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Co-SAM Home Environment Working Papers

Report 1: Rapid appraisal of the home environment during convalescence for children with severe acute malnutrition: Key findings from Harare, Zimbabwe

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Co-SAM: Rapid appraisal of the home environment during convalescence for children with severe acute malnutrition: Key findings from Harare, Zimbabwe

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Executive Summary

- Severe acute malnutrition (SAM) is a life-threatening form of malnutrition and is often complicated by other underlying factors including HIV, disability and infections, and requires admission to hospital.
- It is estimated that one-in-ten children die within a year after discharge from hospital. The risk of dying among children with HIV and SAM is three times higher than among those with SAM alone. Children have a high risk of readmission to hospital, and adverse long-term impacts on learning and growth. Conducive home and caring environments are vital for children to survive and thrive given that children often leave hospital before multiple body systems fully recover and are usually discharged back to the same home environment.
- The interdisciplinary Co-SAM project aims to define causal pathways underlying poor recovery in children afflicted with SAM and co-morbidities and develop and test multimodal interventions addressing the biological and social factors preventing convalescence. Funded by the National Institute for Health and Care Research (NIHR), UK, the project is organised into five work packages with research being conducted in Zimbabwe (Harare, Chitungwiza), Zambia (Lusaka) and Kenya (Migori, Kilifi).
- The *Home Environment* work package of the Co-SAM project seeks to better understand the social and environmental contexts within which child convalescence takes place. This report presents the preliminary results from the Zimbabwe case study. It is based upon seven focus group discussions (FGDs) conducted as part of a broader rapid appraisal assessment of local conditions for children with SAM and their primary caregiver.
- A total of 66 participants were recruited to FGDs conducted with key stakeholders. These were identified as health care workers (comprising community, qualified and trainee and assistant health care workers) and 'influencers' identified as older women (grandmothers), men (including male faith leaders), and young women.
- Facilitated by Zimbabwean social scientists, areas of discussion were stakeholders' awareness of SAM and perceptions of home caring environments; caregivers health-seeking behaviours; health workers understanding, and experiences, of the convalescence needs of children with SAM; and the role of shame/shaming and stigma/stigmatising in shaping health and care seeking practices. Given the particularly poor outcomes among children affected by both HIV and SAM, this group of high-risk children (here termed HIV-SAM) formed a focus of the discussions, but many of the issues discussed are likely to be relevant to the broader group of children with SAM and other comorbidities.

- The causes of malnutrition were attributed to individual behaviours and wider structural factors. Primary caregivers, commonly identified as mothers, lacked nutritional awareness, especially the significance of a varied '4-star diet', as well as engaging in poor feeding practices. The latter included feeding children local snacks which have no or poor nutritional value as well as 'cold' food. There was some consensus that these practices, and broader food insecurity, were shaped by economic precarity, with caregivers working long hours in unsteady employment in the informal economy.
- Home environments were identified as being impoverished. Many children with SAM lived in high-density, informal settlements, which were frequently deemed unhygienic and characterised by a lack of access to running water and sewage facilities. Children living with HIV and SAM tended to come from families that either rented a room in multi-occupancy housing or lived in the homes of their paternal family. High levels of mobility (defined as frequent movement between rented accommodation) also featured heavily.
- Gender and generational norms clearly shaped perceptions of primary caregivers who were identified as mothers and, in some cases, grandmothers. The majority of FGDs participating in the all-male and health worker groups were critical of mothers' parenting practices. The young age of mothers, and their employment as vendors and particularly as sex workers, drew sharp criticism from health care workers. Child neglect in the form of leaving children on their own was raised as were poor feeding practices and adherence to health advice.
- The role and responsibilities of fathers was strikingly absent from discussions, including those taking place within male FGDs. Opinions on grandmothers were divided with some participants arguing they were well placed to support their adult daughters and/or provide care for grandchildren with HIV and SAM due to their older years and perceived experience. Others suggested grandmothers no longer had the knowledge and experience to do so.
- Caregivers have diverse support networks which range from family members to neighbours (including female co-lodgers) and the community as whole. These networks provide emotional, material (financial) and spiritual support. The benefits of the support received may be counter-balanced by inaccurate advice (e.g., on diet, weaning practices, health-care access) as well as by the poor-quality of support provided (e.g., by community-based day care centres).
- A hierarchy of healthcare-seeking practices was evident with advice often sought initially from younger women, older women (grandmothers and/or local female elders referred to as *Gogos*), faith leaders, traditional/spiritual leaders and Community Health Workers (CHWs). This has implications for the timeliness of

accessing formal health care, which often follows prolonged periods of child ill-health.

- Factors shaping healthcare-seeking practices reflect a close entanglement of belief systems. Children with HIV and SAM might be perceived to be bewitched which partly explains referrals to traditional and/or spiritual healers. An important element is the proximity of these healers, as they often live in, or within walking distance of, families' accommodation. Additionally, the low cost of the advice and remedies received by healers compared to the cost of treatments recommended at the clinic was identified as important.
- Despite living in the same communities as them, CHWs encountered significant challenges when engaging with primary caregivers. This was attributed to fear of gossip and stigma as well as religious beliefs. Despite this, CHWs can act as a bridge to accessing more formal healthcare in clinics. CHWs said that they knew when and where to refer sick children.
- CHWs play a key role in providing post-discharge care advice including the importance of adhering to treatment, advice on feeding practices, and nutritional content of diets and attendance of review visits. However, caregivers were noted to follow this advice for only a short time, especially with regards to ART guidance. Poverty, distance from health facilities, lack of awareness, and poor time management were commonly identified as factors shaping poor adherence although in a few cases the 'laziness' of the primary caregiver was also mentioned.
- Stigma plays a significant role in shaping healthcare-seeking practices. FGDs noted the prevalence of negative community perceptions regarding children living with HIV and SAM. Significantly, some healthcare workers were identified as being unnecessarily harsh, engaging in shaming behaviour which put some primary caregivers off seeking their care. This was reinforced through primary accounts from caregivers of children with SAM themselves. Health workers also came forward with ways in which their own health-giving practices might improve.

1.0 Introduction

1.1 Background

Malnutrition in its most life-threatening form, severe acute malnutrition (SAM), can require hospital admission in children under 5 years of age to treat medical complications and regain weight. Despite the best available treatment, up to one-in-five children die in hospital, and one-in-ten die in the year after discharge (Bwakura-Dangarembizi et al., 2021). One-third of children hospitalised with severe acute malnutrition in sub-Saharan Africa have HIV infection. If children have both SAM and are living with HIV (HIV-SAM), the risk of dying is three times higher, and there are long-term effects on learning, growth and lifelong health. SAM and HIV affect multiple body systems, including metabolism, immune defence, hormone pathways, and gut function. Children leave hospital before all these systems are fully restored, meaning there is an ongoing risk of dying after discharge. Mortality following hospital discharge is predominantly driven by infections, compounded by poor nutritional convalescence. Moreover, children are discharged to homes characterised by poverty and multiple caregiver vulnerabilities including caregiver depression, and poor engagement with medical care. As such, there is an urgent need to improve recovery in children living with SAM, HIV and other comorbidities after they leave hospital, particularly if they have additional vulnerabilities such as HIV.

CO-SAM, funded by the National Institute for Health and Care Research, UK (NIHR), aims to define causal pathways underlying recovery from complicated SAM, particularly in children with comorbidities such as HIV, and to develop and test multimodal interventions addressing the biological and social factors preventing convalescence, to ensure that all children can survive and thrive (see Figure 1). This ambition necessitates an interdisciplinary approach to better understand underlying biological and social pathways and to inform new intervention approaches. Co-SAM brings together two networks of researchers from southern (Zvitambo – Zimbabwe, TROPGAN – Zambia) and east Africa (CHAIN Network – Kenya) with extensive experience of SAM. Organised into five work packages, the project will ultimately inform a randomised controlled trial (RCT) of biomedical and psychosocial approaches to improve clinical outcomes, across multiple sites in Zimbabwe (Harare, Chitungwiza), Zambia (Lusaka) and Kenya (Migori, Kilifi).

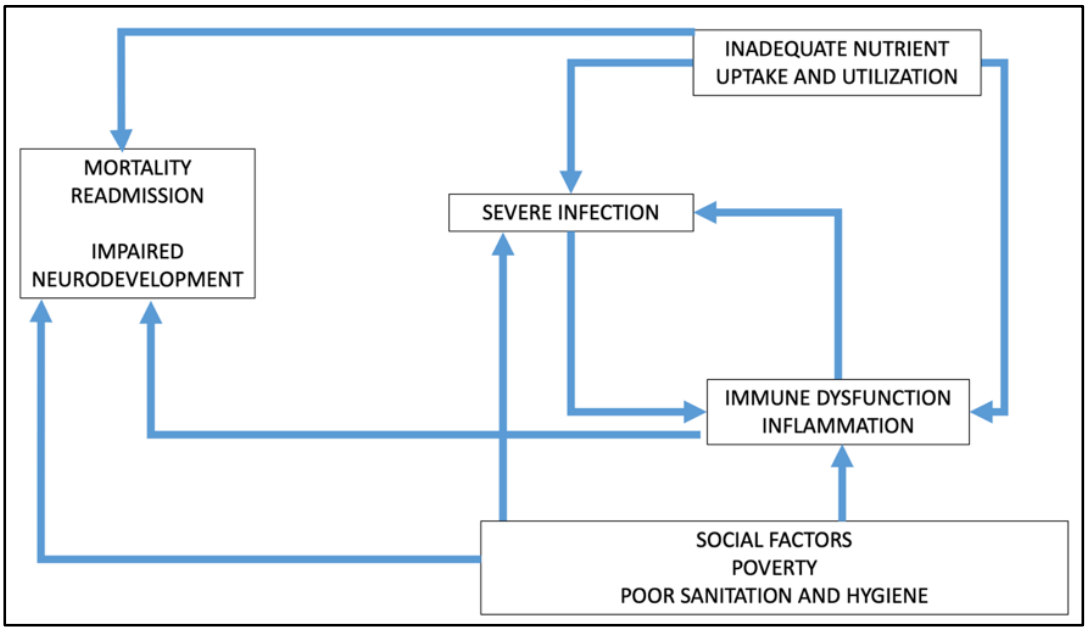

Figure 1. Conceptual framework of the multimorbidity underlying SAM

The *Home Environment* work package, which is covered in this report, builds upon previous work which documents that recovery from SAM requires a conducive home environment to promote nutritional rehabilitation (Kabongo et al., 2021). However, children are routinely discharged back to home environments characterised by economic precarity, entrenched poverty, food insecurity and hunger, which are root causes of SAM. These factors are exacerbated by co-existing HIV infection: in our CHAIN Network, research has identified that child HIV status is associated with household assets, food insecurity, and maternal mental ill-health. Caregivers themselves are often contending with the effects of living with HIV, including shame and stigma, as well as with other chronic health conditions, including depression. Female caregivers may lack decision-making autonomy within their households because of gendered and generational social relations and are at risk from gender-based violence. They often undertake seasonal and/or risky employment (e.g., sex work) to sustain themselves and their children. Mothers living in such precarious economic and social circumstances are often highly mobile within and between urban and rural areas, but the spatial and temporal mobility of children may differ due to extended networks of carers.

1.2 Methodology

Recognising the impact of multiple social and environmental determinants on the context in which child convalescence occurs, a 'rapid appraisal' has been undertaken at each site to provide an assessment of local conditions of children with complicated SAM and their

primary caregiver, who were recruited at the time of discharge from hospital. To address the additional complexity that comorbidities bring to the child's recovery trajectory, we have focused specifically on HIV, given our previous findings that mortality is three-fold higher in children with HIV and SAM together; however, our goal is to extrapolate our inferences to the broader group of children recovering from complicated SAM. The rapid appraisal technique has been readily adapted to the kinds of contexts found across each of the countries we are working in and is widely used as a cost-effective tool for providing a quick assessment of local conditions and for informing the design of subsequent interventions. The rapid appraisal was co-ordinated across the three countries, with local social scientists and trained lay workers undertaking the research at each site. A mixed-method approach has been deployed, with some variation across each of the study sites, combining:

- *Baseline survey:* Conducted by trained lay workers, surveys focused on questions relating to household structure (e.g., number and order of children), maternal health, and caregiving capabilities, as well as spatiotemporal mapping of the primary carer's caregiver network.
- *Household observation and semi-structured interviews (IDIs):* Trained lay workers undertook home visits to observe the caring environment, mapping caregiver support networks, understanding the mobility of the carer and child, identifying barriers to HIV and nutritional care, and assessing stigma.
- *Focus Groups Discussions (FGDs):* FGDs were conducted with caregivers of children admitted to hospital with SAM and living with HIV, as well as stakeholders identified as impacting upon their health-related experiences and practices. In addition to healthcare workers, these included community members (referred to as 'influencers' hereon) such as, faith leaders, traditional healers, female elders, and men. In addition to exploring stakeholder awareness of HIV and SAM, the FGDs, which were facilitated by local social scientists, engaged the participants in a range of individuated but interrelated questions:
    - Caregivers: health-seeking behaviours and experiences of shame and stigma, including within healthcare settings.
    - Health workers: understanding the convalescence needs of children with HIV and SAM; experiences of providing healthcare to children with HIV and SAM; perceptions of home caring environment; and role of health workers in creating shaming and stigmatising environments.
    - Community members: nature, incidence and types of consultations with local caregivers seeking advice relating to children with HIV-SAM; advice provided to caregivers, including relating to access to formal healthcare settings; and connections with healthcare providers.

1.3 Data Analysis

All qualitative data collected through FGDs and IDIs were conducted in the local language/dialect, recorded, transcribed, and translated into English, and checked for accuracy and meaning by field researchers in each study site. Typed transcripts were either entered into NVivo for subsequent coding and analysis or were coded and analysed manually, dependent upon research team preference. Initial codes were produced for each country before being shared for group discussion and review, this process was repeated to produce a single coding framework that was acceptable and consistent across the three countries. Thematic analysis was used to identify key categories and recurrent themes in alignment with the study objectives and illustrative quotes were selected to reinforce the analysis. Findings from the IDIs are presented using anonymised case-codes applied to the individual participants rather than pseudonyms, or according to group membership and stakeholder type (e.g., faith leader) for the FGDs.

2.0 Study Setting: Zimbabwe

This report presents project findings taken from the Zimbabwean study site in Harare. At a national scale, the country 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; WFP/IOM/FAO, 2022), is reflected in food and nutritional security among children and adults (see ZimVac 2020, 2022). As the most 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.

Having previously conducted baseline surveys and semi-structured interviews with the caregivers of children with SAM (REF), the rapid appraisal undertaken in Zimbabwe involved focus group discussions with a range of healthcare workers from the participating hospitals involved in delivering care to children with comorbidity and SAM while in hospital and following discharge, and different groups of community members (see Table 1). The former were identified as a significant group to engage in discussion because they help to shape caregiver experiences of the clinical settings children are admitted to, both positively and negatively. The latter groups were selected based on findings from the

interviews which identified younger women and older women (e.g., grandmothers or '*Gogos*'), traditional healers and faith leaders as playing an influential role in health-seeking behaviours. Men were added to this group recognising the ongoing importance of gendered social relations in what remains a deeply patriarchal society.

Table 1. List of Focus Group Discussion Participants

Focus Group Discussion participants	Date of FGD	Number of participants	Length of FGD (hours: minutes)	Reporting code
Healthcare workers: Community health workers	25/08/22	13	1:08	FGD_Community health workers
Healthcare workers: Qualified healthcare workers, e.g., Registered General Nurses	07/07/22	9	1:24	FGD_healthcare workers_qualified
Healthcare workers: Trainee and assistants healthcare workers	07/07/22	7	1:50	FGD_healthcare workers_trainees and assistants
Key influencers: Men (including male faith leaders)	16/08/22	8	1:07	FGD_key influencers_mixed men
Key influencers: Men	25/08/22	11	1:33	FGD_key influencers_men
Key influencers: Older women, grandmothers (*Gogos*)	18/08/22	8	1:16	FGD_key influencers_older women
Key influencers: Younger women	23/08/22	10	1:05	FGD_key influencers_younger women

In the following sections we present the findings from this research. In section 3 we focus on awareness of the causes of malnutrition which ranged from aspects of food access, practices, and nutritional awareness as well as cross-cutting factors such as precarious livelihoods and home environments and adverse perceptions of caregiver's capacities to look after their children. Section 4 details the healthcare-seeking behaviour of caregivers as perceived by those participating in FGDs. Here we identify perceptions of caregivers' networks which operationalise potential sources of advice as well as the trajectory of health seeking behaviour, paying particular attention to the role of stigma in shaping health-

seeking behaviour. In the concluding Section 5, and based on evidence presented here, we highlight key findings and offer some recommendations.

3.0 Awareness of The Causes Of Malnutrition

In this section we focus on discussion related to participants' perceptions of malnutrition and its causes within the communities they serve. Opening with a focus on the issues of food security and poor feeding practices, the section moves on to discuss perceptions of nutritional awareness amongst the caregivers and of the home environments within which care is enacted, as well as of the caregivers themselves. Here, a pejorative discourse emerges around the survivalist strategies that some of the caregivers adopt which appear to enhance the vulnerability of children within their care.

3.1 Access to Food

Limited access to food was highlighted as a primary cause of child malnutrition by focus group discussants. This was attributed, inter alia, to economic hardship and an inability to provide children with a '4-star diet.' Taking these in turn, precarious livelihoods were identified as key factor shaping access to food with discussants agreeing that *"malnutrition is mostly because of lack of food. Most people in [case study site] are not working and it's difficult to make ends meet" (FGD_Key influencers_mixed men)*. It was not only lack of access to food that was identified, but also to cooking oil, which is mainly imported into Zimbabwe, and is required for preparing foods that cannot be eaten raw:

> *"Yes, having vegetables without any cooking oil, in some cases due to sheer poverty, not having anything at all, and yet the child would be on medication, which requires one to be having nutritious food." (**FGD_Key influencers_older women)**"*

The lack of access to food was so extreme in some cases that children were observed to be *"picking up vegetables from garbage areas because there is nothing [to eat] at the homes"* (*FGD_Key influencers_men*). Malnutrition was compounded where caregivers had to provide for their other children which, when combined with limited incomes, made it difficult for them to prioritise the children living with HIV who were also malnourished.

Healthcare workers also raised the significance of the 4-star diet, information which is shared with caregivers during their child's admission by a wide-range of healthcare professionals. Comprising a balanced diet that includes the four major food groups (staples, legumes and seeds, fruit and vegetables, and protein), one discussant highlighted the difficulty that caregivers face accessing the foods identified. Noting, for example, with regards to protein-rich foods, that "*instead of giving eggs [the caregivers are advised to] give something they can afford so protein will be available" (FGD_Healthcare workers_qualified).* This was further

developed by a community health worker who observed that "not giving children the right food or just giving carbohydrates only, will cause children to have SAM" *(FGD_Community health workers)*. As this suggests, the issues identified not only relate to educational provision and understanding but also to the broader problem of food access, with many caregivers simply unable to secure access to the foods identified in the 4-star diet unless it is adapted to their precarious economic circumstances.

3.2 Feeding Practices

Poor infant feeding practices, explained as feeding children snacks and poor/irregular meal timing, were identified as contributory factors to the development of SAM. This was explained in relation to the economic precarity of caregivers with long working hours resulting in insufficient time to prepare nutritious meals, irregular feeding times as well as feeding children non-nutritious but readily available food. Interestingly, while the significance of the informal economy, and vending, are noted in terms of providing an income, perceptions of male focus group discussants were less favourable:

> *"Vending is very rampant among the caregivers; some can even come back home as late as 10pm and will not have time to prepare a proper meal for the family. This will cause them to feed the children with just any available convenient food."* ***(FGD_Key influencers_mixed men)***

This observation reflects cultural gender norms, and a perceived tension between mothers fulfilling their reproductive and productive responsibilities. Similar moralising was apparent in a focus group held with Community Health Workers, where 'sisters/ladies' frequenting beerhalls (perhaps, alluding to sex work) were judged for having insufficient time to "*settle down/prepare a proper meal for the child not to be malnourished" (FGD_Community health workers)*.

Another feeding practice highlighted by several participants as a cause of malnutrition was early weaning based on a cultural norm/belief that pregnant women should not continue to breastfeed. Unplanned pregnancies resulted in early weaning of children which, healthcare workers argued, compromised the nutritional needs of the young child:

> *"Another issue is that these caregivers give birth to subsequent children too soon before the older sibling is old enough. If you walk into the malnutrition cubicle you will find a caregiver with two very young children with maybe the older one being less than 2 years. Culturally it's not acceptable to breastfeed while you are pregnant."* ***(FGD_Healthcare workers_trainees and assistants)***

Shedding further light on this cultural belief, a participant in a FGD with healthcare workers (trainees and assistants) attributed early weaning to a myth that *"the child will fall ill and die if she continues to receive breast milk from a pregnant mother."*

3.3 Nutritional awareness

Participants highlighted that community awareness around nutrition in general, and the specific nutritional needs of children living with HIV and having experienced SAM, was limited. Caregivers, it was felt, lack knowledge of 'optimal child-care' and nutrition. In some cases, the lack of prioritisation of the recommended 4-star diet (see above) resulted in malnutrition and SAM in children in their care, particularly children with HIV. In turn, *"feeding the child cold foods in the morning, maheu in the winter morning,"* (*FGD_Key influencers_older women*) was also perceived as being not nutritious. As previous research has identified, *maheu*, which is a fermented, maize- or millet-based drink which can be produced in the home, has been replaced by more readily available, commercial products.

Several interconnected issues were raised in relation to nutritional awareness. First, most participants mentioned that children with HIV are at greater risk of developing SAM, especially when they lack a balanced diet. They highlighted that these children have greater nutritional needs due to a compromised immune system. Often their nutritional needs are unmet due to poverty and lack of access to adequate food. The lack of adequate food also results in non-adherence to ART medication.

> *"We work in the community with caregivers who take care of HIV positive children and at most, these children are at risk of developing malnutrition. The caregivers are not in a position to offer proper care and often neglect children who are HIV positive…What I know is that a child who is on ART has more nutritional needs and often feels hungry a lot more than a child who is not on these medications and for the caregiver to appreciate this still it is a challenge and it leads to the child having SAM."* ***(FGD_Key influencers_men)***

This issue was particularly highlighted by healthcare workers who pointed out it was more challenging to provide care for a child with co-morbidity of the two conditions:

> *"Yes, these children are at greater risk, because they have inadequate food, their lives are at greater risk. We see them in our community that the child's health is not good, because of shortage of food, you note wavy thin hair, and they will be begging, resulting [in] not adhering to their medication well because of shortage of food."* ***(FGD_Community health workers)***
>
> *"I would say there is high risk in an HIV positive child. She/he might be getting ART as prescribed but [the] major challenge is on getting the food to eat…Children who are HIV*

infected are at high risk of having malnutrition more so if the caregiver has other things to concentrate on other than taking care of the ill child, their life is at risk." ***(FGD_Community health workers)***

They cited vomiting after taking medication, oral thrush (making swallowing difficult), diarrhoea and fever, as common experiences among children with these co-morbidities. As such, the discussants in this focus group concurred that:

"I think they are different, because the one with only SAM, they recover quickly compared to the one with HIV and SAM." ***(FGD_Healthcare workers_qualified)***

"The patient with NOSAM [non-oedematous] and HIV some may have adverse effects /reactions, vomiting, diarrhoea, fever, compared to the one with OSAM [oedematous] only." ***(FGD_Healthcare workers_qualified)***

Second, a lack of nutritional awareness was attributed to poor parenting practices. Thus, despite children being born to "young and energetic" parents, they were at risk of having malnutrition *"because of lack of knowledge in most people in our community" (FGD_Key influencers_men)*. The young age of *mothers* was discussed at particular length in this FGD with men. 'Teenage mothers' were identified as lacking awareness of nutritional issues as well as experience and knowledge of caring for children, especially those with SAM. Indeed, they were singled out for not knowing how to take care of children overall, identified as being unable *"to do a simple task like carrying the child on the back,"* and lacking awareness of *"a proper diet to their children or even recognise the importance of good nutrition in a child" (FGD_Key influencers_men)*. Even young mothers who could access food suffered, in the opinion of this focus group, from a *"lack [of] knowledge on feeding the child. Some of the caregivers are too young and have no idea on care and feeding of the child, and [the] child has [a] swollen body" (FGD_Key influencers_men)*.

Third, and related to the discussion above, intersecting deficits in knowledge and time, led to children being fed highly processed foods *"like zapnax [cheese puffs], freezits [flavoured frozen sugar water]"* as well as being *"admitted to school at a tender age." (FGD_Key influencers_mixed men)*. The role of such foods in the diets of very young children is likely to reflect the women's circumstances as well as those of the wider food environment, which, as Tawodzera and colleagues (2019) report, is heavily reliant on informal vendors and tuckshops. Although this was connected back to perceptions of young women frequenting beerhalls and neglecting their children:

"Most are teenage mothers who are not able to give a proper diet to their children or even recognise the importance of good nutrition in a child. A case I witnessed, all the caregiver was able to do was to find easy and cheap convenient foods to give to her children before she leaves for the beerhall. She would lock the children in the house and

would buy them some mahewu etc. This caregiver would only come back the next day. There is really nothing that the caregiver will get from the time spent at the beerhall, usually it's just from hand to mouth." ***(FGD_Key influencers_men)***.

3.4 Unsuitable Home Environments

Several participants highlighted that in most cases children living with HIV and having experienced SAM come from impoverished homes. As Bandauko and colleagues (2022) recently reported, Harare's informal settlements are home to people displaced from Harare City as well as other internal and external migrants, with a mix of permanent and semi-permanent structures; the housing stock is generally constructed from poor quality materials (mostly bricks and mortar) and the inhabitants either own their homes or rent rooms in shared housing, sometimes with more than one family per room. In addition to economic precarity, many live with the fear of eviction as they lack secure tenancy. This is the home environment that many of the children with SAM are discharged into and was reflected in the focus group discussions, with some participants describing the environment as similar to squatter camps. In the words of one participant:

> *"Unhygienic, dirty living environment, the child not bathed [with] flies all over him compounded with giving cold food, not being fed porridge in the morning." (****FGD_Key influencers_older women)***

Comparing the mud structures they encountered as being "similar to the medieval era," *(FGD_Healthcare workers_trainees and assistants),* focus group discussants identified a lack of services – electricity, clean running water, sewage – as well as overcrowding, a lack of employment and "many children under 5" *(FGD_Healthcare workers_qualified)* as typical problems associated with the area. Commenting on the lack of sanitation, one participant remarked that "the bush system" was used in the absence of sewage facilities *(FGD_Healthcare workers_qualified)*. Another participant from this group, remarked that the community was "*characterised by filthiness, ever infested with sewage areas with no electricity supply and this impacts preparation of meals for the child" (FGD_Healthcare workers_qualified)*. It was not only the lack of sanitation and hygiene that was remarked upon when reflecting on food preparation but also the use of traditional fuels such as charcoal or cow dung. The overall impression given was of an environment that was ill-suited to the nurturing care of children convalescing following SAM.

3.5 Caregivers and Family Set Up

Negative perceptions of the home environment were also expressed in relation to the caregiver and family set-up. There was some discussion about who and what constituted 'ideal' caregivers for children with malnutrition. The focus of these discussions was on

women – as mothers or grandmothers – with very limited reference to the role of men in parenting. Indeed, some participants felt that children living with HIV and having SAM typically came from single parent families while another participant observed that:

> *"To add on to your question about the role of the father in advising the caregivers on child health issues, 75% of the caregivers are single caregivers and majority of the under 5 children are being taken care of by the grandmothers who might not even know what to do."* ***(FGD_Key influencers_men)***

A range of views were expressed about the (in)ability of mothers to care for their children (see above also). Only one focus group participant strongly felt that mothers were the best caregiver as their maternal instinct motivated them to sacrifice for their child in a way only a mother could:

> *"I think it's the mother [who] is the best person to care for this child. As the mother I can even forgo whatever I have been doing for the sake of my child's recovery. I can forgo my business for a while so that my child gets time to recuperate then I can always restart when the time is convenient."* ***(FGD_Healthcare workers_trainees and assistants)***

As such, most of the participants concurred that mothers were not the best caregiver for children living with HIV and SAM, an opinion they explained in relation to the nature and hours of work (as sex workers and vendors) as well as their youth/age which led to child neglect:

> *"These caregivers … are always busy doing something, vending and may not have time even to bath the child, they leave home around 4 AM, the child is then only fed corn snacks and the commercial maheu."* ***(FGD_Healthcare workers_qualified)***

> *"The mothers are very young, some on the ward compete going out with boyfriends, even whilst there, [they] admitted [to] some having affairs with the guard; they don't stay on the ward with the child."* ***(FGD_Healthcare workers_qualified)***

The inability of mothers to care for their children was also explained in relation to their work and especially as sex workers, often referred to as *"sisters"*. Focus group discussants concurred that this work made it difficult for them to adequately care for their children as they were usually out all night or for extended periods. Healthcare workers (qualified) said that in their experience children were left alone locked inside the home or in the care of siblings (who may be no older than 10 or 11 years old), aunts or neighbours. This made it difficult to consistently provide medication and adequate nutrition for the children in their care.

"In some cases, these would be single parent families, some will be frequenting the pubs to look for father/male, when she comes home with alcohol or drugs, the child would have been left locked in the house all day and would not have eaten anything." ***(FGD_Key influencers_older women)***

"Some are the sisters/ladies who go to the beerhalls such that they do not have enough time to settle down/prepare a proper meal for the child not to be malnourished. These are the children who wander about, no one is looking after them, [they have] no food to eat and we end up referring them for support." ***(FGD_Community health workers)***

"The 'sisters' usually leave the children on their own/alone; they just go as they will be looking for money to support the family; no one will be looking after the children." ***(FGD_Community health workers)***

"At times there is no food in the house, and these 'sisters' will find something to eat at the beer hall and the child is left with nothing." ***(FGD_Community health workers)***

Extreme cases of child neglect were also noted whereby one healthcare worker noted that she had witnessed a child being 'drugged up' with high doses of cooking oil which made the child sleep through the night. The mother, a sex worker, was then able to lock the child in the home (*FGD_Healthcare workers_qualified).* Describing the practice, the participant explained that *"when a child is full, he will sleep, so with high fat food, they feel tired and sleep …[the cooking oil] is high fat."* The practice of feeding cooking oil to children was also noted as a remedy suggested to caregivers by religious and spiritual leaders *(FGD_Key influencers_mixed men).* As one participant explained in the case of a sunken fontanelle, *"you mix egg, oil and lemon…give the concoction to the child to drink, the child will vomit the phlegm, will purge the dirty stuff in his stomach…so [it] induces diarrhoea" (FGD_Key influencers_older women).*

4.0 Healthcare Seeking Practices

We turn our attention now to detail the health-seeking behaviour of caregivers, again viewed from the perspective of healthcare workers, community healthcare workers, and influential men. Our discussion is centred around mapping (i) caregiver's networks which identify key sources of support; and, (ii) trajectories of health seeking behaviour, paying particular attention to delays in seeking advice to first points of contact and adherence to advice post hospital discharge. We especially focus on stigma, which has a significant bearing upon health seeking practices.

4.1 Caregiver Support Networks

Participants mentioned that caregivers of children living with HIV and SAM received support from varying sources. Before delineating this, support was defined as including looking after

the child when the caregiver was away as well as emotional, material (including, financial) and, importantly for this community, spiritual support for the caregiver. In turn, networks encompassed family members, neighbours (including female lodgers) and the community as a whole as well as community based day-care centres:

> *"They are supported emotionally and spiritually in prayers because after all we are spiritual beings. They may provide material support such as food items, or avail cash for transport to the health facility."* ***(FGD_Key influencers_ younger women)***
>
> *"Their neighbours, those around them, mostly, their co-lodgers."* ***(FGD_Healthcare workers_qualified)***
>
> *"They also send children to these sprouting preschools in their areas which are not registered. The child is said to be going to gogo [grandmother] Jennifer's, where you pay $5 per month."* ***(FGD_Healthcare workers_qualified)***

There was some discussion about who was likely to be called upon for support. In one FGD, it was felt that caregivers might prefer to leave their children with a neighbour rather than a relative for fear of being asked too many questions. As one participant noted when speaking from the perspective of a mother: "*If I leave the child at [my] brother's house, I cannot lie that I'm going to work, I can't lie to him" (FGD_Healthcare workers_qualified)*. Outside of this, grandmothers, as opposed to '*Gogos'* [a Shona word for grandmother or older women] who are not kin relations, featured prominently within these care networks:

> *"Ah I think the grandmothers are in better position to care for these children because most of the time they are the ones willing to stay with the same child during the admission period … At times the mother is only going to bring the child to hospital for admission but by the time this child is fit for discharge the grandmother is the one who will be taking care of the child and the mother may be rushing to try to make ends meet through vending. I think the best person to care for this child is the grandmother."* ***(FGD_Healthcare workers_qualified)***
>
> *"Some would forget they came to the hospital because of the child, the others will be busy with issues of their lifestyle…. And will not have time to care for the child."* ***(FGD_Healthcare workers_qualified)***

However, some participants, especially younger women, as well as the more junior healthcare workers who may have more day-to-day contact in the hospital, highlighted that grandmothers were not necessarily better suited, because they also faced challenges in providing for the child. In this case, mothers were thought to be the best caregiver. This appeared to be especially so for children living with both HIV and SAM:

> *"I know of such case in the rural area, where the child had HIV and later had malnutrition. He was in the care of his grandmother, who didn't have much support in*

*terms of adequate food. She would give him a drink in the morning or at times cold left-over food before she went to work in her garden. This then led the child to have malnutrition. Unfortunately, the child later died." (**FGD_Key influencers_ younger women)***

*"Never mind the stepmothers, there are grandmothers who are not caring, like this case where the paternal grandmother would tell the grandchild that 'your mother died of HIV'. That child is always sorrowful, always thinking/stressful, for fear of dying of the disease that his parents had.... and he spends time at the youth peer group clubs. Grandmothers need to be taught on how to care for such children." **(FGD_Key influencers_ younger women)***

*"She came with her grandmother [who] wasn't aware that the granddaughter was also positive, and only knew this when the child was tested, the gran got to a point that she didn't want to touch the child, wanted to wear gloves. She couldn't even help feed the child or wipe the saliva…she felt dirty and would scrub her hands." **(FGD_Healthcare workers_trainees and assistants)***

4.2 Trajectories of Seeking Healthcare

Interviews conducted with caregivers identified the range of 'influencers' who shaped their health seeking journeys, oftentimes delaying the decision to seek treatment at a clinic or hospital. As mentioned previously, in addition to younger women who may share the same accommodation, this included 'grandmothers' (local female elders or *Gogos*), faith leaders, traditional/spiritual leaders, as well community health workers (see following section). An important element of this story is the proximity of such people, as they often live in, or within walking distance of, caregivers' homes. As such, they were more accessible than the hospitals that the children were admitted to when they are diagnosed with SAM. As one participant observed, *"They [caregivers] come from all over, be those nearby or some from far. They are advised by their peers to seek an elderly [woman] within the neighbourhood, its walking distance." (FGD_Key influencers_older women)*. Although, as this participant suggests, sometimes caregivers do travel from further afield.

However, it was not only physical proximity that is important here. As this extract from the younger women's focus group discussion suggests, there is a close entanglement of belief systems in operation:

"In their minds they believe there is someone who wants to bewitch and eat my child. At the hospital they don't believe in traditional practices or masowe [the Masowe Apostolic movement], but at the end of it all its to no avail."

"Many believe that if it is nhova [shrunken fontanel], the child will die at the hospital, yet many children with dehydration [leading to a shrunken fontanel] benefit from the

treatment at the clinic, instead of at the shrine where they will be busy [engaging in] kukwesha nhova [traditional remedies such as rubbing salt on the fontanel]."

(FGD_Key influencers_ younger women)

While acknowledging that treatment from a clinic is required if the child is to survive, the participants' discussion highlights how differing beliefs systems are intertwined and how these may impact upon people's decision-making practices. Indeed, as one of the male participants noted, the importance of the faith leaders and traditional/spiritual healers reflected the mothers' *"strong religious beliefs" (FGD_Key influencers_mixed men)*. Moreover, as another from this group remarked, *"people do not need to travel long distances to get help, there are a lot of the spiritual healers in the community."*

Believing a child is bewitched, for example, will not lead a caregiver to take them to a health clinic but rather to seek treatment from a traditional healer or faith leader who aligns with their spiritual beliefs. The importance of such belief systems to people's health seeking behaviours was also commented upon in other focus groups. For example, in the discussion with older women, it was noted that caregivers might delay attending a clinic and would even forgo seeking advice from them because they themselves become identified as the source of the problem:

"Because some of these [mothers] delay taking [their] sick child for medical care, whilst consulting the prophets, faith healers, and other elderly women whilst the condition will be deteriorating, so by the time they come to us … I advise they go to the clinic first and be prayed for later." ***(FGD_Key influencers_older women)***

"From another perspective on this issue of kwashiorkor, there is a belief they get from their peers that the child is being bewitched, instead of getting advice to take the child to the clinic. Because of early marriage amongst our children, we become grandmothers early too. You end up being implicated as witches, this is what they are told by the prophets. So they no longer come back to us for advice." ***(FGD_Key influencers_older women)***

Yet, it was in the focus group discussions with men that the clearest articulation of the ways in which belief systems potentially impact upon health decision-making was given. As this participant suggested, such beliefs were implicated in the order in which decisions were taken:

"another big challenge is that some mothers have strong religious beliefs which bar them from seeking health advice from a health facility at an early stage. At first, they consult the spiritual healer and when the condition of the child does not improve that is when they will decide to inform the father about the child's illness. This is maybe 3 or more days from the time of onset of the illness and mostly the father will only know

about the health challenge when the condition is extremely bad." ***(FGD_Key influencers_mixed men)***

As this account suggests, some of the men suggested that remedies provided by spiritual healers and/or faith leaders, such as influential prophets, formed the first step in a child's path to the clinic. It was not until this had failed that (absent) male partners are notified and potentially other treatment sought. Moreover, for some caregivers, the option of seeking medical care is closed to them by their strongly held beliefs. As another male participant noted, *"[g]oing to the clinic is against their religious beliefs and as such they only get help from the church where they are given remedies" (FGD_Key influencers_men)*.

Despite the presence of religious leaders in at least one of the focus group discussions, some of the men did articulate their concerns with this group of influencers. Referring, for example, to people being "led astray" and associating the child's illness with "evil spirits", as well as to the "self-professed" status of some of the healers. Indeed, it was not only the status of spiritual healers and faith leaders that was questioned by some of the men, but also the status of 'grandmothers':

"Still on the issue of where they seek help, in my opinion caregivers also consult their peers who would have had a previous experience to theirs, or grandmothers, who now are very young people given they married early and now have their own children and are now classified as grandmothers … The knowledge they share is not accurate; in some cases it had a negative effect on the health of the child, since it does not encourage attending the clinic." ***(FGD_Key influencers_men)***

However, perhaps a more important point to note here is that this group of influencers (healers, peers, and grandmothers) were identified as a readily accessible source of advice amongst a community that lacks the funds to attend a healthcare clinic:

"The lack of money to pay for services at the clinic as compared to the spiritual healers (madzibaba or madzimai) where no payment is required. Long ago people used to be treated for free at most primary health care institutions… but these days people are being made to pay for almost everything."

"Not all mothers will keep the child's illness to themselves but because of poverty the family will seek help from the prophet because they do not have the funds to pay for the services at the clinic."

(FGD_Key influencers_mixed men)

While this participant appears to suggest access to the spiritual healers is free, other men, as well as participants from other focus groups, identified a range of ways in which the remedies provided by the healers were paid for: *"[The cost] depends. It can be USD$10 for*

the treatment of nhova, or 2 litres of cooking oil, 2 kg rice, whilst others give the service free of charge. It just varies" ((FGD_Key influencers_ younger women).

4.3 The Clinical Setting: Before and After Discharge

The Community Health Workers (CHWs), who are a Ministry of Health and Child Care (MoHCC) cadre that work directly in the community for a stipend, and as such an extension of the healthcare system, recognised the challenges that they faced engaging with the caregivers even though they *"stay in the same community and they [caregivers] literally know where to find us"* (*FGD_Community health workers)*. Although living in close proximity, the issues appear to be similar to those stated by the caregivers themselves when discussing the challenges of caring for a child living with HIV and SAM; notably, fear of gossip and stigma. This was hinted at by one of the CHWs who remarked, *"caregivers do consult us and we refer them but some caregivers do not want to share their life stories" (FGD_Community health workers)*. Taking this account further, the participant noted that caregivers do not always want to disclose their own or their child's HIV status. This was a view shared across the other focus groups (e.g., by trainee and assistant healthcare workers), although some CHWs were more judgemental when discussing the challenges they faced engaging with women in their community: *"Laziness alone will cause people to be jealous, gossiping about others and some caregivers do not want to get constructive ideas from others."*

We will return to the specific issue of stigma shortly, but another issue identified during the FGDs with Community Health Workers was the tension between some of the caregiver's strongly held religious beliefs and their resultant inability to access mainstream healthcare services. The issue was mentioned on multiple occasions, with the CHWs regarding such women as *"hard-to-reach"* because they *"do not believe in seeking medical care." (FGD_Community health workers)*. This concern was not associated with all forms of religious belief and/or spirituality but with particular sects of the Apostolic Church: *"People from the [Johanne] Marange sect have this adage, 'if a child dies, one can always give birth to another. Same when the wife dies; the man can always marry another person'."* Here, the participant from the CHW focus group discussion was recounting a story where a child had died because the father refused to allow them to be taken to the clinic. The strength of antagonistic feelings that the CHWs sometimes encounter in the community was also noted: *"I recall how we were shouted at when we visited an old lady …The head nurse had to be firm and strict for us to gain entry" (FGD_Community health workers)*.

Despite the challenges working within the community, the CHWs, as well as other community-based influencers such as the older women, described acting as a bridge between the areas they served and the more formalised aspects of the local healthcare infrastructure. Describing their decision-making processes, the CHWs explained that they

made decisions based upon the gravity of the cases they encountered and those that might be dealt with through advice and health education. There was, however, an acceptance that the advice they provided and the referrals to clinic that they made were not always followed:

> *"there are always reasons [for not following advice], for some it's just about being too lazy to visit the clinic or they will say it's of no use for me to just be following the queue at the clinic for the whole day. At the prophets they are just prayed for and given some remedies to use at home and that's it."*
>
> *"for some, you give them a referral letter and they will tell you they will visit the clinic. When then you make a follow up, that is when she will tell that she could not get money and this is why they did not take the child to the clinic."*
>
> ***(FGD_Community health workers)***

The challenges of encouraging caregivers to adhere to the advice given by healthcare professionals does not end once they arrive at the clinic, if they do go. The FGDs with those healthcare professionals working within the hospital setting were equally revealing about the challenges they faced. As they noted, the advice they give to caregivers on caring for the child after discharge including adherence to treatment, encouraging caregivers to pay close attention to the child's health status and attend review visits. Advice on feeding practices and how to provide optimal nutrition was also a major element of the guidance that healthcare workers in the clinics provided to caregivers after discharge. An important element here, especially given the context the caregivers would return to, was identified as translating the '4-star diet' into foods that the women may have access to. As one of the participants in the trainee and assistant healthcare workers FGD commented:

> *"For a malnourished child we advise the caregiver to give the child food that is rich in protein like beans, fish, milk, eggs or if the caregiver cannot afford to buy these, we encourage them to get other sources of proteins which are affordable or locally available e.g., kapenta, mopani worms (madora), beans or something they can afford."*
> ***(FGD_healthcare workers_trainees and assistants)***

The importance of recognising that caregivers may not be able to access foods identified as part of the 4-star diet was also acknowledged by the participants in the qualified healthcare workers FGD. As the following extract suggests, the advice also emphasised the importance of ensuring access to ready-to-use therapeutic food (RUTF) as well as feeding 'hot' rather than 'cold' food. The distinction between hot and cold food was noted in the interviews with caregivers, although the reason for it remains unclear:

> *"I think one other thing we look at very much for malnourished children on discharge is that we also check with the caregiver about the type of food she is able to provide for this child, then we work from there, give advice based on whatever they would have*

said. We also make sure they get the therapeutic feed as prescribed, keep the child warm, give her warm food - not cold food - and feed the child at the appropriate times." ***(FGD_Healthcare workers_qualified)***

Participants across the different focus group discussions had varied views on caregivers' adherence to the advice they are given, highlighting the challenges faced by some caregivers. In their opinion, some caregivers adhered to the advice for a short period of time before defaulting to their usual practices. Adherence to ART was noted as a particularly significant issue among some caregivers, who, according to the qualified healthcare workers and men, consistently failed to give their child the prescribed medication.

"It's typically the issue of adherence to drugs. In a hospital set up, drugs come in time e.g., at 12 and then at 3pm but at home they may be committed with something at 3PM and those end up missing their medication." ***(FGD_Healthcare workers_qualified)***

"The issue of drug adherence is a challenge depending on the caregiver, whether she will give adequate food, seeing as it is not their biological child. [The child] may not be getting that [drugs] on time." ***(FGD_Key influencers_men)***

At times they just say, 'yes,' but they do not [follow the advice] ***(FGD_Key influencers_men)***

'Poverty', 'distance from the health facility', 'ignorance', and 'poor time management' were cited as reasons why some caregivers do not adhere to advice given on nutrition, ART and the need for follow-up visits to the healthcare facilities. Moreover, as the following extract from the FGD with healthcare trainees and assistants suggests, there is an acknowledgement amongst staff in the clinics that the failure to adhere to advice may not always be due to "laziness" but to competing time commitment and he pressures they face living in precarious circumstances and in a society stratified by patriarchal social relations:

"Ahh it's all centred on the current economic hardship. Of course, the caregiver would have received health education about what she is required to do for her child to get better but the main problem is that this same caregiver is assuming a dual role and is the father and the mother of the house and will be trying hard to make ends meet. If we are to take history, SAM is most prevalent in children whose caregivers spend most of the time trying to fend for the family, be it selling second hand clothes and so forth. They do not have the time to even prepare the meals as recommended. For a child to develop kwashiorkor its mostly that the primary caregiver is not the mother and usually that child is being taken care of by someone else or the child is being cared for by the mother who will also be busy with other things and for them to come back home and

have time to prepare food for the child, it's a challenge." ***(FGD_Healthcare workers_trainees and assistants)***

4.4 Encountering and Responding to Stigma

As previously noted, the issue of stigma was a theme covered in the focus group discussions and the focus upon the issue reflected the findings from previous interviews with caregivers. In this section, we look in more detail at the role of stigma from the perspective of a broader range of actors, as it is recognised to have an overarching influence on health seeking behaviour and practices. Indeed, the FGDs highlighted negative community perceptions associated with having a child living with HIV and SAM. While there was some variation in opinion, with some participants mentioning that HIV carried more stigma than SAM, the dominant view was that both HIV and SAM continue to carry with them a significant degree of social stigma:

> *"It [SAM] makes other people laugh, its associated with inadequate food, and when the child is then given plumpynut."* (***FGD_Key influencers_younger women)***
>
> *"Another thing is by the time you know your child has kwashiorkor the people around would have long known and be laughing and talking about your child's loss of weight, without you knowing…"* (***FGD_Key influencers_younger women)***
>
> *"There is high stigma associated with having a malnourished child. People always mistake HIV for SAM, same signs and symptoms: thinning hair, loss of weight etc. and this alone will cause stigma. This is the reason why most caregivers seek help from the faith healers."* (***FGD_Key influencers_mixed men)***
>
> *"For the one with HIV, stigma is more pronounced than the one with kwashiorkor because the latter is less understood in the community. Once HIV is disclosed, people associate it with immorality, and the affected also blames themself and cannot explain how he contacted it. SAM can be treated whilst the one with HIV lives with it though the virus can be suppressed."* ***(FGD_Key influencers_men)***
>
> *"The caregiver will not be ready to disclose their HIV status and would just leave her child with the char lady without telling them the truth for fear of stigma. (illustrating as an example) 'number 3's condition is fast deteriorating' or 'don't you know she's taking HIV medication' so telling people in the community is a no, I would rather share with my mother in the rural areas."* ***(FGD_Healthcare workers_trainees and assistants***

Importantly for this study, we aimed to understand whether the stigma and blame associated with a child's HIV and SAM status was limited to encounters within the community. The response of the younger women provided a somewhat mixed response to this question. Some healthcare workers were described as unnecessarily harsh and impatient:

> *"This is the reason why in our community many would prefer going elsewhere other than the clinic. You get the plumpy nut after a good telling-off by the staff. Whilst if one goes to Masowe Shrine the child is just sanctified and given whatever and one goes back home." (**FGD_Key influencers_younger women)***

However, for many other participants, their encounters with healthcare workers in hospital was much less problematic. As this extract reveals, the expectation of experiencing harsh treatment had put off a participant from attending the hospital but their experience was much more rewarding than expected: "*The stories I heard were not true, best is for one to find the truth for yourself. I never encountered any negative reception…when I eventually came here my child was managed very well" (FGD_Key influencers_younger women)*. Moreover, the main source of stigma experienced by caregivers appears to relate to being identified as having a 'kwashi' baby within the community:

> *"I also noted that with my neighbour, when her child was prescribed plumpy nut she would bring [it home] wrapped up in a cloth, so people would not know of it. Plumpy nut is very beneficial, but some are not comfortable giving it openly. Some will laugh, saying 'the mother has failed to feed her child,' or, 'she spends time making herself look trendy yet cannot feed the child.' Others will not feed the child but will hide the plumpnut entirely, or even feel uncomfortable that she been prescribed it." **(FGD_Key influencers_younger women)***

Although there was some acknowledgement by the healthcare workers that some may contribute to the shaming of caregivers, as one noted "[y]*a some health workers will get to the extent of saying, 'why didn't you use a family planning method, when you are not capable of caring for your children?' " (FGD_Healthcare workers_qualified),* this was much less of an issue than anticipated. Indeed, the healthcare workers who participated in the focus group discussions, provided a range of ways in which their encounters with often vulnerable caregivers might be improved:

> *"Just give the caregiver support and understand the challenges and the possible causes of SAM unlike just being harsh to them as it does not help anything. It's something different when the child only has SAM and has no underlying HIV. A child with SAM and HIV has a lot of other challenges and health care workers just need to understand this." **(FGD_Healthcare workers _trainees and assistants**)*

> *"If we are to welcome them warmly when they bring their children with SAM or HIV; we don't bluntly mention that her child has kwashiorkor, we gradually counsel her and eventually she will realise that she was not aware on admission that the child had kwashi. We then open up to her about that, and by then the child would have recovered. Instead of telling her off… if we receive them well, whenever the child gets sick again,*

they will feel free to come back to us, and ask for advice on their child who would be vomiting or whatever. She will report early." ***(FGD_Healthcare workers_qualified)***

5.0 Conclusion and Key Recommendations

The purpose of this study was to further develop understanding of the home and neighborhood environments within which children aged under 5 years living with SAM convalesce upon discharge from hospital. Conducted as part of a wider rapid appraisal, this report is based upon focus group discussions (FGDs) with a range of local stakeholders. These groups had been previously identified as playing an important role in shaping caregiver decision-making practices related to their access to healthcare services, as well as forming a significant and influential element of the wider socio-environmental contexts the caregivers inhabited.

Our conclusions from this report identify three areas of particular concern: first, precarity shapes the context within which care is provided to children living with HIV and having SAM but some of the solutions to relieving it may reinforce the conditions that lead to undernutrition. Second, greater attention is required around the impact that a positive experience of formalised healthcare has on caregiver's health-seeking behaviours especially in a context where alternative belief systems are more affordable and more accessible. Third, stigma and social shaming remain a significant barrier to accessing health care prior to, and after, hospital discharge. We elaborate on each of these in turn below.

The home environments that these children convalesce in are characterised by extreme poverty and the study site for the focus group discussions was home to some of the area's poorest and most marginalised inhabitants. Compared in the FGDs with people from 'squatter camps' and offering little in terms of hygienic or sanitary infrastructure, it is important to recognise that such settlements are often the most affordable and are seen to act as "springboards" out of poverty because of their access to urban economic opportunities (Bandauko et al., 2022: 3). However, for our participants, the lack of local economic opportunities as well as the often precarious and risky livelihood activities that caregivers engaged in were regarded as causal factors in the development of their children living with HIV and being hospitalised with SAM as well as in their poor convalescence upon discharge from hospital.

While acknowledging the caregivers' precarious circumstances, often their incapacity to provide an environment within which a child recovering from SAM was able to thrive, was a source of some admonishment especially, but not only, from male participants. Caregivers were described across the focus groups as 'lazy', while also being reprimanded for adopting livelihood strategies that meant they were either too busy to care for their children (e.g.,

vending) or which involved leaving their children alone for extended periods of time (e.g., sex work). The most striking examples of neglect were reported when discussing the latter, with CHWs highlighting their being witness to a range of practices that left vulnerable children at significant risk of harm, including being left unattended to for extended periods of time or being fed and inappropriate amount of cooking oil. These findings reveal a significant tension with regards the nature of the public health interventions put in place to support mothers and the children they care for. Specifically, interventions that recognise the role that economic precarity plays in the caregiver's lives have tended to emphasise approaches that promote income generation, including vending. However, such informal forms of income generation are also identified as the reasons behind caregiver's incapacity to care as well as they could and their reluctance to engage in the formal healthcare system.

A second conclusion that can be drawn from these findings relates to understanding how the healthcare system sits within the caregiver's belief systems and the influence this has on their decision-making practices. The children in this study are discharged into the same contexts they arrived from, including both their cultural as well as their socio-economic contexts. Local traditional healers or faith leaders were identified as being the likely first step in the caregiver's decision-making practices once family, peers, and other influential figures (e.g., *Gogos*) had been consulted. For some focus group participants, this was explained by people's religious and/or spiritual beliefs with formal healthcare not an option. Outside of this hard-to-reach group, the decision to consult with traditional healers or faith leaders was also linked to their proximity, relative affordability, and the fear of being scolded or shamed by healthcare workers. What is not clear from our findings is whether caregivers' positive experiences of the formal healthcare system act to disrupt this pattern of health seeking behaviour. There is some sense that it does. For example, interviews with caregivers suggested that they were more likely to consult CHWs in the future and seek clinical care for their child. Yet, the focus group discussion with the CHWs also indicated an ongoing reluctance to consult them despite their prominence within the community.

Finally, it is clear that stigma and social shaming plays an important part in the story both prior to hospital admission and following discharge. As the research demonstrates, stigma and shame are significant contextual factors when it comes to explaining the caregivers' willingness or otherwise to seek care for their child or adhere to treatment post-discharge. The significance of this is likely to be amplified in places where caregivers live in very close proximity with each other, and possibly within the same household unit. There are several issues revealed in the report findings. CHWs identified the issue of caregivers concealing their problems and being unwilling to 'open up' about their problems. This was explicitly linked to fear of gossip, which has been recorded in related research conducted within rural settings (Brown et al., 2022). In turn, the caregivers revealed that fear of gossip within their communities was also associated with a reluctance to seek care for their child as well as to

adhere to treatment that might be associated with having a 'kwashi' baby or one with an HIV-positive status. It was also apparent that the healthcare workers might contribute to the feelings of stigma and shame experienced by the caregivers, which was apparent in the somewhat moralising and pathologising language used to describe them and the places they inhabit.

Key Recommendations

1. This report highlights the multiple and competing challenges that caregivers face, which are amplified when caring for children living with SAM, HIV/AIDS, and other comorbidities. It is important that the precarious livelihoods that caregivers face and the likely impact of this on their capacity to maintain therapeutic regimens or follow nutritional advice is carefully considered when interventions are designed.
2. Complex networks of people are involved in caregiver's health-related decision-making practices (including, family relations, male partners (including those who are absent), older women/grandmothers, religious leaders and traditional healers). Such 'influencers' may delay access to life-preserving treatment either prior to or after discharge from hospital and may provide advice that is not in the best interests of a child convalescing from SAM. It is recommended that:
    a. further research is undertaken into the post-discharge behaviours of caregivers, especially with regards to understanding the ongoing role of community influencers.
    b. interventions identify ways in which pathways to accessing formal health care might be improved paying attention to the important social and cultural role played by community organisers, as well as male partners/fathers.
3. This report identifies that caregivers of children with SAM and comorbidities such as HIV are recognised to experience stigma and shaming. The sources of stigmatising and shaming vary from health professionals to family and community members. While perceived or real, it is important to redress the impact of stigma and shaming given the impact on caregiver's health-seeking decision making and willingness to maintain therapeutic regimens that include foods that are identified with recovery from SAM. It is recommended that:
    a. targeted educational and training interventions are developed to promote greater awareness of SAM and its comorbidities and of the wider socio-economic drivers of undernutrition, as well as on identifying stigmatising and shaming behaviour/language and how this might be mitigated.

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