

# **Co-SAM Home Environment Working Papers**

Report 4: Caring for children convalescing after hospital discharge with Severe Acute Malnutrition: Key findings from interviews with primary carers in Harare, Zimbabwe



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# Caring for children convalescing after hospital discharge with Severe Acute Malnutrition: Key findings from interviews with primary carers in Harare, Zimbabwe

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## 1.0 Introduction

## 1.1 Background

World Health Organisation (WHO) guidelines suggest that children with SAM, especially those with comorbidities, are best cared for within inpatient clinical settings in order to prevent short-term morbidity and mortality, achieve sustained nutritional recovery, as well as longer term healthy development (Bhutta et al., 2017). The risks associated with SAM diagnosis do not end here. It is widely recognised that children in recovery from SAM, especially in its 'complicated' form, remain vulnerable to risk of death because of a range of biological and social factors; for example, immune impairment, comorbidity with chronic infections such as tuberculosis and HIV, as well as exposure to a socio-ecological environment which was partially responsible for the development of SAM in the first place.

The experience of poor survival rates for children hospitalised with SAM is reflected across southern Africa. HOPE-SAM (Health Outcomes, Pathogenesis and Epidemiology of Severe Acute Malnutrition) was an observational cohort study that enrolled children under 5 years of age hospitalised for complicated SAM at three tertiary referral hospitals in Lusaka, Zambia and Harare, Zimbabwe between August 2016 and March 2018 (Bwakura-Dangarembizi et al., 2019). As Bwakura-Dangarembizi and colleagues report, almost 44 per cent of children in the HOPE-SAM cohort had ongoing SAM at the point of discharge and were twice as likely to die in the first year post discharge compared to children who had recovered (Bwakura-Dangarembizi et al., 2021). This vulnerability to early death was heightened with the existence of comorbidities such as HIV.

It is widely recognised that improvements to the immediate and long-term outcomes for children recovering from complicated SAM is extremely challenging, especially for those living in resource poor settings with fragile health systems (Khanum et al., 1998; Stobaugh et al., 2018; Wiens et al., 2013). It was for these reasons that a small sample of caregivers from the Zimbabwean arm of the HOPE-SAM study were recruited to take part in a parallel investigation led by social scientists, and more especially geographers. It is upon this study that we report here.

## 1.2 Study Setting: Zimbabwe

At a national scale, Zimbabwe remains one of the world's most food insecure. In 2020, the UN Special Rapporteur declared that some regions in the country were "one step away from famine" (UN 2020) and, in 2022, the Food and Agriculture Organisation and the World Food Programme jointly identified the country to be one of 20 'Hunger Hotspots' globally (FAO/WFP, 2022). This national picture, which has been worsened by the combined impacts of COVID-19, the global effects of the Russian-Ukrainian war and a reduced maize harvest for the 2021/22 season (Trotter et al., 2020), is reflected in food and nutritional security among children and adults (see ZimVac 2020). As a recent assessment in urban areas reveals (ZimVac, 2020), only 12 per cent of children in Harare consumed a minimum acceptable diet and 3.9

per cent of children were suffering either moderate or severe acute malnutrition. These figures are likely to have increased considering the current situation.

The national picture is reflected across Harare, the country's capital city and site for this study. Harare is the most populous urban settlement in Zimbabwe, with an estimated 2.4 million of a total 15.2 million people living in the city (Zimstats, 2022). Although there are pockets of wealth, the decades long economic and political crises that have affected the country have resulted in a declining urban middle class and an increase in households living in poverty. The most recent urban livelihoods assessment, undertaken by the Zimbabwe Vulnerability Assessment Committee (ZimVAC), highlighted the implications of this for food and nutrition security in Harare. For example, the ZimVAC survey completed in 2020, reveals significant levels of food insecurity in areas containing some of the city's poorest districts. In the domain covering Mbare and Sunningdale, both high-density areas to the south of the city's business district, 34% of households were reported as having poor levels of food access and 18% were borderline (ZimVAC, 2020). Similar figures were reported in Epworth (33% and 41% respectively) and other domains containing areas of high-density housing, for example Tafara, Mabvuka, and Caledonia, where levels of poor food access were reported in 30% of households.

While we do not identify the specific areas the individual participants in this study were residing in at during the period it was undertaken, all of the women participating were living in areas of the city characterised by poor food and nutrition security.

# 2.0 Methodology

The study we report on was a qualitative investigation involving participants recruited to the main HOPE-SAM cohort study. HOPE-SAM involved recruiting 745 children aged under 5 years old and diagnosed with complicated SAM (Bwakura-Dangarembizi et al., 2021). The children were recruited from three hospitals, one in Lusaka, Zambia and the other two in Harare, Zimbabwe: Harare Central and Parirenyatwa hospitals. The oldest of the Zimbabwean hospitals, Parirenyatwa hospital, was established in 1890 and near to the city's central districts and Harare Central was constructed in 1958 and was closer to the city's then affluent southern suburbs. Both are major public referral hospitals serving a catchment population that stretches across urban, periurban, and rural districts (Matamanda and Nel, 2021).

It was from the cohort of children in the Zimbabwean arm of the HOPE-SAM study that the women for our investigation were themselves recruited. All caregivers of children in HOPE-SAM had undergone a process of 'sensitisation', which was undertaken by study nurses on the project prior to informed consent being sought. The children were cared for according to hospital protocols and clinical teams decided when they could be discharged, at which point caregivers recruited to the study were requested to complete a morbidity diary to record any episodes of illness after discharge and to be available for follow-on home visits from the study team at regular intervals - weeks 2, 4, 12, 24, and 48. At each of these visits, the study clinician undertook a clinical assessment of the child and a study nurse captured health and

socioeconomic information using a standard follow-up form (full protocol details are available here: <a href="https://osf.io/29uaw/">https://osf.io/29uaw/</a>).

Caregivers of child participants on HOPE-SAM were recruited to the qualitative investigation by the study nurses who purposively sampled based on a range of factors, including household characteristics (e.g., family structure and size), identity of child's primary caregiver (e.g., mother, grandmother), as well as the nurse's perception of the participant as an information-rich case. A total of ten primary caregivers were recruited and in-depth, semi-structured interviews were conducted over a period of two months between October and November 2018. In 2021, a follow-up investigation of children recruited to the HOPE-SAM study was undertaken. As a part of the follow-up, the previously interviewed women were invited to take part in further in-depth interviews. A total of six of the original participants agreed to take part in the second round of interviews, with a further 14 women recruited from the HOPE-SAM follow-up study. The sample allowed for credible and meaningful insight into the experience of caring for a child discharged from hospital having recovered sufficiently from SAM to be allowed to return home.

In the first round of interviews, a narrative prompt or vignette, devised by the field researcher from field notes taken during home visits, was utilised as an icebreaker and as a way of helping the participants understand some of the wider issues the research team wanted to discuss. For example, the interviews sought to better understand the participants' knowledge of SAM, the interconnectedness between livelihood strategies and caring practices, as well as the migration and mobility patterns of the primary carers and their children. In the second round of interviews, the vignette was replaced by a recall question which prompted the participants to share their memories of the child's hospitalisation and recovery. Subsequent questions targeted themes from the previous round of interviewing (e.g., caring practices, health-seeking behaviours, indigenous knowledge systems and knowledge recall, and informal protection networks), as well as introducing new questions relating to food cultures and experiences of COVID-19. The latter two topics are excluded from this report.

The interviews were undertaken within or outside of the participant's homes, they were recorded with the oral and written consent of the participants, and subsequently transcribed in Shona, translated into English, and checked for accuracy and meaning by the field researcher prior to being input into NVivo 12 for coding and analysis. Interviews across both phases of the study lasted between 30-60 minutes and covered a range of topics relevant to the participant's experience of caring for a child with, and convalescing from, SAM. The coding process was based upon the framework method often employed in multi-disciplinary health-related research (Gale et al., 2013). A coding frame including deductive and inductive codes was established through a repeated process of coding and group review until codes were acceptable and consistent (MacQueen et al., 1998). Findings from the interviews are presented using anonymised case-codes applied to the individual participants rather than pseudonyms (e.g., PTID 101).

# 3.0 Caring for Children Discharged with SAM

In the following section we present the findings from the first stage of the research, occasionally this is augmented with interview extracts from the second phase of interviews. The focus for this section is on the women's description of the child's embodiment of SAM and perceptions of its causes, their recall of the nutritional guidance provided in the hospital and their enactment of it. The section also explores the caring networks the women were able to draw upon to support them in caring for the convalescing children as well as on health-related decision making.

## 3.1 Signs, symptoms, and causes

Throughout the interviews, the caregivers provided insights into their understanding of SAM and how it was physically presented in the bodies of their children or the children they were caring for. Symptoms such as swelling of the feet, legs, tummy, hands and face, wasting, not sleeping well, loss of appetite, lethargy, pale skin, thin reddish hair, hot body, diarrhoea, vomiting, and other associated illnesses were all identified. Although the women were able to identify symptoms that are associated with SAM, both in its oedemus and non-oedemus forms, many expressed their surprise and uncertainty with regards their child's condition.

"I was troubled about the sickness of the child, wondering what condition this was. I did not understand what was really paining him. I was concerned that he had this sickness before and now it's back again, what is it? What type is this that doesn't go away? I did not know the cause of it, I was just concerned." (PTID\_107)

The uncertainty expressed by this participant appears, in part, to have been shaped by the information they received from women living in their community. Other women associated the embodied symptoms of SAM with gender differences (e.g., boys eating more than girls) and with inherited physiology (e.g., slimness). Even when the children had been diagnosed with SAM, some of the women struggled to believe the diagnosis provided. As one of the mothers explained:

"She was sick with diarrhoea. So, the nurses looked at her and said this is malnutrition. I said, 'how can she have malnutrition when she is breastfeeding?'" (PTID 102)

Outside of describing the signs and symptoms of SAM, the caregivers also discussed what they believed were the causes of their child's illness. In broad terms, explanations tended to focus on the economic and social environment the women inhabited and their inability to access food, decision making around breastfeeding and here especially early weaning, as well as wider socio-cultural explanations based upon religious and/or traditional belief systems, including those associated with witchcraft and bewitchment. The importance of these different explanations is made apparent later in the report where the interrelationship between belief systems and health-related decision making is identified. In the subsections below, we firstly provide a little more detail relating to the main explanations the women provided for their child's diagnosis with SAM.

## Food insecurity

Food insecurity, especially in terms of the economic and physical *access* to food and stability of food supply, was identified as a significant issue for most of the participants. One caregiver believed her child was repeatedly admitted to hospital with SAM due to the degree of food insecurity she was experiencing, and another that her husband's lack of employment left her unable to care for the child. As the latter described, "[w]hat happened ... was that the father was no longer going to work, and food was difficult to get so we gave him [the child] the little we had" (PTID\_104). As this caregiver continued, "what really made him sick was food, that is what I noticed, was the fact that there is no food" (PTID\_104). The participant's lack of access to food resulted in their pursuing a range of livelihood strategies. As the previously quoted participant described, "I went to fetch water on someone's behalf and earned 50 cents and I was able to buy potatoes for my child." Another participant stated "at home, at times, things will be tight, not even 10 cents to buy anything. No money" (PTID\_108). When asked what she did in those circumstances, the participant replied "I would beg."

Begging and undertaking domestic chores for neighbours were only two of the examples the mothers provided of the strategies they were forced to adopt; moreover, they were the least common. More often, the women described a mix of petty trade and casual labour. For some, this included vending, as one of the participants outlined: "I normally do vending ... I used to sell tomatoes, onions, cucumbers and mangoes when in season" (PTID\_109). The profits from vending, were utilised to re-stock as well as to buy household necessities like cooking oil, laundry soap and items such as sugar, salt, and where the profits allowed, clothes. For other participants, vending was adopted alongside other informal strategies such as hairdressing. However, the reality, at least for the women in this study, is that such strategies provided only temporary relief rather than a long-term solution to their economic precarity.

## Feeding practices

Most caregivers believed their children developed SAM because they had weaned them too early with a range of reasons given for doing so, including death of the birthmother, the desire to encourage the child to eat solid food, and to allow employment opportunities to be pursued. Other factors affecting breastfeeding, including pregnancy with several mothers mentioning they were advised to stop by others in the community.

"I then realized that I was pregnant again then, I then stopped breastfeeding, I had been told the milk will make him sick ... They say if you continue breastfeeding unknowingly its ok, but once you realize you are pregnant, the child will get sick." (PTID\_203)

"What caused the child illness was that when I was living in Kunanga a friend of mine advised me to stop breastfeeding at 5 months, then she looked well and health." (PTID 206)

"It was said a pregnant woman cannot feed, the children's bodies will swell up, not sure how ... They were these elderly men..." (PTID 215)

The caregivers appeared knowledgeable about the consequences of weaning their children too early, perhaps a reflection of wider education programmes, with one of the caregivers noting the potential link to their developing SAM:

"I weaned [child] at 1 year 4 months. From my thinking, I think what made [the child] sick was that I had stopped him. I stopped him early." (PTID 104)

Living in circumstances where access to nutritious and age-appropriate food is a daily challenge, many of the participants described relying on a range of locally available snackfood items. These ranged from processed versions of drinks such as *maheu*, a traditional millet- or maize-based drink given to young children, to *maputi* (Zimbabwean popcorn), 'freezits' (frozen drinks) and other snack foods.



Figure 1 Street Vendor, South Harare, Harare. Photo Credit: Tim Brown

The food items are readily accessible in economic and physical terms and are sold via street vendors or at nearby tuck shops (see Figure 1). They were primarily a source of comfort for children who were otherwise refusing to eat.

"I just used to buy her maputi and freezit, that's what she liked to eat, but all the other things I bought her she refused to eat. Even when you cooked Sadza for her, she would refuse it." (PTID\_101)

"The truth is [child's name withheld] would drink them because when I bought him one packet, he would drink it very fast, and start crying for more. So I was also giving him because this is what he wanted." (PTID\_108)

"I also did not know ... the child was drinking the artificially flavoured ones [maheu], he would cry and we would give him more. ... I thought we could give her whatever we have, hoping it will help her. And we later realised it was not." (PTID 109)

An area of concern that emerged in the interviews was a belief that feeding 'cold food' to children was a cause of risk for SAM. As one of the participants explained, "[i]f you give him cold food he will end up with kwashiorkor, because inside his stomach it will be cold" (PTID\_109). This belief was shared by other women, and the participant's discussion of the problem highlighted a range of wider issues. As the participant describes below, this included lack of access to fuel for cooking as well as a reliance on poor quality care provided by community carers:

"Where I was living then, there was no electricity and there was no kerosene stove, I cooked outside on an open fire, I then cooked more food, and would leave some for later. Later on I fed him cold food, just making do with the situation and that made it worse, because he was consuming a lot of cold food." (PTID\_108)

"She would give them [maheu packets] cold straight from the fridge, not warmed, yet a child this age needs something warm. He would start crying and she would just open a packet and give it to him. I even used to think it's alright, before I was taught that you don't give a child cold food. You should wait for the maheu to warm up to room temperature, not when you just buy them and they are still cold." (PTID 108)

## 3.2 Post-discharge care

As noted in the introduction, one of the key aims of the project was to better understand the women's capacity to care for children who were discharged from hospital having sufficiently recovered from SAM. In this section of the report, we focus upon three main themes that emerged from the interviews: firstly, the women's awareness of the nutritional guidance they were provided with prior to discharge; secondly, related changes to feeding practices that were adopted; thirdly, their ability to implement changes and the challenges they faced in doing so. The latter illustrates the significant difficulties that remain for women living in often impoverished circumstances and within a context where little formal social protection is available.

## Awareness of guidance

Many of the caregivers, although not all, demonstrated awareness of the guidance they received at the health facility they attended on how to care for a child with SAM, including dietary advice. As the extracts below demonstrate, the caregivers recounted information about the timing of feeds and what different meals should consist of. Here, there is strong awareness of the different elements of the '4-star diet' which is a key element of the messaging provided.

"In the morning when the child wakes up, he should eat porridge with peanut butter, or with margarine if it's not there, but mostly we put peanut butter or milk. If I add

peanut butter today, the following day I add milk and peanut butter, I cook butternut and add peanut butter, or rice and peanut butter. Sadza with vegetables, kapenta, eggs. Even the meat the child should have or soya chunks or beans, if you give these to the child he will grow well." (PTID 102)

"We had been taught that in the morning you prepare porridge for the children, children do not have 3 meals, morning, afternoon and evening meal as with adults. So feed him porridge, after a while give sadza and beans. It could be mealie meal porridge mixed with ground cowpeas and cooking oil, which build healthy body." (PTID\_106)

"[We were taught] that when I get home I should cook for him in time. A child should have porridge in morning, add peanut butter. He was having 2 packets of plumpy nut per day, so I gave him that in the afternoon and evening. I cooked sadza for him, same diet as the one in hospital. Gave him a fruit, an egg and meat, without adding a lot of salt or sugar to his food." (PTID 108)

Outside of the nutritional requirements of the post-discharge care, the women referred to the importance of a hygienic environment, of feeding hot, rather than cold, food, as well as of play. With regards to the latter, one of the caregivers highlighted that playing with other children helped their child's recovery: "...playing with other children; when a child plays with other children, when he is sick it will make him feel better" (PTID\_104). Another of the participants, this time one of the grandmothers, appeared to draw a generational distinction with regards to play. Referring to young mothers, she suggested that they did not recognise the association between play and encouraging children to eat.

"No a child does not refuse, you give him some, then play for a while, do what he wants and give the child more food. He may not want it, but you just coax him until he knows that he has to finish." (PTID 103)

"So what happens with these young ones, if the child is not wanting to feed they will just say the child refused. But for someone who is grown up you don't say the child has refused, you find ways, you know the child is hungry but that he has no appetite." (PTID\_103)

## Changed feeding practices

Caregivers' perceptions of what helped their children to recover after discharge were mostly centred around food and the need to make the necessary changes in feeding practices. As one of the caregivers declared, "I think food is the best medicine" (PTID\_102). For this participant, educating the mother was of primary importance with regards to ensuring children are adequately nourished. As she continued,

"I'm not sure that he can be helped because he goes into hospital, gets treated and recovers but if he is still not getting food and if he is not eating he will be back again to being sick. What is really needed is for the child to eat, to educate the mother so

that she will be able to feed the child, because she is actually killing the child." (PTID\_102)

The emphasis placed upon education was reflected in other responses, especially with regards to following the nutritional advice provided in hospital or other guidance relating to feeding children whose appetites were constrained by their health condition. One of the participants, a grandmother, highlighted the importance of patience and gentle persistence in helping her grandson to recover: "Even if he took 2 spoonful's, I would say well done, even one spoon, I never got tired of preparing his food. And that helped him to quickly pick up some weight" (PTID\_103). As this participant emphasised, time is an important element here too, "When feeding a child like this one, you don't rush, [you] dedicate a lot of time to feed that child" (PTID 103).

Despite the emphasis the participant placed upon patience, there was some suggestion of a more forceful approach to feeding being adopted. As the grandmother continued, "the times when I went to the clinic, they just said I should force the child as the only solution, so I knew I had to force him to eat" (PTID\_103). Other participants referred to similar approaches being adopted.

"When I then took her to the hospital when she was sick, I was then taught that I should force her to eat porridge in the morning even if she does not want it, in the afternoon she should eat food like rice, or any other food as long as it is warm. She should not have too much cold food." (PTID\_101)

"We force fed her porridge and maheu and noted some changes up until now. Like now, she has lost some weight because she has flu and sores in the mouth and is refusing to eat, though it's now clearing." (PTID\_109)

## Barriers to compliance

While caregivers expressed a desire to adhere to the guidance provided on caring for their child post-discharge, most reported that they lacked the economic means to do so. Unsurprisingly, a key issue here was the lack of regular employment: "The problem I had was that my husband was not getting paid ... we tried to make things needed by the child available, but money was hard to come by" (PTID\_108). Other participants made similar comments and often referred to how this impacted their ability to respond to the nutritional guidance they had received as well as to regularly attend.

"I don't have the means, and cannot afford the food she wants at that time ... Yes, there are other challenges, like now they had said she should go back on milk, but I had weaned her and am buying chimombe [full cream milk]. I had to take her off the milk because the money was not enough for me to buy every day." (PTID\_101)

"Having food for the child, because we were supposed to buy eggs, peanut butter etc., besides, he was not the only child. It was tough for me. I was pregnant and needed preparation for the unborn baby and to book for antenatal care." (PTID 108)

As the quotes suggest, the lack of money was a primary issue for the participants but so too were other demands placed upon their limited resources. This was reflected throughout the interviews. For example, in the extract below the participant discusses issues of accommodation as well as the lack of access to such items as cooking oil or soap.

"What was most difficult was accommodation. I had no soap and the food was not quite enough, that was what was difficult. I ended up feeding him sadza and vegetables, or cabbage without any cooking oil. When I thought of cooking fish again, I had no cooking oil. The other thing was he would now and then become sick, have diarrhoea, because he did not get adequate things." (PTID 107)

In circumstances such as these, the women described some of the strategies adopted to feeding their convalescing children. In some instances, this meant only partially meeting the nutritional guidance they were taught, in others, placing the child's needs ahead of their own.

"I was following instructions, except for the fruits etc., I do not want to lie, and I occasionally got them. However, I just gave him whatever food was available at that time." (PTID 106)

"We just had to make sure that the milk is there, the money for the milk is available and we would go get it for her. It got us out of our budget. We would take some of the money meant for our grocery. What we would consider is 'this is for adults, and not necessary', then we would buy for the child." (PTID\_101)

"We did not consider ourselves, because we were fighting for him to eat." (PTID\_106)

Outside of the difficulties some of the women faced meeting the nutritional requirements of the '4-star diet', another issue related to their ability to attend reviews. It is important to recognise here that many of the women lived at a distance from the two main hospitals and were required to travel a significant distance as a result. Lacking regular income meant the cost of transport was raised as a significant barrier and was one that was not always easy for the women to overcome.

"[T]hese days it's a challenge to travel. Like where I am staying now, it is far from where the child was receiving treatment. So, if you have to come here you end up using what I was to get for transport because it's expensive and far, the public transport is charging US\$1.50 or so." (PTID\_103)

"Like the last time I went with a colleague of mine from HOPESAM, she said, 'let's go together' and I told her that I didn't have any money for transport, and she said it was the same case with her and she promised to find out if her mother could help and she came back with enough bus fare for both of us." (PTID 104)

"The other difficult thing for me was not having transport money to attend the reviews." (PTID 106)

## Readmission and relapse

Challenges conforming to guidance appear to have resulted in poor recovery outcomes, with some children being readmitted to hospital after relapsing. While it is not possible to make a causal link between a child's relapse and the care received, the caregiver's inability to meet the nutritional guidance would certainly play a part. This possible association between relapse and lack of food was recognised by some of the women.

"He was discharged and then readmitted. It happened twice [because of] this lack of food. At the beginning I was not working, that's when I decided to work and was able to buy for him. He was having porridge and was eating well and it did not take long for him to recover. I would say he started recovering while he was still in hospital, he just gained weight and has been like that ever since." (PTID\_107)

In other accounts, readmission to hospital was linked to misunderstanding of the guidance provided. As another caregiver, a grandmother, explained, she did not understand all the instructions she had been given and missed all the reviews. Moreover, she lacked the income to provide adequate diet and the child in her care relapsed.

"I think it was my mistake because, when I got discharged the first time, they had said to come for the check-up so they could assess her growth, but I did not know and had not asked how to go about it, so I stayed at home. She fell sick again and then I took her back and this is when they told me I should have gone for reviews, they explained that, when you come for check-up, they review the child's health. What had gone wrong then was the food, she loves milk even up to now, and at that time, I did not have money to buy, and she got sick again, so I had to go back." (PTID 109)

## 3.3 Caring networks

Although there was some variation in experience, gender norms operating in Zimbabwe meant that it was the mothers and other female caregivers who usually took responsibility for the immediate care of the convalescing children. As one of the mothers indicated, this takes its toll both physically and emotionally, and in research conducted elsewhere we have noted the association with women's experience of common mental health disorders (see Fernando et al., 2021; Brown et al., 2022).

"He used to help me, since it was two of them. The chores were many, I wanted to cook, wash the dishes, clean the house and everything. He was helping me, plus helping in looking for money." (PTID 102)

"When a child who is staying with the mother and father gets sick, the mother will be left in the hospital whilst the father goes. So, the mother is the one who usually suffers the pain. The mother has the most pain. Like for me I had the most pain because I was with him." (PTID\_104)

In such circumstances, and in the absence of formal social protection as noted previously, we were interested to understand more about the care networks the women drew upon to care

for the children. In the sections that follow we focus on several dimensions of this topic, beginning with the family before looking at the role that others in the community played. At the end of the section, we focus on the importance of support provided through more extended networks including those associated with the sending of cash or in-kind remittances.

## Grandmothers, sisters and aunties

Extended kinship networks, although under stress, remained an important source of support for some of the women in the study. In most instances, the support provided was from female family members living nearby to the participants. However, there were women within our cohort who had travelled significant distances to provide support for the convalescing children. For example, one of the grandmothers interviewed had returned from South Africa to take on the role, as she described: "I just thought the mother is still young, and it's difficult to care for the child alone without seeing her husband [who was also working in South Africa]. That's when I decided I should stop working across [the] border and focus on looking after this child, and the mother should go and stay with her husband" (PTID\_103). Other women described taking their children to relatives living in their rural homelands or in other parts of the city; however, this was not as frequent an occurrence as anticipated.

The support provided by family members varied. As suggested above, the grandmother returned to Zimbabwe to take over the fulltime care of her convalescing grandchild. In this instance, she was responsible for all aspects of their care and appeared to receive little input from either her son or the child's mother. This was atypical, and the support provided by family members tended to come in the form of small amounts of money, food or caring for the child when the mother was engaged in other, usually income-generating, activities.

"My young sister had some money, and I was looking up to her to make the payments." (PTID\_102)

"The other relatives just accepted it, and some were helping me. My mother told her sisters and these aunts would give money to my mother to buy something for the child... His relatives from Chitungwiza used to come when I was in Parirenyatwa." (PTID\_104)

"So I will be with him most of the time, except when I go visit my sister in Mutoko. When I will be busy with the plaiting, she will be caring for him, she understands him and his needs." (PTID\_106)

"Helping me with other things, when I did not have food, or when I did not have transport money to take [child's name withheld] for reviews, they helped me." (PTID\_108)

"Haa. Things were hard, the [paternal] aunt was working and from the little she got, we bought what was needed for the child." (PTID\_109)

## Friends, neighbours and community carers

Informal social protection networks are not limited to kinship relations and involve a range of others usually living or working in close proximity. As a part of the study, we were also interested to understand the role that such networks played in caring for the convalescing children. For example, the extent to which the children were cared for by other women in the community and the impact that this may have on caring practices as well as on adherence to the nutritional and other health advice provided prior to discharge from hospital.

As expected, the women described examples where they drew on other women in the community, usually friends and neighbours, to support them. In most cases, the support provided was to enable the women to look for or undertake paid work. Although this practice was common among the women, there were some mothers who were less comfortable leaving their child with others, especially for longer periods of time.

"I usually leave her with the lady who stays here, my neighbour, next door neighbour. I never packed anything for her, she was just eating whatever the other child who was there was eating." (PTID\_101)

"That friend of mine; she has 2 children. I just tell her that I'm going out to look for work. I sometimes go out with him not having eaten anything, I would have gone out to look for food for [child's name withheld], when I come back, he would have already eaten and even [been] bathed." (PTID 104)

"Aaa, it never has been a good thing to leave a child with a friend except for a couple of hours only. You don't know what happens when you are not there. It is always said, 'there is no woman who is capable of looking after someone else's child.' Whether the mother has left the child temporarily or has died, I cannot leave [name of child withheld] with someone. The way I care for my child is different from how someone else would do it." (PTID\_111)

As the above indicates, some of the children were left with neighbours and the expectation was that they would be looked after in the same way as other children. This was also a reciprocal relationship, with some of the women in the studying mentioning that they looked after other children too. The nature of these informal networks extended to other forms of support, including loaning small amounts of cash, or sharing food items during lean times: "That friend of mine, she usually helps me, if I ask her for mealie-meal she gives me ... At times my friend would buy for him and say 'give the child this banana' or whatever" (PTID\_104).

While such informal caring relations appear to rely on friendship and trust, others were more commercially oriented and included paying nearby 'community caregivers' or childminders. In these cases, small amounts of money were exchanged for caring for children for longer periods of time. This was a fairly common practice but appeared to be associated with a heightened risk of developing SAM, at least according to one of the participants.

"I was involved in a dance group. I used to leave him with someone and ask her to look after my child and I would pay her when the show was over ... But the child-minder would not care for the child the way I do. This woman used to care for many children. So, for her to be concentrating on my child alone, was not possible, because she had other children. The other children were left at home in the care of my landlord." (PTID\_108)

"She looks after many children, I had left [child's name withheld] to live there, because picking him up at night at times was disturbing their sleep at night. I decided to leave him there and I would go and visit him every day. He had not stopped breastfeeding when I started taking him there, so I would go there and feed him there. I then realised it was not working and I then bought him milk." (PTID\_108)

## As this participant continued,

"He had developed big cheeks and I wondered what this was, but she was saying it means the child is getting healthy. Another woman who had her child there, also withdrew her child; her child had developed a big tummy." (PTID\_108).

As the exchange suggests, both children had begun to develop the visible signs of malnutrition. The explanation for this, at least in the terms provided by the child's mother, was the food that the community caregiver was providing the children. As she recounted, money was left with the caregiver to feed the child, but this primarily came in the form of *maheu*, a traditional millet-based drink that is widely available in an affordable, ready-to-drink format. As the participant described, "she would say your child drinks a lot of it [*maheu*], at night he drinks about 5 of them! I don't blame her because she said that is what he likes."

## **Community carers**

In the follow-up interviews, one of the mothers (PTID\_206) provided a more detailed picture of the circumstances that led to her child being left with a community carer. In so doing, she provides a more detailed insight into the context within which the child developed SAM. Although the story cannot be read as being typical of the caregivers, it is illustrative of the complex social environment that some of the children with SAM are discharged into and of their heightened vulnerability to relapse or worse. The story is presented in four parts, which include extended extracts of text for each.

## **Story 1: Child neglect**

During the interview, the mother mentioned leaving her child alone. When explaining why her child had been left, the mother revealed how a somewhat chaotic lifestyle had resulted in her neglecting the child.

Interviewer: Alright. When you left her alone, the [unnamed] doctor will find the

child alone in the house?

Mother: Yes, and with no one to cook and feed her.

*Interviewer: Where would you have gone to?* 

Mother: I would have gone betting (playing 'njuga'). At other times, I would

just be with my friends and go wherever we think of, and I would

leave the child alone.

Interviewer: What would you be doing, wherever you would have gone with

friends? Would it be a party or what?

Mother: Yea. Party ... and leave the child. I was also a dancer and would be

given money from that ... We just would dance to any music played

for us, that's how we get money.

## Story 2: Gambling and addiction

'Njuga' or 'makasi' involve placing a bet, whether cash or other items, based on the odds of a specific playing card being turned over. As the mother went on to explain, her gambling addiction came at a significant cost.

Interviewer: Are you always lucky?

Mother: Not as such, and these days I am not playing. I realized it will damage

me

*Interviewer: What happened when you did not win?* 

Mother: You end up selling household assets or even your clothing or

children's clothes ... I sold household utensils, gas cooker, saucepans and plates and the clothes I would have bought for the child. Or you pledge new clothes or phone for an amount US\$10, which you agree to pay plus interest US\$15, you end up losing your property just for

that amount.

*Interviewer: How did you come out of it?* 

Mother: I eventually left the game, after the child's illness, and others were

encouraging me to give more care to the child. That is why I stopped.

## Story 3: Care and uncare

When asked to describe how she felt about leaving her child alone, the mother's response is a complex and revealing one. Recalling her inability to find others within her community to care for her child while she was away, the mother reveals both the normalcy of this practice but also its limitations.

Interviewer: How did you feel, leaving your child [alone] crying? Mother: I just felt I didn't want to go home, and that's it.

Interviewer: And when you heard the child has been taken away, how did you

feel?

Mother: I would then follow them to the hospital and end up being

admitted in hospital.

Interviewer: Would you have asked for someone in the locality to care the

child, and found none?

Mother: People were then refusing to because the child's condition was

critical, she was all skin and bones sticking out. They thought the child would die on them. There was a rumour one time that the child had died, whilst I was in Pari [hospital]. When I arrive home,

some had come to pay their condolences.

Interviewer: Had you come home without the child?

Mother: I had come back with her. Only, I had asked my best friend, she is

like a sister to me, to care for the child. So, people thought the

child had died, yet she was alive.

## Story 4: Care at a distance

In the final story, the mother provides a much clearer picture of the caring network that she relied upon, its relationship to her everyday survival strategies, and its relevance to her child's developing SAM.

Mother: I was supposed to send my child to the rural home where my

friend's children were living, then we would find ways of making a living. I stopped breastfeeding, bought NAN replacement milk, and took the child to the rural caregiver. The caregiver had TB and also reported to me late that the child was not feeling well.

Interviewer: How long after you had sent her did this happen?

Mother: She was 5 months when I left her and went to pick her up at 8

months ... While she was there, I never got to know that the child was sick. The caregiver also thought the child was well each time I called, and would ask for supply of milk, and I would send some.

I had thought that the child was safe with someone older.

Interviewer: What did the caregiver say when you got there?

Mother: She had phoned me. When I got to the house, she had the child

on her back. Since the child had kwashiorkor, she had swollen cheeks, I just took the child put her on my back and came back. When I got home and took the child off my back, that's when I noted the child was just lethargic, the next day the child had

cracked lips, and face.

## Alternative support networks

As is widely acknowledged, informal social protection is provided outside of family and friendship networks and includes the support provided by religious organisations, local and international NGOs, as well as by research organisations such as our own. With regards the latter, there was, unsurprisingly, some acknowledgment of the role played by HOPE-SAM in supporting the women in caring for their children. A number of the women highlighted how they benefited from participation in the study, including help with feeding and parenting skills, access to medicines, and with other everyday items.

"He was so wasted, plus [child's name withheld] mum mentioned that she met people who will be able to help, she also told me about the people she met whilst she was in hospital, the HOPE-SAM team. I forgot the name but I knew about the people, she said we are very lucky our children will be helped by HOPE-SAM." (PTID\_103)

"I heard from the others who were there saying HOPE-SAM is good, those people help. I told them that my husband is not working, and I asked for something to go give my child and they gave me money from their own pocket and advised that I go look for food for the child. If there was no one to help he would have gotten worse, I still would be in Pari by now." (PTID\_104)

"When the child was still in hospital, they [HOPE-SAM] helped in getting more medication when it ran out, so you had adequate medicines." (PTID\_106)

"I was encouraged by the HOPE-SAM team, they helped with diapers and stuff, when I didn't have food for myself, they helped me. I didn't have any other assistance." (PTID\_107)

Outside of the support provided through participation in the HOPE-SAM study, other women described the role that community churches played in times of crisis. For example, one participant reported being provided with food and psychosocial support and another received food aid from a church in her community.

"...including the people from church, they also helped. They supported me with food. They used to come to visit her, visit me and see how the children were and the situation as it was and would ask me what I needed." (PTID\_102)

"At times, I was being helped at the Presbyterian church, they gave me food every month - 2kg rice, 2kg sugar, beans, 2 litres cooking oil, and 2 litres mazoe drink." (PTID\_106)

"When her mother died, I never had anyone to help me, except for some people from church who lived nearby." (PTID 109)

## Lone-caring, non-caring, and stigma

Recent academic research has begun to challenge the dominant discourse on caring as a positive good, identifying situations of 'non-caring' or 'uncaring'. Although most of the

women in this study were able to describe the informal support that was provided to them, some also highlighted their experiences where caring networks were lacking and situations where they were fending for themselves.

"No one I was alone with him, even when I went to hospital it was just me and him until he was discharged, no one came to see or do anything... No, I have none. No one. All the others, my mother's sisters in law are there at home but they never came. My mother died." (PTID\_107)

This caregiver highlighted that her mother died, and all the relatives refused to help her look after her child, even when her child was sick. This caregiver added that her relatives were not willing to help look after her child because she and the child once had TB, for which they had been treated.

"My nieces, my mother's brothers' children, they said each one for himself, let each one look after their own children. He was sick and I also had developed a sore throat and I asked for them to care for him, whilst I looked for a job and accommodation. That way I could get started and get rental money. They said everyone should look after their own children, so I persevered to go to work with him, that is when I got a place to stay, now I am renting and going to work." (PTID 107)

"When he then got sick, they did not want him. They were taking it that the mother had TB and that others will contract it, because he was also diagnosed with TB when he was in HOPESAM, and they were afraid he would infect others; that is why they refused to have him up to now. Up to now they don't want him, they say he will infect our children. Up to now they are afraid of him for that." (PTID\_107)

Although somewhat distinct, we cover the issue of stigma and blaming here too. There were mixed perceptions around whether the mother/caregiver was to blame for her child having SAM. In some cases, the caregiver was blamed by family and those in the community for failing to take care of her child, and this came with a lot of stigma. Caregivers consistently highlighted negative community perceptions and stigma associated with having a child with SAM.

"Generally, when a child has kwashiorkor, people talk. [They say] 'certain people do not cook for their children, they do not care for the child', yet you will be doing your very best for the child making every effort. Most of the time, you will not be having anything to help him with, people out there will not understand because they are not in the situation." (PTID \_106)

"Like this sister of mine, Mai Ane, she just says you have no care for the child you do not cook for him." (PTID\_106)

"My friends were laughing at me, 'look at your child now has kwashiorkor'." (PTID\_108)

However, one caregiver highlighted that there is more judgement associated with having your first child develop SAM than when it happens to subsequent children. She explained that her sixth child is the one who developed SAM and none of the other children ever had it.

"Maybe also if this was the first child people would have said I have failed, but since this was the sixth, I might have been lenient about it. They may say 'how could you have failed on the sixth when you did well with the other?'" (PTID 102)

This caregiver went on to explain that people in her community would laugh at her and she felt that it was natural for people to laugh. They used to laugh at her when she was going to collect her child's premix porridge, which was associated with kwashiorkor and highly stigmatised. The mother highlighted that there is more stigma associated with kwashiorkor than there is associated with HIV.

"People will laugh at you when they know that your child once had malnutrition. They used to laugh at me when I was going to collect the porridge. For some who have the plumpy nut they eat it in hiding. People are ashamed or shy to be seen receiving the plumpy nut or premixed porridge, or other forms of aid, but it doesn't even matter at all, it doesn't bother me."

"They will be laughing indeed, truly they will be laughing that my child has kwashiorkor, things that make people laugh are not light matters, that is why many people do not go or they hide. Otherwise, a person with HIV will be more open about it than to be said you have kwashiorkor it's much more difficult." (PTID 102)

Another mother highlighted that kwashiorkor is 'shameful' and 'not acceptable'. It is a disease associated with failure on the mother's part.

"Aaa laugh or stigmatise. During the days he was sick, I just heard people were backbiting me, that her child is sick. Another would come as if to visit the child, yet they would have come to analyse, then go around saying 'I saw it myself, the child has kwashi'. Having a child with kwashiorkor is shameful. They think you are not cooking for the child; the child will not eat has kwashiorkor. Just the name Kwashiorkor is not acceptable." (PTID\_108)

## Stigma

The question of stigma and the affect that gossip had on the women was also discussed in the follow-up interviews. As the extracts below reveal, being labelled as the caregiver of a child with 'kwashi,' remained significant in terms of the women's experiences of social stigma and blaming.

"People in the community will say, 'She is not capable of caring for child, look the child now has kwashiorkor.' They will say all sorts! ... You end up stressed by their talk, they blame you for failing to care for the child. Yet, a child can have kwashiorkor after a bout of diarrhoea where the child loses a lot of fluids. Gets dehydrated, cause the child not to eat that much food, [and] ends up with swollen body and kwashiorkor." (PTID\_216)

"I no longer was bathing him outside because he had lost so much, and I was ashamed, embarrassed that people will start commenting on his weight loss." (PTID\_218)

Significantly, the women also discussed how this might impact on caregiver's willingness to enrol on a study such as HOPE-SAM and on its emotional impact upon them.

"Yes, some denied it when they were informed that the child had 'kwashi', and indicated they will rather not even join the study and have their child labelled as SAM. While some of us we accepted the diagnosis and enrolled in the HOPE-SAM program."

"Just having her child labelled as having kwashi, some will deny it in your face. 'He does not have kwashi', they denied it ... They will shun you if you advised them to join HOPE-SAM study." (PTID\_209)

"People talk a lot of discouraging comments. Yet, that is the time you are alone and needing support to care for the child. What you expect from people will not be fulfilled. When you are in hospital you don't get much of that negative influence from people, you will be focusing on the child and doctors and the relatives visiting you." (PTID\_212)

## 3.4 Health seeking behaviours

We turn our attention now to detail the health-seeking behaviour of caregivers and our discussion here is centred around the 'trajectories' of health seeking behaviour, paying particular attention to first points of contact and delays in seeking treatment within the formal health-care system. As the sections below reveal, the women tended to seek advice from within their community first and this was often in the form of traditional healers or faith leaders.

## Pathways to care

A number of caregivers mentioned when their child was sick, they first visited faith leaders and especially members of the Apostolic Church which has a significant following in Zimbabwe.

"I usually go to church and tell the prophet, the prophet will then pray for the child. When [child's name withheld] was sick, I used to go to church. It was the prophet who told me that there are some cases that need the doctor. That's when I started going to the clinic." (PTID\_104)

Other caregivers highlighted that they went to various faith leaders based on the advice of female elders in their community.

"This other lady said her child once had it, and said it was not SAM and advised me not to go to the hospital or else the child will die there. She told me to go to faith healers. I then took her to the faith healer ... After that I then went to another lady, a faith healer, and she said it's too late the child is gone. They told me the child was already dead, he had an encounter with someone who had charms, yet, he had scales on his skin due to malnutrition." (PTID 108)

"They said take your child to the hospital and I said ok. I had thought let me go and see someone different, and she told me to go to the hospital. I said since these people have refused to give my child water or anything, I will take the child to Parirenyatwa." (PTID\_108)

As these exchanges confirm, faith leaders play a significant role in the women's lives and help to shape their decision-making practices. Another important group of 'influencers' are traditional healers but, as the following extract reveals, there is a degree of scepticism with regards to the remedies provided.

"We went to faith healers and they helped us with prayers, but it still got worse. (PTID 108)

"Yes, and the second time people said I should go to the traditional healer, but it only got worse. You know what it is like with faith healers, they said it's the evil spirits from your family, and when then I found that he was worse, that's when I got some money

to take him to the hospital. I had noticed that he was seriously ill and not eating; if you gave him water he would vomit and his feet were swollen. When I gave him the holy water, I had been given to give morning, afternoon and evening, that's when his feet started swelling, and I said let me go to the hospital with him." (PTID\_107)

Although other women reported being sceptical, most also described going to faith leaders or traditional healers prior to taking their child to hospital.

"I tried it though, but these days I'm tired of it because I am not seeing any change from it. I went to a prophet in Marimba and went to Kuwadzana 4 at that ground where there are many Apostolic Faith Healers. I went because of his condition. Most of the time they told me it will work, he will be able to walk and talk, but it still has not happened until now." (PTID\_106)

"They came and assisted in different ways, like advising on what to give the child in terms of herbal medicine. Others advised that I prepare nutritious food for the child. Others advised that I go see a native doctor or faith healers, the latter I never did. I just believed that in God's time the child would recover." (PTID 111)

Based on her experiences with faith healers, one caregiver highlighted that she would advise anyone whose child is sick to visit the health facility and not waste time with faith healers.

"I saw another mother on the ward whose child had the same condition as mine, the belief of witchcraft was a common discussion on the ward. I told them not to be fooled about this witchcraft thing, but rather if a child is brought to the hospital and is given injections and F75 milk all that will go away, the swelling will subside. Don't listen to the faith healers' lies about witchcraft." (PTID\_108)

"It's better to borrow and take him to hospital because the hospital is the best place when the child is sick." (PTID 108)

## Delays in health-seeking behaviour

As the above suggests, faith leaders and traditional healers play an important role in the children's pathways to care because their caregivers, as a result of their own beliefs or because they are encouraged by other, generally female, influencers in their communities, tend to turn to them first for advice and support. There were, though, other factors that shaped health-related decision making outside of the role played by faith leaders and traditional healers. For some of the women, delays were associated with the fear of being blamed for the child's illness, as several participants explained.

"I gathered guts, even if they tell me off, as long as they treat my child. When I got there, I wasn't even scolded as I had thought earlier, they went ahead and gave him treatment, I had no hope that my child would recover." (PTID\_108)

"...he [the participant's husband] always urged me to take the child to hospital because he had noticed that he was sick ... The truth is initially I thought I would be told off by

the nurses, that 'how can you keep this child in this condition'; I was afraid that I would be told off. Scared of being told off for making my child sick." (PTID\_108)

Others appeared not to understand the seriousness of their child's condition. As another caregiver explained, it took her about six months before she took her child to the hospital, highlighting that by the time she got to the hospital the child was extremely ill.

"I think [the child was ill] from the beginning of August to December, into January. He was still sick, he kept going up and down. I then took him in January from August of the previous year, his feet kept swelling. When I got into the hospital, he was not able to talk, he refused to eat, refused water. When I had stayed for 3 days, I noticed that he sat himself up, and was calling out, talking, wanting to drink water, asking to eat any type of food." (PTID 107)

In contrast, another of the caregivers took her child to hospital much more quickly but commented that many of the mothers she encountered had failed to do so and the result was their children looked more seriously ill.

"... in my case when they said, 'take the child to hospital', right there and then I took the child. There were some I saw and could tell my child is better because there were some who were even [more] serious." (PTID\_104)

As the caregiver continued, during her child's hospitalisation she felt anxious about her child's condition and feared that he might die because she witnessed the deaths of two children.

"I saw 2 children die in Parirenyatwa right before my eyes. Those children died and those were the things that were worrying me, especially looking at mine who at times woke up very ill, I thought he would die but the doctor came to see him until he got better." (PTID\_104)

It is likely that there were other factors delaying the women, including those associated with cost. Whatever the reason for the delay, it appears from the women's accounts that by the time they took their children to satellite clinics operating nearby their health had significantly deteriorated.

"I took him to the satellite clinic, and they told me the child had SAM, then they gave him premixed porridge and I started giving it to him but there was not much of a change and I took him back and told them that there was no change, that's when they gave me a referral letter to go to Pari (Parirenyatwa general hospital). When I got to Pari I was admitted and they started giving him F75 then F100 milk, that is when he started to eat, but he was having soft healthy food." (PTID 104)

"I took him to Kambuzuma clinic, and they referred me to Harare Hospital. At that time his face, legs were swollen, and I did not know then what kwashiorkor is like. I only got to know he had kwashiorkor at Harare hospital." (PTID\_106)

## 4.0 Follow-up interviews

The follow-up study provided an opportunity to discuss a range of topics identified in the first round of interviews in more depth and with a larger group of participants. Here, we focus on several core themes already developed in the previous sections: pathways to care, nutritional awareness and post-discharge caring practices, and informal social protection.

## 4.1 Pathways to care

As noted, many of the women in the first round of interviews described turning to faith leaders and traditional healers prior to seeking medical care for the child they were caring for. In order to better understand the impact of this, especially in terms of delays in accessing the formal healthcare sector, the women in the follow-up study were asked a range of questions relating to their preferences for caring for a child with SAM and the factors that influenced their decision-making.

This section focuses on several elements of the women's responses: firstly, it considers how the women learnt to care for their children; secondly, it explores the interrelationship between family, faith and gender in shaping decision-making; thirdly, it identifies challenges to implementing any guidance received.

#### Learning to care

As expected, several of the mothers referred to the knowledge that was shared with them by women in their extended families or through observing other's child-care or undertaking it themselves, as well as by other women in the community.

"I don't know how I got to learn on childcare [laughs], it could have been that I cared for other people's children, because I stayed with some of my sisters who were caring for their children then, I must have learnt from them." (PTID\_205)

"[I learnt] from my grandma, that if the child is refusing to eat, force him to eat. Yes, that because the child is refusing to eat, you leave him; no, you have to force him to. Don't say 'my child does not eat.' The child will eat. There is no person who does not eat. You are eating and are full, then you leave the child to his own will. No, you don't do that with young children, force him to eat." (PTID\_207)

"I learnt about childcare as I was growing, and by observing." (PTID 209)

"I have learnt so much from various people, some sharing their experience of nursing a child with the same condition." (PTID\_217)

In the following, more detailed, exchange, one of the mothers highlighted the multiple influences on her childcaring practices.

"Respondent: The women shared the problems they were encountering, like how the child was sick. You also will be learning and in the event it happens to you, you will be able to solve it.

Interviewer: How about your relatives or friends, did they not share on the kind of porridge they feed their children?

Respondent: Relatives, friends, and elders, some who had children before us. They advise on preparing fermented porridge, and that it is nutritious.

Interviewer: What else was mentioned?

Respondent: That when a child gets to a certain age, he can be fed sadza and soup. Feeding your child a morsel of sadza with soup, he will be full and settled."

(PTID\_213)

For other women, however, there was little reference made to kin-relations or their childhood experiences when discussing their caring practices. Some referred to the influence of health clinics and specific programmes, however most mentioned they had learnt in the hospital following their child's admission with SAM. It is likely these women's responses related to caring for a child with malnutrition.

"This is when I joined your HOPESAM study, and began to learn how to care for a child in this condition ... I had no idea, though I had other children." (PTID\_203)

"I wanted to be assisted and also to learn. They counselled me on the care of child after discharge..." (PTID\_209)

"Aaa (laughs)! I learnt on proper care of the child during [their] illness, that is when I first learnt about it. Before then I had no clue on care of the child. Before then I would wake in the morning feed the child with left over sadza, or just give him bread. Never thought the child needs hot meals, at lunch time I would give him whatever was available, even drink in the morning, because I did not know about caring for the child." (PTID\_211)

"Most of my information, I got it in hospital during my child's illness and the times I was attending the reviews. They would ask me the food I fed the child the previous week and I would explain, and they in turn would give me more counsel on that. Encourage me to feed at least a banana when you get it, that's when I learnt of it at the hospital." (PTID\_218)

A small minority of the women indicated that they had little understanding of how to care for their child.

"I wasn't taught by anyone as such. I just learnt how as I went along, because I knew I just have to do it. My mother is late and I did not have the luxury of having to send the child to stay with my mum ... I just used to come up with the ideas myself." (PTID\_202)

"You just learn it on your own." (PTID\_208)

## Family and faith

The complex interplay between family, friends and faith is an important one with regards to the pathways to care that the women followed when deciding how to respond to their child's ill-health. The interviews revealed a range of perspectives and experiences, with some of the women explaining that their faith did not delay them seeking hospital care while others detailed the ways in which it did.

"I first took [the child] to be prayed for and then went to the hospital. The reception at the hospital was very good, I believe God had already intervened, even when I then met with your team it was all because God was in the situation."

"We keep having faith in the prayers for things to go well with us at the hospital, when I look back it was not all because of my ability to care for the child in hospital, but it was all by God's grace and your support and with all these efforts, all went on well, I never encountered any problems in seeking treatment." (PTID\_204)

In contrast to this participant, who was one of the four grandmothers interviewed, another woman, this time the mother of the child, living alone in shared rented accommodation while her husband worked away, highlighted the impact that a person's belief system can have on the decision-making process. In the extract below, the mother explains in detail how her husband's, rather than her own, faith, in this case membership of the Apostolic Church, led to significant delay in seeking hospital treatment.

"My child started losing weight gradually. My husband's family belong to an Apostolic sect, and my husband was not home at the time. I took the child to my husband's elder brother who is a prophet, he assured me that the child will be well and that I visit the faith healer shrine. They did the rituals there, then referred to this other lady, who said the child had problems with his fontanelle, and rubbed the roof of his mouth, by this time the child was very sick, and his feet were cold. I then realised that consulting the Apostolic faith healers was of no use, I then came back home."

Although the mother did not provide details of the time delay, her account suggests that it was some time before the child was eventually taken to hospital by which point they were significantly unwell. What is also significant about this extract is the role that gender played in the decision-making process, with her husband taking responsibility for the decisions and disrupting the child's pathway to the hospital.

"My husband then decided that we go to the rural home, when we came back, that is when I noted that [the child's] feet were swollen ... I then took him for growth monitoring, and I asked the nurse to check on my child's swollen feet. In my mind, I thought it was due to sitting for a long time in the bus. She called me into a private room, and asked to see us both, my husband had accompanied me for growth monitoring. She informed us that she was transferring the child to Harare hospital immediately..." (PTID\_201)

Other participants noted the influence of the Apostolic Church on people's health-related decision making, as another commented: "Those who attend apostolic churches are not allowed to seek hospital care, this affects the children, it is not proper for a sick child, he should seek hospital treatment" (PTID\_214). However, the interplay between family influences, faith and gender was a constant theme and not limited to a particular church nor only to religious belief systems.

"I informed [my husband's family] that if the child is to die, that will be God's doing and wish. If it's illness it will resolve, I am not in a position to go and consult a witchdoctor with the child. Beside the child is not mine, he belongs to the husband's family I am married to. That family believes in prayer. How will I ever take other people's child to the native doctors? In what role will I be doing that?"

"Some will say that evil spirits from my family or my husband's family are the cause, and that I would take the child to traditional doctors. At my church we don't practice consulting prophets, all that will be done will be pray for the child, if Satan is the cause, this condition will go away ... My mother accepted it but my uncle's, my father's brother, were discouraging me from following the church advice and wanted us to consult prophets or traditional doctors." (PTID\_209)

## 4.2 Post-discharge caring practices

The follow-up interviews offered an opportunity to better understand the women's recall of the nutritional guidance provided to them in hospital, their longer-term implementation of the guidance, and their capacities to implement it. As we noted earlier on in the report, even though the women did not recount the detail of the '4-star diet' they were aware of the main attributes of it and were keen to implement it even though this proved challenging.

## Recalling and implementing nutritional guidance

Some women continued to demonstrate quite a detailed knowledge of the nutritional guidance they had received in the hospital, highlighting awareness of the various food groups that should be included in their child's diet.

"The other important thing is to give the child a diet with all nutrients, because feeding same foods, sadza in the morning then rice then home-made bread, it's all energy foods. Yet, you should also give fruits, milk here and there, egg, I just bought eggs for \$2 and have boiled some for the children. I know how to care for the child. I feed them an egg each, a cup or half cup milk and also fruits. There should be beans, [soya] chunks and matemba (dried fish; also known as kapenta) in the house, also feed them meat to build their bodies. The food should be varied, sadza with beans, porridge with peanut butter." (PTID\_216)

However, in contrast to this mother, most tended to recall a general awareness of the nutritional guidance they were provided, and this was generally framed in terms of a meal plan for the day with the aim of ensuring the children were fed a varied diet. As one mother

explained, "one should not feed sadza then porridge and potatoes they are all from one group: it's not correct feeding. You should give a variety of foods" (PTID\_217). The mother then went on to outline her feeding practices.

"I prepare porridge with peanut butter in the morning, then give her tea with milk, then bread or rice with peanut butter, but if you have had peanut butter in the morning you then need to feed something else. Lunch you should not serve vegetable with peanut butter because you would have already served peanut butter in the morning, but rather sadza and matemba." (PTID 217)

As other women explained, the guidance they received emphasised the need for variation in the diet and also sought to ensure the messaging around the '4-star diet' was culturally appropriate for the women.

"Aaa! It was varied foods, they impressed not to repeat the same foods. If you feed porridge with peanut butter in the morning, afternoon give bread with eggs, not bread with peanut butter which she had in the morning. Afternoon, lunch, you could also give rice with beans at times. Supper meal can be sadza with chicken. Not to repeat the food items she had earlier on the same day." (PTID 202).

"I was counselled to feed him porridge first before giving other foods, also to add margarine or cooking oil to it if there is no peanut butter. Midmorning, around 10, give her tea together with the others, then she should have a meal at lunch time, be it fruits or rice, then supper time the same meal. What really struck me was that she should not go for a day or 2 without being given an egg." (PTID\_203)

Outside of the information recall about what foods the women should be feeding their child, the women also recalled the information received about the foods they should avoid. In the main, this related to avoiding local snacks such as 'zapnax' and 'freezits' which many indicated they had fed their children prior to their hospitalisation. However, the question of feeding hot rather than cold foods was also an important element of the women's recall.

"I recalled the day I took the child to clinic; I was drinking a freezit and comments were 'I hope she will not feed the child that'. I later learnt that from the nurses that I should not feed the child freezit, or soft drinks, or maheu; it's better to feed him milk. You can see that child of mine drinking his milk, its only 30 bond and freezit goes for 20 bond. So, which is better? I'm now used to buying the milk instead of the freezit." (PTID\_205)

"Before I left the clinic, I had been taught not to feed plain potatoes but add chunks or feed plain gravy, but feed early morning. Not to give him zapnax snacks. We were taught to feed healthy foods like butternuts, can give him 2 boiled eggs per week but not too much of them. Can feed popcorn but not zapnax, not much of sweets. For fluids to give juice, but not feed cold meals in the morning. You could vary the meals, porridge with peanut butter, next day margarine, milk, or fermented, but not cold. It is different now how I am feeding her." (PTID\_211).

"I banned the Zapnax. Even now that she is going to school, I don't give her pocket money in case she buys them from school, I give them packed lunch. I learnt that some of these snacks the children are eating, will cause them to lose appetite, children don't even tell you when they are hungry for other nutritious foods. Those snacks are no good, children end up with kwashiorkor, and you face so many challenges." (PTID\_216)

As the above suggests, some of the women were keen to articulate their implementation of the dietary guidance and outlined in some detail changes they had made to their feeding practices.

"I have to go find what she likes, she likes sadza and milk, she likes porridge with peanut butter, but I don't have the peanut butter at the moment. I will have to give him sadza, warm it up for him and serve it with milk. He also eat okra, any other food he is not keen on even meat, he will just eat the gravy, not even the vegetables. I have limiting him from eating too much freezits." (PTID 201)

"One time, when I went for review, they advised me to get some beans and feed her, also matemba when you can get them, add some tomatoes, and make gravy, or cowpeas, meat and fish. I still feed her those foods whenever we have them, from the time of discharge till now." (PTID\_204)

"Of late, after his malnutrition issue, I enhanced my care practices. Now I make sure I cook rice with soup for my children or add eggs to the soup. Others in the neighbourhood may laugh at us for eating rice and soup. It's no longer rice and potatoes, I now know I can add peanut butter to rice and soup. I don't want ever to go back to ward B1 [laughs]." (PTID\_205)

"The grandfather worked in Mbare [market] and he would buy fruits like banana. I learnt that I needed to give a variety of foods. I fed porridge in the morning, at teatime we had bread, but gave her potatoes, gave her a snack or maheu. We were advised to buy milk to feed her occasionally, also to feed her hot meals. I looked for mufushwa [indigenous green vegetables, usually dried] and will serve it with sadza. Initially she did not like it, and I had to force her to eat it, gradually she regained her appetite, and would eat various foods." (PTID\_216)

"Then we were discharged home and I was advised to take good care of him. Give him food on time, not to feed cold food, not to leave food uncovered, or give left over food, but to feed hot meals. I was to feed such foods as matemba, beans, butternuts, at least a fruit per day be it banana or orange. That is what I was counselled on, in hospital and I adhered to this at home and my child was well no longer having diarrhoea. I now give myself time to wake up early and prepare well-cooked porridge, and later feed him other family foods, I have been doing this since, and my child is well." (PTID\_218)

## Challenges to implementation

Perhaps unsurprisingly given the ongoing economic crisis in Zimbabwe (REFS), the challenges the women faced implementing the dietary guidance were the same ones they highlighted in the first round of interviews. Many simply recalled their lack of access to the required ingredients as the primary reason they were unable to comply.

"At the hospital, I was advised on feeding hot meals to the child. I keep trying to do that. When I was staying alone it was kind of difficult, because at times I had no food to prepare. At other times, I would have got the maheu and continue feeding him that. It was just difficult ... Food like potatoes, most of the time I don't have the money. It will be difficult." (PTID\_208)

"The challenge at home, is not having the food. You know what is required to feed the child for him to recover, but may not have the money to buy the recommended foods ... That one is a big problem, because you will need money to source the variety of the foods ... I resorted to give the child whatever I have available; however, whenever I get the money I would try to get the varied food." (PTID 213)

As this participant explained further, "it was not difficult, as such, to follow the topics taught. [The] issue is feeding child frequently also providing variety of food, whenever the money is available, to buy foods such as beans and store [them]." The lack of access to food was repeated by almost all of the women: "There was no food, we continue giving sadza and vegetables" (PTID\_215), "Yes, you would have been instructed on varied diet and yet not having the money to buy the foods, I had that challenge myself. Not having money." (PTID\_217).

As another of the women mentioned, this time one of the grandmothers, part of the challenges they faced was generating an income which, for many, came from informal employment.

"The challenges I'm facing is that the parents are not getting a substantial amount of money since they have been in South Africa. Therefore, getting food for them [the children] requires much effort to access it. I have to order goods for sale and from the proceeds, I buy them peanut butter. When the parents send the little they have, I buy goods and its spent. At times the items are not bought, and you cannot force people to buy. Also, there are a lot of vendors at Muzinda where we sell from." (PTID 214)

## 4.3 Informal social protection

In this section, we return to the question of the women's support networks, which, as our first round of interviews highlighted, were vital to enhancing their capacity to cope. For the most part, the women describe the everyday support received from female family members. However, we were also interested to better understand other forms of informal support and several of the mothers and grandmothers described receiving a range of remittances,

including cash and food. The latter tended to be provided through male family members, usually brothers/brothers-in-law and sons in the case of the grandmothers.

## Family and Friends

Most often, the women referred to the support they received from female family members. As the extracts below highlight, this tended to be in the form of short visits from nearby relatives who would provide a range of support to the mother, including bringing food, supporting them with other domestic chores, or offering guidance on how to look after the convalescing child.

"Yaa, my sisters assisted me. They brought me food whilst I was in hospital, they will be outside the complex and my husband would go and receive the food. And at times I would go out there to meet them." (PTID\_201)

"My aunts used to come and go end of day. Yaa, they came and spend the day, and at times do the dishes and laundry and then leave at the end of day." (PTID\_202)

"Traditionally from relatives, my mother, and my sisters. When they learnt of the admission, they brought so much food in the house, I was amazed by the degree of love. Such foods as chunks, bean, cowpeas, round nuts, all those nutritious stuffs. Little did I know that they knew of the healthy foods, that are required for the child growth." (PTID\_205).

"My sister would give me food when I ran out, but not give me money." (PTID\_208)

"No one, except for one of my sisters the time [child] was sick. She became close to me and advised me to grind matemba and add dovi [peanut] or add them to porridge and feed the child. She really counselled me, until I was able to care for the child. Otherwise, I would have broken down, not able to continue with the situation I was in." (PTID\_212)

In some cases, the mothers described how the convalescing child or other of their children were taken to the rural areas and were cared for by grandmothers. For the mothers concerned, this level of intervention was welcomed even if it hadn't been pre-arranged.

"My mother is late, paternal grandma is still alive. She just came and took the other children to the rural home. Yes, grandma came by bus visited me, then informed me that she was taking the other children with her to the rural, and that after discharge from I could go and collect them ... I was so happy, because in my mind I was thinking of the situation both – at home and at the hospital, I was imagining the children being home alone. Their father spends the day at work, so it was going to be just difficult." (PTID 203)

"Yes, she [mother-in-law] did well, very motherly. She never scolded me that I was not capable of caring for the child. She observed that her grandchild was not a good eater, and she would try out a variety of foods. Adding egg to porridge, she also would sit down to feed him. She at one time asked that she takes the child with her to her rural home, felt the child was playing up on the parent. She took him with her for a short

while. He would say he was full when he hadn't eaten anything, so Gogo really pinned him down. Other members like uncles and aunt tried to get him to eat, they all got to accept the way he was, adamant to eat sadza or at times meat." (PTID\_212)

As reportedly previously, in some instances the grandmothers took over the role of primary caregiver either because the mother had moved away or had deceased. However, as the following account highlights, caring for a convalescing child is a role that is sometimes shared with other members of the family. In this case, the grandmother describes how the child eventually came into her care after relapsing following their initial discharge.

"When she was discharged from hospital [after the first hospital admission], my husband's brother asked to look after the child for a while and I informed them on the foods to give the child and no zapnax, and I thought they had understood me well.

When she was discharged [after the second hospital admission], I took over the care of the child and I never took her back to the mother. I got fully involved in buying food, specifically for her, though there were other children younger than her. I would cook for her and hide the food from the others." (PTID 216)

## Remittances, other social support, and none

An area we were especially interested to find out more about was the importance of remittances, whether cash, food, or other in-kind services, as a form of informal social protection. As the extracts reveal, several of the mothers described receiving support of this kind from relatives living at a distance.

"Most of the time my husband got support from his sister, she since passed on ... He just used to call and tell her things are tight this end, she would come over and leave some money. I would also jokingly tell her we need this, and she would meet the need. She would leave the money or she would buy whatever we required ... Some other time, she would bring us rice and cooking oil from Mozambique or phone instructing us to go collect the items she would have sent, at her young sister's place." (PTID\_202)

"Yes, my brother-in-law in South Africa, used to send us money to purchase food requirements for the child ... He sent money through Mukuru money transfer ... I recall him sending US\$20, the other time he had sent US\$15." (PTID\_211)

"One of my brothers sent money towards the purchase of the child's nutritious food. When it was explained to him the cause of the child's illness, and he was very understanding and pledged to send money stating that when one is discharged from hospital, they need better food. He continues to send at least 2 or 3 times in a year." (PTID\_219)

However, there was little evidence that the mothers received remittances either from absent husbands or from other family members. The only explicit example provided was from one of the grandmothers who reported that she received assistance from a son-in-law as well as from her grandchild's father, who had moved to South Africa with his wife, and other children.

"The auntie had always assisted even up to now, when she got married the husband decided that I live with them, so her husband is also assisting. He is the one assisting us and the other boys [her sons] who are not here. The other one is in South Africa; he also helps whenever he can.

When we inform him that we have run out of food, he sends the food. Not on a monthly basis, it could be after 6, 7, 8 months. When I call him, he does send in bulk. He can send rice, cooking oil, flour, and sugar. And at times soft drinks and biscuits, what else...? Oh yes, he sends soap and powdered soap and beans.

Last Christmas, he sent us some money. The other one in Botswana, he went there in April, he came and brought us some groceries - mealie meal, cooking oil, soap, and was expressing that times were hard." (PTID\_204)

Outside of these examples of support from wider family members, there were examples where the mothers reported receiving little or no support during the child's convalescence. As one of the mothers reported, "no one ever gave us assistance" (PTID\_213). Another reported receiving support in the form of food but not cash: "Aaa, nothing, but they bring some things, they would bring potatoes, share a plate full for the children" (PTID\_215). Other mothers explained that the only support they received was from outside of their family, including members of the HOPE -SAM intervention team.

"Respondent: I never had assistance given, from anyone.

Interviewer: How then did you manage? You stated that the doctor was buying medication for you, what happened when you were away from him, did you have to go there?

Respondent: When he did not come around, the child did not take the medication, she went without." (PTID 206).

# 5.0 Intervention preferences

An important question for the research team was to better understand the women's preferences for future interventions targeting childhood malnutrition, recognising the challenges that many faced in complying with HOPE-SAM. In this final section of the report, we focus on three dimensions of this question: firstly, the women preferences in terms of the nature of nutrition-oriented interventions, secondly on the spaces in which they prefer to care for their sick and convalescing children, and thirdly the reasons for engaging with the HOPE-SAM study.

## 5.1 Nature of interventions

The main focus here was on the preference for food programmes versus cash transfers, the latter were presented to the participants as a possibility given the interest in this approach more generally. Somewhat surprisingly, given the emphasis placed on the money received

through enrolment on the HOPE-SAM study (see 5.3), food assistance was identified by many of the participants as the preferred form of support.

"What is required would be a food programme, because if you talk of money, it will be used for other things, but if you give food this can be given to the child. Money could be used for other things that have nothing to do with the child." (PTID 101)

"I personally would advise that people be given food. One can be given the money and fail to know that it's for the child's food and goes and buys clothing other things with that money. But if they are given food, it's obvious they will have to cook it for the child." (PTID 106)

Although such assistance is not provided through HOPE-SAM, caregivers revealed how they used the therapeutic foods provided to feed other children, especially when they experienced food shortages in the house.

"The food support was very important. I was happy to go and collect the porridge premix, because I knew that once I got it, even if I do not cook sadza, my children will have it. Even if we didn't have any other food, I trusted that the premixed porridge is nutritious. So, such programs as this — I didn't even know where the premixed porridge was coming from, I just used to receive, these programmes, or organisations who source premixed porridge or plumpy nut are so important, they are so helpful." (PTID\_002)

"Food was hard to get plus the other thing that saved him was the plumpy nut that we were being given at Pari, but hey it was hard." (PTID\_104)

Another reason why food was preferred, related to the suggestion that some mothers might use the money they receive for purposes other than feeding the convalescing child. Such responses were sometimes framed in quite moralizing terms, suggesting that "there is temptation with money" (PTID\_101). According to one of the caregivers, "some mothers will not know that the money is for the child's use only. They will think the money is for them and the child." (PTID\_103). This response was common to other caregivers.

"When they were giving us as premix, we used to cook it for the children, it was less likely for someone to go and sell the food." (PTID\_102)

"Giving people money is a challenge. Because once I have the money, I think of other things, fashion clothes yet you have no food in the house." (PTID\_108)

For some of the women, the concern here was that the children would not recover and would relapse.

"Some will not buy food for the child, and resulting in him ending up with SAM again, and yet money would have been availed to buy his food." (PTID 107)

"It ends up being used for other things when it's supposed to be for the child, this will result in the late recovery of the child." (PTID\_103)

## 5.2 Spaces of care

Outside of the form that interventions might take, there was some discussion about the spaces the women preferred for caring for their sick and convalescing children. Although not directly related to the topic of intervention preferences, the picture that emerged was a complex one and might offer useful insights in terms of the settings in which interventions are located.

## Anxiety and the hospital atmosphere

For some of the women, the hospital setting represented a space of anxiety and dread as the following extracts suggest:

"In hospital you see children who are critically ill, including the new admissions, and you become anxious that your child will not make it. At times, I would plead with the doctor that my child is much better, 'please allow me to go home and care for her there' and come back only for reviews ... comparing my child's condition with that of other children on the ward, mine was far much better. The doctor will then explain that he child condition was not yet fit for discharged." (PTID\_201)

"I was scared and ashamed that other people will think I am not capable of caring for my child for cooking food for him, but when I got there [hospital] and realised I was not the only one in that situation, and when I saw that my situation was better than of others, there were plenty others." (PTID\_218)

In the following extract, one of the mothers provided a somewhat contrasting perspective on the atmosphere in the hospital. On the one hand, she highlighted the anxiety she felt being surrounded by children who were severely unwell or perhaps who had died. Yet, on the other, she reported that the counselling she received from other mothers in hospital was an important source of support to her.

"Ha! Because in hospital there will be ... you will be very anxious. The mother next to you, her child has died, that environment. You look at that scenario and feel I'm next in line. Because of that one feels it is better being at home ... being home away from other people, the atmosphere in hospital environment is different" (PTID 202)

"Had it not been the counselling we got from fellow parents in the hospital, they would say 'you are crying for this child of yours who is awake, this child of mine you see there, was dead cold when she was admitted, what are you crying about?' At that time, I just could not eat anything in anxiety. When they visited and brought me food, I would ask my family to take it back home with them. As I received more counselling from the others in the hospital, who urged me on, saying 'your [child] is getting better now, come and see this new admission over here.' You come and look at the new arrival and feel, 'yes, mine is better.' I gradually began to take food..." (PTID\_202)

Yet, for other mothers their dislike of hospital space was such that they indicated they actively hid from the HOPE-SAM study nurses.

"I used to live down the other end, I just saw the study team car and I ran away. I didn't want to go and stay at the clinic. The child was readmitted at the hospital, this was the 3rd admission. From that time, I made effort to care for my child, administering her medication as prescribed up to now, she is healthy. But they kept on visiting me." (PTID\_206)

## Hospital versus home

Outside of these concerns about the atmosphere of hospital space, there were mixed responses when the women were asked whether they preferred to look after their recovering child at home. For some, the hospital provided a welcome routine and access to medical expertise.

"Hospital would be good, though no one is happy to be admitted. In hospital you will be all attention on the child, whilst at home you are interrupted by other commitments. For example, if I am to feed this baby every 3 hours but would be busy with laundry and forget to feed the child. But in hospital they will even remind you to feed the child. After all, they would have given you the milk, so they follow you up." (PTID\_205)

"In hospital you have to adhere with what they tell you. Secondly, the child will be well monitored on his recovery progress. They will counsel you on the care of child and you will also be observing it. At home you are free to do what you want but in hospital its better, though children die in hospital, and it is so upsetting." (PTID\_207)

"Hospital is best place because you have the experts around you, the doctors and nurses, who will be advising you on the food the child is to be fed, and even the refusal of food may need treatment that will boost his appetite. Yet, at home, one is not able to do that." (PTID\_212)

For this mother, home was associated with a host of challenges that appeared to limit her capacity to care for a child recovering with SAM. As she continued: "At home people get affected, they get stressed, think of all sorts of things, on the cause of the child's illness, would it be he was bewitched. Those thoughts run through your mind, and you get pressurised that you cannot care for the child properly. People in the locality may not be that encouraging especially when the child is sick…" (PTID\_212).

However, for other mothers, it was the space of the home that presented the best environment for caring for their recovering child.

"At home ... in [a] relaxed setting. Considering that you have to wait for the child in hospital to recover, yet, one has other children at home who also require care. Yes, you can wait for the child to recover in hospital but what about the other ones?" (PTID\_209)

"Hospital is ok, but home is good, you will be monitoring him and taking him to hospital where they will assess how well you are doing in caring for the child." (PTID 211)

"Your real home is best for nursing a sick child, whether the home is in rural or urban. At home you have all the freedom, to prepare food of my choice in time, you do what you like in your own home. Hospital is ok in that all is provided for you, while you are seated (laughs), but some of the things you want to give your child at a given time, you will not be able to get them in hospital, the hospital only provided what they have." (PTID\_213)

"At each review visit, we received transport reimbursement, and from that I could afford a banana, or peanut butter or sugar for the child. They really helped us a lot." (PTID 203)

"When I left the hospital, I had some money from the HOPESAM program which I had joined. Whenever I visited, I held on to the transport reimbursement. I bought grocery from that money and people were surprised that someone who was in hospital with the child would afford to buy grocery." (PTID 219)

## 5.3 Intervention participation

Recruitment onto the HOPE-SAM study took place prior to discharge, and as one of the mothers indicated, there were some women who were reluctant to join and others who appear to have been recruited in their absence, with gender-norms playing a role here. For others, they had heard through word-of-mouth about the programme and were encouraged to join by their peers.

"some on the ward were saying, 'why join these programmes?' I responded, but the team took time to sit down and explained in detail for those who want to join. It was up to the individual rather than listen to other people's comments who were discouraging others" (PTID\_219).

"He was so wasted, plus [another mother] mentioned that she met people who will be able to help. She also told me about the people she met whilst she was in hospital, the HOPESAM team. I forgot the name, but I knew about the people, she said we are very lucky our children will be helped by HOPESAM." (PTID 207)

In this context, where some women may be discouraging or gender-norms may override women's decision-making, it is helpful to understand the factors that motivated these mother and grandmothers to participate. Amongst the answers provided, several themes emerged: material support, care and recovery, and knowledge and knowledge sharing.

#### Material support

Some women responded by pointing to the material support provided for those participating, especially the transport money. As the extracts below suggest, mothers were made aware of the programme and appeared motived to join because the reimbursement money acted as another source of income, one they could use to buy food or pay for medication.

"My desire was..., I heard from the others who were there saying 'HOPESAM is good, those people help.' I told them that my husband is not working, and I asked for something to go give my child and they gave me money from their own pocket and advised that I go look for food for the child. It was just difficult even now it's just make do." (PTID 104)

"I wanted to buy medication, so when I was in HOPESAM I could get the medication. Now since discharge from the hospital I had a bill owing. When he was in hospital, he became anaemic needing blood transfusion and that is US\$40/pint. I got US\$10 from HOPESAM, because the hospital required a deposit of \$10 before they could start him off. Up to now, I have not been able to pay off the debt since I left hospital, and already receive text messages reminders, which means they want their money." (PTID\_106)

"The US\$10 transport reimbursement, I got and I would hold on to it, and at times would buy mealie meal. 'God's intervention,' I would say to myself ... I would use US\$1 for transport, and at times I would negotiate to pay less, the remainder I would buy the child banana or mealie meal for the family." (PTID\_207)

"When I left the hospital, I had some money from the HOPESAM program, which I had joined. Whenever I visited, I held on to the transport reimbursement. I bought grocery from that money, and people were surprised that someone who was in hospital with the child would afford to buy grocery." (PTID 219)

## Care and recovery

For other women, observing the recovery of children enrolled on the study was also a key motivator: "I had observed other caregivers who had joined that their children were doing well" (PTID\_207). The mother continued to explain that the information, care, and approach provided by the study team also prompted her to enrol in the study.

"Also, they gave care to the children when they followed them up. Even now, today you still are following them up to ensure the child is growing well. During his illness, I asked questions about how I would care for him when he recovers, and they counselled me, explained the study procedures well. They were very kind, understanding, and loving and jovial people. Not tight faced and serious people, whom you cannot even approach. The team was just good and a happy lot." (PTID 207)

The emphasis placed upon the support of the study team was also raised by mothers.

"All this showed that the HOPE-SAM team was very loving. Had it not been for them, the truth is this child would have died. Even everyone in this compound knows that [without] the HOPE-SAM team effort, the child would be dead because they would persuade me to take the child to the clinic. That really urged me on, till now." (PTID\_206)

## Knowledge and knowledge sharing

Other women were less explicit about their motivations but did point to the importance of learning how to care for their children and sharing their knowledge with other mothers in their community.

"I knew it will benefit others in future. After all, it is not only your child who will get sick, many other children get sick, and you also will be learning." (PTID\_203)

"I wanted to be assisted and also to learn. They counselled me on the care of child after discharge, to have zinc with me in case of child having diarrhoea and not to wait until one gets to the clinic. That was the first time I ever heard about zinc for diarrhoea treatment." (PTID\_209)

As one of the mothers declared, "No, I am the one instructing them now!" (PTID\_219). As the mother explained, she utilised the information she had learnt to support other women.

"I started telling others in the community that it is not good to feed children with zap and maheu, especially for children who have stopped breast feeding; it results in kwashiorkor. One should prepare porridge for the child in the morning and ensure that child is fed on time, hot meals. When the child is sick, you should take her to the clinic first instead of asking the lay person in the community." (PTID 219)

"I would have gone there [the clinic], and you notice that the child is not well, and I then talk to them [other mothers]. There is this friend of mine who stopped breastfeeding her child and early morning she is feeding the child left over food and I advise her to prepare porridge for the child, otherwise the child will get sick." (PTID 219)

## 6. Conclusion

As this in-depth study of mothers and other women caring for children recovering from SAM highlights, the long-standing recognition that children are often returned to the contexts in which malnutrition developed holds true (e.g., Wen et al., 2022). The mothers and other primary caregivers indicated throughout the interviews that the greatest challenge they faced was feeding their children. The term that was most often mentioned here, at least in its translated form, was 'lack.' This is a word with a rather simple meaning in English – as it refers to 'being without' or in a situation in which 'there is not enough of something' – but its simplicity appears to capture the complexity of the situations the women described. It is not only that the women often lacked enough food in terms of an absolute lack (i.e., they described having nothing to feed their children). Rather, they also described lacking the resources (financial but also social) to access food, as well as the knowledge and skills necessary to provide age-appropriate and nutritious foods.

However, the report also reveals other aspects of the women's lives that may have a significant impact on their capacity to care for children recovering from SAM. Perhaps most important amongst these is the uneven access that the women had to informal social

protection provided by family and friends. In a context where national programmes of social protection are themselves uneven and fail to adequately cover the most vulnerable people (e.g., Ramachandran and Crush, 2021; Ncube et al., 2023), especially in urban areas, such informal mechanisms are vital. There is, though, an important question to be addressed here and it is one that this study was not setup to answer. Specifically, although we have highlighted the unevenness in the women's access to informal social protection, we have not been able to adequately identify its protective properties. The women in our study discussed the support they received; however, they all had children who were hospitalised with SAM. As such, we need to better understand the benefits accrued by a wider range of women who are supported by informal social protection and determine why some children present with SAM and others do not.

A part of the answer may, of course, relate to other aspects of our findings. For example, it is apparent that there are differences in the women's responsiveness to the signs and symptoms of their child's illness. The reasons for this are many and varied, including: knowledge of malnutrition and its relationship to diet and nutrition, gendered social relations operating within Zimbabwean households, individual as well as familial belief-systems and how these shape explanations for a child's ill-health, and the timing and nature of health-seeking behaviours. All of these factors were in play prior to the child's admission to hospital, and all are likely to remain so once they are discharged. While several of the mothers and other primary caregivers advised that they would go to hospital firsts, others continue to seek the advice of traditional healers and faith leaders as well as other significant influencers within their communities. This pattern of behaviour is unlikely to change, and the most effective response may be to determine how best to enrol influential figures in behaviour-change programmes.

As we have noted, another important factor that appears to disrupt timely intervention by some of the mothers is their experience of societal stigma surrounding malnutrition as well as their fear of being scolded when they do seek it. Although a small study, there did appear to be an age dynamic at play here. Some of the older mothers seemed to be more resilient and, while they acknowledged experiencing stigmatising discourse, they appeared unaffected by it. In contrast, some of the younger mothers, especially those living alone in shared housing, discussed trying to conceal their child's illness and refusing to enrol on interventions such as HOPE-SAM because it would involve disclosing their child's nutritional status. Interventions that work on normalising SAM and to de-stigmatise it may help to encourage more mothers and other primary caregivers to seek help for their children at an earlier stage. Again, this is likely to be of benefit to children who first present with SAM as well as those who are recuperating from the condition and might involve educational programmes that highlight the prevalence of undernutrition in food insecure contexts such as those in Zimbabwe.

In a final point of conclusion, we comment here on the settings for health-related interventions and the contrasting views of the women interviewed. Here, we were seeking to

discern the most suitable location for subsequent programmes aimed at supporting the women and to better understand their preferences. In part, our questions were driven by a belief that their capacity to access such programmes would be negatively impacted by distance and related to this by negative externalities associated with time (e.g., travel time, participation time, time away from domestic responsibilities and livelihood strategies etcetera). However, there were contrasting views. For some of the women, the hospital setting represented a place of significant anxiety as it was associated with death and with the potential for exposure to other illnesses. Hospitals were also talked about in terms of cost (although transport was reimbursed), the negative impact on other family members, as well as their income-generating activities. Yet, other women associated the hospital setting with access to medical expertise, as a site of learning (e.g., about caring for children with SAM), and as a place where support could be given to, and received from, other mothers and caregivers. It was also a space in which the mothers could focus on their child, away from other distractions and at a distance from the uncaring environments in which gossip circulates. As this suggests, there was no straightforward answer to our question on the women's preferences. However, the message that can be taken away from their responses was the setting for an intervention or support programme does matter and consideration should be given to these different perspectives when deciding on a location.

## 7. References

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