Original Article

Quality of care in nutritional rehabilitation in HIV-endemic Malawi: caregiver perspectives

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Abstract

In Malawi, HIV and malnutrition are two of the most common causes of childhood morbidity and mortality. This qualitative study based in Nutrition Rehabilitation Units (NRU) in HIV-endemic Malawi explores caregiver's (staff and family) perspectives on quality of care for severely malnourished children.

Three carer focus groups and 30 carer and staff in-depth interviews were conducted in two NRUs. The interviews and data analysis used a grounded theory approach, using both male and female Malawian researchers. Trustworthiness was enhanced through the researchers' prolonged engagement with the study setting and participants. The use of multiple methods – interviews, focus groups and observation – allowed for triangulation of the data. Data was then cross-referenced between staff and family caregiver reports.

The analysis generated five themes. 'We have different blood' referring to staff attitudes and underperformance, 'What wrong did I do to God?' referring to stigma and chronic illness, 'My other children back home' referring to the carer's multiple responsibilities and challenges, 'Always in short supply' referring to resources available in the NRU (milk, medicine, space, hygiene) and 'you are always lagging behind' referring to the need for change and participants recommendations. Quality of care is a complex issue, bound by resources and capacity, influenced by stigma and hierarchy and limited by caregivers' conflicting responsibilities. Valuing and involving caregivers is essential in improving quality of care. Care should be patient and family centred and HIV services should be integrated into malnutrition care at the hospital and community level.

Keywords: child nutrition, focus group, HIV, HIV and nutrition, malnutrition, stigma.

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Background

More than a third of child deaths globally can be attributed to maternal and child undernutrition (Black *et al.* 2008). Quality of care and operational capacity have been identified as key elements in improving survival of malnourished children (Bryce *et al.* 2008; Heikens *et al.* 2008a,b). Care for children with severe acute malnutrition (SAM) at the facility

and the community level is provided by health care staff, and by mothers and other carers. These caregivers have a unique insight into factors affecting survival of children with SAM. Little research has been done to understand the perspectives and recommendations of these different caregivers on providing quality care.

Severe malnutrition is one of the most common causes of paediatric hospital admission in Malawi.

Severe malnutrition, as defined by the World Health Organization (WHO), occurs when children are <70% weight for height and/or have bilateral pitting oedema (WHO 1999). In 2005, approximately 20 000 children with severe malnutrition were admitted to the 96 inpatient Nutrition Rehabilitation Units (NRUs) for therapeutic feeding in Malawi (UNICEF 2006). Nutritional rehabilitation programmes provide therapeutic feeding and medical care for children with severe malnutrition (WHO 1999; Ministry of Health 2003).

In Malawi, several studies have reported on the prevalence of HIV in NRUs; with prevalence estimates varying from 34.4% in Blantyre (Kessler *et al.* 2000), to a mean of 21.6% from data in 12 NRUs nationally (Thurstans *et al.* 2008) to 17.4% in three NRUs in Lilongwe district (Chinkhumba *et al.* 2008). HIV infection is also common among mothers of children with severe malnutrition, with one study reporting that 23% of mothers and other carers of children with severe malnutrition were HIV infected (Fergusson *et al.* 2008a). Mortality is high among children with SAM, in particular for those with HIV (Schofield & Ashworth 1996; Fergusson & Tomkins 2008).

The UNICEF conceptual framework for malnutrition identifies food, health and care practices as key underlying causes of malnutrition (UNICEF 1990). Care practices are under explored factors in the literature on child survival in malnutrition. Caregiver perspectives, including both staff as well as mothers and other carers are critical to the better understanding of nutrition rehabilitation. As early as 1951, a study in two orphanages in post-war Germany showed that attentive and affectionate care by staff was a more important determinant of weight gain in children than additional rations (Widdowson 1951). A 2008 study conducted in an NRU in Bangladesh

established that psychosocial stimulation between carers and children significantly increased child growth and development (Nahar *et al.* 2008). Studies in programmes providing nutritional rehabilitation to children with SAM have demonstrated the importance of staff training, implementation of guidelines and staff commitment to providing quality care to reduce mortality among children with SAM (Deen *et al.* 2003; Ashworth *et al.* 2004).

Maternal health and well-being also have a powerful impact on child growth and survival. Maternal HIV infection has been shown to impact on incidence of premature birth and low birth weight as well as infant malnutrition and mortality (Halsey *et al.* 1990; Nakiyingi *et al.* 2003). There is also a growing body of evidence to show that poor maternal mental health negatively affects child growth and nutritional status (Rahman *et al.* 2002, 2004, 2007, 2008). Maternal health is particularly important in nutritional rehabilitation, as researchers observed that staff to patient ratios are very low, and mothers and other carers provide most of the hands-on care for their children, including feeding.

The link between HIV and increased mortality in children with severe malnutrition is now well established in the literature (Kessler *et al.* 2000; Bachou *et al.* 2006; Chinkhumba *et al.* 2008; Sadler *et al.* 2008). However, it is recognized that social, operational and programmatic factors also have a dramatic impact on child survival in severe malnutrition (UNICEF 1990; Ashworth *et al.* 2004; Collins 2007; Heikens *et al.* 2008a,b). There is little evidence available exploring these factors and their impact on quality of care in nutrition rehabilitation from the caregiver perspective.

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Key messages

- Quality of care for children with severe malnutrition in HIV prevalent settings is a complex issue, bound by resources and capacity, limited by stigma and hierarchy and influenced by caregivers' conflicting responsibilities.
- In order to improve quality of care, the central role of both staff and family caregivers must be recognized and valued.
- Care for severely malnourished children should be patient and family centred, and HIV services should be integrated into treatment at the hospital and community level.

Malawi conducted a study to investigate the clinical effect of HIV on malnutrition rehabilitation, the details of which have been published elsewhere (Chinkhumba *et al.* 2008; Fergusson *et al.* 2008b). Along with this investigation of clinical outcomes, a substudy was conducted in partnership with Reach Trust in Malawi to explore caregiver perspectives on quality of care in nutrition rehabilitation in the context of HIV. This paper reports on qualitative research that explores caregiver perspectives (including staff and mothers) on quality of care in nutrition rehabilitation in Lilongwe, Malawi in the context of high HIV prevalence.

Methods

Study design

The research design was explorative, this was particularly important as prior qualitative research in this area was lacking and the subject was both contextually and culturally bound (Barnett *et al.* 1997). The use of qualitative methods allowed researchers to explore the attitudes of different groups, in particular the unheard voices of mothers and other carers. (Eng 1990; Aubel *et al.* 1991; Pope & Mays 1995). The study methodology was rooted in grounded theory principles (Glaser 1998). Ethical clearance was granted for the study by the Malawian National Health Science Research Committee.

Study setting and sample selection

In this study of caregiver perspectives on quality of care in the treatment of severe malnutrition in children, the term caregivers refers to both hospital staff and also mothers and other carers. Hospital staff will be referred to as staff, and specified by their job title. Almost all of the carers were mothers. In the corresponding cohort study using quantitative methods, 95% of carers were mothers (Chinkhumba *et al.* 2008). Other carers were grandmothers, fathers, aunts or neighbours. Mothers and other carers will be referred to throughout this paper as carers.

Carers and staff were purposively sampled from one MOH and one Christian Health Association of Malawi (CHAM) NRU in Lilongwe district, central

Malawi. Kamuzu Central Hospital (KCH) NRU is situated in Lilongwe, the capital city of Malawi, and is a 1000 bed referral hospital for Malawi's central region. St. Gabriel's is a rural mission hospital with 200 beds. Care at MOH hospitals is free and during the time of this study, CHAM hospitals had an agreement with the MOH in Malawi not to charge for certain services, including the care of severely malnourished children. During the time of this study, researchers reported that the nurse to patient ratio at KCH during the hungry season was approximately 1 : 50 during the day when there were usually two nurses working, and 1 : 100 during the night, when only one nurse was on duty. At St. Gabriel's, the ratio was approximately 1 : 75 during the day and as much as 1 : 150 during the night. Inclusion criteria were being a staff member working within the NRUs or accompanying a child to the NRU. Carers remained in the NRU until the child reached nutritional recovery (defined as >85% weight for height and no oedema for 10 days), usually for about 3 weeks.

Maximum variation purposive sampling (Patton 1990) was deployed to ensure inclusion of different voices and perspectives, male and female and younger and older carers and those that had been in the NRU for shorter and longer periods were all interviewed. The sampling frame for staff included women and men from different cadres ranging from cleaners to nurses and doctors.

Three carer focus groups and 30 carer and staff in-depth interviews were conducted in two NRUs. Sixteen carers (14 females and 2 males) and 14 members of staff (12 females and 2 males) were interviewed between October 2005 and March 2006. The 16 carers also participated in one of three focus groups. Most of the interviews took place while the children were hospitalized receiving therapeutic feeding, but two of the interviews with carers took place at the follow-up clinics, when children returned to the facility for assessment and a supplementary food ration. The research was conducted by both male and female Malawian researchers from REACH Trust, Malawi with experience of using different qualitative research methods (interviews, focus group discussions and observation) to explore sensitive topics such as HIV in the Malawi context. The

researchers remained within the NRUs conducting observations, interviews and focus groups for 6 months. Trustworthiness was also enhanced through the researchers' prolonged engagement with the study setting and participants. Participants were recruited directly by the researchers within the NRU. Informed consent was negotiated with all participants and confidentiality maintained through the process of data collation, analysis and presentation.

Data collection

The process of data collection was explorative and involved constant comparison between data and emerging theory. Multiple methods were used to collect data, including interviews, focus groups and observation. This allowed for triangulation of the data. The Information was then cross-referenced between staff and carer reports.

The research team used a grounded theory approach (Glaser 1967, 1998), with the team of researchers regularly reviewing the transcripts and observation records to develop and tailor the question guides to capture all emerging themes.

In-depth interviews were conducted to explore lived experiences, beliefs, perceptions, and motivations or values (Britten 1995). These were complemented by focus group discussions to obtain information about attitudes and behaviours sparked through interaction (Kitzinger 1995) and were cross-checked through observation.

All carer interviews and focus groups were conducted in Chichewa (local language) and then transcribed and translated into English. Staff interviews were conducted either in Chichewa or in English according to participant preference, and then transcribed. Observations were recorded daily in researcher field journals. Note takers were present at all interviews and focus group discussions (FGDs).

Approach to analysis

All observations and transcripts were read and analysed by the entire team in a process led by P.F. Data was then hand-coded using line by line analysis (Glaser 1998). S.T., an experienced qualitative

researcher reviewed the coding during the research process, and two independent researchers reviewed and coded the transcripts and generated similar themes. The entire research team met regularly to discuss the coding and emerging themes.

Results

The analysis generated five themes, as described in Table 1. These themes are discussed in the results section, drawing on first the carer and then the staff perspectives for the first four themes. In the final theme of recommendations, staff and carer perspectives are integrated together.

'We have different blood': power and hierarchy

Differences between the staff and the carers are evident from the reports from researcher observation. Most hospital staff have a higher socio-economic status than carers. This is evident by differences in dress, appearance and possessions. For example, staff tend to be educated, have mobile phones, and wear shoes, while carers have less education, wear chitenjes (fabric wrapped skirt) and are barefoot. The relationship in the NRU between carers and staff appears to be hierarchical. Carers often come and bow before nursing staff, or avert their eyes downward when they are requesting care.

Carer perspectives

Carers report that some of the staff are warm and welcoming with them, but that others are unkind. Illustrative quotes include:

Table 1. Themes generated from analysis

Theme	Description
We have different blood	Carer's perceptions of staff attitudes and underperformance
What wrong did I do to God?	Stigma and chronic illness
My other children back home	Carer's multiple responsibilities and challenges
Always in short supply	Resources available in the NRU: staff, time, space, medicine, hygiene
You are always lagging behind	Need for change and participant recommendations

Some are good while others are harsh. Some they do their work as nurses, very friendly and humble while others instead of helping you they say bad things to you. (Carer, KCH, in-depth interview)

You can not interact with all of them nicely, some are good but others we have different blood. (Carer, KCH, in-depth interview)

Some of the carers reported that they felt the doctors were authority figures, like parents:

But on the part of doctors there are no problems of course as doctors they are just like a parent who can not just stay without rebuking his children if they are not doing what he expects them to do. (Carer, St. Gabriel's FGD)

And other carers reported being made to feel inferior in their interactions with staff:

Because if the doctors are not considerate we feel under-rated as if we are just stupid to be here, as if we asked God to be in the hospital. (Carer, KCH, in-depth interview)

Staff perspectives

This disparity is echoed in the interviews with staff. One ward attendant said:

... so we can't be the same because of our different backgrounds and upbringing. On the part of mothers, I would say a carer is a carer we can't be the same. (Female ward attendant/cleaner, KCH, in-depth interview)

There was also evidence of a lack of effective communication between staff and carers. Staff expressed some frustration at lack of understanding and compliance in carers:

They are not all that understanding. They do not understand what is it that we really require them to be doing. So I can say they lack understanding. (Female research nurse, KCH, in-depth interview)

There is a strong feeling of hierarchy, with the carers subordinate to the staff:

As a health worker I can say that the relationship with mothers is always good as long as they agree and do whatever we tell them to do, we stay together without any

problem. (Female ward attendant/cleaner, KCH, in-depth interview)

One staff member likened the relationship between staff and carers to the relationship between parent and child. Some of the language used by staff when referring to the carers seems to indicate a lack respect for the carer's situation. Carers are said to complain about 'trivial matters' to offer 'lame excuses' to be 'cunning' and to 'lie' and to 'ignore responsibility'.

'What wrong did I do to God?': stigma and chronic illness

Stigma is present in the malnutrition ward, related to malnutrition itself, and related to chronic illness, including HIV. Many carers associated their children's illnesses with spirits and divine punishment and report experiencing stigma in their interaction with other carers:

Carer perspectives

Ah I don't know because I just say it is the making of Satan why others are ok like his twin brother is OK walking and good health and they are saying this one is malnourished. So I just say it is the work of the Satan. (Carer, KCH, in-depth interview)

Yes the problems we face, you know ladies like myself my child reached the target weight but now it is dropping, so those whom God have blessed their children reach target weight and get discharged, as they go home they say bad things like, 'you just want to stay here, you are happy staying here you won't go home,' so we find this to be burdens in our hearts. We tend to wonder what wrong did I do to God, because my friends find and leave me here and they say as if you are happy and just like to stay in the hospital. So, those are the problems we are facing here. (Carer, KCH, in-depth interview)

One HIV-positive mother from St. Gabriel's commented that some of the staff treated her with dignity, while others did not. She explained her experience of when she approached a staff member for help:

(the staff member said) ... I just wanted to trouble her with my HIV/AIDS status. (Carer, St. Gabriel's, in-depth interview)

Although results from the clinical arm of the study show that 36.3% (61/168) and 7.4% (13/176) of children from KCH and St. Gabriel's tested positive for HIV (Chinkhumba *et al.* 2008), only one carer was open about her HIV-positive status. She said:

As for me I do not keep my status as a secret. I usually give counsel to some people. (Carer, St. Gabriel's, in-depth interview)

Another carer reported being afraid to test for HIV:

They teach us about HIV/ AIDS. They tell us that it does not take long for one to get the results of the blood test. They also tell us that if found positive you just need to live positively – not to be worried. Many are afraid to go for a blood test fearing that other people will know their HIV status. (Carer, St. Gabriel's, in-depth interview)

Staff perspectives

This theme of hopelessness was also explored in the interviews with staff members. One nurse from KCH told a story of a grandfather who refused treatment for his grandchild. He vehemently shouted at her saying:

What's the use of drugs even if he dies I thought this diseases once you catch it you never recover the end is death. (Nurse, KCH, in-depth interview)

The grandfather left the hospital with the child, however, the father later brought the child back for treatment.

When asked, all staff members reported that they do not treat HIV-infected and uninfected children differently; however, some statements reveal differences in staff attitudes towards HIV-negative and HIV-positive carers. HIV-negative carers are seen as more forthright and cooperative than HIV-positive carers. For example:

The difference in relationship is that as I have already said mothers whose children are HIV-positive become stubborn and cunning due to lack of hope . . . mothers whose children are HIV-negative are not that difficult to handle. They are always understanding and fast learners willing to implement whatever they are being told to practice unlike their friends. (Female auxiliary nurse, KCH, in-depth interview)

Other statements by staff members were positive:

Actually there is no difference because all of them are our patients to seek care. And we treat them all as our patients. We don't treat them differently. (Female research nurse, KCH, in-depth interview)

Some staff members also spoke of loving their patients:

Love is the fundamental tool for health workers in order to comfort them and make them forget their worries. (Male home craft worker, KCH, in-depth interview)

'My other children back home': carers conflicting responsibilities

All of the carers interviewed reported that they felt a conflict between their responsibilities at home in the hospital.

Carer perspectives

. . . I also left other children back home, they also need me. So having seen that my child has improved I can ask the hospital to discharge me and continue getting the rest of the treatment as an out patient because without doing that then my child at home will starve to death with hunger. (Carer, KCH, in-depth interview)

Carers reported being concerned about their crops and home, and about their marriages. One woman spoke of her husbands' resistance to take an HIV test and explained that he ran away from the testing centre. Some carers also spoke about fear of violence or desertion:

Some they say we overstay here so they fear that their husband may take another wife. (Carer, KCH, in-depth interview)

The concerns expressed by the carers were often described as trivial by members of staff. Nurses felt that it was their duty to convince women to stay in the hospital and prioritize their sick child above responsibilities and other children at home. They reported that they were almost always successful in convincing the women to stay, and that very few absconded.

They probably have indeed other issues to attend to back at home . . . (but) we never bow down to their excuses. (Male home craft worker, KCH, in-depth interview)

Staff perspectives

Staff were also concerned about carers who presented at the NRU with health problems:

Sometimes the mothers seem to be undernourished and possibly sick or pregnant or are also HIV-positive. (Female nurse, St. Gabriel's, in-depth interview)

There are no facilities in the NRU to care for carers, and so these women must be sent to other wards within the hospital to receive treatment, requiring them to leave their children in the NRU alone, and sometimes incurring fees.

'Always in short supply': staff resources and capacity

Both mothers and staff mentioned the lack of resources in the hospitals and how this impacted on care. This included shortages of milk and medicine for the children, as well as lack of food, soap and blankets for the mothers. Most of these shortages were also recorded in researcher observations, with the exception of therapeutic milk. This shortage seemed to be rare, and only occurred due to staff forgetting to order the milk.

Concern over infection control in the NRUs was one of the common themes identified in the interviews with both carers and health staff.

Carer perspectives

They spend days without mopping so . . . children who just pick up things anyhow and put in their mouths like they spend about two days without mopping the floors. Like some go to toilet and come to step on that floor and the children crawl over that dirty [floor] which has not been mopped for a week . . . the children play on dirty floor picking up other wastes, which leads to chronic illnesses. (KCH, in-depth interview with a carer)

Staff perspectives

Staff also reported concerns with supplies for hygiene on the ward:

I think as an institution we have so many problems like materials that we are supposed to be using they are always in short supply and that makes it difficult for us to do our work properly. (Female cleaner, KCH, in-depth interview)

Because if we doing the dustings without soap, or we just mop the surfaces of the cupboards with just water, not any disinfectants. I don't think we can be able to do away with infectious diseases. That is a problem. (Female auxiliary nurse, KCH, in-depth interview)

Research staff observing the wards reported that carers and children were often sleeping on the floor of the NRU on mats due to overcrowding. Not all carers and children had blankets for sleeping, although the ward was sometimes cold at night, despite the guidelines for nutrition rehabilitation of children with SAM (Ministry of Health 2003) stating that children must be kept warm to prevent hypothermia. Although the NRU has sinks with running water for the carers to use, soap is often not available. Children are playing and sleeping close to one another in unsanitary conditions, risking cross infection.

Time and human resources were also constrained in the NRU. Researchers reported through observation that the census in the NRU was sometimes over 50 children, with only one or two nurses on duty. This shortage of staff means that mothers and other carers provide most of the care for children, feeding, bathing and monitoring them. Some staff reported working a night shift, and then when not relieved in the morning, being asked to cover the day shift as well, for a total of 24 hours. Cleaning staff and home craft workers reported their concern with regard to being asked to assist with nurses' duties without proper training due to nursing shortages.

Staff rotate frequently between departments, and it is difficult for management to maintain a trained workforce. Some members of staff mentioned they felt they needed more training for their post. A male nurse at St. Gabriel's commented that although children were presenting in the NRU with complex medical conditions like malaria, tuberculosis and

HIV, the children were not being regularly seen by a doctor or clinical officer. A doctor working at KCH shared this nurse's concerns:

What I found be shocking when I came here was that there was no medical assistant to these nurses. (Female doctor, KCH, in-depth interview)

'You are always lagging behind.'

Recommendations for improved care

The study participants (carers and staff) made several recommendations to improve quality of care for malnourished children. The recommendations included improving the one-on-one carer and health care provider relationship and interaction. For example:

Of course we do try having health talks with these people like on Mondays, Wednesdays and Fridays. But I think we should also be having special meetings with them individually. (Female nurse, KCH, in-depth interview)

Some members of staff also favoured maternal and child care programmes. Staff were concerned that some of the carers were sick or malnourished, yet they could not be given care within the NRU, for example:

We feel sorry for the mother because we refer to other doctors... but sometimes they come back without being helped. So we would rather like if they would be helped here. (Female research nurse, KCH, in-depth interview)

The carers agreed, with a typical quote as follows:

I would suggest that the hospital should also be providing drugs for the mothers that are caring for the children in the NRU as mothers can also fall sick anytime. (Carer, St. Gabriel's focus group discussion)

Some of the recommendations focused on improved care at the community level and improved links between hospital and community.

One staff member suggested that:

What can help I think it would be good if we have people who can be going to the villages educating the people more on nutrition. (Female research nurse, KCH, in-depth interview)

Another explained:

For example when a certain carer was taught about giving a child porridge made from maize flour mixed with groundnut flour, as one of the best food for the child, she got puzzled because she said she grows groundnuts. (Female auxiliary nurse, St. Gabriel's, in-depth interview)

This example illustrates the need for further nutrition education. This mother had an abundance of groundnuts, but was selling them rather than giving them to her child as she did not realize their nutritional value.

Most carers and staff agreed that HIV testing and treatment services should be offered within the NRU. One carer said:

I think ideally all the children should be tested. I can say ideally the whole Malawi should be tested, the whole world should be tested.

Many members of staff expressed concern that children were arriving in the NRU with already advanced malnutrition, sometimes complicated by tuberculosis and/or HIV, and that the best opportunity to intervene and prevent mortality has passed. For example:

The moment they come to NRU it's already too late. They should have had food at their home they should have started ARVs earlier they should have been detected to have TB earlier so you are always lagging behind, and for some children it's too late. (Female doctor, KCH, in-depth interview)

It was suggested that if care could be provided at the community level, that malnutrition, tuberculosis and HIV may be detected and treated earlier. Community-based treatment was also advantageous to families as it does not require one parent to stay with the child in the hospital for 1 month. Several of the carers reported that they would rather have their child treated at home. One man who had brought his child in for supplementary feeding at the follow-up clinic reported:

In my case I can choose to be accessing treatment from home. As you might know my village is very far from here and my bicycle is not reliable. Again during the rainy season travelling is difficult. And it might happen that you have

prepared to come to the hospital that is when it starts raining. (Male carer, follow up clinic, St. Gabriel's)

Discussion

Research to date on HIV and malnutrition has largely focused on clinical outcomes. The different qualitative methods deployed in this study enabled us to go beyond clinical outcomes, and examine the experience and impact of quality of care including a holistic analysis from caregiver perspectives. The qualitative findings show that the ways in which quality of care for children with SAM is affected by resources and capacity, shaped by power and hierarchy and complicated by the ways in which stigma shapes experiences of both HIV and malnutrition.

One of the most important findings in this study is the importance placed by both staff and carers on the impact of organizational, structural and resource issues on quality of care. Shortages of medical, food and basic hygiene supplies limit the quality of care and infection control. The challenge posed by limited human resources for improving health has been well documented in sub-Saharan Africa (WHO, 2006) and in particular in Malawi. Malawi has the lowest coverage of medical staff in the region, with just 25.5 nurses per 100 000 population, compared with 113 in Zambia and 368 in South Africa (Palmer 2006). A 2003 survey found that average numbers of nurses per facility in Malawi was 1.5 (Palmer 2006). NRU staff lacked any specialized training on HIV counselling and testing, and were also overstretched, with ratios of patients to nurses sometimes as high as 50 : 1. Most staff commented that they felt they lacked adequate training to manage severe malnutrition and HIV. These weaknesses in human resources place stress on the care relationship between staff, carers and children, negatively impacting on quality of care. Staff who lack time and training are less likely to be able to provide the personalized care that carers and children presenting with complicated medical and social issues require.

Beyond limited human resources, the quality of care for children with SAM is further complicated by stigma, power and hierarchy. A power hierarchy also seemed to exist between staff and carers. Staff were better educated and usually wealthier than carers.

Although some of the staff spoke warmly and supportively of carers, many staff comments indicated a lack of respect for the challenges carers were facing and a lack of belief in carers' motivation and ability to care for their children.

Parker and Aggleton (2003) explore how stigma plays a key role in producing and reproducing relations of power and control and argue that power relations needs to be considered while evaluating the impact of stigma (Parker & Aggleton 2003). Stigma is an important, although not universally reported issue in malnutrition care. The stigma experienced in the NRU was sometimes focused solely on HIV, but often it was linked to malnutrition and to chronic illness generally. Several of the carers linked their experience of stigma to God, religion and spirits. Nyblade *et al.* (2003) discusses the interplay between religion and stigma in Ethiopia, Tanzania and Zambia, and how HIV can be interpreted as a punishment from God (Nyblade *et al.* 2003). Carers may benefit from support and counselling to help them to accept their own HIV infection and/or family members living with HIV.

Based on the analysis of caregiver perspectives, the following recommendations can be made to improve quality of care for nutritional rehabilitation in regions of high HIV prevalence. These recommendations are relevant for care at the facility or the community level.

To provide good quality care, it is essential that resources are sufficient, including staffing and supplies. All cadres of staff require regular training, in both malnutrition and HIV care. Malnutrition programmes require an uninterrupted supply chain of medical, food and hygiene products. Our study findings emphasize the importance of ensuring that carers are also well cared for, with sufficient food, clothing and hygiene supplies. Facilities should provide safe places for carers to cook, clean toilets and bathing areas, and beds within warm blankets where carers are able to sleep with their children. HIV testing kits and drugs for treatment are essential, including cotrimoxazole and ARVs.

Medical staff as well as administrative and support staff on the wards should be included in HIV sensitization training. It is important that positive mes-

sages for both carers and staff about malnutrition, chronic illness and HIV be communicated and popular myths be dispelled through counselling and education. It is interesting to note that some of the most stigmatizing comments made by staff came from the cleaners and auxiliary nurses, who may be less educated about HIV than the Registered Nurses (RNs). It is important for caregivers, staff as well as carers, to recognize their joint role in providing care for children with SAM. The shared nature of responsibility for caregiving in the NRU, and the importance of both the carer and the staff role should be emphasized during training and sensitization.

As identified in the UNICEF conceptual framework, malnutrition has roots in disease, food insecurity and care practices and is impacted by factors such as intrahousehold distribution of resources, education, health services as well as economic and political factors (UNICEF 1990). The influence of this complex set of social and medical issues was evident in the perspectives shared by caregivers of HIV-infected children with severe malnutrition. Nutritional rehabilitation programmes should be designed to provide family-centred care, including HIV testing and treatment for children with SAM, their siblings and their carers. The involvement of a well-trained, multiprofessional team will be best able to assist families to manage these issues. This team will include medical and nursing staff, but may also include social workers and representatives from faith based organizations.

Finally, where possible, nutritional rehabilitation for severely malnourished children should be carried out at the community level (WHO 2007). This both limits the chance of cross infection due to poor hygiene and overcrowding in the NRU and also allows families to stay together during the nutritional rehabilitation process.

Study limitations

The main limitation of this study was the lack of input from fathers and other male family members. Almost all of the carers were female, and almost all of those were mothers. Further research should be done to

explore ways of increasing male involvement in care for severely malnourished children at the community and facility level.

Another limitation of the study was that while REACH trust qualitative research staff remained within the NRUs for 6 months conducting interviews and observations, some of the participants may have seen these REACH staff as being affiliated with Action Against Hunger. As Action Against Hunger played a role in providing support and resources to the NRU, some of the participants, staff in particular, may have been hesitant to give negative information. The REACH Trust staff attempted to mitigate this risk by being transparent about their role and affiliation.

A final limitation of this study is that it was conducted at the facility level. This study only included participants who elected to come to the NRU, and did not gain the perspective of those carers of severely malnourished children who did not come to the NRU for services.

Conclusions

Through unpacking both carer and staff perspectives on quality of care in malnutrition, five key themes are revealed. Quality of care is a complex issue, bound by resources and capacity, influenced by stigma and hierarchy and limited by carer's conflicting responsibilities. This paper explores both carer and staff perspectives, and therefore gives fresh insights into potential improvements in quality of care in nutritional rehabilitation programmes. In order to further improve quality of care and thereby reduce mortality for both HIV-infected and uninfected children with severe malnutrition, the central role of caregivers must increasingly be recognized and valued. Nutritional rehabilitation programmes should build on areas of good practice in staff and carer relationships and strive to further improve patient and family centeredness. HIV services should be integrated into malnutrition care at the hospital and community level. The lessons learnt from these caregivers can be incorporated into nutritional rehabilitation programme design and delivery to improve quality of care.

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Conflicts of Interest

None declared.

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