



Co-SAM Home Environment Working Papers

*Report 2: Co-SAM: Rapid appraisal of the home environment
for children convalescing with HIV-SAM: Key findings from
Migori and Homa Bay Counties, Kenya*

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CO-SAM: Rapid appraisal of the home environment for children convalescing with HIV-SAM: Key findings from Migori, Kenya

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Executive Summary

- Severe acute malnutrition (SAM) is a life-threatening form of malnutrition that requires admission to a hospital and is often complicated by other underlying factors including HIV, disability, and infections.
- 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 there are 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 organized 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 Kenya case study. It is based upon 14 focus group discussions (FGDs) and 7 in-depth interviews (IDIs) conducted as part of a broader rapid appraisal assessment of local conditions for children with SAM and their primary caregiver.
- Focus group discussions (FGDs) and in-depth interviews (IDIs) with key stakeholders, including caregivers of HIV-SAM children, social influencers (traditional healers senior and junior, herbalists, religious leaders), and healthcare workers (nurses, mentor-mothers, nutritionists), were undertaken with 129 respondents.



- Facilitated by Kenya social scientists, areas of discussion were stakeholders' awareness of SAM and perceptions of home caring environments; caregivers health-seeking behaviors; health worker's understanding and experiences of the convalescence needs of children with SAM; and, the role of shame/shaming and stigma/stigmatizing 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 associated with low purchasing power leading to food insecurity and poor feeding practices. There were instances when caregivers sold eggs and bought mandazi (fried dough) and tea. The social influencers cited this as being a result of caregivers' lack of knowledge about the nutritious value of food.
- Male involvement is low in the journey of child treatment and recovery. Children are taken care of by mothers or grandmothers and in most households, mothers are the breadwinners, undertaking casual work alongside their other domestic responsibilities. Caregivers described returning home with very little money to buy food for the children, leaving the family food insecure.
- The provision of a healthy and nutritious diet is not only a challenge for primary caregivers. During focus group discussions, healthcare workers reflect on the provision of nutritious food to severely acute malnourished child admitted to the hospital wards. Describing the meals provided, which sometimes included porridge in the morning, and no nutritious meals for lunch and supper, one nurse noted that during periods where food supplements were not available ('stockouts') no proper treatment can be offered, even to severely malnourished children.
- Within the hospital setting and prior to discharge, the nutritionist is a key player in ensuring that nutrition services are offered to the primary caregivers of all malnourished children in the facility. The services range



from provision of supplements (albeit with the caveats mentioned above), nutrition reviews, and nutrition counseling.

- All service providers highlighted that adherence to treatment advice was one of the main challenges they faced. The healthcare workers commented that young mothers are not good adherers and grandmothers, who are caregivers of the recovering child, are at times left with no choice other than failing to adhere to the advice because of their impoverished household circumstances. This was described as one of the main contributing factors to relapse.
- Existing family support networks are drawn upon by the primary caregivers of children with HIV-SAM, however the mothers revealed they prefer taking care of them at home alone, although they are happy to receive money or food from their social networks.
- When family support networks are drawn upon, maternal grandmothers of the sick child are the most trusted and that is where the mother would take the child if needed.
- The caregivers also prefer to concentrate on caring for their sick children rather than continuing to work at their businesses or jobs and noted that caring for a child with HIV who has developed malnutrition poses an additional challenge, since this child needs more care than malnourished and HIV negative child.
- Poor health-seeking behavior has been promoted by community perceptions on HIV-SAM, culture, family influence, financial constraints, anxiety, shame and stigma. Healthcare workers took part of the blame, citing the challenges they go through in hospitals that can interfere with the treatment plan. Post-discharge follow up is still a big challenge for healthcare workers because of understaffing, so in most cases there are no household follow-ups with discharged children.
- Stigma persists in the recovery process, which can be challenging for caregivers. Although the families of HIV-positive children are required to maintain confidentiality and not disclose information to community members, SAM children are more frequently the target of stigma, leaving caregivers with no choice but to care for their children.

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. Up to one in five children die in the hospital, despite the best available treatment, and one in ten die in the year after discharge (Bwakura-Dangarembizi et al. 2021). One-third of children hospitalized with severe acute malnutrition in sub-Saharan Africa have HIV infection. If children have both SAM and HIV infection (HIV-SAM), the risk of dying is three times higher, and there are long-term effects on learning, growth and risk of heart disease as adults. SAM and HIV affect multiple body systems, including metabolism, immune defense, hormone pathways, and gut function. Children leave the 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. They are often discharged to homes characterized 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 with complicated HIV-SAM after they leave hospital.

Co-SAM, funded by the National Institute for Health and Care Research, UK (NIHR), aims to define causal pathways underlying multi-morbidity in HIV-SAM, and to develop and test multimodal interventions addressing the biological and social factors preventing convalescence, to ensure that children with HIV and SAM 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, TROPAN – Zambia) and East Africa (CHAIN Network – Kenya) with extensive experience of SAM. Organized into five work packages, the project, which is a randomized control trial (RCT), is being carried out across multiple sites in Zimbabwe (Harare), Zambia (Lusaka) and Kenya (Migori, Kilifi).

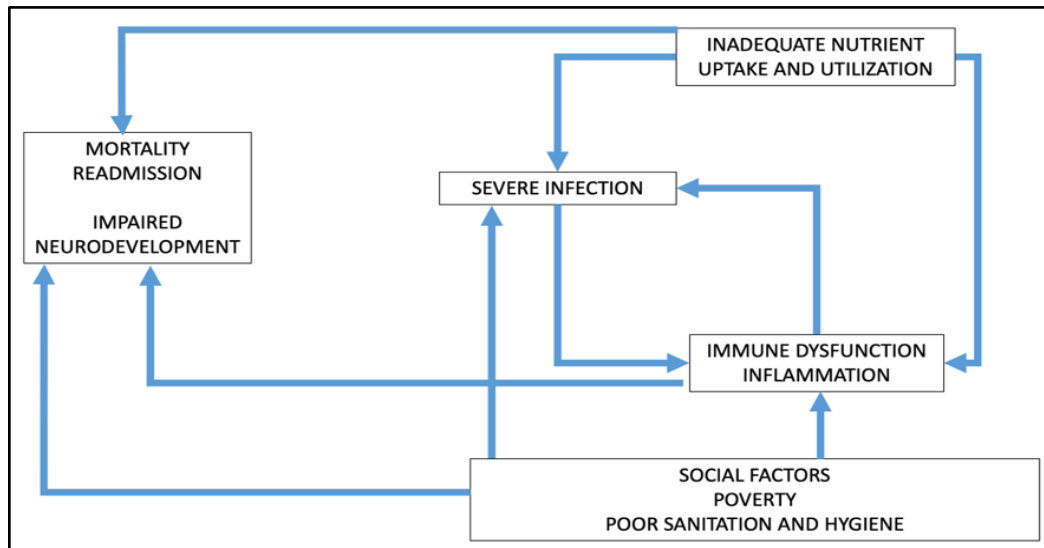


Figure 1. Conceptual framework of the multi morbidity underlying HIV-SAM

The *Home Environment* work package, which is covered in this report, builds upon previous work which documents that recovery from HIV-SAM requires a conducive home environment to promote nutritional rehabilitation (Kabongo et al., 2021). However, children are routinely discharged back to home environments characterized by economic precarity, entrenched poverty, food insecurity and hunger, which are root causes of SAM. These factors are exacerbated by coexisting 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 the extended network of caregivers.

1.2 Methodology

Recognizing 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 HIV-SAM and their primary caregiver recruited at the time of discharge from hospital. 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 coordinated across the three countries, with local social scientists and trained lay workers undertaking the research at each site. A mixed-method approach was 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 caregiver network.
- *Focus Groups Discussions (FGDs)*: FGDs were conducted with caregivers of children admitted to hospital with HIV-SAM 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) religious leaders, traditional healers, and herbalists. In addition to exploring stakeholder awareness of HIV-SAM, the FGDs, which were facilitated by local social scientists, engaged the participants in a range of individuated but interrelated questions:
 - Caregivers – caregiver's health-seeking behaviors and experiences of shame and stigma, including within health care settings.
 - Health workers – understanding the convalescence needs of children with HIV-SAM; experiences of providing healthcare to children with HIV-SAM; perceptions of home caring environment; and role of health workers in creating shaming and stigmatizing 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 focused group discussions were conducted in the local language/dialect, recorded, transcribed, and translated into English, and checked for accuracy and meaning by a social scientist at the study site. Typed transcripts were entered into Dedoose version 4.12 for subsequent coding and then were analyzed manually. 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 FGDs are presented using anonymized case-codes applied to the individual participants rather than pseudonyms, or according to group membership and stakeholder type for the FGDs.

2.0 Study Setting: Kenya

This report presents project findings taken from the Kenya study sites in Southern Nyanza these are Migori and Homa Bay County Referral Hospital (see Figure 2).

Migori County has a population of 1,116,436 with a population density of 427 people per KM² persons and is approximately 2,586 km², the major economic activity is agriculture. Other activities include fishing, manufacturing and mining (Kenya National Bureau of Statistics, 2019).

Homa Bay County is popularly known for its many bays, it houses 80% of Lake Victoria and it is a major source of livelihood. It has a population of 1, 131,950 and covers 3,154.7KM² with a population density of 359 people per KM² (Kenya National Bureau of Statistics, 2019).



Figure 2. Map showing Migori County and Homabay County

Focus group discussions and in-depth interviews were conducted with caregivers, traditional healers, religious leaders and herbalists and healthcare workers recruited from these two sites, which are among KEMRI-University of Washington study sites in South Nyanza. Healthcare professionals took part in FGDs and IDIs across both study sites, but only in Migori County were caregivers of HIV-SAM children, traditional healers, herbalists, and religious leaders enrolled in FGDs. The PMTCT, Maternal Child Health Clinic, Nutrition Clinic, and Pediatric Wards were able to identify and secure the participation of the caregivers. Caregivers' referrals were used to identify the social influencers; these are the people that caregivers turn to more frequently when their children are ill. The traditional healers requested that the interviews be scheduled, and they also suggested that they be

grouped according to seniority. They were divided based on experience, with those with more than 5 years of practice being grouped together and those with less were given their own FGD session. Table 1 lists the focus group discussion timetable, participants, and length of each session.

Focus Group Discussion participants	Date of FGD/IDIs	Number of participants	Reporting code
Healthcare workers (Migori County)	24/06/2021	8	FGD_Healthcare Workers_MGR
Healthcare workers (Migori County)	25/06/2021	8	FGD_Healthcare Workers_MGR
Healthcare workers (Migori County)	28/06/2021	5	FGD_Healthcare workers_MGR
Healthcare workers (Migori County)	28/06/2021	1	IDI_Healthcare worker_MGR
Healthcare workers (Migori County)	28/06/2021	1	IDI_Healthcare worker_MGR
Healthcare workers (Migori County)	28/06/2021	1	IDI_Healthcare worker_MGR
Healthcare workers (Migori County)	28/06/2021	1	IDI_Healthcare worker_MGR
Healthcare workers (Homa Bay County)	01/07/2021	1	IDI_Healthcare worker_HMB
Healthcare workers (Homa Bay County)	02/07/2021	1	IDI_Healthcare worker_HMB
Healthcare workers (Homa Bay County)	03/07/2021	1	IDI_Healthcare worker_HMB

Caregivers of HIV-SAM positive children	19/07/2022	8	FGD_Caregivers_1
Caregivers of HIV-SAM positive children	19/07/22	8	FGD_Caregivers_2
Traditional Healers	20/07/22	8	FGD_Social Influencers_Traditional Healers
Traditional Healers	20/07/22	8	FGD_Social Influencers_Traditional Healers
Herbalists	20/07/22	8	FGD_Social Influencers_Herbalists
Herbalists	21/07/22	8	FGD_Social Influencers_Herbalists
Religious Leaders	22/07/22	8	FGD_Social Influencers_Religious Leaders
Religious Leaders	22/07/22	8	FGD_Social Influencers_Religious Leaders

3.0 Awareness of the Causes of Malnutrition

The crucial roles that food access, feeding practices and nutrition awareness play in child malnutrition. Different sessions of Focus Group Discussions focused on these factors and understanding the repercussions.

3.1 Access to Food

A child is likely to suffer malnutrition due to lack of food. This is commonly experienced in families because they lack employment and hence have low purchasing power, exposing the household to food insecurity.

"I want to give example, like my baby, being that I did not have a good job, my baby became malnourished. He was not feeding well and was not getting a balanced diet." (FGD_Caregiver_HIV-SAM Children)

"For me, in my opinion, for a child within those years to lack food, there can be a problem. One problem is lack of income and due to lack of money this can lead to inadequate food getting into this house." (FGD_Caregiver_HIV-SAM Children)

"After giving birth and because she was not feeling well, she didn't have enough breast milk, and the baby is also there. She was breastfeeding the child and she didn't have enough food. Then being that she also didn't know that when she is not taking medication it was going to be easier for the baby to contract HIV, the baby got HIV and they both got weak." (FGD_Caregiver_HIV-SAM Children)

Caregivers are noted to have the positive attitude of going out to work for money with the intention of purchasing food. However, this is not guaranteed as what they earn in most cases is insufficient to purchase food for the children in the house. Sometimes they have no option other than reducing the number of times food can be served, leaving them with either feeding once or twice a day.

"The reason why a child can suffer from malnutrition is because first, the income of the parents, the parent will leave in the morning to look for money or food since she doesn't have a job, he didn't get money he'll come back hence will not be able to eat, so that will happen for such a long time, meaning today you got something tomorrow, maybe you just get breakfast which may just be porridge, lunch time you go without food." (FGD_Social Influencers_Religious Leaders)

3.2 Feeding Practices

Inappropriate feeding techniques may include early introduction of complementary foods, insufficient breastfeeding, or unhealthy food options.



Children's nutritional intake can be hampered by ignorance of appropriate feeding methods, age-appropriate food selections, and meal frequency, and are some the drivers of malnutrition.

"What can cause malnutrition in a child first is lack of knowledge, because you can find that a mother has eggs but instead of cooking eggs for the child, she sells the eggs and buys a mandazi for the child. So, if she gives the child a mandazi all the time the child will have problems. Secondly, people are going to look for means of survival, people nowadays are busy looking for means until they forget about the child. This can also cause malnutrition in a child." (FGD_Social Influencer_Herbalist)

Early childhood feeding practices have a significant impact on how well fed and healthy a child is in general. It can have serious repercussions when some children are left to care for themselves and learn to feel hunger on their own. The potential effects of letting children take care of their own feeding and learning to recognize their hunger cues are likely to contribute to malnutrition.

"At times you can force the child to eat but he doesn't want, then you decide to leave him. When he gets hungry he will eat, so you leave the food there thinking the child will get hungry and eat but going to check you find he has not eaten the food. So you realize the child is losing weight." (FGD_Caregivers_HIV-SAM_Children)

"When he has loss of appetite, even when you give him something to eat, he does not want so, you end up giving up saying, 'I am tired of you, you are disturbing me, and you have given me enough problems.' Now, you will not bother with the child's feeding because you feel whether or not I give him food he will not eat. This makes the weight continue to decrease because the child is not getting enough proper food and that can cause other diseases in the body." (FGD_Caregiver_HIV-SAM_Children)

Stress and anxiety can affect milk production in lactating mothers. This was articulated by lactating mothers who noted that 'having too many things in mind' could affect milk production. Other reasons were the kind of income-generating activities mothers are involved in which leaves them tired, hence compromising how they feed their children.

"After giving birth and because she wasn't feeling well, she didn't have enough breastmilk and the baby is also there. She was breastfeeding the



child and she didn't have enough food. Then being that she also didn't know that when she is not using medication it was going to be easier for the baby to contract HIV, the baby got HIV and they both got weak.” (FGD_Caregiver HIV_SAM Children)

3.3 Nutritional Awareness

The caregivers understanding of nutrition care for children who are malnourished and living HIV negative and those who are malnourished and are HIV positive differed in terms of care on who should be prioritized first in the household. According to some caregivers, HIV-SAM child need attention because of the interconnected health conditions in comparison to a child who is malnourished but HIV negative; indicating an additional level of complexity.

“The one who is HIV positive and malnourished, this one you must take good care of because she has two problems, she has malnutrition and HIV. This is a child that you must make sure eats on time and gets a balance diet, and you give them medicine at the right time so that they recover.” (FGD_Caregivers_HIV-SAM_Children)

However, some caregivers thought that malnutrition, no matter of HIV status, requires appropriate care: “According to me, the one who is malnourished I can care for. I will just take care of both but the one who is malnourished I can be keen on his care.” (FGD_Caregivers_HIV-SAM_Children)

Participants in the FGDs noted that caregivers in poverty trapped households find challenges caring for these children as much as one may want to take care of them well.

“The challenge that can be there at times how to get job and earn and buy food for your baby to eat and be fine can be impossible. What you can tell yourself is, should I cook anything that I find because at times earnings are little.” (FGD_Caregivers_HIV_SAM Children)

4.0 Healthcare Seeking Practices

This section highlights important factors shaping a child's journey during malnutrition right from household, community and to the hospital. Health trajectories, what leads to delays in seeking health advice, adherence to advice



before and after hospital discharge and finally stigma, how it affects health seeking behavior.

4.1 Health seeking trajectories

When children get sick at home, their health-seeking trajectories starts; beginning a journey that is influenced by a variety of factors. Although it might initially appear to be beneficial for the child's health, it ends up being a challenging process for them to get to the proper location where trained medical staff can give them the attention they need and begin a new phase of treatment. Participants had a chance to discuss a wide range of factors that affect caregivers' choices to seek hospital-based medical care as well as how they handle caregiving before and after discharge. These factors included distance, family influence, gender-based norms, embarrassment and self-stigma, and cost. With regards the latter, several participants identified the high costs of medical care and medication led to delayed and/or prevented them from accessing hospital treatment.

The distance to the hospital was one important barrier identified, despite the contradiction in the influencers' discussion of proximity. Influencers admitted it was uncommon for them to travel outside of their homes to treat sick children at the caregivers' homes. Additionally, caregivers are expected to pay for transportation costs when at-home visits do take place. Referrals from the community rather than available funds are what ultimately determine where a patient will receive their medical care. The family of a sick child can visit a social influencer regardless of distance or cost.

"Sometimes you may delay due to lack of money, sometimes the hospitals are far and also when you get to hospital you require money so may decide to just buy medicine hoping that the child might get better after taking the drugs." **FGD_Caregiver_HIV-SAM)**

"Lack of money can cause you to delay taking the child to hospital, may be the hospital is far and you don't have money for transport."
(FGD_Caregiver_HIV-SAM)

"[You] can find a caregiver sometimes; she doesn't have money and the hospital is far. So, she doesn't have means to reach [the hospital], so that can be a challenge." **(FGD_Caregiver_HIV-SAM Children)**

Family influences

The role of family relations in shaping caregivers' decision-making is a complex one. On the one hand, the advice and practical support of family members plays an important role in health-related decision making. As the quotes suggest, for some participants the advice of their family members is sought first before reaching out to professional health workers.

"If my child is sick, I normally call my sister because my mum already died. So, it is my sister I call, she is the one who gives me advice, she will ask me if I have money or not. If I don't have, she sends me to go to hospital and check what is wrong with the child. Then my other sister would tell me to go to 'Jatak' traditional healer to check the child, so it is the first one that I normally prefer going to." (FGD_Caregiver HIV-SAM Children)

"Now you know my baby added a lot of weight at once, I asked myself, 'the whole body was swollen'. So, I asked my dad 'what could be the problem today, I have noticed my baby has become fat at once?' He told me to take him to the hospital, I went to the hospital, the doctor examined him and said there is nothing wrong." (FGD_Caregiver HIV-SAM Children)

The decision-making processes of caregivers are significantly influenced by gender-related norms in addition to family influences. Many caregivers emphasized the need to uphold gender-specific roles, whereby they felt obligated to consult and discuss the child's diagnosis with the father before beginning treatment. The quotes offered shed light on the complex interaction between gender dynamics and healthcare-seeking behaviors, highlighting the necessity of taking these norms into account when discussing healthcare access and household decision-making. In order to promote equitable and inclusive healthcare practices for all people involved in the caregiving process, it is critical to acknowledge and address these gender-related influences.

"[...] you can find out she cannot decide on her own because the husband factor has to come in, and that even affects us when it comes to taking care of these sick children. The child is so sick that you see this one needs to go to the ward, but the mother will tell you, 'Doctor, wait first let me call the father, if he accepts, we will go, if he refuses then we go back home.' So, it affects a lot." (FGD_Healthcare workers)



Relatedly, some participants described how a stressful domestic environment and risk of gender-based violence impacts the capacities of women to make decisions about the care of a child.

"The people I live with may bring you stress, maybe he has come late, and he begins to stress you. You are stressed, you probably don't sleep at night, and sometimes the child is also sick. He is also quarreling [with] you, so even to think of taking the child to hospital, because at times it is just serious quarrels all the time. Maybe your spouse is a drunkard, or he has come home drunk, and he has found the child sick. So, for him to even think that the child should be taken to hospital, he can't think of it. The child is sick, you don't have money, and so for you to even think of going to look for money and take the child to hospital you don't think." (FGD_Caregiver-HIV-SAM Children)

Stress, embarrassment and stigma

Although caregivers may be able to tell if their child is sick and know that they should take them to hospital, stress, embarrassment and social stigma, either from immediate family or community members, may discourage them. As the quote below suggests, caregivers may rely on more readily available treatments before deciding to take their child to hospital.

"Sometimes, maybe the mother is an odd job person, jua kali [daily casual jobs]. You leave early in the morning to go look for food for the children. So, when you've gone and worked so hard, coming back home you are tired, you also didn't eat anything, the child has fever. So, you realize you have Panadol and tell yourself, 'let me try if Panadol can bring the fever down.' Then, in the night the fever get worse and you give the child Panadol again. So, you find that delaying." (FGD_Caregivers_HIV positive-SAM Child)

Also, they may take the decision to either stay home or go to a traditional healer just to avoid confirming the truth on the nutritional health status of the child.

"It depends on the caregiver of the child. Sometimes she can be embarrassed because she is already HIV infected and she suspects that the baby has already been infected. So, she can be embarrassed because she thinks that she is going to meet some people who are going to find out that she is sick" (FGD_Caregivers_HIV-SAM_Children)



Conversely, the fear of having a child die at home motivated some caregivers to ensure the child was taken to hospital.

"First, fear can make mother decide to rush one by one to hospital because maybe she has used herbs and there is no change and then secondly [baby playing] she can feel that in case the baby dies in the house, how will it look, how will people perceive that? They will wonder what happened that the baby was not taken to the hospital. So, she can decide to come with the baby even if the baby dies, it happens in the hospital and not in her hands at home. So, fear can make that to happen." (FGD_Caregiver-HIV-SAM)

4.2 Indigenous knowledge and traditional medicine

Culture is a strong predictor of where the sick child will be taken to for health attention first. This may also be a result of cultural superstitions and beliefs. Some people may hold the opinion that their parents' bad behavior may have triggered a sickness or summoned spirits or other supernatural forces.

"The first instinct is to go to the herbalist or traditional healer."
(FGD_Caregiver_HIV-SAM Children)

"Later after 3 months she noticed that the baby health is a bit different. She said her baby is bewitched, she started going to the herbalist so she can treat the baby because her baby was bewitched, and when they went to the herbalist was just removing what the baby feeds on because she felt her baby was bewitched. So, later our mother in-law advised her to come to hospital being that the baby had visited several herbalists many times, but there is still no change. So, she was asked to come to the hospital so they can find out what was happening to the baby. On visiting the hospital, the baby was in bad condition even on looking at him, the baby was tested and found to be HIV Positive and initiated into food treatment."

(FGD_Caregiver_HIV-SAM)

"What I can say, a mother can be scared like what she has said then advice like if your child is sick and you go tell a neighbor, 'I am seeing my child losing weight and all that, you can be advised that you are being unfaithful and it is affecting the baby, go and look for some grandmother to treat your child that the baby has 'chira' (illness due to evil done by parents). So, you know someone can delay because she is still giving the child herbal



medication to treat and there are no changes, So, advice that someone give to another can at times not help.” (FGD_Caregivers_HIV-SAM_Children)

On some occasions caregivers decide on visiting herbalists and other traditional healers even after getting treatment from the health facilities, due to the thought that the sick child will be better treated outside hospital because of relapse or other reoccurring illness.

“Another mother would think that she already took the child to the hospital and the baby did not get better, so she will feel it is not something that cannot be treated in the hospital so she can decide to go to the witchdoctor.” (FGD_Caregivers-HIV-SAM Children)

Participants in the ‘social influencers’ focus group discussions had different experiences of health care seeking practices. They mentioned that most of the time they are recognized by the caregivers and most of the sick children are first rushed to them before being taken to hospital.

“I also want to contribute, these people come to us with different kinds of illnesses due to the fact that they know us, the illnesses that they bring to us, she’ll run to us even before going to the hospital, this child has diarrhea that has bubbles that is “orienyanja” (prutis) even before examining you will just see, you will just look at the child get medicine that treats “orienyanja” (prutis)’ and the child will get better. These people come with different issues, they come with “chira” (illness believed to be invoked by breaking cultural rules) sometimes it may be planting or he is promiscuous and unfaithful all of them we refer to them as “chira” they come to us, you will prepare the medicine and give to her, those are not treatable at the hospital, they come to us with very many illnesses you may find that the child is in this home but the middle of his head is sunk (sinking fontanel), those ones we still add them there, we find medicine and they get healed.” (FGD_Social Influencer_ Traditional healers)

In conclusion, improving access to high-quality healthcare services requires an understanding of the variables that affect caregivers’ decision-making when selecting a doctor for their child. In order to allay families’ fears and anxieties about seeking medical care, healthcare providers must be aware of cultural beliefs and social influences on where parents choose to take their sick children. They must also work to establish trust with families.

4.3 Adherence before and after discharge

During the FGDs with healthcare workers, a critical observation was made about the difficulties they face in providing healthcare services. These difficulties go beyond the scope of home follow-up and are primarily attributable to the caregivers' reluctance to disclose their health status to family members, including spouses or in-laws. This lack of disclosure poses significant challenges, especially when trying to find a caregiver so that the child can receive follow-up care. The situation is made worse by the fact that the caregivers go to great lengths to conceal their HIV status; sometimes to the extent that they even change their names and seek treatment at different hospitals. Healthcare professionals struggle to ensure the well-being of both the caregiver and the child because of the level of secrecy and identity alteration that stands in the way of effective care and treatment.

"The funniest thing they are doing nowadays, clients have got different names now. When you go to Makongeni (Health Centre), she has another name, when you go to Nyalkinya (Health Centre), she has another name, when she comes to district, she is now a bantu now. So, it is difficult now. To help this client is hard because the other side she had defaulted, Makongeni, she defaulted and she wants to come here as new client, 'I want to be tested,' 'I have never known my status is when I got married,' they are very innocent." (FGD_Healthcare workers)

The discussions made clear how negatively gossip and embarrassment affect caregivers. It becomes clear that the emphasis on shame and rumors has a significant impact on how caregivers care for their sick child, potentially having a negative impact on the mother's and the child's health. If the child doesn't show any signs of improvement despite the mother's best efforts to feed and care for them, she might be accused of neglecting them, which could add to the mother's mental exhaustion. This emphasizes the negative effects of social stigma and judgment on the wellbeing of both the caregiver and the child, underscoring the necessity of a nurturing and compassionate environment that enables caregivers to provide adequate care without worrying about being judged or subjected to gossip.

"In the community it's a challenge. In the community, I have seen a neighbor hiding food by prescription. Not being able to give to the sick child, only some children are sneaking them out ... 'it is in so and so house,' but the



person who it is intended for is not taking, even that porridge, they take it as for HIV kids.” (FGD_Healthcare workers)

The advice given to caregivers regarding their sick child health condition exhibits some variation among healthcare workers, family members, and other social influencers while there may be diverse perspectives a predominant focus of the advice revolves around the medications prescribed for the child.

“Okay, when baby is malnourished they will encourage you. There are some lessons they will give you on group of foods, if possible, you should feed baby and most of the time caregivers think that balance diet is expensive and they can’t afford. They don’t know the person who has eaten chicken and who has eaten egg costing Ksh.15, have eaten same class of food. Take even green vegetables and avocado or one banana and take water. They will even teach you on cheap foods. If baby’s weight has gone down, they will give you plumpy nut, flour and if it is a baby who can already eat, you will be given nutritional advice on what to feed the baby on.” (FGD_Caregiver HIV-SAM Children)

This advice can have a significant impact on how strictly medications are taken or other aspects of how care is managed. In some cases, trusted social influencers in the community, such as religious leaders, family members or friends, can play a crucial role in determining how strictly a caregiver follows medical advice. It is important for healthcare providers to recognize this influence and work with social influencers to ensure that they provide accurate information and support proper adherence to treatment plans.

“After being discharged from hospital, I’d normally go to our church preacher (pastor). He is the one who gives me advice, because when you’ve come from the ward, like she came from the ward with the child, it is the preacher who came to encourage her and told her to have courage after coming from the ward, and that God will heal her. So, he asks you if you’ve been given drugs to give to the child, if I don’t give the child she will not get well.” (FGD_Caregiver HIV-SAM Children)

By working together with trusted individuals in the community, healthcare providers can help ensure that sick children receive optimal care during their consultations and ensure that sick children receive quality care both during their hospital stay and after they return home.



During a child's hospitalization, caregivers frequently experienced a wide range of things. Parents may feel guilty if they leave their own children at home, whether they do so alone or with family members. Seeing other seriously ill children can be both extremely stressful and deeply upsetting. Additionally, many caregivers emphasized that the hospital's patients were not offered any special food options, and that not all children would necessarily benefit from the food. Given all of these worries, it makes sense that hospitalization could be a trying time.

"I didn't see any problem, I also did not see anything good because in the ward it is just giving the child medicine, sometimes you've been brought cabbage the child doesn't eat cabbage and maybe you don't have money so it forces you go give the child whatever has been brought even if she can't take it. That is what I saw in the ward." **(FGD_Caregivers HIV-SAM Children).**

Despite the grim circumstances, there was one bright spot: getting to know and bond with other families who were in the same situation. Even though there were downswings and sad moments, the help and compassion of other caregivers had a positive and consoling effect on one another. Sometimes, the hospital was compared to prison life as a place that no one wanted to return to. Meeting other parents who were also looking after their kids in the ward had both positive and negative effects on each other.

"Okay some will see as if they are in prison because you'll be told 'this child by the time you leave this place it will be like 2 or 3 months', so you find that the work/business you were doing goes flat like that there is no profit you'll make. Others reach a point they feel like 'shouldn't I just disappear leave this child here and go do my things'. Others will tell you 'ah, just let the child die the costs will reduce'. So, it depends on you as person how you feel and what you see as the benefit in your sick child staying in hospital." **(FGD_Caregiver HIV-SAM Children)**

The limited adherence of caregivers to the guidance offered to them is one of the major challenges faced by social influencers and healthcare professionals. This noncompliance causes extended healing times, relapses, or even no improvement in the child's health. Young mothers, and sporadically the sick child's father, stand out among the caregivers as being particularly reluctant to take the advice given. It was brought up during the healthcare worker group discussion how difficult it can be to interact with and collaborate with caregivers, particularly those who are

young mothers. The difficulty in achieving the best possible health outcomes for the children under their care due to this refusal to heed advice highlights the need for focused interventions and efficient communication techniques to resolve this problem.

"Yes, the adolescent mothers usually it is really a problem because even after discharge, we will ask them how are you going to take care of this child back at home? They will tell you I will just leave the baby with a volunteer or grandmother or any other...anybody who could take care of that child. And we used to really...we only see that with that one, the child is not going to pick it up. So, they end up even dying, coming back with severe malnutrition again and then they die, so it has really been a challenge, especially on the young mothers." (FGD_Healthcare-workers- Migori)

The reasons for the caregivers' failure to follow the medical advice given by health-care provider after their child was released from the hospital and throughout the recovery process were explored during the focus group discussions. These discussions produced two main themes: socioeconomic limitations and caregiver negligence. First, it was determined that two important factors influencing adherence to medical advice were financial limitations and a lack of social support. Due to financial constraints, caregivers reported having trouble paying for the necessary medications, follow-up visits, and suggested healthcare procedures. Further complicating these difficulties was the lack of a strong support network at home, which made it more difficult for caregivers to successfully carry out the recommended treatments and interventions.

"And then third we have the caregiver you may have done your screening and you give the supplements if they are there but you find out that when they go back home due to socio-economic status even if it is the flour that was given it's shared among the whole family so you find out when you do the follow up that this child is not gaining weight, there is no improvement at all." (FGD_Healthcare- workers)

"At times carer has no money. You find that a mother sometimes has nothing and the spouse she is living with is also a difficult person asking him for money is not easy. So, you find the mother lacks money to buy the child something or food to eat." (FGD_Caregiver_HIV-SAM_children)



Negligence was acknowledged as another influential factor in non-adherence. Some caregivers were noted to be negligent and overlook the importance of certain aspects of recommended care.

"I feel there are some caregivers who are too busy more than caring for the baby. They feel that once the baby has got drugs he will recover, so even if she does not follow those other things the baby already has medication so they concentrate on other schedules." (FGD_Caregiver_HIV-SAM_Children)

In order to support adherence to medical advice and ultimately improve the health outcomes of sick children, it is critical for healthcare providers to address these barriers and collaborate with caregivers to find solutions.

4.4 Encountering and responding to stigma

It has come to our realization that many children are highly affected by HIV-SAM, but the numbers recorded for life-saving treatment are lower than should be expected. This led to the acknowledgement of stigma as a key barrier to accessing healthcare treatment. Health-related stigma is the negative stereotyping and discrimination of a certain group of people based on their health status. It is because of structural discrimination perpetuated by decades of political and economic policies. This has resulted in the caregivers' lives being shaped by the stigmatization they face together with their children. They live in fear and often feel unworthy of respect, value, love, or support in society. The acknowledgment of stigma as a barrier has yielded insight into the reasons for the slow progress in the improvement of children suffering from HIV-SAM. They include fear of rejection, denial that the child's condition is malnutrition, lack of confidence in the program, and relapse of the program. This can lead to a decrease in quality of life and emotional stress.

"Some people when they see that your child is sick, they just sit back and talk about you saying that you even have nothing to eat. You know everyone has a different mind like say your mother in-law, your husband's sister would pass comments like 'she has passed on an illness to her child and telling her children not to use a cup that has been used by you because you are sick and has passed on to the child.'" (FGD Caregivers HIV-SAM Children)



Caregivers' mental health and overall well-being is severely impacted by stigma toward those who are undernourished. In severe cases, it can even result in suicide. It can also cause depression and anxiety. Caregivers may hesitate to seek out medical attention or support services out of fear of being judged or rejected by society. Communities need to be aware of how stigma affects these at-risk groups and work to foster a welcoming atmosphere where everyone feels valued and supported. The realities of living with HIV or malnutrition can be made more widely known through education campaigns aimed at reducing stigma.

"Some will take you as a promiscuous person, one who is not taking care of her home so they do not want to associate with you that you are not a person people should associate with closely. They look at the health of your child and decide that maybe you are promiscuous, and this affects the health of your child that is why your child has bad health. Some people take you to be useless in the family because you are sick and positive and unproductive to the community because you have numbered days and you will die soon. There is stigma you through when you have that disease."

(FGD Caregivers HIV-SAM Children)

"Many will tell you, your child is thin and when people start telling you your child is thin, you get discouraged. So, if you go back home you start crying alone in the house by yourself asking yourself 'why are they telling me this', 'what will I do to help my child so that they don't talk about my child like this?' So, you keep having hopes for your child but what one should do is to continue having hopes even if they tell you don't care what people will say. You, yourself, you are aware of what is wrong with your child so you don't have to care what people will say about your child." **(FGD Caregivers HIV-SAM Children)**

Stigmatization can occasionally be self-initiated, and this is most common among carers of malnourished children. Because there is no acceptance of HIV-SAM, the treatment of these children is hampered by the self-judgment and assumptions of the caregivers. The healthcare workers cited, when they give supplements to malnourished children, some caregivers choose not to take the supplements out of concern that they might be linked to HIV patients.

"Maybe in addition to that, there is also stigma. Maybe a client has come, we are able to give this client, maybe let's say flour, maybe even the process of carrying the flour to their home. Carrying the flour to their home becomes



difficult because the narrative outside there is, when they see you with the flour you are HIV positive, so they fear, that stigma.” (FGD_Healthcare workers)

Mothers or other family members who are aware of the child’s health status are keen to maintain the child’s privacy and keep the diagnosis from reaching the public; this has helped in reducing the stigma associated with HIV, thus allowing the child to lead a normal life.

“For me where you live, may be many do not know; it is you in the house who knows. So, the ones who are outside they will not know that the neighbor’s child has HIV, so they will not treat them badly without knowing their status.” (FGD Caregivers_HIV-SAM Children)

In order to deal with the stigma and shame connected to these conditions, caregivers of children with malnutrition or HIV may employ a variety of coping mechanisms. While some caregivers might prefer to move to an area where they are less well known, others might decide to confront gossipy neighbors or individuals or report to village administrators.

“If you hear what she has said the first time you can let it pass, the second time you can also let it pass, the 3rd time you confront her and tell her ‘you have talked about me like this and I am not happy about it.’ So it depends on her response she might be polite or become rude alternatively you could go to the village elder and report her.” (FGD_Caregivers_HIV-SAM Children)

In addition to the previously mentioned socioeconomic barriers and caregiver negligence, it is significant to note that some caregivers understand the importance of following medical professionals' recommendations as a way to fight stigma and shame. These caregivers are aware that by adhering to the recommended medical advice, they can improve their child's health outcomes and help them fight stigma and social stigma associated with their condition. For them, following medical advice turns into a way to combat the unfavorable assumptions and misunderstandings surrounding their child's illness, fostering a more understanding and supportive environment. Encouraging and promoting this viewpoint can help strengthen caregivers' adherence to medical advice and, as a result, enhance the overall care and wellbeing of the children they are in charge of.



"Okay to stop all these you need to follow the instructions you have been given at the hospital and when you go back the following visits and they see that you have changed, they will be happy that they scolded you, but you have changed. So, you have to follow instructions."

(FGD_Caregivers_HIV_SAM_Children)

As they navigate intricate and difficult situations, it is crucial to understand and respect the coping strategies used by caregivers. Healthcare professionals and communities can help to lessen stigma and promote the wellbeing of both the child and their caregivers by offering a supportive environment, resources, and a nonjudgmental attitude.

"Okay you'll feel painful, and even feel like you should even stop taking the drugs and just leave and die because now you have become the topic in that village. So, you feel bad and ask yourself if it was your fault to be the way you are. But if you see it has become too much, they are talking about you too much, alternatively you can look for a house elsewhere and relocate where people don't know you and go and live there and when you are going there don't expose yourself to these people." (FGD_Caregivers_HIV-SAM Children)

5.0 Conclusion and Key Recommendations

Due to a lack of food, a child is likely to experience malnutrition. Families frequently experience this because they have low purchasing power due to unemployment, which exposes the home to food insecurity. Families need to be made aware of the importance of a balanced diet and how it enhances their overall health. With the help of nutrition education programs, families can discover how to cultivate their own vegetables, create wholesome meals on a budget, and develop healthy eating habits. A child's weakened immune system brought on by malnutrition makes them more susceptible to illness.

It is emphasized that stress and anxiety, insufficient knowledge, and poor feeding habits can all contribute to children becoming undernourished. It places a strong emphasis on the necessity of educating and supporting families — particularly lactating mothers — about proper nutrition and feeding techniques. Additionally, having access to medical care and counseling can aid in the prevention and



management of stress and anxiety, enhancing the general health and well-being of mothers and their offspring.

The study discovered that HIV-SAM children's health and well-being can suffer significantly from malnutrition as well as from delayed or ineffective treatment. There are no current policies that emphasize the special nutritional requirements of children with HIV/SAM, and caregivers are unaware of these needs. Additionally, cultural values and customs may influence how people seek out health. The analysis suggests addressing cultural beliefs, encouraging prompt medical attention for illnesses, raising awareness of and education about the special nutritional needs of HIV-SAM children, and enhancing access to reasonably priced healthcare services to address these issues.

Access to life-saving treatment is hampered by stigma, which causes fear, denial, and a lack of faith in the treatment plan. The importance of raising public awareness and providing more information about HIV-SAM, as well as the need for programs to combat the stigma attached to the condition, are emphasized. The quality of life for children with HIV-SAM and their caregivers would improve if these issues were resolved.

Key Recommendations

1. Families should be educated about the importance of a healthy diet and eating practices through nutrition education programs. These programs should teach families how to make wholesome meals on a budget in addition to teaching them how to grow their own vegetables. For the purpose of preventing illnesses and advancing general health, the provision of healthcare services, such as immunizations and scheduled checkups, is also essential. By implementing these strategies, it is possible to reduce the prevalence of childhood malnutrition and improve the health of children.
2. Implement a multifaceted strategy that includes social support, medical care, and education initiatives to address the difficulties faced by those who care for children with HIV/SAM. The objectives of this strategy should be to raise public awareness and educate the public about the special nutritional requirements of HIV-SAM children, promote prompt medical attention for illnesses, address cultural beliefs and practices that might influence health-seeking behavior, and increase access to reasonably



priced healthcare services. It would be possible to improve the health outcomes of HIV-SAM children and guarantee the best result for their well-being by putting such an approach into practice.

3. Raising awareness on malnutrition through health talks and CHVs visits is crucial to curb and treat it on time, reducing the poor quality of life and mortality. Enhancing food production during antenatal clinics through health talks and CHVs visiting households to confirm the implementation of kitchen gardens can promote good feeding practices and ensure access to food even after delivery and child growth.
4. Breaking the taboo surrounding HIV-SAM and actively battling the stigma attached to it are imperative. To inform the public and lessen stigma, a creative and entertaining public awareness campaign that uses social media, celebrities, and community leaders could be put into place. The quality of life for people affected by HIV-SAM can also be improved by specialized initiatives that offer knowledge, assistance, and resources to children and their caregivers. We can significantly improve the lives of children with HIV-SAM and their families by taking these steps.
5. Through support groups sponsored and supported by health facilities, caregivers can learn of interventions like food production through kitchen gardens. Not only food production but also nutrition-enhancing agriculture. Income generating activities managed by the caregivers who are members of the group. Through support groups there will be retention of post discharged malnourished children in the community this will, in turn, reduce cases of relapse and no response to treatment. These groups will also help in building the mental health of caregivers of malnourished children and smooth walk through stigma.
6. The government of Kenya should work on building a referral system from social influencers like; religious leaders, herbalists, and traditional healers to identify sick children before they are treated with potentially harmful herbs. However, this system will only be successful if the Ministry of Health provides health pieces of training for social influencers to have them understand that malnutrition is dangerous to a child's health and can only be managed in a hospital.

7. The Nutrition board in Kenya with the use of IMAM guidelines should develop locally-made supplements to improve the availability of supplements in health facilities. In summary, it is important for the government of Kenya to prioritize staffing of personnel in government hospitals to ensure healthcare workers are not overworked and can deliver quality services. Additionally, more research studies on malnutrition should be implemented in Southern Nyanza.

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