

## ORIGINAL RESEARCH



# Perceptions and experiences of caregivers of severely malnourished children receiving inpatient care in Malawi: An exploratory study

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## Abstract

### Background

Severe acute malnutrition (SAM) affects approximately 18 million children under the age of five and is associated with more than 500 thousand deaths per year. Existing research has indicated that a high number of caregivers of children admitted for inpatient treatment of SAM experience psychological distress, depressive symptoms, and suicidality. However, no published studies in Malawi have been undertaken to qualitatively explore caregivers' perceptions and experiences regarding their children's malnutrition and inpatient treatment.

### Aim

To explore caregivers' perceptions and experiences surrounding childhood acute malnutrition and the experience of inpatient care in Malawi.

### Methods

Interviews were conducted utilising a semi-structured topic guide and were coded using thematic analysis.

### Results

Caregivers (N=30) gave informed consent to participate in interviews. Caregiver understanding and perceptions of their children's illness varied. Some caregivers identified a physical cause, with a minority identifying lack of dietary protein. Other narratives were around characteristics of the infant, other circumstantial events and religious and spiritual influences. One-third of caregivers described their own health difficulties and marital and relationship stressors. Challenges such as poverty, lack of access to food, poor food variability and competing demands for caregiver time were explained. Both positive and negative experiences of family and community support and hospital-based care were reported.

### Conclusion

The themes identified contribute to a greater contextual understanding of the multifactorial and integrated approaches required to address malnutrition. This study indicates that healthcare providers need to take a multi-faceted view of malnutrition and be aware of the many factors that may influence healthcare experience and response to treatment. Acknowledging pluralistic belief systems may improve engagement with care. This demands a broader appreciation of perceptions and experiences of malnutrition, hospital-based care, sources of support and stressors within the caregiver, family and community environment as well as consideration of social determinants such as poverty and how these influences present within a clinical context.

**Key words:** maternal mental health, nutritional rehabilitation unit, severe malnutrition, caregiver experience

## Introduction

Almost 6 million deaths occur globally each year in children under five<sup>1</sup>. Malnutrition is directly or indirectly responsible for approximately 45% of these deaths, with mechanisms including fetal growth restriction, suboptimal breastfeeding, stunting, wasting, and inadequate micronutrient supply<sup>1-3</sup>. In Malawi, a high proportion of children under five are affected by malnutrition, with 12%, 37% and 3% being underweight, stunted, and wasted respectively<sup>4</sup>.

Severe acute malnutrition (SAM) is diagnosed in children with at least one of the following: a mid-upper-arm

circumference below 11.5cm (severe wasting), a weight-for-length or -height z-score less than -3 SD below the median (severe wasting), and/or the presence of bilateral pitting oedema (kwashiorkor)<sup>5</sup>. If medical complications develop, such as systemic infection, HIV disease, or respiratory infection, inpatient treatment is required<sup>5-7</sup>. Approximately 600 severely malnourished children are admitted each year to the Moyo Nutritional Rehabilitation and Research Unit at the Queen Elizabeth Central Hospital in Blantyre, Malawi, a tertiary referral site<sup>8</sup>. During hospitalization, primary caregivers are responsible for feeding their child every

three hours<sup>6,7</sup>. This is a highly demanding role that requires caregivers to be attentive and responsive to their children throughout the day and night.

A prospective study of psychological distress amongst mothers of children admitted to a nutritional rehabilitation unit in Malawi identified that 71% of mothers scored significantly high on a screening tool for depression, the Self-Reporting Questionnaire (SRQ-20), and that 15.6% reported experiencing suicidal ideation in the previous four weeks<sup>9</sup>. Factors which were significantly associated with high levels of depression included having an older child, lack of a confiding relationship with a spouse, and having a previous child die<sup>9</sup>.

Researchers have clearly established an association between maternal mental health and child growth and development. Several different pathways link these domains and are thought to operate bi-directionally<sup>10,11</sup>. In Malawi, community-based research has indicated that up to 30% of mothers attending an under-five immunization clinic scored positively for depression<sup>12</sup>. This was significantly associated with reduced length-for-age in their children<sup>12</sup>. Evidence from high-income countries has also indicated that post-natal depressive symptoms are inversely associated with responsive feeding of infants<sup>13</sup>.

The need for interventions to take into consideration the complex contextual factors that are associated with childhood malnutrition has been recognized, particularly within an integrated early childhood development framework<sup>14</sup>. Whilst it is known that nutrition-specific interventions are necessary, it is acknowledged that they are not sufficient<sup>14,15</sup>. Interventions such as behaviour change communication and responsive parenting have provided promising benefits. However, there has been limited exploration of underlying cultural barriers that may affect feeding practices, and the need to contextualize interventions has been highlighted<sup>16</sup>. Qualitative interviews have not been conducted on the sample population of inpatient caregivers of infants admitted for SAM. It is not clear if this group varies significantly from community samples of infants and their families examining infant feeding, compared to management of SAM.

Thus, while targeting psychosocial influences have been identified as a potential area of intervention for both childhood malnutrition and maternal mental wellbeing, there has been little in-depth qualitative work undertaken in low- and middle-income countries to explore experiences of caregivers to improve understanding of the relationship between the known influences on childhood malnutrition and maternal mental health and wellbeing. Using a qualitative approach, this study was developed to explore the perceptions and experiences of caregivers of children diagnosed with SAM within a hospital-based setting in Malawi.

## Methods

### Study design

This study was qualitative, aiming to obtain information regarding the psychological and social context of caregivers and their children which may not be identified during the use of routine questionnaires or clinical care. A qualitative methodology allows exploration of the perspective of caregivers, who play an important role in recovery from SAM. The caregiver perspective is not necessarily explored during routine care and understanding the perspectives of caregivers is important if longer term outcomes are to be

improved. Semi-structured interviews were chosen to allow caregivers to disclose thoughts and feelings that they might not feel comfortable disclosing within a group environment, particularly as psychosocial stressors and mental health are potentially stigmatizing topics. This approach was chosen to enable an open framework of discussion, allowing the interviewer and participant to follow a structured conversation yet also explore topics in greater detail.

### Participants

The study was conducted at the Moyo Nutritional Rehabilitation and Research Unit of the Paediatric Department at the Queen Elizabeth Central Hospital, Blantyre, Malawi.

The inclusion criteria were caregivers of children between 6 and 59 months admitted to Moyo for inpatient treatment of SAM defined by the WHO criteria as:

- 1) Weight-for-length or -height z-scores below -3 SD from the median;
- 2) Mid-upper-arm circumference of below 11.5cm; and/or
- 3) Nutritionally-induced bilateral pitting oedema<sup>5</sup>.

This age range corresponded with the age range of children admitted to the SAM ward at the time of the study.

Caregivers included the primary caregivers or guardians for the infant during their hospital stay, often the child's mother, but not exclusively. In Malawi, each child admitted to hospital is accompanied by a guardian who may be a mother, close family member or other caregiver. In this study, the term caregiver refers to the primary caregivers of the infant during hospital admission. Caregivers were identified using purposive sampling and participants were enrolled after providing informed consent. The exclusion criterion was caregivers who were not willing or able to provide informed consent.

### Data collection

Data collection occurred between 31 March and 2 May 2014, with recruitment of 30 caregivers. Baseline demographic information was recorded, including age, parity, educational level, residential setting, occupation, and HIV status. Semi-structured interviews were conducted in the local language (*Chichewa*) by three male Malawian medical students and were audio-recorded. A topic guide was developed by identifying themes from the existing literature and consulting clinicians involved in management of SAM and mental health. It was used as a basis for the interview and encouraged discussion on the following topics: child health and wellbeing, caregiver wellbeing and concerns, food security, social support and the experience of hospital admission.

### Ethical considerations

This study was approved by the College of Medicine Research Ethics Committee (SP 061317). Verbal and written information was provided (in *Chichewa* or English). Written consent was obtained; for participants unable to read or write, the information was read in *Chichewa* and consent by signature or thumbprint was witnessed.

For caregivers who were identified as having ongoing mental health problems or social difficulties, a referral pathway for assessment at the local psychiatric clinic was available. A protocol was developed for child protection concerns.

### Data management and analysis

Interviews were anonymized and transcribed verbatim from

audio recordings and translated into English. One author cross-checked the back-translation of the interviews for accuracy. Data were coded using thematic analysis by two reviewers: one research assistant, and one supervisor of the project (SGW). Coding was structured around the key topics of the interview and emerging themes. Both researchers reviewed and coded the manuscripts independently, before reviewing areas of difference together and agreeing final themes. The final themes were cross-checked with one of the senior researchers (CB). Interview data were reported descriptively and illustrative quotes were used anonymously where appropriate. Contextual information that could identify the participants was removed.

## Results

### Baseline demographics of participants

Of 30 caregivers enrolled, interview data was available for analysis on 27 participants, as three of the interview audio files were corrupted and not possible to analyse. Characteristics and demographic data of caregivers and their children are reflected in Table 1. Whilst the majority of caregivers were also the mother of the infant, a minority were another family member or social contact such as neighbor (n=3).

**Table 1: Characteristics of children with severe acute malnutrition and their caregivers**

Child characteristics	
Age (months), median (range)	24.0 (9–48)
Sex, n (%)	
Male	11 (37)
Female	19 (63)
Caregiver characteristics and demographics	
Age (years), median (range)	24.5 (16–36)
Education, n (%)	
Primary	13 (43)
Secondary	17 (57)
Living setting, n (%)	
Rural	3 (10)
Peri-urban	14 (47)
Urban	13 (43)
Maternal Occupation, n (%)	
Business	3 (10)
Cleaner	5 (17)
Housewife	17 (57)
Student	3 (10)
Farmer	2 (6)
HIV status, n (%)	
Positive	7 (23)
Negative	17 (57)
Unknown	6 (20)
Maternal Marital Status, n (%)	
Single	4 (13)
Married	24 (80)
Divorced/ Widowed	2 (7)

### Core themes

Recurrent themes identified from the interviews included:

perceptions and attributions of infant health and illness; maternal wellbeing and interpersonal relationship stressors; family and community supports and stressors; and household resource limitations such as food insecurity, unemployment, poor housing, and material conditions of poverty. Positive and negative experiences of hospital-based care were also discussed by caregivers.

### Perceptions and attributions of infant health and illness

Caregiver understanding and perceptions of their children's illnesses varied. In some descriptions (n=5), the children's illnesses were understood in terms of a physical cause. Several informants gave a narrative of seeking help for a particular physical health presentation, such as diarrhoea or malaria, which was later narrated as being related to malnutrition. The understanding of malnutrition as the cause was not universal in these narratives, with some caregivers remaining unclear: *"What's bothering me is that she is showing signs of malaria but once they test her they are finding that she is malaria free so I am wondering as to what the problem is."*

In some instances, caregivers described features of clinical presentation of malnutrition, but did not indicate specifically that this was malnutrition, rather describing other potential causes such as 'lack of blood'. Whilst some caregivers demonstrated an understanding of inadequate nutritional intake as a cause of the child's illness, specific nutrients such as protein were not mentioned. Other food groups were highlighted such as a lack of fruit and vegetables. Caregivers identified that the lack of nutritional intake did not necessarily relate to intake of nsima (a form of maize), the main staple food in Malawi. In these narratives, a number of different influencing factors were identified, which included social triggers and circumstantial events. Some of the physical features of malnutrition were identified and some understanding of the role of inadequate nutritional intake in response to healthcare-derived knowledge was demonstrated, as in this example: *"What happened this time around is that I got on a bicycle with him, I think that's why his feet have swollen... – they [the healthcare professional] are saying it is because he lacks food in his body... but they don't mean food like nsima but fruits and vegetables."*

A small number of caregivers (n=3) identified their children as difficult or "fussy" eaters, which affected nutritional intake. In these narratives, the impact of a child being a difficult eater was amplified by the care environment, such as lack of persistence within nursery or school feeding programs to address the specific child's needs, as in this example: *"We are okay only that he is a difficult child. I go to school and so does he and when he comes back and they attempt to feed him, once he refuses they let him be because there are other children in need of care there too."*

A proportion of caregivers (n=6) identified religious or spiritual influences as alternative causes of childhood illnesses. At times, these attributions were described when the caregiver did not have a clear medical explanation for the child's illness, as in this example: *"He has many health problems every month as it seems he was bewitched. We came here after he fainted and the doctors were unable to find any sickness."* (Interview 8, 36 years, small-scale business woman, peri-urban setting)

A small number of caregivers related the impact of the illness on their relationship with the child and the extended household environment, highlighting how child illness may have much wider repercussions for caregiver health and household wellbeing: *"I was affected in such a way that when a*

*child is sick, nothing progresses in the home and he isn't happy when sick."*

### **Maternal wellbeing, resilience and interpersonal relationship stressors**

One-third of informants identified that they had experienced their own physical illness or health difficulties, whether during pregnancy, the postnatal period, or at the time of the interview (n=9). In several cases, caregivers identified that their current health difficulties originated from pregnancy complications with their affected child. Some of the informants were other caregivers, as the mothers of some children were deceased or unwell. In one case, this appeared to relate to a severe mental health condition of the mother which rendered her unable to care for her child:

*"She's [mother of infant] at home. She's got a mental health problem. As soon as she gave birth. Her husband married someone else and so we suspect that the other woman is the one who bewitched her.... No, she doesn't talk. She just goes to drink water when she is thirsty. We feed her because her hands no longer function. At night, she doesn't want to sleep but rather to walk around. I have just gotten the news whilst here that she is being troublesome now that I am here."*

Caregivers described fears and anxieties in relation to a number of marital and relationship stressors. In several cases, there was a clear description of interpersonal events such as the husband leaving the household, after which food provision and survival became more challenging.

When reflecting on pregnancy and the postnatal period, caregivers described experiencing different levels of support from the main household providers, their husbands or partners.

Relationship difficulties were described by a third of participants (n=9), with a number of different sub-themes emerging including: the father of the child not accepting responsibility or involvement with the caregiver after conception; the husband being unemployed and not providing for the family; relationship difficulties and arguments; the husband leaving the caregiver or chasing her away from the family home; infidelity; domestic violence; the husband living in a different geographical area; and the impact of substance misuse. In one case, the father of the child was described as being physically unwell due to HIV and unable to support the family. Some informants described beliefs that witchcraft was involved as a cause of some of these difficulties, such as infidelity.

Relationship difficulties were thus described as having a direct effect on caregivers' wellbeing and nutritional status, particularly where the informant is dependent on her husband for food security, as is the sociocultural norm, as illustrated in this example: *"With the neighbour it is all well but it is not well with my husband. ... We argue and stay for a whole month without talking to each other, sometimes he goes to work without leaving money to buy food."*

However, many caregivers (n=13) described positive relationship support and 4 informants gave descriptions of both positive and negative support in their relationship.

### **Family and community supports and stressors**

Family supports and stressors were commonly mentioned by participants. A minority (n=5) reported difficulties in looking after their children. In some cases, there was regret about having another child and description of child-rearing capacity being overstretched, indicating a compromise of

personal and family resilience. In two cases, other children or community members were described as the main caregivers to the affected child due to lack of financial support and assistance within the nuclear family environment.

Concerns about lack of support from family members were described: *"We are just women in our home. My brother went away and married there and he doesn't even help us or our elderly mother. He doesn't even send one tambala. He doesn't even call."*

Positive descriptions of family and community support were also reported, particularly by other women in the extended family network such as mothers and sisters. Both positive and negative supports in the community were described. One informant reported being reliant on neighbours to provide care to the family due to her husband's absence: *"It is quite difficult since I am not there at the moment and my husband has also gone to work. We just depend on the neighbours... [we are] relying on neighbours to help look after [the] family"*

In contrast, a minority of caregivers reported difficulties in their local communities. These narratives had a number of different components, relating to lack of material wealth or fears regarding the intentions of neighbours. In some cases, this was linked to attributional concerns regarding the child's illness being due to influences of witchcraft. These similar attributional fears were also found in descriptions of lack of support from family members.

### **Household resources, limitations and resilience**

Most of the caregivers reported reliance on other family members for financial stability. For women who were the main breadwinners in the family, pregnancy and the demands of childcare presented a period of financial stress increasing vulnerability to food insecurity. Other factors that could increase the risk of food insecurity were misuse of alcohol or other substances by the head of the household, often the husband, described specifically by two informants: *"Sometimes he [husband] would take her money which she worked hard for and go drink."*

Amongst respondents, financial circumstances varied. Some caregivers identified themselves as having financial stability and being able to buy food and other necessities regularly. Others reported being able to access a regular supply of food, albeit with limited dietary diversity, but having other material limitations in the household. Several caregivers described difficulties in ensuring adequate food provision on a regular basis and the impact this has on the caregiver: *"It was very difficult for me, even to find food for me and my children... it is difficult for me to find food to feed them ... I get stressed because I am the only one taking care of them."*

Work-related stressors and the challenges of sustaining work while looking after children were also described. For those informants who reported being dependent on farming, seasonal availability of food was identified as an issue, highlighting vulnerability to climate change.

A minority of informants (n=2) described good food availability within the household: *"I take maize, fish, beans, groundnuts and grind together. If this flour is not available, we simply take oil and drop a little to the porridge and then feed it to the child. Sometimes we feed him porridge with ground nut flour at seven o'clock, at eight o'clock we mash potatoes or pumpkins with sugar and then feed him."*

Several informants (n=3) reported poor housing; in some cases, houses had fallen down while the caregiver was at the hospital, a potential barrier to community recovery.

### Perceptions and experience of healthcare access and treatment

Challenges identified by informants included difficulties in accessing appropriate and timely care in the community. Positive experiences of hospital-based care in the nutritional rehabilitation unit were reported, including recognition of progress, provision of food, and support: *“His cheeks would shrink because he had diarrhoea. They told me to feed him Thanzu ORS [Oral Rehydration Salts]. Things wouldn’t change and people encouraged me to come here. I think things have improved for me here.”*

However, a small number of informants reported concerns regarding the hospital-based care they were receiving. This appeared to relate to fears regarding child survival, although it was difficult to clarify from the accounts whether this was attributed to the illness or the quality of care received and limited understanding of hospital treatment protocols: *“We are just worried if our children will come out alive. Some people are refusing to get admitted and some are even running away... It’s just that they refuse for us to feed the children. They ask us why we are giving them food...”*

### Discussion

The findings from this study provide further information regarding the complex social context of SAM and the experiences and perceptions of caregivers of children admitted for inpatient treatment at a nutritional rehabilitation unit. The emerging themes identified are similar to findings from other qualitative studies in Malawi exploring the experience of caregivers in the community in relation to mental distress, notably poverty, lack of support, and fears of witchcraft<sup>17</sup>. Relationship stressors have also previously been identified as stressors to caregivers in the community, particularly in relation to fears regarding infidelity, abuse, and abandonment<sup>17</sup>.

The experiences described by caregivers illuminate some of the tensions faced particularly when there is reliance on other providers for income and food and where the provider is unable or unwilling to meet these obligations, in the absence of other community supports or social security system. Caregivers may have limited power or choice over food purchasing and decision-making to improve dietary intake of their children. Almost one-fifth of caregivers indicated that they were struggling to meet the demands placed on them

by their children. This may be compounded by other factors such as high birthrate in Malawi and lack of birth spacing. In order to care properly for their children and to ensure nutritional recovery, they need additional support from healthcare professionals and social care services. This could include identifying if lack of food, limited food diversity or lack of decision-making power is a contributing factor and signposting families to relevant community-based programs.

Additional narratives highlighted situations in which children are cared for by siblings, neighbours, or other care providers who are unable to support these children’s basic nutritional requirements and emotional care needs. In these contexts, the mother may not be the main care provider for a child and has little influence or agency over certain aspects of care such as emotional need and attention, which may not be recognized as important by other caregivers.

In these circumstances, social care services may have a role to play in identifying and providing additional social support to families who are struggling to consistently meet the needs of their children.

The results clearly highlight the vulnerability of caregivers to dependence on the quality of their support network including marital relationships. When marital stressors are at play, caregivers may have limited capacity to ensure appropriate nutrition, care, and provision for their families, particularly in this low-income setting where there are very limited or no other forms of financial or material support.

Informants also highlighted a number of themes in relation to the understandings and attribution of causality of malnutrition and treatment approaches, particularly in relation to attributions to spiritual and religious influences and perceptions of treatment failure. These factors require further exploration to enable healthcare professionals to provide culturally-sensitive interventions that acknowledge the range of attributional beliefs held by caregivers. This may benefit short-term management and longer-term recovery, for example by improving collaborative care, therapeutic alliance and concordance. Evidence from other countries indicates that if healthcare providers acknowledge pluralistic belief systems explicitly, usage of healthcare services can improve<sup>18</sup>.

This paper also suggests that further educational work is required in inpatient settings and to ensure that caregivers

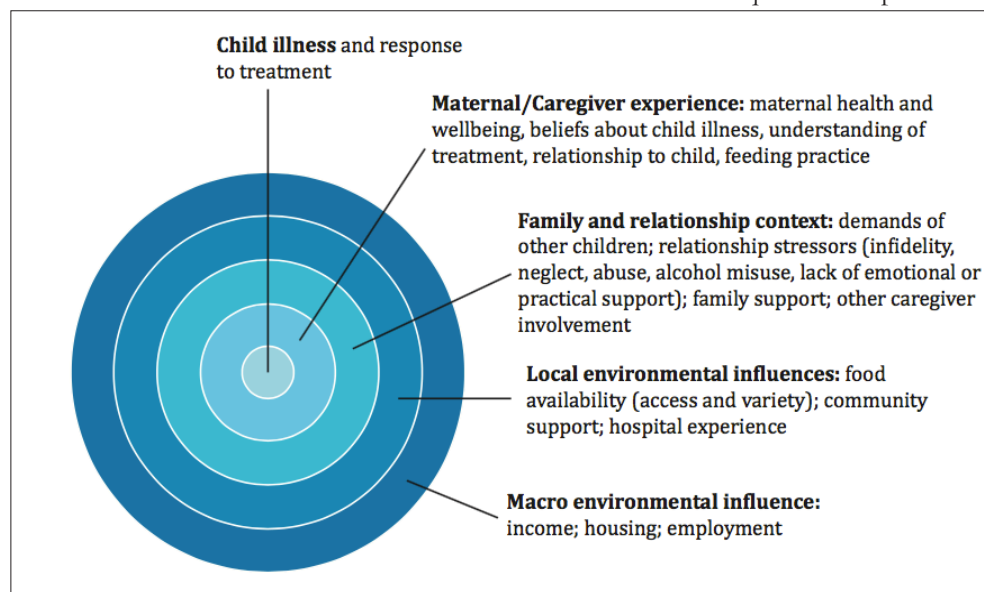


Figure 1: Framework of factors influencing caregivers of children with severe acute malnutrition

understand the interventions being provided. This is particularly important in the context of inpatient treatment of SAM, as the feeding schedules at nutritional rehabilitation units can be demanding, especially where a child has poor appetite or other feeding problems. Caregivers may struggle to encourage their children to feed, particularly if their children are acutely ill. Caregivers may also be juggling a variety of competing demands with other children at home and may have limited support systems in place in the community, and healthcare staff may not be aware of these factors.

This study indicates that healthcare providers need to take a multi-faceted view of malnutrition

and be aware of the multiple factors that may influence healthcare experience and response to treatment. Healthcare interventions need to be multi-faceted and address the wider family and social contexts, as simply providing nutritional rehabilitation may not address these underlying complex factors. Using a framework approach (Figure 1) may help clinicians consider a holistic approach to supporting children, their caregivers, and families to recover.

In addition, it may be important to identify subgroups such as vulnerable families that require tailored interventions, including adapting information to improve understanding and collaborative care, and signposting to other community resources or social care.

Commonalities and exceptions in the narratives highlighted other subgroups warranting further exploration such as those caregivers who have access to reasonable food supply and variety; those caregivers who have positive support but not access to adequate nutrition; caregivers who do not have access to social support; and those who are reliant on other caregivers within their neighbourhood and family.

This research contributes to the call for formative research to identify local practices and barriers to optimal feeding<sup>16</sup>. It adds to the literature that has indicated the importance of understanding competing demands on caregivers' resources, such as financial and time constraints identified in research undertaken in other low-income countries like Bangladesh<sup>18</sup>.

### Study limitations

Limited information was provided by informants regarding the nature of the emotional relationship to the affected child. This may have been due to informants feeling this information was irrelevant, the interview process, or cultural differences in ways of describing the caregiver-infant relationship.

Some informants provided a narrative that appeared to provide conflicting information such as agreeing that they had availability of food in the household and then later in the interview disclosing a lack of nutritional sources. This may have been due to interviewer bias, performance and social acceptance bias, or to the interviewers' limitations in exploring their initial meanings in adequate depth.

Other limitations included that since this study employed purposive and opportunistic sampling, other views may not have been represented. However, a sample size of approximately 30 is typically adequate for data saturation in a qualitative sample<sup>19</sup>.

This study only included infants from 6 to 59 months of age. SAM affects infants and children of all ages; therefore, the findings are limited to this age range. Future studies may be valuable to explore the experiences from more specific age bands across a wider range of years, to ascertain whether certain experiences are associated with specific age cohorts.

The approach of this study, to use medical students to undertake qualitative research, enabled information to be generated; but the depth of data was limited. Interviews were undertaken by three male medical students. Their own perceptions and different socioeconomic position in relation to the caregivers may have influenced the information provided during the interviews and contributed to bias.

The experience of using medical students for interviews and data gathering also highlights the need for medical students to receive undergraduate qualitative method skills training,

which can encourage the development of 'soft' transferable interpersonal skills and interview techniques.

### Conclusions

In summary, this exploratory qualitative study contributes to the evidence supporting the need to consider the multifactorial nature of childhood malnutrition, and encourages clinicians to identify the sociocultural, family and community influences, and to explicitly engage with caregivers' pluralistic belief systems.

### Conflict of interest statement

No competing interests are declared by the authors.

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Kate Chidzalo assisted with the transcription and coding of the manuscripts. Dumisani Nkhoma, Yohane Mulaheya and Sylvester Nkunika undertook interviews of participants. Jacqueline Daniel assisted with graphic production.

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None

### Author contributions

S Gleadow Ware and W Voskuyl contributed to the design and implementation of the study. Coding was undertaken by K Chidzalo and S Gleadow Ware and cross-checked with C Bandawe. K Chidzalo and D Kokota contributed to translation. A Daniel assisted with the drafting of the article and data presentation and R Stewart contributed to the final approval of draft and analysis.

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