Abstract

Background: Follow up after hospital discharge is a recommended and common medical practice for high risk infants like those born with low birthweight and at preterm, this however is a challenge in Low income Countries (LIC). Premature babies are at risk of long term disabilities and require continued care both at home and in designated facilities. We sought to describe the attendance of scheduled follow up clinic visits for low-birthweight preterm infants post hospital discharge.

Methods: A review of available records for all infants seen in the preterm clinic at Mulago National Referral Hospital between January and December 2016 was done. After discharge from the Special Care Baby Unit (SCBU), infants are followed up in the Kangaroo Mother Care (KMC) clinic every fortnight until they weigh 2500gms. They then transition to the Preterm Care Clinic (PTC) where they are followed up every two to three months until they are at least 18 months of corrected age.

Findings: Between September 2014 and December 2015, 7224 neonates were admitted to the Special Care unit of Mulago Hospital. Of these, 3537 (49 %) weighed less or equal to 2500 grams (low birthweight), thus majority were eligible for follow up in the special clinics after discharge. Of the 590 babies registered in the PTC during the study period; 423 (71.7%) were included for analysis and 167 (28.3) % were excluded due to missing or incomplete data. Most of the infants
weighed 1501-2000gms (50%), only 3% weighed less than 1000gms, 14% more than 2000gm and 5%
record of birth weight was missing. Almost 90% of the visits during KMC clinic were on schedule as
compared to 64% during the PTC attendance. The average number of visits in the KMC clinic were
three per baby; 105 babies had between 4-5 visits and 13 had 6-7 visits. About 15% of the
participants were still attending the clinic by one year of age or more and only one was from the less
than 1000gms category. Many babies were not seen in the clinic after the age of 6 months.

**Conclusion:** Scheduled follow up clinic attendance for low birthweight preterm infants is suboptimal
with only one out of every for four children were still being followed up by one year of life hence
missing out on the benefits of longer follow up. There is need to strengthen utilization of available
services, community support and devise means to improve the long term follow up for especially the
extreme preterm infants.

**Key words:** Preterm, Low birth weight, Scheduled follow up, clinic visits, post hospital discharge

**Abbreviations:** HIC High Income Countries, LMIC Low & Middle Income Countries, LBW Low Birth
weight, KMC Kangaroo Mother Care, PTC Preterm Care, SCU Special Care Unit, WHO World Health
Organization

**Introduction**

Follow up care after hospital discharge is a known medical practice and it is highly recommended for
patients at risk and/or with chronic ailments (1). Benefits of early Out Patient follow up after hospital
discharge is variable according to patient complexity (1-4). To survive and thrive, preterm infants
require a continuum of care from preconception to adulthood but this is still an uphill task in many
L/MIC settings. The care given to the infant during the neonatal period and early infancy/childhood
affect their quality of life later (3-6).

Prematurity is on the rise worldwide due to advances in medical technology, urbanization and
growing populations especially in cities posing a major public health concern due to constraints on
the limited resources in many LIC (7). In 2012, 15 million preterm infants were delivered globally, majority in South Asia and Sub Saharan Africa (7-9). In Uganda, one of every seven newborns is preterm, contributing 14.3% of total deliveries annually and this is the highest in the East African region (10).

Preterm birth and low birth weight are significant risk factors for morbidity and mortality in early infancy. Prematurity and its complications is now the second leading cause of death in children under-5 years globally, and the single most important direct cause of death in the neonatal period [8, 9].

Survivors are at risk of lifelong disabilities some of which may be identified shortly after birth and others later in life hence the need for longer follow up post discharge. Early identification and appropriate management of disease helps prevent complications and increase survival for this high risk infant [11]. Preterm birth accounts for 3.1% of all Disability Adjusted Life Years (DALYs) in the Global Burden of Disease, more than for HIV and malaria [12].

In many low and middle income countries (LMIC), efforts geared towards prevention and care of premature infants is limited compared to that in high income countries. The cost of care, resources and commitment towards this is minimal because the burden of prematurity has not been weighted in these countries (7, 8).

Mulago National Referral Hospital runs a follow-up clinic for preterm babies and this has been in existence for more than 30 years. Initially the clinic run once a week and later two clinics KMC (the ambulatory kangaroo clinic for infants weighing less than 2500 grams) and PTC (preterm clinic for infants weighing more than 2500 grams) were introduced still operating once a week each. For the past five years, the frequency KMC and PTC clinics has increased to twice a week each due to the increasing number of preterm infants over the years. Services offered in the clinics are majorly professional including health education, medical, growth and development assessment of the infants. These are offered by Nurses, Resident Doctors and Paediatricians, all services are free of
charge. Clinic attendance has not been assessed before and this could have significant implications on the outcome of the infants both during the short and long term. Drawing on program data with the view of generating insights to improve follow up in preterm and in line with proponents for operational research (13, 14). We assessed the attendance to scheduled follow up clinic visits for preterm infants after discharge from Mulago National Referral hospital in Kampala.

**Methodology**

**Study design:** This was a Descriptive Retrospective Chart review.

**Setting**

*Care and discharge practices in the Special Care Baby Unit (SCBU) of Mulago Hospital*

The SCBU is based and operates in the Directorates of Obstetrics and Gynaecology (OBGYN) and Paediatrics to care for newborn babies who require special/additional care shortly after birth. Care provided is of level II-III NICU, no intensive care services are available in the unit. On average 480 babies are admitted to the unit every month. The commonest reasons for admission include prematurity, LBW and birth asphyxia. Almost half of the babies admitted are preterm/LBW infants and about 20% of these die annually before discharge. Most of the babies (more than 90%) are in-born and the rest are referred from neighbouring health facilities and/or community. The unit serves the urban and peri-urban communities around the hospital and is the largest neonatal training unit for Makerere University College of Health Sciences and other institutions. In the SCBU, care is offered by five Paediatricians and 19 nurses who work in three shifts; the junior and resident doctors rotate in the unit for a week to a month based on their academic program. All services in the hospital are free except for some investigations and medicines.

The low birth weight and preterm infants are admitted and discharged to the ambulatory Kangaroo Mother care Clinic (KMC) when they are considered stable. This implies that they are free from medical illnesses; can tolerate feeds well; require no respiratory support and can maintain normal
body temperature in KMC/cot. The mother too should demonstrate ability and knowledge in aspects of baby care like feeding at the breast or using alternative methods; should be able to identify danger signs and shows willingness to bring back the baby for follow up. Discharge from our unit is not based on acceptable weight gained of 1500gms, as per the WHO guidelines and facilities in high income settings. Early discharge is mainly due to constraint on space, resources and sometimes social reasons by the caregiver (20).

In the KMC clinic, babies are reviewed on a weekly to fortnightly basis until they gain 2500 grams. They then transition to the Preterm Clinic (PTC) where they are followed up until the age of at least 18 months of corrected age and/or are transferred to specialized clinics when needed. Follow up in the Preterm clinic is at intervals of two to three months based on individual concerns/age; every two months for the first six months of life and then every three months thereafter.

At the initial visit at the KMC clinic, a document in form of a book is opened for every infant where all information regarding birth and other clinical information is captured at each visit. In the KMC clinic, the parents keep the books when they transfer to the PTC clinic, the book is kept at the central registry and retrieved when the baby is brought for review during follow up.

The KMC clinic is run near the SCBU based in the OBGYN directorate while the PTC clinic is based in Child Health premises in the Directorate of Paediatrics to ease access of care for a baby requiring medical attention beyond or more than what is available in the clinics.

In the clinics, babies are assessed for physical wellness, majorly health, feeding practices, motor skills, immunization status, growth and development monitoring. Other concerns are addressed as they arise, no standardized follow-up guidelines or protocol for community use are available at the moment. Aspects including family structure/function, cognitive development and pre-academic skills are rarely assessed. One Paediatricians, 1 or 2 Paediatric resident doctors and one nurse care for the babies during each clinic visit. On average 50 babies are seen every week.
Apart from the professional services regarding health and child care, it is solely the responsibility of the family/caregivers to bring babies back to the facility for review. There are no incentives given in the clinics, such as, transport refund, reminders for attendance or baby supplies/medications during follow up.

**Participants**

The study participants were all preterm/LBW infants that were in the follow up clinic in 2016. All medical records for preterm infants registered and attending the Preterm Clinic (PTC) at Mulago Hospital between January and December 2016 were included for review and analysis. These infants were born and admitted in the SCBU between the period of September 2014 and December 2015. Permission to use infants’ records was obtained from the Mulago Hospital Paediatrics Directorate Administration, no babies’ names or other identifiers were added in the data.

**Data collection and analysis**

Raw data was collected from the participants’ medical records, entered in excel and analysed using Stata version 13.0. Baseline characteristics of the participants included demographics, clinic visit dates, serial weights and clinical variables were captured and summarized as shown in Table 1. Univariate comparisons were made between the different categories. Results are reported in counts and percentages with p-values.

**Results**

Baseline data

Participants were infants seen in the Preterm clinic between January and December 2016. There were 590 babies registered in the PTC during this period; 423 (71.7%) were included for analysis and 167 (28.3%) were excluded due to missing or incomplete data and or entries of less than three visits. Patients’ records (in form of books) are kept in the clinic and they are retrieved when the infants are
brought for follow up. On the first visit every baby is assigned a clinic serial number for the year, for example x/16 or a/18 with x and a as serial numbers and 16 and 18 as the year of attendance.

Slightly more than half, 52% of the participants were female.

Table 1: Characteristics of participants

| Variable               | N=423 | Frequency (%) |
|------------------------|-------|---------------|
| **Sex**                |       |               |
| Female                 | 222   | 52            |
| Male                   | 201   | 48            |
| **Birthweight category** |     |               |
| <1000g                 | 13    | 3             |
| 1001-1500g             | 111   | 26            |
| 1501-2000g             | 213   | 50            |
| 2001-2500g             | 61    | 15            |
| Unknown                | 25    | 6             |
| **KMC visits**         |       |               |
| Scheduled              | 1232  | 87            |
| Unscheduled            | 191   | 13            |
| **PTC visits**         |       |               |
| Scheduled              | 738   | 64            |
| Unscheduled            | 422   | 36            |
| **Follow up status**   |       |               |
| ≥ one year             | 63    | 15            |
| < one year             | 360   | 85            |
**Weight distribution and changes**

Regarding the birthweight, half of the infants were in the 1501 to 2000 grams category.

Only 13 (3%) of the infants weighed less than 1000 grams and 61 (15%) were between 2001-2500 grams. For 25 infants, birthweight was not recorded/unknown. Only near complete (at least more than three entries during follow up) or available records were included for analysis, a limitation for a retrospective study design. The average birthweight was 1719 grams. By the first visit to the KMC, 260 (62%) had gained weight, 88 (21%) had not gained while for 75 (17%) infants this information could not be established (table 2).

Of the 63 infants who were still in care by one year, 20 (32%) weighed between 5.1-7.5 kgs; 40 (63%) weighed 7.6-10 kgs; 1 (2%) weighed more than 10 kgs; and for 2 (3%) weight was unknown. Only eight (13%) infants had attained 10 kgs or more by one year and one infant in the less than 1000 grams category was still in care.

**Pattern of visits**

There were 1417 visits in KMC, 1232 (87%) were on schedule while 191 (13%) were not on schedule.

The average number of visits was 3; 117 (28%) had 2 visits 145 (34%) infants had 3 visits, 105 babies had 4-6 visits and 13 had 6-7 visits on schedule. Of the babies whose visits were not on schedule, majority it was only once or two times, 89%.

There were 1161 visits in the Preterm Clinic (PTC), 738 (64%) were on schedule while 422 (36%) were not on schedule. The mean number of visits on schedule to the preterm clinic was 2.8.

Scheduled clinic attendance was better in the KMC clinic than the preterm clinic. Only a quarter of the infants 63 (15%), were still in care by one year and/or more (Table 2).

**Duration of hospital stay and age of participants at clinic visits**

The average hospital stay in the neonatal unit after delivery for the participants was 7.6 days. The means for hospital admission for the four categories were as follows: 13.1, 10.1, 6.8 and 4.6 for the
less than 1000gms, 1001-1500gms, 1501-2000gms and 2001-2500gms weight categories respectively. The range of hospital stay was between one to 35 days, three infants stayed in hospital for more than 30 days and for 52 infants, the duration of hospital stay could not be established due to missing information of date of discharge.

The mean age at which the infants were first seen at the KMC was 8 weeks (2-18) and at 10 weeks (4-32) at the preterm clinic.

Table 2: Weight distribution and changes by category for infants during the follow up period

| Weight category (grams) | Birthweight N=423 (%) | 1st KMC visit N=423 (%) | Discharge from KMC N=423 (%) | 1st PTC visit N=423 (%) | At 1 year follow-up N=63 (%) | At last visit* N=360 (%) |
|-------------------------|-----------------------|-------------------------|-------------------------------|-------------------------|-------------------------------|--------------------------|
| ≤ 1000                 | 13(3)                 | 8 (1.9)                 | -                            | -                       | -                            | -                        |
| 1001-1500              | 111(26)               | 107 (25.3)              | -                            | -                       | -                            | -                        |
| 1501-2000              | 213(50)               | 206 (48.7)              | 1(0.2)                       | -                       | -                            | -                        |
| 2001-2500              | 61(15)                | 88 (20.8)               | 69 (16.3)                    | 11(2.6)                 | -                            | 7(2)                     |
| 2501-5000              | -                     | 342 (80.9)              | 373(88.2)                    | -                       | 111(31)                      |                          |
| 5001-7500              | -                     | -                       | 12(2.8)                      | 20 (32)                 | 128(36)                      |                          |
| 7501-10000             | -                     | -                       | 1(0.2)                       | 40 (63)                 | 44(12)                       |                          |
| >10000                 | -                     | -                       | -                            | -                       | 1 (2)                        | 2(1)                     |
| Unknown8**             | 25(6)                 | 14 (3.3)                | 11 (2.6)                     | 26 (6.3)                | 2(3)                         | 68(18)                   |

*Weight recorded during last visit to the clinic; **Unknown=not documented at the time of the visit.

Discussion

We sought to establish the utilization of outpatient care services for preterm infants in a tertiary institution post hospital discharge. Our main focus was to assess performance in the follow up clinic
for this high risk infants during a one year period by looking at how care givers honoured scheduled clinic appointments. Care of high risk infants like those born preterm is extensive and expensive as compared to term and healthy infants, this is not only limited to the facility but also to the parents/community. A normal well term infant will be brought to the health facility probably once after delivery and thereafter at 6, 10, 14 weeks then 6 and 9 months for their vaccines an growth assessment for their first one year of life. The low birthweight/preterm infant will on the other hand require more follow up hospital visits in addition to the routine infant vaccination days. To minimize and/or identify morbidities post discharge is good practice when regular follow up of these high risk infants is done at timely intervals. This will also reduce the unnecessary readmissions and community deaths that may occur when no follow up is done (6, 15). Unlike in other ailments like HIV, where patients report to the clinic when they are sick or come for drug refills, preterm infants will be brought to the facility irrespective of their health status and on many occasions, no medications are required except growth assessment. It is important to often reassure the care givers as to why they have to bring their babies to the hospital to enhance compliance (12).

**Clinic attendance pattern/trend**

We noted in this study that compliance to visits in the first few weeks after hospital discharge was higher as compared to attendance in the PTC. The reason for these differences in attendance is probably the intervals in between appointments, whereas; visits in the KMC are every fortnight, they are every two to three months in the PTC. This would imply, shorter intervals between appointments are better honoured and remembered by caregivers than longer intervals. Secondly, the uncertainty of babies’ outcome shortly after hospital discharge probably causes dependence on professional care leading to better health seeking behaviour. This dependence reduces when the baby is considered bigger in weight, older, more stable and their growth considered similar to any other normal infant. During the ambulatory Kangaroo clinic visits, some babies still have their nasal feeding tubes in situ, this too probably motivates caregivers to return with the hope of having the tube replaced or removed for those who can suckle. When no complication is noted after several
months then none is anticipated and probably caregivers find no reason for more clinic visits. The baby’s state contributes significantly to the caregiver’s decision to bring the infant for follow up, for example some unscheduled visits were sick visits in both the KMC and PTC clinics.

**Timing of Follow up after hospital discharge**

The mean period of admission in hospital in this group was 7.6 days and the average stay in the KMC clinic was 11.2 weeks. The expected number of visits to the KMC would therefore have been six times at a fortnightly interval after discharge and at least four visits to PTC in the first one year. The infants therefore would benefit from closer monitoring and longer follow up at this rate. This however was not what we established in this study where the average number of 3 and 2.8 visits in KMC and PTC clinics respectively was observed. Only 63 (15%) of the infants were still in care or had been seen in the PTC by one year of age or longer depicting suboptimal utilization of longer follow up services at our facility.

Most infants were not seen in the clinic after six months of age. The common practice in the PTC is schedule visits after three months if no health issues are identified by this age. This further proves that probably long intervals between appointments affect follow up as compared to shorter intervals.

Since most of the infants miss out on longer follow up, their growth and neurodevelopment assessment as well as appropriate rehabilitative care is minimal. The parents also miss out on the needed support to enhance their parental competences for their infant care.

The reasons for the poor clinic visits were beyond the scope of our study however other studies have documented factors affecting health seeking behaviour for children. These include; long hospital waiting hours, unavailability and poor attitude of health workers, long distances to facilities, family relocation, poverty and other social economic determinants of health (19, 20). We would envision death of the infant or mother, relocation, economic status and the stable condition of the baby to influence the attendance of follow up care for the preterm infants in our setting.
In this study we did not look at the factors that would affect attendance, however, in clinics or settings where follow up is mandatory like the HIV clinic and Young Infant Clinics, incentives like drug refills, laboratory investigations for monitoring disease progression and vaccines, probably drive performance. There are no incentives in our follow up clinics and caregivers pay for their transport fares and any medications the babies may require including the supplements which are prescribed for them.

**Weight trends during follow up**

The average birthweight in this study group was 1719 grams, many infants were within the LBW category with moderate prematurity and these have a high potential to survive as compared to those in the ELBW category who are also extremely preterm babies (20).

Weight is a specific anthropometric measurement considered easy to interpret by both the health workers and the mothers when routinely and correctly taken. It can be used to monitor growth and when there is no appreciable change, there is reason to be concerned (21) and probably impact on the caregivers’ health seeking behaviour. Poor weight gain may be an indicator of inadequate feeding or ill health (24). Many of the infants in our setting are exclusively breastfed for the first six months despite the many challenges that have been associated with the practice among preterm and low birth weight infants (25).

From this study, of the infants who were able to utilize the service to one year and more, 40 infants (63.5%) weighed between 7.5-10kgs, only one baby weighed more than 10kgs. It is worth noting that using weight to monitor the growth and development for preterm infants requires long term follow up because their catch up has been shown to be beyond one year (24) as compared to their term counterparts.

In this study we did not look for or at the factors nor the trends affecting weight gain among our study participants. We were also not in position to account for every dropout to follow up due to the design of the study and the aim of the study which was to establish utilization of the services in the clinic. Although stability of the infant, death of either infant or mother, relocation, lack of transport
fare, etc are some common reasons for unscheduled visits and eventually early drop out from facility care, loss to follow up is often inevitable (26).

**Study strength and limitation:**

This is the first study to describe the attendance of scheduled clinic visits for low birth weight and preterm infants in our setting. The study draws on real life program data, highlighting gaps and need for new strategies to improve care for the preterm infants (13, 14). We did not describe factors associated with failure to honour scheduled clinic appointments after hospital discharge because this information is not recorded. Like many chart review studies, missing data affected the level of analysis in our study. Nonetheless the low level of attendance to long follow up documented in this study highlights a need to strengthen and support this vulnerable population beyond mere survival from the NICU.

**Conclusion and Recommendations**

Scheduled clinic attendance for low birth weight preterm infants is suboptimal with only one out of every four children were still being followed up by one year of life hence missing out on the benefits of longer follow up. There is need to strengthen utilization of available services, community support and devise means to improve the long term follow up for especially the extreme preterm infants.

What is already known? Follow up of patients post discharge is good clinical practice.

What this study adds? Shorter intervals between follow up visits impact compliance to attendance.

Health seeking practices are not common in absence of illness.

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