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'I never thought that this baby would survive; I thought that it would die any time': perceptions and care for preterm babies in eastern Uganda

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Summary

OBJECTIVE To explore the current care for and perceptions about preterm babies among community members in eastern Uganda.

METHODS A neonatal midwife observed care of preterm babies in one general hospital and 15 health centres using a checklist and a field diary. In-depth interviews were conducted with 11 community health workers (CHWs) and also with 10 mothers, six fathers and three grandmothers of preterm babies. Three focus group discussions were conducted with midwives and women and men in the community. Content analysis of data was performed.

RESULTS Community members mentioned many features which may correctly be used to identify preterm babies. Care practices for preterm babies at health facilities and community level were inadequate and potentially harmful. Health facilities lacked capacity for care of preterm babies in terms of protocols, health workers' skills, basic equipment, drugs and other supplies. However, community members and CHWs stated that they accepted the introduction of preterm care practices such as skin-to-skin and kangaroo mother care.

CONCLUSION In this setting, care for preterm babies is inadequate at both health facility and community level. However, acceptance of the recommended newborn care practices indicated by the community is a window of opportunity for introducing programmes for preterm babies. In doing so, consideration needs to be given to the care provided at health facilities as well as to the gaps in community care that are largely influenced by beliefs, perceptions and lack of awareness.

keywords preterm, newborn, health facility care, Uganda, newborn care practices, community health workers

Introduction

Millennium Development Goal IV – to reduce child mortality by two-thirds – will not be achieved without significant reductions in newborn mortality rates. Reducing deaths related to preterm birth is a crucial part of reducing overall newborn mortality, because low birth weight and prematurity are the direct causes of 28% of newborn deaths globally (Lawn *et al.* 2008a, 2005, 2004). Preterm births are a major cause of perinatal deaths, neonatal mortality and long-term morbidity (Goldenberg *et al.* 2008). Most preterm babies are also of low birth weight, which directly or indirectly contributes to 60–80% of neonatal mortality (Lawn *et al.* 2008b, 2006). Estimated global rates for premature births are 5–13% for high-income countries and 10–25% for low- to middle-income countries (Lawn *et al.* 2005; Unicef 2008). The annual low birth-weight rates are estimated at 15% globally and 12% for Uganda, where preterm births account for 25% of newborn deaths (Government of Uganda, 2009).

Biomedical explanations of causes of preterm labour include maternal infections, chronic diseases and

pregnancy-related complications. Risk factors include low socioeconomic status, advanced maternal age, adolescence, black race, smoking and drug abuse (Goldenberg *et al.* 2008). Preventing preterm birth is a challenge because only a few risk factors such as infections can be identified during regular antenatal care (ANC) (Goldenberg *et al.* 2008). In low-income countries (LIC), prevention is even more difficult because few women attend the four recommended visits to ANC facilities (Villar *et al.* 2001; Carroli *et al.* 2001a,b), and those who do so come late in pregnancy (Government of Uganda, 2009). Additionally, there are affordability, accessibility and quality-related barriers to obstetric care. Only 41% of births are supervised by trained health workers; the rest are taking place either at home or with traditional birth attendants (TBAs).

There is evidence that expensive technologies such as neonatal care units are not prerequisites for handling most cases of preterm births (Darmstadt *et al.* 2005) but that improving essential affordable newborn care practices (clean cord care, thermal care, and early and exclusive breastfeeding) (Marsh *et al.* 2002) can be effective if fitted into a comprehensive newborn care package (Kerber *et al.* 2007). However, we found a dearth of studies that have assessed care for preterm babies from the perspectives of both health facility (supply side) and community care (demand side) in sub-Saharan Africa. The aim of this study was to explore the current care practices at facilities and at home, and related perceptions regarding preterm birth, to inform a community-based, facility-linked newborn intervention (UNEST: Uganda Newborn Study IS-RCTN50321130) in rural eastern Uganda.

Methods

The study was located in two rural districts (Iganga and Mayuge) in eastern Uganda, with a total population of about one million people. Eighty per cent of the population are peasants with 49% of women and 68% of men literate. About 42% of all deliveries in the study area take place in a health facility (Uganda Bureau of Statistics (UBOS) and Macro ORC, 2007). There are various types of community health workers (CHWs) but most are not active because they are neither well coordinated nor supported. About 3500 births per year, of which an estimated 10% are preterm babies, occur in the hospital.

Sampling, data collection, analysis and ethics

Fieldwork took place in two sub-counties in each district, selected because they had relatively active CHW programmes. Among CHWs selected, there was overlap of tasks but not physical proximity. Qualitative methods are conducive to understanding the concepts and perspectives of different groups in the community by enabling them to express their lived realities (Pope & Mays 1995; Eng *et al.* 1990). The respondents for each method are shown in Table 1.

In preparation for health worker training, an experienced neonatal midwife from a tertiary hospital spent a month (2 weeks in the general hospital and 1 day in each of the 15 health centres). She observed events, behaviours and interactions using a semi-structured checklist (Table 2), and recorded activities and observations in a field diary (Mays & Pope 1995). We conducted 30 in-depth interviews (IDIs) with 11 CHWs (three community drug distributors, two breastfeeding peer educators, four safe motherhood volunteers and two TBAs); 10 mothers, six fathers and three grandmothers of preterm babies.

From among the 42 preterm births recorded in the study area hospital over a 6-month period, the mothers of 10 preterm babies were identified because they had supplied complete addresses. Only seven could be interviewed, as three could not be traced. Another three mothers who had delivered a preterm baby at home during the previous 6 months were identified by community members for interview. IDIs with mothers were conducted till saturation. None of the individuals we approached refused to participate. Only one respondent reported having lost her preterm baby. Demographic data were available for 14 respondents. The ages of the respondents ranged from 25 to 45 years; 13/14 women were multi-gravidae; 9/14 were peasants. All were married and 7/14 had attained secondary school education or higher.

After the IDIs, we conducted three focus group discussions (FGD) as follows: one for midwives in the hospital and two in the community with parents but not necessarily of preterm babies (one FGD for men and one for women)

Table 1 Respondents/subjects and methods

Method of data collection	Number of subjects/ interviews/groups
Health facility observations	16 health facilities
In-depth interviews	$n = 30$
Community health workers	9
Traditional birth attendants	2
Mothers of preterm babies	10
Fathers of preterm babies	6
Grandmothers of preterm babies	3
Focus group discussions	
Health workers	1 FGD (6 midwives/nurses)
Men	1 FGD (8 men)
Women	1 FGD (10 women)

Table 2 Observation checklist for care of preterm and other small newborn babies in health facilities and hospital level

Area of assessment	Observed for	Notes
Lay out of the facility (maternity and postnatal ward)	Organisation of neonatal care, cleanliness, staffing, client load and interactions with staff	
Equipment, drugs, supplies and protocols	Observe for availability and use of neonatal equipment, drugs and supplies	
Essential newborn care for newborn babies with special focus on preterm babies	Warm care Observe how newborn babies are cared for at birth. Is STS practiced? Are newborn babies properly covered? When is bathing done? Is delayed bathing promoted? In general, what practices are promoted to keep babies warm after birth within the health facility? For preterm or small babies, how is warmth maintained? Is KMC done? Feeding Observe how feeding is initiated? Is it with breastfeeding? Is it immediate? What else is used and by whom? Is exclusive breastfeeding promoted? How? Cleanliness Observe to see how the cord is cut? Is it clean? Observe to see how the cord is cared for? Is it clean? Is dry cord care promoted or what is put on the cord? Do staffs wash hands prior to examinations? Do staffs use gloves? Is water available? Are beds, linen clean?	
Basic and emergency resuscitation	Observe whether and how basic and emergency resuscitations is done	
Care of sick newborns with special focus on preterm babies	Who treats sick newborns with special focus on preterm babies? Are staffs available close to preterm babies all the time? What drugs are given, what doses, and where are they got from? Are inpatient guidelines available? How are preterm babies monitored? Is there discharge and follow-up guidelines?	
Protocols	Are protocols for preterm babies available? Which? How are they used?	
Records	How are records of delivery, treatment and postnatal done? Are they complete? Is there special recording of preterm babies?	
Other general observations		

to establish general community perceptions about preterm births. Participants representing different age groups were identified by local leaders with guidance from the third author (SNK). Towards the end of each community FGD, participants were shown pictures of a mother practicing kangaroo mother care (KMC) so as to assess knowledge thereof, as well as to glean information about their perceptions and considered level of acceptability.

In-depth interviews and FGDs were conducted by SNK with a note-taker being present. Both SNK and the note-taker were degree holders and had >5- year experience of interviewing. They were supervised by the first author, a medical doctor who is a native speaker of the local language, *Lusoga*. All interviews were conducted in *Lusoga*, tape-recorded and later transcribed into English by the moderator and the note-taker.

Data were systematically coded and analysed manually by content analysis, that is, the first three authors rigorously read the scripts independently and coded them (Graneheim & Lundman 2004). Thereafter, they met to compare and agree on the codes. Recurrent and emerging themes were identified and organised into meaningful categories and sub-categories. Relevant quotes were extracted, of which some are presented verbatim. The data collected from the picture viewing were analysed through free listing of opportunities and challenges of preterm care.

Ethical approval was provided by the Makerere University School of Public Health Ethics Board. During

the health facility observation, any errors identified in the care of a baby were corrected immediately.

Results

Care of preterm babies at health facility level

Health facilities lacked capacity for preterm care in terms of infrastructure, practices, skills, equipment, drugs and other supplies. Only the hospital had a neonatal resuscitation kit, 7/16 had a delivery kit and 7/16 had a weighing scale. Neonatal drugs such as injectable ampicillin and gentamycin were generally lacking, and when needed, parents would be asked to buy them from nearby drug shops and pharmacies. Only 2/16 of the health facilities had a midwife trained in newborn resuscitation. No health unit had a special room for the care of preterm babies. Preterm babies were hosted in maternity wards which often had many visitors, making infection control for the preterm babies difficult.

None of the health units promoted skin-to-skin (STS) care or KMC practice. To keep warm, babies were wrapped in many clothes. It was common to start feeding babies on sugar water instead of expressed breast milk. Similar feeding practices were reported in interviews with community members.

Lower level health units often referred preterm babies to the hospital. However, during referral, use of STS care or KMC was absent. We did not find any specific protocols for the care of preterm babies.

Role played by CHWs in the care of preterm babies

The CHWs available were programme-specific, for example, they were breastfeeding peers, community drug distributors and safe motherhood volunteers. Generally, we found that CHWs were inactive because the vertical programmes that had introduced them had ceased. Only breastfeeding peers had been trained in aspects of caring for newly born babies which especially focussed on breastfeeding. Six CHWs reported that they advised mothers on newborn care practices such as ANC, breastfeeding, cleanliness and the need for health facility deliveries. Three CHWs promoted only malaria prevention and the other two promoted mainly family planning. These roles were related to the training CHWs received after selection.

However, some CHWs reported that promoting hand washing was a challenge because community members do not easily accept it. '*Sometimes mothers don't wash their hands before breastfeeding; a mother leaves the toilet and just breastfeeds baby without washing hands even after gardening*', *IDI, CHW*. Similarly, other community members cited the community practice of visiting and 'seeing' the newborn which often entails holding the infant for a period because '*amaiso ag'omuntu gali mungalo*', translated as 'one's eyes are in his hands', as another challenge. '*One asks you to unwrap the baby for him/her when it is not the right time, … and as you know people, their eyes are in the hands*', FGD, men.

Traditional birth attendants are occasionally involved in the care of preterm babies. They identify prematurity by using features such as 'baby at birth is very small', 'not able to suckle', 'skin is wrinkled' and 'inability to open eyes at birth'. TBAs said that such babies are called '*empuna*' in the local language, meaning '*a baby who came very early*'. TBAs reported that when they realise they have helped deliver a preterm, they give advice on care which includes keeping the baby warm and clean, and feeding. '*I told the mother that you must not let the baby out, cover it, and never switch off the lamp*', IDI, CHW.

However, TBAs reported that some desired practices were difficult to achieve especially among the poorest women: '*Those women come when they don't know what to do. She comes when she doesn't know anything. No clothes, no gloves, polythene paper, razorblade, no thread (for tying the cord)*', *IDI, CHW*.

The advice some TBAs gave on some practices was poor. For example, some TBAs reported that they advised the use of sugar water for initiation of feeding if a mother was perceived as not having enough breast milk. '*We first used hot water, cooled it and put in a bottle like that one where we drink modern water from. We covered it and put a little sugar in it. That is what I told her to be giving it, until it learns to hold or to suckle breasts*', *IDI, CHW*. In general, we found that CHWs were not knowledgeable on STS care or KMC, but once we described the procedures, they showed willingness to promote them if trained.

Recognising preterm babies: 'Too early, tiny and weak'

In the *Lusoga* language, various labels are applied to preterm babies including *musondole*, *empuna* and *akabulaku*, which translate as 'a baby born before birth'. Citing the 'months' of pregnancy was a common way for fathers, mothers and grandmothers to recognise preterm birth. '*We identify it from the months. If the baby is born before nine months, we say that aa-ah, it is a premature. Here in our community, men and women try hard to count months from conception to birth. So it comes so easy to know that it is a premature*', FGD, men. The features that were reported as being used by community members to identify preterm babies were similar to those described by CHWs. Others said that newly born preterm babies were

pale and that their skin is similar to that of 'newly born rats'. '*Depending on the way it looks like, the fact is that a preterm looks like a newly born rat*', FGD, men.

Local explanations of causes of preterm births

Biomedical-related explanations for causes of preterm births included diseases (syphilis and malaria) or other medical complications. However, many community members associated preterm births with causes such as witchcraft from a 'co-wife', God's will, and the occurrence of earthquakes (called *musisi* in the local language). '*I know that when an earthquake happens, there is miscarriage in both humans and animals and sometimes preterm birth happens*', *IDI*, Mother of a preterm baby.

Care for preterm babies at community level

Three of the 10 mothers of premature babies whom we interviewed had not attended ANC, while the others indicated that they had done so because of complications. In general, respondents believed that if well treated, preterm babies could survive, and mothers reported that they treated these babies in the same way as other normal babies. However, some mothers were fatalistic: '*I wished that I had had a miscarriage instead of delivering this preterm, it would be better. I never thought that this baby would survive; I thought that it would die any time*,' *IDI*, Mother of a preterm baby.

We found that a number of the practices for preterm babies at the household level were not appropriate. Although the need for warm care for a preterm baby was well known among the respondents, community members had little knowledge on STS care or KMC. The generation of warmth was improvised through covering and wrapping of babies in many clothes, lighting lamps and charcoal stoves placed under the baby's bed, and hot water jerry cans or plastic bottles put in close proximity to the baby. Community members reported that they received most of this information from health workers and TBAs. '*The midwife told us to cover the baby in a clean place, not to bathe it, to get cooking oil and a clean cloth and smear it always. She also told us to put a lamp or a charcoal stove where it sleeps so that it gets some warmth and never to remove it from its cover or bed till after one month. That is the method I used to look after it*', *IDI*, father of preterm baby.

Mothers were also advised by health workers to delay bathing babies for several weeks or to use warm wet wipes. However, some indicated that the baby had to be bathed immediately. The use of cooking oil on the baby's skin was reported to be common and is even promoted by health workers with the belief that it 'makes the skin strong'. In FGDs, when shown a picture of a mother in a KMC position, women, but not men, easily identified the KMC practice. After it was described, both men and women were supportive of the method, but most men thought that KMC was exclusively for women. Possible problems to the promotion of KMC practice at community level that were mentioned in FGDs included: fear of hurting the baby because 'the cord is still fresh'; women needing to work yet 'the baby has to be in the chest all the time'; and the perception that KMC is tiring. '*It is tiresome because day, night, day, night, you can even become sick. You can even start bleeding again*,' FGD women.

The challenges for caring for preterm babies (Table 3) that were mentioned included: increased workload for women; labour intensive, time-consuming and tiring care; limited male involvement other than financial support; expenses because of the need to buy fuel (charcoal and paraffin) and oil to smear the baby; accessing care at facility when infant is sick; and the nature of rural homes (small, congested and dusty). '*Time came and I said that paraffin was expensive and my neighbours advised me to always put hot water in a plastic jerry can and always put it under the bed of the baby in order to provide most warmth*', *IDI*, mother of preterm baby.

Discussion

This study, which explored care for preterm babies across the maternal and newborn continuum of care, contributes to the understanding of newborn health in sub-Saharan Africa where there is a dearth of data on newborn care. Care for preterm babies in this setting is inadequate from both the perspective of providers (supply side) and consumers (demand side). However, the relatively good knowledge and perceptions about preterm babies offered important entry opportunities for promoting the care of preterm babies in health facilities and at community level.

On the supply side, health units and care providers (facility-based health workers and CHWs) lacked adequate knowledge and skills on essential newborn care practices, as well as facilities for preterm care (such as a KMC room). Even basic practices, like keeping the baby warm and breast-feeding, which should be universal (Darmstadt *et al.* 2005), were not properly promoted. Although medical care is meant to be free in Uganda, neonatal drugs such as injectable ampicillin and gentamycin were generally lacking, and when needed, parents would be asked to buy them from nearby drug shops and pharmacies. Further, there were no protocols and behaviour-change materials guiding the appropriate care of preterm babies. These findings could be a reflection of the fact that newborn care has been

Table 3 Opportunities, perceived complexities and challenges in the care of preterm babies in rural Uganda

Respondents+/level of care	Opportunities	Challenges
Hospital/health facilities	Provide antenatal care and delivery care Referral sites for preterm care Source of advice on care Willing to implement STS and KMC Have some qualified staff	Lack of adequate access to care No space, equipment nor drugs for preterm care Staff not trained in preterm care STS and KMC not promoted Lack of protocols and guidelines No postnatal care and follow-up services
Community health workers	Available in communities Have some knowledge on preterm care Some promote maternal and newborn care Some ability to identify preterm babies Willing to promote maternal and newborn care	Not coordinated nor supervised/facilitated Limited knowledge on care for preterm babies
Community/household members	Some ability to identify preterm babies Willing to adopt essential newborn practices such as STS and KMC	Potentially hazardous care practices Fatalism Limited knowledge on care for preterms Burden to women Poverty and poor house structure Limited male involvement Some negative beliefs, customs and attitudes

KMC, kangaroo mother care; STS, skin-to-skin.

a relatively neglected area (Tinker *et al.* 2005) with no update training for health providers in the study districts. Some of the reasons that have been reported for this lack of attention include are that neonatal deaths are undocumented because of a lack of vital registration systems; babies remain unnamed for a long time because of a sense of fatalism; and there is a perceived complexity in reducing newborn deaths (Tinker *et al.* 2005).

In Uganda, although newborn care has been prioritised in the national health policy since 2005 (Goververnment of Uganda, 2005), there are currently no specific programmes and facilities for their care. In Kenya, a survey of eight hospitals in four of the eight provinces found that hospitals did not have a safe hygienic environment; sufficient staffing and organisation; and lacked some key equipment, drugs, consumables and management guidelines (Opondo *et al.* 2009). The implication here is that inadequate facility care is widespread, with consequences for neonatal mortality in SSA.

On the demand side, the care of preterm babies in this setting is mainly at home or community level. Community members attributed this to several factors including poor quality facility care, poverty and the need for mothers to be at home because of household chores. However, we found that preterm care at home mainly consists of potentially harmful, improvised measures such as using lanterns/charcoal stoves or clothes to keep the baby warm, or feeding it with sugar water rather than expressed breast milk. Studies in Tanzania (Mrisho *et al.* 2008), Ghana (Tawiah-Agyemang *et al.* 2008) and India (Kesterton & Cleland 2009) reported similarly inappropriate practices, such as early bathing and discarding of colostrum for newborn babies. These findings call for maternal and newborn interventions which strengthening both the demand and the supply side.

Community members generally had a positive attitude towards survival of preterm babies, as was also found in Malawi (Tolhurst *et al.* 2008). CHWs, including TBAs, were willing to promote essential newborn care (ENC) practices. It is well known that appropriate newborn care interventions do not require specialist and high technology equipment such as neonatal care units with incubators (Darmstadt *et al.* 2005); simple promotion of low cost ENC practices is a good beginning. These can be provided at lower level health facilities (Bhutta *et al.* 2009), and also at the community and household levels (Bang *et al.* 2005a,b). Because community care for newborn babies, including preterm babies, has been successful in Asia (Bang *et al.* 2005a,b), task-shifting of preterm care to lower level health workers and linkages with CHWs with appropriate referral supports need to be explored in Uganda. However, programme developers need to take into consideration some of the existing community perceptions (such as earthquakes and bewitching as causes of preterm births), as well as practices such as late attendance of ANC, home births, and inadequate practices for warmth and feeding. Successful Asian models, although not yet implemented to

scale, suggest that some of these challenges can be addressed through community mobilisation with high levels of community involvement (Bang *et al.* 2005b; Darmstadt *et al.* 2008; Bhutta *et al.* 2008; Baqui *et al.* 2008a,b).

Thus, to improve care for preterm babies in Uganda, capacity needs to be built for health facilities to be able to promote ENC practices and KMC. At community level, methods for easy identification and care of preterm babies, including use of CHWs, need to be developed.

A limitation of our study is that we interviewed only 10 mothers who had experienced a preterm birth, of whom only three had delivered outside a health facility. Mothers of preterm babies born at home or elsewhere were difficult to find, so their views may be under-represented. However, we triangulated our findings by using different methods, such as observations of actual care provided and cross-checking data from mothers of preterm babies to FGDs with community members, and through interviews with other key actors, such as CHWs. A key strength of this study is that, besides exploring care practices, we also observed the actual care.

Conclusions

In rural Uganda, the care provided to preterm babies at facility and community level is grossly inadequate, and health facilities lack capacity for care of preterm babies. However, the acceptance stated by community members of key preterm care practices such as STS, KMC and breastfeeding provides a window of opportunity for introducing preterm care programmes across the continuum of care in Uganda.

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