Caregiver experiences and health care worker perspectives of accessing healthcare for low birth weight infants in rural Kenya

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ABSTRACT

**Background:** Low-birthweight (LBW) infants (<2500 g) are at greatest risk of mortality in the neonatal period, particularly in low- and middle-income countries. Timely access to quality healthcare averts adverse outcomes.

**Aim:** To explore caregiver experiences and healthcare provider perspectives of accessing healthcare for LBW infants in rural Kenya.

**Methods:** This qualitative study was undertaken in Homa Bay County of rural western Kenya in June 2019. In-depth interviews were conducted with eleven caregivers and four healthcare providers. All interviews were transcribed verbatim, and transcripts in the local languages were translated into English. A thematic framework was used to analyse the data.

**Results:** At the community and individual level, community misconceptions about LBW infants, inadequate infant care practices after discharge, lack of maternal support networks, long distances from healthcare facilities and lack of financial support were key challenges. In addition, long hospital waiting times, healthcare worker strikes and the apparent inadequate knowledge and skills of healthcare providers were disincentives among caregivers. Among healthcare providers, health system deficiencies, (staff shortages and inadequate resources for optimal assessment and treatment of LBW infants) and maternal illiteracy were key challenges. Education staff during antenatal visits and community support groups were enablers.

**Conclusion:** Accessing healthcare for LBW infants in this community is fraught with challenges. There is an urgent need to develop and test strategies to address the barriers both at the community and health system level to optimise outcomes.

Introduction

Low-birthweight (LBW) (<2500 g) infants, who include preterm and small-for-gestational-age infants, account for 20% of annual births worldwide [1,2]. They are more likely to die in the neonatal period (<28 days of life) or to suffer other adverse outcomes than infants of normal birthweight [2,3].

Progress in reducing neonatal deaths globally has been slow and it is therefore a global health priority and a key item on the United Nations (UN) development agenda [4,5]. Specifically, sustainable development goal (SDG) 3.2 aims to reduce neonatal mortality in all countries to at least 12 deaths/1000 live births by 2030. Up to 80% of the 2.4 million neonatal deaths annually are attributable to LBW, so improving the care of these infants would enhance the efforts to achieve SDG 3 [5–7].

The greatest burden is in sub-Saharan Africa (SSA) and South-east Asia where 95% of these infants are born [8]. In these low- and middle-income countries (LMIC), a large proportion die in the neonatal period and survivors often have feeding difficulties with the associated risk of wasting (weight-for-age >2 standard deviations below the WHO Child Growth Reference Standards median) and stunting (height-for-age >2 standard deviations below the WHO Child Growth Reference Standards median), cognitive impairment and life-threatening illnesses in early childhood [9–11]. As adults, they are at increased risk of obesity, cardiovascular disease and metabolic syndrome [12,13].

Community perceptions in many rural areas of SSA favour home delivery, a real drawback to the care of LBW infants [14,15]. It is estimated that if all infants were delivered in healthcare facilities, over 1 million neonatal deaths per year could be prevented [16]. However, specialised neonatal care in SSA is sparse [17], and the lack of community outreach programmes is an important contributor to a poor outcome in these infants after discharge [18]. It has been estimated that,
if maternal, neonatal and child health (MNCH) interventions in LMICs were increased by 20%, as many as 486,000 infant lives could be saved per year [19].

Addressing the high burden of morbidity and mortality in LBW infants is a major priority in Kenya [20]. In Kenya, there are significant disparities between urban and rural communities in the survival of LBW infants, with a significantly worse outcome in rural settings [14,15]. A primary reason for this is the high level of poverty in many rural communities in Kenya [21]. This is exacerbated by low literacy levels in women, poor maternal health and mothers’ other competing responsibilities which make it challenging to prioritise the health of their LBW infants [21–23]. In addition, community health services in rural areas are often deficient, particularly those for vulnerable infants [24].

This study, therefore, aimed to explore the experiences of accessing healthcare for LBW infants by caregivers in a rural community in western Kenya along with the perspectives of healthcare providers (HCP) in order to identify gaps to aid the development of interventions to improve outcome in these infants.

Subjects and methods

Study design and setting

This qualitative study used in-depth interviews to explore the experience of accessing healthcare for LBW infants by caregivers and HCP. It was undertaken in the rural Homa Bay county of western Kenya which has a mainly rural population of approximately 1 million [25]. Nearly two-thirds of the population live in extreme poverty, 60% suffer from food insecurity and over 27% have little or no formal education [26]. An estimated 6% of infants are LBW and only 39% are exclusively breastfed for 6 months. It also has one of the highest maternal (583/100,000 live births) and neonatal (57/1000 live births) mortality rates in Kenya [27,28]. Only 37% of women have a skilled birth attendant during childbirth and only 40% of deliveries are in a health centre [29].

Study population and sampling

The study participants were caregivers of LBW infants and HCP working in the maternal and child health services at the Homa Bay County Teaching and Referral Hospital. Convenience sampling was used which enabled the sampling of mothers of LBW infants who received healthcare at the hospital and healthcare workers who cared for mother-LBW infant pairs in the hospital, but focussing on those who were accessible for interview [30]. Caregivers with LBW infants <24 months of age were identified from the neonatal and postnatal ward registers at the county hospital or were those who were known to the community health volunteers. They were contacted by telephone or home visits.

Eleven caregivers of LBW infants were recruited and stratified according to whether the infant had suffered any adverse event such as death or admission to hospital after discharge from neonatal care (five) versus those who had not (six). Four healthcare workers were recruited from the maternity and postnatal wards and from the maternal and child clinics at Homa Bay County Hospital.

Data collection

Data were collected during a 1-week period in June 2019. The in-depth interview topic guides were pilot-tested before data collection and further revised during the period of data collection. Informed consent was obtained from all participants before interview. In-depth interviews were conducted by a trained research assistant who was fluent in the local languages (Swahili and Dholuo) and had significant prior experience of conducting qualitative interviews in this community. The interviews lasted up to 90 minutes and were conducted in the privacy of rooms within the research area at Homa Bay County Hospital to ensure confidentiality. All the interviews were audio-recorded and stored on password-protected devices. They were then transcribed and translated by the same research assistant.

Data management and analysis

A total of 15 participants (eleven caregivers and four HCP) were interviewed which enabled us to reach ‘data saturation’ where there were no new emerging themes [31]. Data were analysed using a thematic framework approach. Data analysis was undertaken concurrently with data collection. This helped to identify new emerging themes which could be explored further during subsequent data collection. After a process of intensive familiarisation with the transcripts, two of the study team agreed on a coding framework which guided identification of the key themes [32]. A matrix was developed to allow efficient organisation of the codes from all transcripts and then allowed analysis. The conceptual framework in Figure 1 guided analysis.

Ethics

The study was approved by the Kenya Medical Research Institute’s Scientific and Ethics Review Unit (protocol number: KEMRI/SERU/CGHR/03/02/19/3851) and the Research and Ethics Committee of the Liverpool School of Tropical Medicine, UK (protocol number 1913).
Results

All 11 caregivers were female and the majority (81%) were aged >25 years. All four HCP were also female and most (75%) had <10 years’ experience of working in healthcare.

Barriers to accessing healthcare for LBW infants

Barriers to accessing healthcare for LBW were expressed unanimously by all caregivers and healthcare workers. There were many overlapping themes in the two groups but also some which differed.

Community’s negative perceptions of LBW infants

Both caregivers and HCP reported that community perceptions of LBW infants were often negative as many believed they had no potential to survive. These infants were viewed as a ‘curse or punishment from God’. In addition, mothers were blamed by community members for not attending antenatal clinics, not feeding their unborn infant or using contraception. Mothers were also assumed to be HIV-positive.

‘Some tell you that those are curses from not following traditions, that maybe you did something during pregnancy …’ C6, Mother, Homa Bay County

‘You are ashamed, you do not even want people to see you. You hear some people say that it is a curse, some say that the baby sick and should be taken for tests.’

C1, Mother, Homa Bay County.

Consequently, caregivers felt that community support including by neighbours and extended family was extremely poor.

‘So the community has not fully understood the community has not embraced (the fact) that these babies are supposed to live and how to support the mothers, so they go through a lot of discrimination and marginalisation . . . mothers tell us they hear a lot of (sort of) funny things about their babies and you will find that most of the time they hide their babies in the houses to stay away from other community members’ HCP4, Homa Bay County

‘My neighbours and my husband really feared this baby. He did not even want to be close to her . . . When he came to see my baby, I saw that he was surprised and he was so much afraid of the baby’ C6, Mother, Homa Bay County

Therefore, these babies received fewer visitors and their mothers received less support than mothers of normal weight infants. These misconceptions caused mothers significant psychological stress and they felt unprepared to deal with the challenges. Many of them had feelings of guilt and worried about acceptance by the community. This, coupled with the hospitalisation of the infants with complications, made the whole experience very traumatic, and these mothers were in particular need of support and counselling to help them cope. This in turn had a negative effect on the care the infant received.

‘I knew that my baby would be rejected, and he would not be loved or that someone would tell me that the baby would die’ C4, Mother, Homa Bay County

‘It is not a good psychologically . . . . . . . It takes counselling, it takes talking to them to accept’ HCP3, Homa Bay County

Challenges with physical access to healthcare facilities

Physical access was an important barrier. Weather conditions during the rainy seasons, unsuitable roads, distance from the healthcare facilities and available transport all contributed to the challenges of accessing care.

‘Sometimes it is raining and when the baby is unwell, there is no transport to get there very fast to get help. It is very difficult and sometimes if the baby was to be helped there is no means of getting there faster’ C4, Mother, Homa Bay County

Figure 1. Conceptual framework of accessing care for low-birthweight infants.
Mothers feel incapable of caring for their LBW infants in the community

Mothers commonly felt unprepared for discharge, either owing to a lack of knowledge or because they had not received information from HCP on how to look after their infants. A lack of knowledge was cited by one caregiver as the prime reason for the death of LBW infants in the community.

‘The baby should not die but she will die because there is no proper care that is provided, and lack of the knowledge’ C4, Mother, Homa Bay County

Traditional birthing practices

Despite being discouraged from this by HCP, many mothers delivered at home. This hinders timely access to appropriate healthcare, particularly for LBW infants whose arrival is often unexpected. Some caregivers also explained that many opt for traditional remedies for their LBW infants before seeking help at healthcare facilities because they were more accessible.

‘The way I treated it (the infant’s illness) … I went to the traditional birth attendant who gave me a herb to take.’ C5, Mother, Homa Bay County

‘I went to the herbalists for the herbs, they removed the upper and lower teeth and then the following day after leaving the place, he now started breastfeeding.’

C3, Mother, Homa Bay County

Impact of maternal illiteracy on acquiring the knowledge and skills of caring for LBW infants

HCP were concerned that many of the mothers with LBW infants were poorly educated and did not understand the importance of accessing care promptly or of attending hospital appointments either antenatally or postnatally. This also affected mothers’ ability to care appropriately for their infants with regard, especially, to hygiene, thermal care and breastfeeding.

‘Most of them don’t turn up for their (follow-up) appointments, you give them those visits (appointments) after 4 weeks, some of them will tell you I went for funeral, some of them I forgot.’ HCP4, Homa Bay County

Staff shortages

Staff shortages were a key barrier to care and these were exacerbated by the frequent HCP industrial strikes in Kenyan public hospitals. Some HCP felt that this resulted in longer waiting times for LBW infants to be assessed and treated in hospital, resulting in a poor outcome. This then discouraged caregivers from accessing health services and instead they opted for traditional healers with detrimental consequences. On other occasions, HCP strikes resulted in no-one being available to care for the infant.

‘Long waiting time because if the mothers are so many and could be few staff . . . . Some of them may get bored and feel like if I go to the TBA (traditional birth attendants) I will get that attendant with only one person then I’ll be attended to very fast’ HCP2, Homa Bay County

Because of staff shortages, trained staff were not always available to support mothers of hospitalised LBW infants and so trainee nurses often worked with limited or no supervision. Their limited competence was noted by the caregivers who lost confidence in the healthcare they were receiving.

‘I was attended to by trainees, so I did not know who was doing the right thing and (and who was doing) the wrong (thing). They (baby) were not handled in the right way.’ C1, Mother, Homa Bay County

Inadequate infrastructure and shortage of supplies

HCP felt that the poor infrastructure of health facilities coupled with inadequate supplies of drugs and equipment hindered the provision of optimal care to the large numbers of sick LBW infants who present to them.

‘Whatever we are given in relation to patient ratio is very little’ HCP1, Homa Bay County

This often resulted in infants being discharged prematurely to accommodate sicker infants.

‘This is a referral facility receiving referrals from all over these peripherals, so the quality of care may not be that standard because we need space for another room to come up to stabilise, so maybe we will be forced to get this almost stable baby out of the neonatal baby unit to accommodate a new unstable baby’ HCP3, Homa Bay County

Financial barriers to caregivers at the community and health system level

Financial barriers were discussed by both groups of participants. Mothers explained that it is the norm to be asked to pay for care or other expenses such as fuel for the ambulance, ambulance transfers to a larger, more specialised hospital and for supplies such as aseptic gloves. These financial barriers to accessing hospital care discouraged some caregivers from attending healthcare facilities in the first instance.

HCP reported that although the national policy of free maternal and childcare in public hospitals had been implemented in Kenya, health facilities often had to ask patients to part-fund their healthcare; for example, to purchase essential drugs not available at the facility. Therefore, patients sometimes opted out of healthcare, were discharged prematurely or in the worst-case scenario left to die from treatable illnesses because they could not pay. One mother described the
early cessation of her infant’s medication owing to financial constraints:

‘They treated him because there is a drug that we bought. We bought it at (KES) 800, I think it has 24 tablets, we used all of it while in the ward and they told us to get more but we did not because we did not have enough money. We did not buy it and so we just treated it by ourselves.’ C2, Mother, Homa Bay County

‘We work within our limit to what we can afford, what they can afford to give us, but we are not offering the best … We see some of them die still here because we have to … they are looking for funds.’ HCP1, Nurse, Homa Bay County

Inability to care for LBW infants appropriately

Mothers found caring for their LBW infants incredibly time-consuming and struggled to adhere to the recommendations when they were back home. They had other responsibilities such as other children, housework and income-generating activities. Some mothers interviewed were as young as 22 and many returned to school and left the infant with family or neighbours, and thus were unable to breastfeed exclusively. This often meant that the person left to look after the infant might not be familiar with LBW care strategies including thermal care, identification of danger signs and the prompt access of life-saving care.

‘Mostly I was focused on my studies since I was still learning … I left him at home then I went back to school, when I went back to school, was given my mother’s sister, she also then went back to school, so I left the baby to my neighbour.’ C2, Mother, Homa Bay County

Facilitators of access to health facility-based care for LBW infants

Impact of accessing antenatal care

Supporting mothers to understand LBW infant care strategies should ideally start in the antenatal period. Typically, outcome was better in infants of mothers given information about preterm delivery in the antenatal period. One facilitator of this care was the government-initiated ‘Linda Mama Cards’ which allow free antenatal healthcare for all mothers in Kenya.

‘It is a card that helps pregnant mothers … you do not pay anything, and it can also help the baby or the mother when they are sick during pregnancy, it offers free treatment.’

C1, Mother, Homa Bay County

Appropriate support by skilled HCP

The education of mothers by staff in the newborn unit was a key facilitator of care of LBW infants. Education was provided by HCP, but caregivers also benefited from interacting with other mothers in a similar position who shared information and gave psychological relief.

‘There are nurses who helped me and taught me how to do the kangaroo, they told me how to take care of the baby … so, by the time I was leaving I had received a lot of support from the hospital and then there were also many mothers who had small babies, I was not alone. We were around five and we encouraged each other so that we could be strong for our babies that they may live and that whatever the people were saying could not happen.’ C4, Mother, Homa Bay County

Benefits of LBW infant lives saved

For both caregivers and HCP, the most positive thing to come out of caring for an LBW infant was seeing the infant thrive. This encouraged HCP to continue giving the best possible care to LBW infants, despite the resource constraints, and it encouraged new mother of LBW babies to persist with the critical care of their infants.

‘The most rewarding aspect for this low birthweight, when they pass in your arms, and you see them through as they grow every day in your arms, and you see their weights increasing, and you see them when you see them free out of infection, this one actually makes you feel what we call you are motivate (motivated).’ HCP4, Homa Bay County

Mismatch between caregivers’ experiences and HCP perceptions of community support

Caregivers were very critical of the post-discharge care of their infants. However, HCP disagreed, stating that the community health volunteers worked closely with the hospital to provide access to healthcare. They described the facilitation of ambulance transport when required and follow-up in the community. The contrast between the opinions of caregivers and HCP may suggest that there are challenges in implementing community follow-up for these infants.

Discussion

Community misconceptions about the causes of LBW in infants and their survival presented a huge challenge to caregivers in this community and was an important contributor to delays in accessing healthcare for these infants. In the context of poverty, there were financial barriers at the individual and community level and this was exacerbated by deficiencies in the health system which meant that caregivers were asked to make financial contributions to healthcare. Conversely, access to antenatal care and community support networks were important mitigating factors.
There are three contributors to delay in receiving care: delay in deciding to seek help, delay in transportation to a healthcare facility and finally a delay in receiving care [33].

Individual- and community-level barriers

In this rural community, beliefs about LBW infants were typically negative. There was a great deal of stigma attached to having an LBW infant which appeared to demotivate mothers from providing optimal care, including seeking healthcare when required. This can indirectly result in an adverse outcome in the infant [34]. Suboptimal early infant care has previously been associated with malnutrition and developmental delay in children in Kenya [34]. Community-based peer support strategies for these mothers which incorporate both psychological support and help to improve their care of these infants could potentially be an acceptable and sustainable solution for rural and impoverished communities in LMIC [35,36].

The decision to seek healthcare for sick newborns relies heavily on timely recognition by caregivers of the warning ('danger') signs. In this study, HCP reiterated that illiteracy in caregivers was a key challenge to getting them to recognise the signs of a sick child and seek appropriate care. A systematic review of healthcare-seeking for sick newborns in LMIC found that there was a paucity of data on this issue but that limited data from South Asia suggested delay owing to caregivers’ inability to recognise severe illness in their newborns, exacerbated by inadequate availability and accessibility of HCP [37]. Educating women about neonatal health and preparedness for birth through community-based interventions has improved care-seeking behaviour by 4–30% [37].

In this study, mothers reported that they were inadequately prepared to care for their LBW infants owing to limited support in the community. This is consistent with findings from a study in rural Malawi which found that mothers were often unable to sustain optimal infant feeding, thermal care and other care practices after discharge into the community owing to competing household responsibilities and inadequate support [18]. The weak follow-up structures for children at risk after discharge is often a key challenge in sub-Saharan Africa where CHW are often unable to sustain optimal infant feeding, thermal care and other care practices after discharge into the community owing to competing household responsibilities and inadequate support [18,38]. In this study, HCP expected the CHW to support with follow-up after discharge but in practice this was not happening. Community-based peer support strategies have been shown to be effective in increasing the duration of exclusive breastfeeding in infants aged 3–6 months, particularly in LMIC (at 3 months RR 1.90, 95% CI 1.62–2.22; at 6 months RR 3.53, 95% CI 2.49–5.00) [39]. In addition, the use of mobile phone technology to link pregnant women to HCP in health facilities has been described in a study in Homa Bay county where women in the intervention group were linked to CHW teams and motorcycle riders who transported pregnant women to healthcare facilities for medical intervention during illness or labour using a mobile phone-enhanced 24-hour Uber-like transport navigation system, coupled with personalised and interactive gestation-based text messages. It showed that women in the intervention group were significantly more likely to attend antenatal and postnatal clinics and were more likely to spend <60 minutes travelling to a health facility for delivery [27]. There is the potential to incorporate LBW infant care into this strategy, thus aligning it with the global paradigm shift of continuum of care for both mothers and their newborns, in this case, the most vulnerable.

Health-system barriers

Caregivers often had to pay for costs in public hospitals such as fuelling the ambulance and medicines that should have been free of charge. This is supported by studies from other settings in Kenya, in Kariobangi and Kangemi (informal settlements in Nairobi with high levels of poverty) where medicines were identified as unaffordable and not readily available for neonatal conditions [40]. By contrast, in the neighbouring county of Siaya in western Kenya, funding was less of a barrier because families were not charged for the care of their infants [41]. These disparities are owing to Kenya’s devolved healthcare system in which individual counties prioritise and invest in different areas of healthcare [42]. As Kenya moves towards universal health coverage, county governments should be held more accountable to ensure that maternal and child health services are adequately financed [43,44].

Staff shortages were an important barrier to accessing care at the health facility level. Longer waiting times led to delays in infants accessing care which sometimes resulted in LBW fatalities which discouraged mothers from bringing their infants to hospital. Similar situations were reported in the neighbouring county of Siaya where neonatal wards were understaffed. One doctor would be responsible for the entire nursery and maternity wards. This is well below the WHO minimum threshold which stipulates a minimum of 23 doctors/10,000 of the population to deliver essential maternal and child healthcare [45]. Staff shortages are exacerbated by high staff turnover (owing to staff rotations, frequent transfers to other areas or burnout owing to the difficult working conditions), leading to a large number of newborn deaths which could be prevented if resources were available. In this study, the insufficiently skilled workforce also meant that medical, nurse and midwifery trainees were frequently not adequately supervised which affected the quality of care given to these vulnerable infants,
and diminished caregivers’ trust in the advice given and in the care their infants received [46]. This diminished trust could further discourage caregivers from accessing healthcare and encourage resort to traditional care providers who may be thought to be more accessible [33].

An assessment of facility-based readiness for the care of small and sick newborns in neonatal care units in Uganda, Indonesia and India found that inadequate equipment was a key deficiency [47]. This issue was raised by all HCP in this study and was a real frustration as many staff thought it had an immense effect on the quality of healthcare. This issue is not exclusive to Homa Bay County Hospital: less than a quarter of hospitals in Bungoma county in western Kenya have basic equipment for the appropriate care of LBW infants [48]. Exploration of strategies to address the deficiency of equipment for the management of newborns is a priority. The outcome of the NEST360° project to evaluate the impact of a bundle of effective and affordable devices combined with training of clinicians and biomedical engineers with collection of robust data on the quality of newborn care [49] is keenly awaited.

Facilitators to accessing care

In this study, care received during pregnancy was a facilitator to accessing care for LBW infants. However, there were disparities in the views between caregivers and HCP where HCP blamed caregivers for their lack of knowledge, competing responsibilities and ignorance of the importance of antenatal sessions as reasons for non-adherence to the recommendations for accessing care for LBW infants. Indeed, in Uganda, a study found that mothers who delivered at home did not recognise that low birthweight was a ‘danger sign’ in a newborn and therefore did not seek healthcare and consequently had no knowledge of the appropriate infant care practices for LBW infants [41]. However, the quality of antenatal care was not assessed in-depth to establish the content discussed or taught during antenatal sessions, and therefore is a limitation.

Limitations

A key limitation of this study is that all the caregivers recruited were mothers and so the views of other key family members involved in the decision-making concerning care of LBW infants were not explored. Interviewing fathers would have enabled exploration of gender roles in this process. In addition, the HCP were recruited from only one healthcare facility; using additional healthcare facilities could have increased the scope of this research. However, this facility is the main county referral hospital for small and sick newborns and it, therefore, has the most experience of caring for this vulnerable group of infants. Secondly, sampling was entrusted to one senior healthcare provider in the Homa Bay facility. His role in the hospital may have made it difficult to disregard opinions on participant selection and to remain objective. However, well-defined recruitment criteria were established to mitigate this risk. The information obtained is therefore transferrable to similar settings in Kenya and can be useful to develop facilitation of healthcare nationwide. Finally, further exploration of the availability and quality of community-level health services to support the care of LBW and their families is required.

To conclude, the study found that accessing healthcare for LBW infants in this rural Kenyan community is a challenge as barriers occur at the individual and community level and are compounded by health system resource constraints in terms of infrastructure and the availability and competence of HCP. There is an urgent need to address these barriers through multi-level strategies involving community and health-system stakeholders to improve outcome in these vulnerable infants.

Abbreviations


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Contributors

HMN and SU conceived the study; all authors designed the study; SU and FW analysed the data; HMN and SU prepared the manuscript and are responsible for the final content. All authors read and approved the final manuscript.

Data availability statement:

Disclosure statement

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