additional external support (PIH and supplementary funding from donors). While nutrition outcomes from initial implementation of this model were not satisfactory, we have identified critical areas for improvement among this high-risk population that are being acted on through several strategies. Ongoing assessment of PDC interventions will continue in all clinic sites, with continuous quality improvement to enhance the nutritional, medical, and developmental outcomes of infants admitted to PDCs. We will continue to develop and share our model for outpatient follow-up in a rural setting of infants born preterm, LBW, or with other conditions, and to raise awareness of the special needs of this population in developing policies and practices to meet their needs. There are ongoing research studies to assess the factors associated with malnutrition in PDC patients <6m, as well as those 6–59 months, cost-effectiveness, and overall impact of PDC on children's health, nutrition and development to further inform the way forward.

For more information, contact: Katie Beck at kbeck@pih.org

References

- Anatole M, Magge H, Redditt V, et al. *Nurse mentorship to improve the quality of health care delivery in rural Rwanda*. Nurs Outlook. 2013;61(3):137–144.
- Every Preemie Scale. Rwanda: Profile of Preterm and Low Birth Weight Prevention and Care. 2017.
- National Institute of Statistics of Rwanda. (2015). *Rwanda Demographic and Health Survey Final Report 2014–2015*. Republic of Rwanda: Kigali, Rwanda.
- Ngabireyimana E, Mutaganzwa C, Kirk CM, et al. *A retrospective review of the Paediatric Development Clinic implementation: A model to improve medical, nutritional and developmental outcomes of at-risk under-five children in rural Rwanda*. Maternal Health, Neonatology and Perinatology. 2017; 3(13).
- Kirk CM, Uwamungu JC, Wilson K, et al. *Health, nutrition, and development of children born preterm and low birth weight in rural Rwanda: a cross-sectional study*. BMC Pediatrics. 2017; 17:191.