Co-SAM Home Environment Working Papers

Report 3: The social and environmental determinants underlying HIV-SAM: A rapid appraisal to understand the contexts in which child convalescence occurs in Zambia

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Joseph M Zulu, Chileshe Mpandamabula, Miyoba Chipunza, Jacqueline Kabongo, Paul Kelly, Beatrice Amadi

Queen Mary University of London

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Co-SAM: The social and environmental determinants underlying HIV-SAM: A rapid appraisal to understand the contexts in which child convalescence occurs in Zambia

Contents

Acknowledgements 5

Executive summary 6

1.0 Introduction 10

1.1 Problem Statement 10

1.2 Justification 11

1.3 Aims and Objectives 12

2.0 Methodology 12

2.1 Study Design and Approach 12

2.2 Study Participants and Sampling 13

2.3 Inclusion and Exclusion Criteria of the Study Population 14

2.4 Data Collection Methods 14

2.5 Data Management and Storage 16

2.6 Data Analysis 16

2.7 Ethical Considerations 17

3.0 Results 18

3.1 Demographic Characteristics of the Participants 18

3.2. Causes of malnutrition 21

3.2.1 Low-income setting 21

3.2.2 Food availability and feeding practices 21

3.2.3 Competing household responsibilities 22

3.2.4 Lack adequate nutritional information 23

3.3. Health seeking Behaviour 23

3.3.1 Mixed health seeking patterns 23

3.3.2 Reason for seeking formal healthcare 24
3.3.3 Advice during hospitalization 25
3.3.4 Advice seeking after discharge 26
3.3.5 Adherence to advice 27
3.4 Factors Causing Delayed Health Seeking 27
3.4.1 Economic factors 27
3.4.2 Lack of knowledge 28
3.4.3 Personal anxiety 28
3.4.4 Community level factors 29
3.4.5 Stigmatization 29
3.5 Role of influencers in shaping access to care 31
3.5.1 Influencer connection with facilities 31
3.5.2 Referral by influencer 32
3.6 Hospitalization experience 33
3.6.1 Experience with healthcare provider 33
3.6.2 Experience with other caregivers 34
3.6.3 Challenges with hospitalization 34
3.7 Caregiver support 35
3.7.1 Support network 35
3.7.2 Support received 35
3.8 Recovery at home 37
3.8.1 Caregiver experiences 37
3.8.2 Food availability prior to hospitalization 38
3.8.3 Barriers to recovery 38
3.9 Caring practices 38
3.9.1 Ideal place of care and care giver 38
3.9.2 Caring for child with HIV-SAM 39
3.9.3 HCW experiences providing care to HIV-SAM children 40
4.0. Conclusion 41
Appendix 44

Tables

Table 1: Interviews conducted 13
Table 2: Demographic characteristics of children and caregivers 19
Table 3: Household structure 20
Table 4: Support received 36

Glossary of terms and abbreviations

SAM	Severe Acute Malnutrition
WHO	World Health Organization
HIV-SAM	HIV and Severe Acute Malnutrition
IDI	In Depth Interview
FDG	Focus Group Discussion
GCP	Good Clinical Practice
PI	Principle Investigator
UNZABrec	University Biomedical Research Ethics Committee
NHRA	National Health Research Authority

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Executive summary

Study aim

The overall aim of this rapid appraisal was to define the social and environmental determinants underlying HIV-SAM through in-depth qualitative research to understand the contexts in which child convalescence occurs, to identify psychosocial pathways for intervention.

Methodology

Study participants were recruited from the University Teaching Hospital (UTH) and Chawama Level One Hospital. Overall, a total of 138 people participated in the study. Of this number, 64 participants participated in the FGDs as follows: grandmothers - 10; pastors - 8; fathers - 10; traditional healers - 10; health workers (UTH) - 8; health workers (Chawama Level One Hospital) – 10; caregivers - 8. Further, 24 IDIs were conducted while 50 quantitative interviews were completed.

Results

Demographic characteristics of the participants

The targeted sample for the survey was 50 children in UTH and Chawama Level One Hospital. The median age of the children was 19 months (IQR, 13-25), while the median age for caregivers was 26 years (IQR, 22-32). Majority had been admitted for the first time 43(86.0%). A large number of children were HIV negative 40 (80.0%) while 10 (20.0%) were HIV positive. About 34 (69.4%) of had lost the main source of income. Less than half 23 (46.0%) were worried about debt in the last two years.

Causes of malnutrition

Causes of malnutrition included poor access to food, limited nutritional knowledge among mothers or caregivers and inappropriate feeding practices such as irregular feeding intervals, lack of balanced diets and inadequate food. Economic problems, competing household responsibilities and social stigmatization affected providing nurturing care. The environment for most caregivers of children with HIV-SAM was characterized by poor sanitation, low income and education levels, as well as single parenting which affected caregiver's ability to provide care to children with HIV-SAM. Children with HIV were at risk of suffering from malnutrition due to supressed immune system, loss of appetite, as well as lack of nutritious food at household level which exacerbated the situation of opportunistic infections.

In the quantitative survey, in terms food security, more than half of the respondents 26 (52%) reported that their household worried that they did have enough food at least once or twice in the once or twice in the past four weeks. Further, 12 (24%) were not able to eat

the kinds of foods preferred because of a lack of resources (once or twice in the past four weeks), while 28 (56%) reported they rarely experienced this situation. In addition, 13 (26%) had a household member going the whole day and night without eating anything.

Health seeking behaviour

Most caregivers had mixed health seeking patterns. The caregivers sought advice from people they trust, such as grandmothers, neighbours, friends, brothers, sisters, aunties, pastors, and traditional healers and health workers. Factors that facilitated adherence to advice included caregivers being knowledgeable of malnutrition related issues as well as the respect attached to the person who provides advice. Meanwhile, social, economic, religious and health systems barriers, contradictory advice, and household responsibilities affected adherence to advice. Individual level factors such as one's level of knowledge of HIV-SAM and past experience of the diseases, health systems factors such as proximity of the health facilities, as well as social factors such as positive advice from friends, family, health workers, community leaders and church members who had some good experience with the health facilities encouraged caregivers to seek health services. Support networks included grandmothers, trusted neighbours, sisters, brothers, other relatives and members of church communities. The network provided emotional support, prayers, food, advice, financial support, and encouragement. Influential actors such as religious and community-based leaders and community health workers who were located in the communities of the caregivers also influenced access to care.

Economic factors such as lack of money to meet transport costs to the health facility, individual level factors such as lack of knowledge on malnutrition, advice or discouragement from influencers, being overwhelmed with responsibilities, shame/ stigma, as well as anxiety that the child might die, caused delay in accessing health services. This stigma included classifying the children as dying soon, mothers of the children as irresponsible (uncaring) mothers and very poor people. Meanwhile, the only adopted copying strategy among caregivers when stigmatized was ignoring those who stigmatized them.

Hospitalization experience

The majority of the caregivers indicated that health providers supported them while at the hospital. Similarly, the majority of caregivers had a good relationship with other caregivers at the hospital. The challenges included failure to generate income as a result of loss of employment or businesses whilst at the hospital and the impact on the care of other children due to the caregiver's divided attention between the sick child and other household responsibilities.

Caring practices and recovery

The ideal place to provide care for the HIV-SAM child after discharge was at the mother's home and was followed by the grandmother's or sister's place. Caregivers often looked after the children by themselves. Care for the HIV children changed when they developed malnutrition as they needed more attention and variety of nutritious food. Caregivers experienced more problems when caring for the children with HIV-SAM compared to SAM only due to suppressed immune system, an increase in opportunistic infections, and increased hospital reviews. Lack of food and money to use when going for review, and refusal of children to take certain medication, and limited knowledge on locally available nutritious food contributed were the main barriers to recovery.

In the quantitative study a mixed situation was reported in terms of receiving support. Most respondents reported that they received support during the child's illness in the form of cash or non-cash items. Limited support in different areas was reported in the quantitative survey. Almost half of the respondents, 21 (42%) and 17 (34%) reported that they would 'sometimes' and 'most of the times' respectively have difficulty finding someone to go with them to the clinic if they were sick and needed someone to take you to the clinic. Similarly, fewer respondents (34%) reported they 'always' and 'most of the time' had someone to talk to when needed.

HCW experiences providing care to HIV-SAM children

Children with HIV-SAM compared to those with SAM only have many underlying infections which complicate the healing process further. Health workers also struggled to deal with the difficulty faced by mothers to adhere to review dates, as well as the unwillingness of family members to get tested for both HIV and TB.

Postnatal depression scale

Most respondents 24 (48.0%) and 7 (14%) were so unhappy that they 'sometimes' and 'most of the time' respectively had difficulty sleeping. More than half of the respondents 30 (60%) felt 'sad' or 'miserable' some of time, while 10 (20%) reported feeling 'sad' or 'miserable' most of the time. Further, another 30 (60%) reported being 'unhappy' and 'crying'. As result of the challenges they faced, 32 (64.0%) regularly thought of harming themselves.

Recommendations

The recommendations take into account the different individual, social/community, and health systems determinants underlying HIV-SAM.

- **Individual level**: Promote HIV-SAM awareness among the caregivers by increasing the provision of information to caregivers of children with HIV-SAM on types of nutritious food, especially local foods. It is also important to conduct life-skills training and provide economic empowerment to caregivers with children with HIV-SAM, including microcredit support and mentorship to enable them to generate

income to buy nutritious foods and also pay transport fees to health facilities for reviews. There is need to promote positive coping behaviours towards stigmatization, as well as develop support groups for caregivers with children with HIV-SAM.

- **Relationship level**: Provide life-skills training to influencers and family members focusing on the need to provide support to caregivers of children with HIV-SAM. Further facilitate peer discussions on prevention of malnutrition and promotion of access to health care among children with HIV-SAM.
- **Community level**: Provide sensitization to communities aimed at encouraging critical reflection on HIV-SAM stigmatization among community members, and the importance of referring children with HIV-SAM to health facilities. It is also important to form community HIV-SAM action groups, including strengthening of household or home-based care so that caregivers with children with HIV-SAM can meet to share ideas, encourage and support each other.
- **Societal level**: Strengthen the implementation of policies and programmes that provide a favourable environment for government to increase nutrition support, such as the provision of High Energy Protein Supplement (H.E.P.S) porridge and Ready to Use Therapeutic Food (RUTF) to affected households.
- **Health systems level:** Training of health workers on best ways of managing children with HIV-SAM. It is also important to sensitize health workers on the negative effects of health worker HIV-SAM driven stigmatization on health seeking behaviour among caregivers. Health workers should also be sensitized on how to manage self-stigmatization among caregivers and stigmatization from the community. Further, it is vital to enhance confidentiality within the health facilities by developing private spaces were children with HIV-SAM can be managed.

1.0 Introduction

Malnutrition is the condition that develops when the body does not get the right amount of the vitamins, minerals, and other nutrients it needs to maintain healthy tissues and organ function or fails to handle nutrients so as to maintain optimal tissue function. Severe acute malnutrition (SAM) is characterised by wasting (marasmus), oedema (as a result of kwashiorkor), or both (marasmic kwashiorkor), and occurs mostly in children (Bhan et al., 2003). It is estimated that globally 52 million children under-five years of age are wasted, 17 million are severely wasted, and 155 million are stunted. Around 45% of deaths among children under-five years of age, most of which occur in the sub-Saharan Africa, are linked to undernutrition (Adebayo, 2003; WHO, 2018). While Zambia has made genuine progress in reducing malnutrition and stunting since the launch of Zambia's Scaling Up Nutrition (SUN) movement in 2010, the country still has one of the highest rates of malnutrition and stunting in sub-Saharan Africa (USAID Zambia, 2021). The 2018 Zambia Demographic and Health Survey (ZDHS) reports that 35% of children under five years of age are stunted, 12% are underweight, 4% are severely malnourished or wasted this accounts for up to 52% all under-five deaths (CSO M, TDRC U and Macro International Inc, 2009; Charles Michelo, R.M., 2012; Zambia Statistics Agency, Ministry of Health Zambia, and ICF, 2019).

Furthermore, one-third of children hospitalised with severe acute malnutrition (SAM) in sub-Saharan Africa have HIV infection (HIV-SAM co-morbidity). Children with HIV-SAM have 3-fold higher mortality, higher morbidity, slower nutritional recovery and a greater risk of relapse compared to children with SAM alone (Fergusson and Tomkins, 2009), despite current interventions. Mortality following hospital discharge is a significant risk especially in the ensuing year (Bwakura-Dangarembizi et al., 2021). It is predominantly driven by infections compounded by poor nutritional convalescence. Moreover, children are discharged to homes characterised by poverty and multiple intersecting caregiver vulnerabilities. Addressing this complex multimorbidity requires a deeper understanding of the underlying biological and social pathways to inform new intervention approaches. Addressing biomedical factors in the child alone is insufficient to achieve convalescence without addressing the social determinants of this complex multimorbidity. This study sought to define the social and environmental determinants underlying HIV-SAM to understand the contexts in which child convalescence occurs. It was conducted in Lusaka with participants recruited from the University Teaching Hospital, and Chawama Level One Hospital.

1.1 Problem Statement

Malnutrition is a major burden for Zambia, rooted in multidimensional poverty with far-reaching consequences for human capital, economic productivity, maternal and child health, and overall national development. In addition, Zambia still has a high burden of HIV; 11.1% of women and men aged 15-49 years are infected with HIV. Up to one-third of children hospitalised with SAM in sub-Saharan Africa are HIV-positive. Malnutrition therefore remains one of the most frequent manifestations of advanced HIV and these two chronic conditions need to be managed concurrently. The clinical presentation of HIV-SAM is complicated by a greater severity of stunting and wasting, more acute and persistent diarrhoea, and increased clinical complications compared to SAM alone. Children with HIV-SAM have higher mortality than children with SAM alone. Further, children with HIV-SAM have higher excess risk of death despite Antiretroviral therapy (ART) than children with SAM alone. Overall, it is difficult to manage the conditions of children with concurrent HIV and SAM. Therefore, there is an urgent need to improve recovery in children with HIV-SAM after they leave hospital by tackling underlying medical and social causes of ill-health.

1.2 Justification

Children recovering from SAM have poor long-term outcomes, with high rates of relapse, readmission to hospital and major impact on their developmental progress. Many have developmental regression during an episode of SAM. If children have both SAM and HIV infection (HIV-SAM), the risk of dying is three times higher. Among survivors, neurodevelopmental growth and physical function are impaired, with long-term effects on learning and increased risk of future cardiovascular and metabolic disease as adults. 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. In turn, children with HIV-SAM are discharged to a home environment characterised by economic deprivation, entrenched poverty, food insecurity and hunger, and competing demands on scarce resources. Furthermore, there are multiple caregiver vulnerabilities including depression, low decision-making autonomy, lack of social support, gender-restricted family relations. Caregivers have to navigate diverse challenges that impede engagement with clinical care after discharge from hospital. Adherence to Ready to Use Therapeutic Food (RUTF) and ART may therefore be suboptimal due to multiple social barriers to convalescence. Caregivers are themselves frequently living with HIV and contending with

impaired physical and mental health as well as shame and stigma. Hence, multimorbidity in the mother-child pair needs to be considered together. Female caregivers often lack decision-making autonomy within their households because of gendered and generational social relations and are at risk from gender-based violence. Furthermore, caregivers often undertake seasonal and/or risky employment (e.g., sex work) to sustain themselves and their children. Therefore, addressing biomedical factors in the child alone is insufficient to achieve convalescence which requires a robust understanding of the social determinants of this complex multimorbidity.

1.3 Aims and Objectives

The overall aim of this rapid appraisal was to define the social and environmental determinants underlying HIV-SAM through in-depth qualitative research to understand the contexts in which child convalescence occurs and to identify psychosocial pathways for intervention.

Our objectives were to:

1. Detail the home environment and gain a deeper understanding of the social and environmental context in which child convalescence occurs to identify the most effective and sustainable methods for addressing the psychosocial determinants of multimorbidity.
2. Understand child and caregiver mobility through a mapping of primary care's caregiver networks.
3. Explore the specificities arising from co-morbidities – HIV-SAM - and 'ideal' spaces of/for intervention.
4. Identify the nature, incidence and types of health seeking consultations related to HIV-SAM and decision-making processes around taking a child to hospital.
5. Explore the role of stigma in shaping the care of children with HIV and SAM in the community and identify the role of health workers in creating and reinforcing shaming narratives and practices.

2.0 Methodology

2.1 Study Design and Approach

This rapid appraisal adopted a mixed methods research approach combining a quantitative survey with focus group discussions (FGDs), semi-structured in-depth interviews (IDIs), and field observations to gather data. The rapid appraisal technique is widely used as a cost-effective tool for providing an immediate assessment of local

conditions and for informing the design of interventions. FGDs and IDIs were guided by a set of semi-structured guides which focused on examining the social and environmental context in which child convalescence occurs, child and caregiver mobility, the specificities arising from co-morbidities – HIV-SAM, types of health seeking consultations related to HIV-SAM, as well as the role of stigma in shaping the care of children with HIV and SAM in the community among other key aspects.

2.2 Study Participants and Sampling

Study participants were recruited from the University Teaching Hospital and Chawama Level One Hospital. The primary sample for this study were caregivers of children with HIV-SAM, but also included caregivers of children with SAM only depending on the numbers of admissions at the study sites. Eligible participants were recruited sequentially during weekdays at the study sites. We interviewed caregivers of children with HIV-SAM or SAM to understand the challenges they faced once children left hospital, including their own mental health, social support and ability to access care.

For the quantitative survey, participants were recruited using non-probability purposive and convenience sampling methods. The sample size (N=50) was recruited for the survey from across study sites based on the inclusion criteria which has been highlighted in the next section.

Eighteen caregivers of children with HIV-SAM or SAM only took part in IDIs and 10 caregivers of children with HIV-SAM took part in an FGD. The caregivers selected for the FGDs were different from those who took part in the IDIs. This allowed us to gain different perspectives from the caregivers in the primary sample. Two further FGDs were held with secondary participants; key influencers and healthcare workers. Purposive and convenience sampling were used to select four to six key influencer groups. Healthcare workers were also purposively and conveniently selected from UTH and Chawama Level One Hospital. A total of seven FGDs were carried out in this study, each with 8-10 participants.

Overall, a total of 138 people participated in the study as shown in the Table 1 below:

Table 1: Interviews conducted

Type of interview	Total number
FGD with grandmothers	10
FGD with pastors	8
FGD with fathers	10

FGD with traditional healers	10
FGD with health workers at UTH	8
FGD with health workers at Chawama Level One Hospital	10
FGD with caregivers	8
In-depth interviews	24
Quantitative interviews	50

2.3 Inclusion and Exclusion Criteria of the Study Population

Caregivers of children with SAM who met the inclusion criteria and who were interested in the study were approached and further information about the study was provided using the study information sheet and consent form in Nyanja, Bemba or English depending on the caregiver's preference. The inclusion and exclusion criteria are listed outlined.

Inclusion criteria

1. Child aged 6-59 months
2. Hospitalised with severe acute malnutrition (weight-for-height Z-score <-3, mid-upper arm circumference <11.5cm, and/or nutritional oedema)
3. Hospitalised with severe acute malnutrition and tested HIV positive on admission or were admitted with an already known positive HIV status
4. Clinically stable and preparing for discharge
5. Caregiver willing to take part in the survey administered by the study team
6. Caregiver willing to take part in an IDI interview 4 to 6 weeks after discharge
7. Caregiver willing to take part in an FGD 4 to 6 weeks after discharge

Exclusion criteria

1. Caregivers with children who plan to be discharged to a home outside the greater Lusaka area
2. Caregivers of children who meet the inclusion criteria but are unwilling to take part in the study.

2.4 Data Collection Methods

The rapid appraisal was conducted using the following mixed methods approaches:

Baseline survey: Surveys were conducted by trained research nurses and will focus on questions relating to household structure (e.g., number and order of children), maternal health, and caregiving capabilities using a set of tools developed by our team, as well as spatiotemporal mapping of the caregivers' caring network.

Household observation and semi-structured interviews: Trained research nurses carried out home visits to observe the caring environment and conduct semi-structured interviews (each lasting 40-60 minutes) to better understand caregivers' experiences with caring for a child with HIV-SAM or SAM, to evaluate caregiver support, define networks of carers, understand the mobility of the carer and child, identify barriers to HIV and nutritional care, and assess stigma.

Focus Groups: Caregivers, healthcare workers and community members / key influencers were recruited to participate in focus group discussions.

- *Caregivers of children with both HIV and SAM:* This focus group concentrated on understanding causes of SAM, health seeking behaviours in relation to SAM and HIV-SAM as well as nutritional education. The interest will be in exploring the specificities arising from co-morbidities – HIV *and* SAM, and 'ideal' spaces of/for intervention. Anecdotal evidence suggests that health workers while being critical stakeholders contribute to creating stigmatising and shaming environments who some mothers with ill children seem to try and avoid. Therefore, this FGD explored from the caregivers' perspective, understandings of stigma and shame around caring for a child with HIV-SAM or SAM and the role of health workers in creating shaming narratives or practices, as well as how this might be redressed so as to promote early and safe health seeking behaviours.

- *Health workers:* This focus group concentrated on three interrelated questions: understanding the convalescence needs of children with HIV-SAM; experiences of providing healthcare to children with HIV-SAM; and perceptions of the home caring environment. This FGD also explored from the perspective of healthcare workers' understandings of stigma and shame around caring for a child with HIV-SAM or SAM, the role of health workers in creating shaming narratives or practices, as well as how this might be redressed so as to promote early and safe health seeking behaviours.

- *Key influencers:* These are people were identified by caregivers in IDIs and the FGD as being key influencers and pathways to health seeking, playing a pivotal role as the first point of advice for mothers with ill children. These included faith/traditional healers, female elders (grandmothers), significant others, friends or neighbours depending on which groups are most mentioned as having a significant influence

on care seeking practices. Six focus groups explore the nature, incidence and types of consultations specifically those related to HIV-SAM, connections or lack of with health providers including hospitals, and decision-making process in terms of advising caregivers to take a child to hospital.

2.5 Data Management and Storage

Personal information and all data collected including consent forms and completed survey questionnaires were kept confidential and managed in accordance with the requirements of the University of Zambia Biomedical Research Ethics Committee (UNZABrec) and National Health Research Authority. Paper records were stored in a secure, locked cupboard located at the School of Medicine, University of Zambia, in the office of the PI, and kept fully confidential, with access only by members of the study team. Electronic data was entered onto the study databases using password protection on secure research computers. Database data was linked to the paper records through the PID only (pseudo-anonymisation). No personal identifiers were included on the main study database. Data was identified on electronic databases only by PID. Databases were backed up regularly on secure hard drives. The qualitative interview transcripts were also kept in the locked custody of the PI. Paper forms will be destroyed after they have been computerized or are no longer required and after at least 7 years of storage. The study log linking PID with personal identifiers will therefore be destroyed at this stage.

2.6 Data Analysis

Quantitative data was checked for completion and entered into a database as set out below. Data entry and data cleaning was carried out simultaneously with data collection. Quantitative data was entered into the Statistical Package for the Social Sciences (SPSS) 23, an optimal software for the statistical analysis of data, to generate descriptive and inferential statistics.

All qualitative data collected through FGDs and IDIs, was transcribed verbatim from local languages (Nyanja or Bemba) to English. To ensure that no information is lost in translation, a sample of these transcriptions were subjected to reverse translation, that is, translated back into Nyanja or Bemba and rechecked for accuracy. The typed transcripts (in MS Word) were entered into NVivo 12 (qualitative data analysis software) for data analysis. NVivo 12 was used to assist coding and data analysis as well as to search for patterns. The transcripts were subjected to content analysis with the objective of determining the meanings and identifying themes and patterns in the data. Thematic

analysis was used to identify key categories and recurrent themes in alignment with the study objectives. The first and second authors independently analysed the interview transcripts and explored emerging themes and sub-themes relevant to the study objectives. Illustrative quotes were selected to reinforce the analysis. It is important to note that the analysis was an iterative process, with original data reassessed after each analysis to identify any missing information that may be critical for addressing the objectives of this study.

2.7 Ethical Considerations

The study protocol was submitted for ethical review and regulatory approvals by the University of Zambia Biomedical Research Ethics Committee (UNZABrec) and the National Health Research Authority (NHRA). This study was guided by ethical principles including, but not limited to, voluntary participation, informed consent, confidentiality, anonymity, ensuring safety, inclusiveness, respect for dignity and diversity, accountability, honesty and integrity.

Informed consent and voluntary participation

Caregivers of children with SAM aged between 6-59 months who met the inclusion criteria and who were interested in the study were approached and provided further information about the study using the study information sheet. A comprehensive participant's information sheet was given to participants to read or was clearly read to all potential participants informing them about all facets of the study including risks and benefits. The researchers discussed critical ethical issues including confidentiality, voluntary participation, and the right to withdraw from the study. Potential participants were informed about the objectives of the study and reasons for their selection to participate in the study. Potential participants were made aware of the voluntary nature of taking part in the study and that refusal will not warrant any penalty. Efforts were made to provide information to potential participants in formats and language that they understand (Nyanja, Bemba or English, depending on the caregiver's preference) to promote informed decision-making. Potential participants were allowed to ask any questions they had about the study and the research team responded to these. Once caregivers were fully informed and willing to participate in the study, they were asked to provide written informed consent or to provide a thumb print in the presence of an independent witness. Written consent was obtained from all participants before the study. Permission to record interviews on digital audio recorders was sought separately and participants were free to decline digital audio recording and still take part in the study.

Confidentiality

Strict confidentiality was upheld, and no names were used to identify participants. Personal information was kept confidential, and names and identifiable details are not revealed in the report in order to ensure participants' anonymity. Each participant was given a unique Participant ID (PID), which was used to identify the caregiver. During focus group discussions PIDs were used to identify participants and ensure anonymity of caregivers.

COVID-19 considerations

All study staff were provided with personal protective equipment including a face mask, hair cover, gown, and overshoes when working on the ward. Study participants over the age of two years were requested to use a face mask that covered their mouth and nose. If they did not have their own mask, one was given to them by the study team. Hand sanitisers were provided for use during interviews and focus groups. Physical distancing was maintained. During FGDs, in addition to the usual personal protective equipment, physical distancing and limitation of numbers in the venue as required by law was maintained.

Quality assurance processes

All staff who had contact with participants received training on the protection of human subjects prior to conducting any facility or community-based activities. The PI and Co-PI facilitated a workshop to orient research nurses on quantitative data collection methods and qualitative interviewing techniques for FGDs and IDIs, transcription and translation, data management/entry procedures, field procedures, data protection, and ethical issues. Regular meetings were also held with the research team to check progress against set milestones, agreed ethical, safety and quality procedures.

3.0 Results

3.1 Demographic Characteristics of the Participants

The targeted sample for the survey was 50 children in UTH and Chawama Level One Hospital. The participants were admitted to the hospitals between April and September 2022. The median age of the children was 19 months (IQR, 13-25), while the median age for caregivers was 26 years (IQR, 22-32). In terms of being admitted with SAM, the majority of those interviewed had been admitted for the first time 86% (43). A large number of children were HIV negative 80% (40), while 20% (10) were HIV positive, giving us a

prevalence of 10/50 (20%). Most of the children, 92.0% (46), were taken to the hospital by their biological mother. The majority of caregivers were married and had a secondary education (30 or 60%). In terms of source of income, 42% (21) of the households that participated in the study had no earnings (Table 2). About 34 (69.4%) of the respondents agreed to having lost the main source of income in the last two years in the household. Almost half (23 or 46.0%) of the respondents were worried about debt in the last two years while 27(54.0%) .

Table 2: Demographic characteristics of children and caregivers

Age (median)		
Children	19 months	IQR (13-25)
Caregiver	26 years	IQR (22-32)
Age (children)	***N***	***%***
6-12 months	9	18.0
13-24 months	28	56.0
25-59 months	13	26.0
First time admitted with SAM		
Yes	43	86.0
No	7	14.0
Child HIV status		
Positive	10	20.0
Negative	40	80.0
Location of father		
Died	2	4.0
Lives with the child and mother	27	54.0
Lives away but sees the child	10	20.0
Lives away no contact with child	5	20.0
Divorced	1	2.0
Moved away	2	4.0
Whereabouts unknown	3	6.0
Marital status of care giver		
Married	30	60.0
Separated or divorced	9	18.0
Single, never married	8	16.0
Widow	2	4.0
Other	1	2.0
Earn a living		
No earnings	21	42.0
Domestic worker	6	12.0
Skilled worker	2	4.0

Professional	1	2.0
Vendor	18	36.0
Other informal	2	4.0

Details of the household structure and living environments are provided in Table 3. As the table reveals, the majority 86% (43) of respondents lived alone in rented housing, although there was greater differentiation between respondents in terms of their mobility. Just over half of the respondents indicated that they lived in a temporary home (54%), while a smaller number (19 or 38%) indicated that they stayed in the same place. The average household size was five, with 20% of the households having three children under 18 years of age. Many of the respondents (20 or 43.5%) had access to flushable toilets, while 34.8% (16) had pit latrines with slabs. More than half (33 or 66.0%) of the households used piped water, while 14% (7) used borehole water; 66.0% of the respondents stated that they treated the water for drinking purposes.

Table 3: Household structure

No home; staying with friends	*N*	%
Yes	7	14.3
No	43	85.7
Description of caregiver home		
Usual home		
Temporary home	19	38.0
Home of other family members	27	54.0
Staying in servants'	3	6.0
quarter	1	1.0
Toilet or latrine of any type at the household		
Yes	46	92.0
No	4	8.0
Type of toilet/latrine		
Flush toilet	20	43.5
Blair Latrine (VIP)	3	6.5
Pit latrine with slab (non VIP)	16	34.8
Pit latrine with no slab	7	15.2
Main source of drinking water	33	66.0
Piped water	7	14.0
Borehole	2	4.0
Deep well and protected	6	12.0

Water kiosk	2	4.0
Neighbour		

3.2. Causes of malnutrition

3.2.1 Low-income setting

The majority of the participants indicated that most of the households with children with HIV/SAM had low incomes. As a result, most caregivers had difficulties buying food due to lack of money. Lack of finances also made it difficult for caregivers to find finances to pay transport fees to take children to health facilities for medical treatment or medical appointments.

> *"Most of the challenges you find that those mothers are not working so it is difficult to find money to buy the required food for the babies." (FGD, health workers, facility 2)*

> *"The issue is number one is there is no employment, two; women are too playful i.e., alcohol abuse has come about, three they are some parents with children negligence has also come about the cause of all this is hunger you'll find that the man just does piece work what will the children eat the huge issue is money problems, unemployment two; drug abuse among women I think that is the problem that is found." (03 FGD, traditional healers).*

3.2.2 Food availability and feeding practices

In the quantitative survey, more than half of the respondents (26 or 52%) reported that their household worried that they did not have enough food at least once or twice in the past four weeks. Further, 12 (24%) of the respondents indicated that a household member was not able to eat the kinds of foods preferred because of a lack of resources (once or twice in the past four weeks), while 28 (56%) reported they rarely experienced this situation. In addition, 13 (26%) of the respondents reported that a caregiver or household member would go an entire day and night without eating anything or not having enough food (once or twice in the past four weeks). However, a similar percentage reported that this was a rare occurrence.

Poor access to food was one of the major causes of malnutrition prior to hospitalization mentioned in all the qualitative interviews: as one caregiver reported, "*What causes a child to have malnutrition it's lack of food sometimes you find that maybe you feed your child once a day" (IDI, caregiver, 028).* Several issues relating to feeding challenges highlighted. These included inappropriate feeding practices such as irregular feeding intervals, lack of

balanced diets, inadequate food, as well as difficulties in feeding children due to them being selective on what to eat. Some children also refused to eat because of health-related challenges such as sores in the mouth or diarrhoea. Mother or caregiver related factors such as deciding to stop children from breast feeding at an early stage negatively affected nutrition status of the children. Overall, opportunistic infections significantly contributed to loss of appetite among children.

> *"Life is hard because feeding becomes difficulty and a child with HIV is picky with what to eat so you will find that sometimes she eats something nice and refuse to eat vegetables and it's the lack of having balanced meals and no food that she even got sick of malnutrition." (IDI, caregiver 08)*

> *"Like she rightly put it, if the immune system is actually compromised then it's likely that the child might suffer malnutrition, and I think the other, Number 3 also spoke about, lack of food in an event that the family does not […] that what leads to malnutrition. Like any child who is infected with HIV must be able to eat the correct food, the right food for that child's immune system to pick up, if the immune system has to pick then the child must be eating a balanced diet." (02 FGD, pastors)*

3.2.3 Competing household responsibilities

Health workers indicated that caregivers had challenges in attending to the health needs of the children due competing household responsibilities. It was reported that some mothers had informal jobs coupled with household chores, which made it difficult for them to focus on providing nutritious meals to the children. Additional competing responsibilities included caregivers having to look after more than one child with health challenges which affected the quality of care provided to children with HIV/SAM.

> *"Also time management because you find these mothers might have various jobs and they concentrate more on their jobs and not focusing on if their child has taken their meals, […] which again lead to malnutrition time management is also one of the problems these mothers face." (FGD, health workers, facility 2)*

The challenge of competing household responsibilities was more prominent among single mothers who were either widowed or divorced. As single parents, they struggled to access resources to buy nutritious food, prepare nutritious food for the children, and at the same time look after other children in the house.

3.2.4 Lack adequate nutritional information

Some caregivers lacked adequate information on the types of nutritious foods, including traditional foods, to feed their children. It was thus reported that caregivers needed additional health information for example on how to maintain good hygiene and provided a balanced diet to the children.

> *"We have seen that we have got SAM babies. For some, it's not that the don't have the money to buy the food what is needed but the knowledge on the certain types of food that they are supposed to prepare for the baby." (07 FGD, health workers, facility 2)*

3.3. Health seeking Behaviour

3.3.1 Mixed health seeking patterns

Respondents reported that most caregivers have mixed health seeking patterns when a child falls sick. While some people only accessed services offered by health facilities and others preferred going to traditional healers, some respondents simultaneously accessed both traditional and formal health services. This health seeking behaviour was influenced by advice from people they trust such as grandmothers, neighbours, friends, brothers, sisters, aunties, pastors, and traditional healers and health workers. Some caregivers self-prescribed medication.

> *"If I see the child is vomiting and has diarrhoea, the first thing I ask where the ORS (Oral rehydration solution) is. Because if the child has diarrhoea, then the child is losing water. The first we need to get ORS and give to child […] I tell the mother to take the child to the hospital, while she is going there, she'll be giving the child ORS. When she reaches the hospital, the doctor will take it from there to check on the child." (06 FGD, fathers)*

> *"After I saw that the child was sick, I went to my mother and then we took the child at the clinic." (IDI, caregiver 02)*

In some cases, it was only when traditional medicine did not work that they decided to seek medical attention from a health facility. One respondent, for example, shared how she switched from traditional medicine to health facility services upon noticing that the condition of the child was not improving despite administering traditional medicine:

> *"I used to get advice from my neighbours and all the time I could get help using traditional medicine and they will tell you to keep on waiting to see if there will be*

any change and days will pass and there is no any sign of change and that problem keeps on growing." (IDI, caregiver 09)

Other caregivers reported going for prayers or to faith healers before seeking hospital care. Faith healers were prioritised in order to assess whether a child was bewitched. Prayer was also used as means to prepare the caregivers emotionally before seeking health services, or as a way of strengthening or supporting caregivers when they at the health facilities:

"We take the child for prayers so we know if the child has not been bewitched." (01 FGD, caregivers).

"I have got contacts for the men of God so before I go to the hospital, I usually contact them because they also encourage us that before you take the child to the hospital or when you are not feeling well you need to go for prayers to them" (IDI, caregiver, 022).

3.3.2 Reason for seeking formal healthcare

Having tried alternative healing processes and failed, caregivers opted to access health services from formal health facilities. Further, advice from friends, family, health workers, community leaders and church members who had some positive experience with the health facilities encouraged caregivers to seek health services. Health systems factors, such as proximity of the health facilities, played a significant role in encouraging caregivers to go to the hospital. It was also indicated that some caregivers went to the hospital due to fear of their child dying.

"Usually when they are coming to the hospital what is in their mind is that, 'if I don't take the child to the hospital the child is going to die,' and that is what also prompts them to coming to the hospital… in fact, they would come to the hospital at a point when the condition has really advanced" (FGD, health workers, health facility 2).

Most of the caregivers indicated that their families had an influence on their decision to go to the hospital to seek medical attention for their sick children. Families provided advice and encouragement to caregivers to adhere to the medical doctor's instructions.

"They [family] were okay with it in order for the child to get well, so they told me to listen to what the doctor said and that I would be discharged when the child is okay." (IDI, caregiver, 001)

"My mother encouraged me to go to the hospital because the child was not looking healthy but at the time my father was not around." (IDI, caregiver, 011)

Some families, however, did not render any assistance nor did they go and visit the caregivers when caregivers were admitted in the hospital:

"*So, for the family members, most of the times, when you tell them about your problems there is really nothing that they do." (IDI, caregiver, 022)*

3.3.3 Advice during hospitalization

During hospitalization caregivers were advised on feeding practices such as the number of times to feed the child, and the types of foods to prepare especially locally available nutritious foods such as groundnuts and soya beans. The focus at the health facility was sensitizing caregivers on the importance of providing nutritious food to their children.

"Advise them on the importance of giving them locally available foods and not just these foods that they normally, they give just because they are in hurry something like that. Advise on giving locally available foods that contain a lot of proteins so that the baby can be okay and out of that state of SAM." (07 FGD, health workers, health facility 1)

"I was told to be giving the child a lot of fruits, porridge mixed with peanuts or with soya but he refuses porridge even from way back before he was admitted in the hospital. So, I would cook rice mixed with peanut or add milk or sour or if there is beans because I was told I can also prepare it for him and also potatoes" (IDI, caregiver, 025).

Another important component during hospitalisation was providing education on the importance of good hygiene while caring for children which helped to reduce the occurrence of opportunistic infections such as diarrhoea. Additionally, caregivers were sensitised on the importance of administering drugs to their child as per the schedule or guidance from health workers.

"They said that in the morning I am supposed to give ARVs then around 19 hours I am supposed to give TB then around 12 hours I need to give septilin." (IDI, caregiver, 011)

Respondents also reported that health workers provided caregivers with detailed lists that specified the kinds and frequency of food needed to support the healing and muscle

building process. This included a breakdown of the different types or sources of vitamins that were needed for children to regain or improve their health status, as well as specific foods such as *Kapenta* (small fish), beans and other carbohydrates.

> *"Yes, mostly we know to say these children mostly we give them a shorter timetable, like they should give at least five meals a day and also we break it down looking at groups of things that will help them to build back the muscle, maybe to help them heal and also how they can improve on the sources of feeds were they are getting them." (01, FGD, health workers, health facility 2)*

> *"Okay, on the timetable for feeding the child they indicated that at 6:00hrs we can give any food that is available and then around 8:00hrs I can prepare porridge, around 10:00hrs I can give her some sour ad then at 12:00hrs we can eat nshima together, at 14:00hrs I can feed her peanut and then at 16:00 can prepare some potatoes if we have and then supper at 18:00hrs." (IDI, caregiver, 001)*

3.3.4 Advice seeking after discharge

Respondents indicated that after being discharged, caregivers continued to receive advice from health workers. The advice focused on provision of nutritious food and a balanced diet. Mothers were also provided with information on the types of foods which should be avoided, such as *Jiggies,* a South African brand of corn-based snack distributed across the region, because they are not age appropriate and impact on the child's appetite. Further, mothers were also educated on the importance of maintaining good hygiene and adhering to the administration of drugs. The importance of child spacing, including the use of family planning and going for scheduled health reviews, were emphasized. Furthermore, the caregivers were encouraged to start businesses that would help with income generation and thus access to nutritious food for children.

> *"We even encourage them […] that the child is one year and the mother is pregnant, so normally we encourage them to go for family planning, we encourage them to be spacing because you find that in somebody is 18 years she has three children and most of them who are like that they are being kept, and we encourage them to do some business than just waiting for the parents to provide or the husband because most of them these husbands are the ones just who go for just piece works" (01 FGD, health workers, health facility 1).*

> *"Yes, they encouraged me to keep on going for review so that they can go and check from that side" (IDI, Caregiver, 003).*

Others reported receiving advice from the religious leaders and community members upon being discharged from the health facility. This advice, like that given by health workers, also focused on the sources or types of nutritious food that can be provided to children.

> *"The women from church advise me to […] [in morning] cook porridge mixed with groundnuts for the child before doing any work so that […] the child does not get sick again, and then when it's around 10hrs need to cook another meal like maybe porridge mixed with pounded kapenta and then when its lunch time […] and 15:00hrs the child needs to eat maybe you prepare porridge or if there is rice you can prepare, at 18:00hrs you again give the child any food that you are able to manage maybe it's tea and then at night around maybe 20:00hrs if you manage to cook you can prepare some porridge for the child to eat, these are the advices they give me." (IDI, caregiver, 008)*

3.3.5 Adherence to advice

While some caregivers followed the advice that they are given, others did not. Some of the factors that shaped adherence to advice included caregivers being knowledgeable and appreciative of the issues which trigger malnutrition and how malnutrition can be avoided. Further, the respect attached to the person who advised them, especially elderly people and religious leaders, ensured adherence to advise.

> *"I manage to follow everything starting from the time the child started taking medication until now because I was told that for some they are resistant at first and do vomit so you need to be patient once you start giving, but as for me starting from the time I started giving the child she was hesitant but this time around no she does not refuse to take the medicine." (IDI, caregiver, 003)*

> *"The same people from church who used to visit me, they are the ones who encouraged me to continue taking care of the child by doing what I was told at the hospital and not ignore what I was told at the hospital and I need to follow them so that the child completely heals" (IDI, caregiver, 008).*

3.4 Factors Causing Delayed Health Seeking

3.4.1 Economic factors

Economic factors such as lack of money for transport costs to the health facility meant some caregivers missed appointments. Respondents further indicated they delayed taking

sick children to health facilities because they feared that they would be admitted for a long period thereby disrupting the caregivers' businesses and household income.

> *"Okay, so especially if they were admitted to the ward, malnutrition ward, they know that they take long to be discharged for the child to be good, so they know that if we go there we will be kept for like 1 month or two, so they are going to be delaying going to the clinic." (FGD, health workers)*

> *"When it comes to the reviews, it's another problem to find money for transport to go to UTH." (IDI, caregiver, 011)*

Participants indicated that caregivers delayed to seek health care because of being overwhelmed with domestic work and businesses.

> *"The business that she is running you find that when the comes to take the child to the hospital she will decide to run business errands while running those errands the child's condition keeps getting worse." (05 FGD, caregivers)*

3.4.2 Lack of knowledge

Lack of knowledge on the causes and effects of malnutrition among caregivers contributed to delays in seeking care. Some caregivers opted to self-prescribe medication such as Panadol and Piriton instead of taking their children to a health facility.

> *"I think the lack of knowledge [...] if the child is vomiting but they just give them ORS, if their temperature is high they give them Panadol, the child fits they just say, 'I have given him Panadol', they like Panadol and Piriton." (FGD, health workers, health facility 2)*

3.4.3 Personal anxiety

Anxiety associated with accessing services from the health facility affected timely access to health services with some caregivers delaying seeking medical attention for fear of the child dying in hospital. Such fear was triggered by information from their friends who might have seen or experienced death of the child at the health facility.

> *"I just hear that children die, when you go with a child you don't come back with them, so that's why I refused." (IDI, caregiver, 015)*

> *"Sometimes it's the fear we have has caregivers that makes not to take child early to clinic. For example, sometimes you find that this person is about to take child and*

the friend discourages, so she has a fear and won't take the child to clinic." (05 FGD, caregivers)

3.4.4 Community level factors

Many community level factors affected access to services. These factors include advice from the community, religious issues and also social stigmatisation from community members. It was reported that caregivers delayed going to health facilities because they were socialized to seek advice from their families and friends. This advice could result in delays whereby caregivers were instructed to go to faith healers and/or pray. Having done so, some caregivers were told that their child had healed and did not require medical attention. Other caregivers were advised to consult traditional healers or and self-prescribe medication.

"We have said we advise such kind to go to the hospital, but they are some pastors who actually after praying for the person or the child or any person who is HIV positive who they will tell that person to say it is done don't take drugs and there is no need of even going to the hospital." (02 FGD, pastors)

"Some grandmothers may recommend for the child to be taken to the clinic while others will recommend to go to the traditional healers." (04 FGD, grandmothers)

The role of religious factors in delaying access to health care was emphasised in many interviews. Respondents indicated that some caregivers took their children for prayers before deciding to go to the hospital especially when they suspected the disease was a result of witchcraft.

"Like these days we are living in where I live a lot of women like to run to prayers, a lot that were they run whenever they see the child is not looking well they run to pastors to pray for them" (FGD, traditional healers).

3.4.5 Stigmatization

Stigma from both community members and health care workers resulted in delays in seeking healthcare. At the health facility level, health workers reinforced stigma through negative comments that they made whenever caregivers visited the health facilities including blaming the parents for the condition of the children. Other health workers failed to reassure mothers that their children would get better if they received medication and better nutritional support.

"…so, whilst the mother is ahh… within the community there is more of the negativisms which comes from people within the community. So, let's say a child is on ARTs who is HIV positive, we discharge them today, definitely that mother is going to be stigmatized or discriminated." (FGD, health workers, health facility 2)

At the community level, verbal stigma included community members classifying children with HIV-SAM as 'finished' and likely to die soon, while mothers of children with HIV-SAM were labelled as bad or irresponsible mothers.

"Mostly they would backbite with words, like 'see how the child is finished' and also 'those that haven't discovered' or maybe 'they are not positive' they will also say things like that." (FGD, health workers, health facility 2)

Caregivers reported that they were looked down upon as people who neglect their children. Caregivers reported that they were sometimes laughed at, gossiped about them, and sidelined by other people.

"They look at that person as someone who doesn't care about the child and also that they do not have food at home." (IDI, caregiver, 011)

"People say different things, there are some people who laugh at children with malnutrition they say with that their parents go out to play, they do not take care of their children and also they are people who laugh at people with HIV." (IDI, caregiver, 028)

Further classification of caregivers with children with malnutrition as poor also contributed to social stigmatization. It was reported that association of malnutrition with lack of money made it difficult for the caregivers to disclose the condition or illness of the child to others resulting in delays in seeking health care.

"The first thing those people… they don't know the status of the child, what they see is poverty, thinking the mother or that family have no enough money to give the child. So, they pass the comments of saying they are poor. So, that's why you find that it is even difficult for them to mention that they are in the malnutrition ward." (FGD, health workers, health facility)

Caregivers reported that they felt bad whenever they encountered stigma. The commonly adopted coping strategy among caregivers when stigmatized was ignoring those who stigmatized them:

"When you've heard the bad words, we don't talk back because if you tell you start an argument, so when you hear bad words avoid them, act like you have not heard what they have said. So, caregiver after hear those words they want to talk and end up starting an argument." (05, FGD, caregivers)

"It's just to ignore those people because they don't know what they are talking about." (IDI, caregiver, 008)

3.5 Role of influencers in shaping access to care

Most of the influencers such as religious and community-based leaders, community health workers were located in the communities or houses where the caregivers lived. In a few cases, some influencers were based in communities that were distanced from the caregivers but would visit the communities of the caregivers.

"Okay we can say sorry it depends on where the man of God is. Where they want to seek want to seek help form maybe it can be a 10min walk, others will travel sometimes two three days." (02, FGD, pastors)

3.5.1 Influencer connection with facilities

Influencers had different connections with the health facilities. Some influencers, such as health workers, have a formal connection with health facilities. On the other hand, community health workers and a few pastors often have a semi-formal or informal relationship with the health facilities. Traditional healers, grandparents, fathers, as well as some community and religious leaders, may not be connected with health facilities.

"What has happen is that health facilities, clinics, hospitals what they have done is they target the pastors so that they can get them to join them in certain areas like psychosocial counselling and [...] the Zambian Government came up with a system of reaching churches. And you discover that health workers will go to a church, organise with the church, then have an HIV talk with the church and also the use of condoms, which most pastors actually have condemned, of which is one way of family planning. All that, and so they've tried by all means to do that and am one of those that was reached. I did psychosocial counselling and I am attached to the hospital and so they've given me information." (02, FGD, pastors).

Some influencers, such as pastors or religious leaders, indicated that they engaged health providers during health talks in the churches. Some churches have established health committees to facilitate discussions on health matters in the churches.

"Health worker yes because as our church, my church where am coming from, we are very much connected to hospital. So to say, there are times when a situation come which needs the community attention, they do come and says can we work together." (02, FGD, pastors)

3.5.2 Referral by influencer

Some of the influencer groups referred caregivers who consult them to the health facilities for conditions such as diarrhoea, vomiting, high fever, persistence coughing, dehydration and weakness, epilepsy, and HIV. Traditional healers and pastors referred the caregivers when the child was not responding to treatment that they provided to the child or when they simply could not handle the condition. Pastors reported that they referred children because they understood that it was God who introduced medicines by giving wisdom to people to develop medicines.

"What motivates me, is that number one I know that being a spiritual leader I do go to seek for health from the health facility and the other thing is I know to say that it is God that has introduced you know medicine, it's God who gives them the wisdom so those two they motivate me to referrer people to go the health facility." (02, FGD, pastors)

In contrast, traditional leaders often referred to health facilities conditions which cannot be treated by traditional medicines such Asthma. Sometimes, they also referred cases to health facilities because children appeared dehydrated and needed medical equipment to diagnose the health challenge.

"The diseases that I usually referrer to the clinic like the child looks weak, so that child don't need herbs but needs a drip form the clinic. So, whenever I see the child looks weak I just say to them take the child to the clinic. Then also if a child has Asthma those children, even though you give them medicine, it won't work. They just need an injection to ease the cough. So look at the child and you tell them to take the child to the hospital." (03, FGD, traditional healers).

Grandmothers often advised medical attention on observing that their child was not getting better despite being self-prescribed medication. Other grandmothers preferred health facilities as they had the equipment to test or diagnose the health problem of the child was suffering from.

"*When the child has diarrhoea and also when each child is vomiting and even having high temperature because we can try to give the child Panadol, but you realize that there is no change. Then we advise, in that case, to take the child to the clinic especially on diarrhoea and vomiting." (04, FGD, grandmothers)*

"The reason why we quickly advise people to go to the hospital, it's because they have machines to do tests on everything and for us, here at home, we do not have those machines." (04, FGD, grandmothers)

3.6 Hospitalization experience

3.6.1 Experience with healthcare provider

The majority of caregivers indicated that health providers welcomed them, treated them well and reassured them that their child would recover. Health workers also encouraged caregivers when their child was not feeling well, educating them on how to deal with challenging HIV and malnutrition conditions. Caregivers reported that health workers would also regularly check on how they were getting on at the health facility.

"When we reached, they welcomed us and asked where we stay while caring for the child. They would come and visit to check on how the child was doing. I didn't have any problem at the hospital like maybe being shouted at, no, they attended to us well." (IDI, caregiver, 008)

However, some caregivers complained that some health workers were rude and would shout at them for not taking care of their children. Health workers stated that children developed malnutrition because of lack attention and care from their caregivers. Caregivers also complained that nurses did not respond to the caregivers when they tried to seek clarifications. One respondent reported that a nurse gave her child wrong medication.

"There was a time when I tried to ask the nurse before giving the medicine to the other child, but the nurse was very rude and didn't want to answer me. So, I tried to talk to the nurse but, in the end, the nurse gave the wrong medicine to the child because, according to the nurse, every child who there had malnutrition and yet that child had a different problem. So, the nurse ended up giving a wrong medicine to the child." (IDI, caregiver, 024)

3.6.2 Experience with other caregivers

The majority of the caregivers indicated that they had a good relationship with other caregivers whose children were also admitted in the hospital. Caregivers would encourage each other to concentrate on taking care of children and to follow the instructions that were given to them by health workers. In case of death of the child, the caregivers would pray together.

> *"They were also struggling in taking care of the children, but we used to encourage each other to be on the same path so that we focus on the children's problem. We ensure that we give them medicines which they have been given and they will get well and we should not think about the issues at home but let us think about the children that is why we are here at the hospital because we will still find our homes." (IDI, caregiver, 003)*

> *"For both the women I found in the hospital and those that found me, we become united and also give advice to one another to say we need to follow the rules given by the doctor on how to care for our children so that they can get healed. That's how we used to get along with the fellow women, we were united." (IDI, caregiver, 008)*

3.6.3 Challenges with hospitalization

The challenges that caregivers experienced with hospitalization included failure to generate income as a result of loss of employment or businesses whilst at the hospital. Lost income resulted in caregivers failing to pay rent, meet the basic needs of their family, and other children not attending school. As a result of having to be away from their homes and families, caregivers indicated that their other children were not taken care of due to divided attention between the sick child and other household responsibilities.

> *"Before I went to the hospital there was a place where I was working, but I got discharged from the hospital [and] I got fired and was told that am not serious with work and should find somewhere else to work. I tried to explain to them that I was sick, they didn't listen until now am just at home, my children have even stopped going to school. Right now, the child's teacher came to see and told that the balance that accumulated while in hospital and this current balance you'll give when you have just let the child continue going to school." (05, FGD, caregivers)*

3.7 Caregiver support

3.7.1 Support network

Caregivers seek childcare assistance form their mothers, sisters, and other family members. Some caregivers received help from churches and trusted neighbours and friends who had similar experiences of caring for a child with malnutrition.

> *"Like for me, if my mother is going out, I can take my child to my sister's place if I can't leave my child with the six years one." (05, FGD, caregivers)*

About half of the respondents, 51% (28), indicated that the main caregiver was the mother with the other half (25 respondents) indicating they had left the child in the care of another caregiver. A total of 56% (28) of the respondents left their children in the care of others for 24 hours, while 30% (15) of the respondents left the child for days. Most of the respondents, 74% (37), stated that they relied on the same care network during the child's illness and recovery from SAM. Almost half, 44.9% (22), said that they were confident that other people who looked after their child would manage to look after a child with HIV who was recovering from SAM. Caregivers were often free to seek assistance from those whom they had disclosed the health condition of the child to.

> *"Because the child is usually found with the grandma I just pick up in the night, the child's most of the time with the grandma even when the child cries grandma manages to stop the child from crying." (05, FGD, caregivers)*

Respondents also indicated that caregivers sought help from health workers especially if they lived in the same community as the caregivers: "*Sometimes in the community we get help from health workers because we live with health workers, so we get help from health workers" (01, FGD, health workers, health facility 1).*

3.7.2 Support received

More than half of the respondents reported that there is often someone who gives them information to help them understand the HIV-SAM situation. Support received by caregivers included emotional support, prayers, food, advice, financial support, and encouragement. This support was provided by family members, church groups, community members and health workers. Fathers reported escorting the caregivers to the health facilities.

> *"We do encourage them, escort them and also we at least help with financial support." (06, FGD, fathers)*

"People from the church really helped me they provided cooking oil, meal mealie at my home when I was at the hospital and they also sent me money because they said that instead of them coming to visit me it was better for them to send the money so that it can help me" (IDI, caregiver, 09).

As shown in the Table 4 below, most respondents reported that they received support during their child's illness in form of cash or non-cash (groceries, clothes or other goods).

Table 4: Support received

Received support during child's illness in form of cash or non-cash (groceries, clothes or other goods)	*N*	%
Yes	42	84.0
No	8	16.0
Frequency received this kind of support		
Weekly	37	77.1
Monthly	4	8.3
Once every six months	1	2.1
Once a year	2	4.2
Never received	4	8.3
Kind of support received		
Support (food or other goods)	30	62.4
Money	15	31.3
Never received	5	6.3
Lost main source of income in the last two years in the household		
Yes	34	69.4
No	15	30.6
Worries of debt in last two years in the household		
Yes	23	46.0
No	27	54.0

Meanwhile, survey respondents also reported instances of limited or inadequate support (Table 5). Almost half of the respondents, 42% (21), reported that they sometimes have difficulties finding someone to go with them to the clinic if they were sick, while 34% (17) reported that they have challenges finding someone most of the times. Further, 40% (20)

of the respondents reported that 'most of the times' they felt excluded by their close friends. Meanwhile, only about 12% reported that they would always or most of the times count on someone's help when they needed money in an emergency, such as the need to take a sick person to the hospital. Similarly, fewer respondents (34%) reported they was always and most of the times someone one can count on to listen to when they needed to talk to.

Table 5: Inadequate support

Needed money in an emergency, such as the need to take a sick person to the hospital, how often could you count on someone's help	N	%
Always/All of the time	1	2.0
Most of the time	5	10.2
Sometimes	23	46.9
A little of the time	13	26.9
Never/None of the time	6	12.2
Often is there someone you can count on to listen to you when you need to talk		
Always/All of the time	7	14.0
Most of the time	10	20.0
Sometimes	15	30.0
A little of the time	10	20.0
Never/None of the time	8	16.0

3.8 Recovery at home

3.8.1 Caregiver experiences

Caregivers had different experiences while taking care of the sick child at home after discharge. Many reported struggling with providing care after hospital discharge. Some of the challenges faced were similar to those experienced in the hospital included loss of business and work opportunities, the burden of household chores, as well as challenges with administering of medication to the child.

> *"There are no activities anymore. At least I used to go and sell Chitenge materials in other villages, but the business is no more and there are no movements all. I do is stay home and look after the child so that I see how she will be. After the child gets*

well, that's when I will start other movements because I cannot be moving around when the child is not okay." (IDI, caregiver, 008)

"The challenge am facing is when drinking medicine, it's a struggle unless maybe you handle him well until he drinks it." (IDI, caregiver, 025)

3.8.2 Food availability prior to hospitalization

As discussed above, caregivers indicated that prior to hospitalization, they experienced many challenges, some of which contributed to high malnutrition status. These issues included shortage of food and financial resources and was recognised by the community influencers.

"Majority of the people are not working they don't have jobs, then you look at the people running the business when you ask them how much have you made today the usually give the answer that they have made nothing, look at the time spent from morning till evening the person as sold nothing as a result money is not there so even the child at home and the parents they won't be managing to provide proper food at home to eat." (03, FGD, traditional healers)

3.8.3 Barriers to recovery

Barriers to recovery were similar to the causes to malnutrition. Lack of food and money to use when going for review, and refusal of children to take certain medication, limited knowledge on locally available nutritious food all contributed to slowing down the recovery rate among children with malnutrition.

"What gives me a lot of thoughts is the lack of the necessary food that I need to provide for my child because I always think that the fact that I am unable to provide balanced diet food for my child then my child might get sick again." (IDI, caregiver, 009)

"Yes, his difficulty to give especially the one for TB I don't know if it's because of the scent it has, but the one for HIV there is no problem when taking it." (IDI, caregiver, 009)

3.9 Caring practices

3.9.1 Ideal place of care and care giver

Respondents indicated that the ideal place to provide care for the HIV-SAM child after discharge was at the mother's place and followed by maternal aunt's place. Similarly, the ideal caregivers were mothers and followed by grandmothers or sister. These individuals

or places were preferred because they tend to be associated with care, affection, and better understanding of the needs of the child.

> *"Yes, whether in the village or in town, the child should be with the mother because mothers are able to sacrifice even the last money that they have to provide food for the child just to make sure that the child eats." (IDI, caregiver, 009)*

> *"In my opinion, the mother's place is the best place because at least the mother has been equipped with the knowledge. And, I think the care, most the times, some of them, they change, when you give them the knowledge, most of them they change. It just a few, so it's better at the mother's place, you even assess after that, 'okay, is she going to continue with the care or we need to reinforce some other things?'." (FGD, health workers-health facility 1)*

3.9.2 Caring for child with HIV-SAM

In terms of care for children with HIV and malnutrition, caregivers reported that they often looked after children themselves. Caregivers often took up the responsibility of feeding their child as some children did not accept being with another person except the mother. Further, mothers preferred to feed the children due to appetite challenges.

> *"For my child with HIV, I am always close by not whereby I leave her with friends crying, no. Am often closer to the child and make her laugh so that she doesn't feel bad." (IDI, caregiver, 008)*

However, it was reported that care for the HIV children change when they develop malnutrition. Some of the changes included the need for more attention and variety of nutritious food in terms of feeding. These changes were largely due to loss of appetite among children, occurrence of opportunistic infections and need for special meals. Feeding was difficult due to sores in the mouth of a child.

> *"That am not supposed to keep the child hungry for a long time or leaving the child crying because the child will be feeling bad like been secluded, so you need to be close and give all that is needed so that the child feels loved and also encouraged" (IDI, caregiver, 008).*

Caregivers experienced more problems when caring for the children with HIV-SAM compared to SAM only. These challenges that included suppressed immune system due to opportunistic infections, difficulty in recovering, increased hospital reviews and the challenge of administering medications and inadequate availability of food.

"In terms of nutrition we know that those that are positive there is an addition of a high cell breakdown compared to those that are just SAM with underlining causes. So it becomes more difficult for those with a condition to recover compared to those that just have the SAM itself." (01, FGD, health workers, health facility 1)

3.9.3 HCW experiences providing care to HIV-SAM children

Health workers reported that children with HIV-SAM, compared to those with SAM only, have many more underlying infections. These conditions, which include infections like diarrhoea, fever, and vomiting and high cell breakdown, makes it difficult for health workers to provide care and manage children with HIV-SAM in the hospital as compared to those with SAM only.

"Because of too much underlying causes like diarrhoea, fever, vomiting, yes so others it becomes difficult for them to gain their weight fast." (01, FGD, health workers, health facility 1)

Health workers reported that the high cell breakdown, coupled with suppressed immune system, makes it difficult for those with HIV and SAM to recover quickly compared to those that have SAM only. A child that has HIV-related immunity suppression tends to be predisposed to other conditions, which complicates the healing process further.

"In terms of nutrition we know that those that are positive there is an addition of a high cell breakdown compared to those that are just SAM with underlining causes. So, it becomes more difficult for those with a condition to recover compared to those that just have the SAM itself." (01, FGD, health workers, health facility 1)

In addition to child related challenges, health workers also struggled to deal with mothers or caregiver's problems. This related to the difficulties they had in adhering to reviewing dates at the health facility which affected monitoring of the healing process by the health workers.

"And I think also the major problem is how they always fail to adhere to the review dates if they fail to adhere to the review dates as a healthcare team it's difficult to know if there is a continuation in care even after discharge so you find it a challenge because we will not know whether the child continued improving or deteriorating." (FGD, health workers, health facility 2)

Additional challenges that HCWs faced with regards to advising primary caregivers in healthcare setting was the unwillingness of family members to get tested for both HIV

and TB: "you *cannot force them, you can tell them, but they cannot come to the hospital to test so that you know who has TB. So, we'll find that, that baby may catch again TB because of the overcrowded homes" (01, FGD, health workers, health facility 1).*

4.0. Conclusion

Determinants of malnutrition, experiences of HIV-SAM including access to health care, were centred on individual, social/community, and health systems issues: individual factors included low education levels, limited nutritional knowledge among mothers or caregivers, single parenting, and inappropriate feeding practices (e.g., irregular feeding intervals). Economic factors, such as low income, as well as social factors such as negative advice from influencers and social stigmatization, contributed to, or worsened, health conditions for children with HIV-SAM, and affected access to health care.

Most caregivers had mixed health seeking patterns, which included faith healing, use of traditional medicine, self-medication, and accessing health services from the health facilities. The caregivers sought advice from people they trusted such as grandmothers, neighbours, friends, brothers, sisters, aunties, pastors, and traditional healers and health workers.

Individual factors such as ones' level of knowledge of HIV-SAM and past experience of the diseases, health systems factors such as proximity of the health facilities, as well as social factors such as positive advice from friends, family, health workers, community leaders and church members who had some good experience with the health facilities, encouraged caregivers to seek health services.

We believe children need a more holistic bundle of care at home that addresses the multifaceted underlying biomedical and social causes of SAM. Novel interventions during the post-discharge window could enhance convalescence to help children survive and thrive.

Key Recommendations

The recommendations take into account the different individual, social/ community, and health systems determinants underlying HIV-SAM.

- **Individual level**: Promote HIV-SAM awareness among the caregivers by increasing the provision of information to caregivers of children with HIV-SAM on types of

nutritious food, especially local foods. It is also important to conduct life-skills training and provide economic empowerment to caregivers with children with HIV-SAM, including microcredit support and mentorship to enable them generate income to buy nutritious foods and also pay transport fees to health facilities for reviews. There is need to promote positive copying behaviours towards stigmatization, as well as develop support groups for caregivers with children with HIV-SAM.

- **Relationship level**: Provide life-skills training to influencers and family members focusing on the need to provide support to caregivers of children with HIV-SAM. Further facilitate, peer discussions on prevention of malnutrition and promotion of access to health care among children with HIV-SAM.
- **Community level**: Provide sensitization to communities aimed at encouraging critical reflection on HIV-SAM stigmatization among community members, and the importance of referring children with HIV-SAM to health facilities. It is also important to form community HIV-SAM action groups, including strengthening of household or home based care so that caregivers with children with HIV-SAM can meet to share ideas, encourage and support each other.
- **Societal level**: Strengthen the implementation of policies and programmes that provide a favourable environment for the Government to increase nutrition support such as the provision of High Energy Protein Supplement (H.E.P.S) porridge and Ready to Use Therapeutic Food (RUTF) to affected households.
- **Health systems level:** Training of health workers on best ways of managing children with HIV-SAM. It is also important to sensitize health workers on the negative effects of health worker HIV-SAM driven stigmatization on health seeking behaviour among caregivers. Health workers should also be sensitized on how to manage self-stigmatization among caregivers and stigmatization from the community. Further, it is vital to enhance confidentiality within the health facilities by developing private spaces were children with HIV-SAM can be managed.

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Appendix

List of Transcripts HIV-SAM

S/N	TYPE OF INTERVIEW	CATEGARY OF PARTICIPANTS
1	FGD	HEALTH WORKERS-UTH
2	FGD	HEALTH WORKERS-CHAWAMA
3	FGD	SOCIAL INFLUENCERS-PASTORS
4	FGD	SOCIAL INFLUNCERS-TRADITIONAL HEALERS
5	FGD	GRANDMOTHERS
6	FGD	CAREGIVERS
7	FGD	FATHERS

S/N	TYPE OF INTERVIEW	CATEGARY OF PARTICIPANTS
8	IDI	CAREGIVER, PID HS 001
9	IDI	CAREGIVER, PID HS 002
10	IDI	CAREGIVER, PID HS 003
11	IDI	CAREGIVER, PID HS 008
12	IDI	CAREGIVER, PID HS 009
13	IDI	CAREGIVER, PID HS 010
14	IDI	CAREGIVER, PID HS 011
15	IDI	CAREGIVER, PID HS 015
16	IDI	CAREGIVER, PID HS 019
17	IDI	CAREGIVER, PID HS 022
18	IDI	CAREGIVER, PID HS 024
19	IDI	CAREGIVER, PID HS 025
20	IDI	CAREGIVER, PID HS 028
21	IDI	CAREGIVER, PID HS 029
22	IDI	CAREGIVER, PID HS 030
23	IDI	CAREGIVER, PID HS 031
24	IDI	CAREGIVER, PID HS 032
25	IDI	CAREGIVER, PID HS 037