

INVESTIGATING PERINATAL DEPRESSION,  
BREASTFEEDING, AND INFANT NUTRITIONAL  
STATUS AMONG SOUTH SUDANESE REFUGEES IN  
UGANDA: A MIXED METHODS STUDY

By

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Abstract:

Mothers in refugee settlements face challenges, including an increased risk of developing perinatal depression as well as complex barriers to breastfeeding. Issues of food insecurity and child undernutrition are common. Evidence suggests an association between maternal mental health status, breastfeeding practices and infant nutritional status exists. However, associations have been scanty studied among refugees and the scope of perinatal depression among refugees in Uganda is unknown. The purpose of this mixed-methods study was to investigate perinatal depression, breastfeeding, and infant nutritional status among South Sudanese refugees in Uganda. Qualitative data were collected through focus group discussions and in-depth individual interviews. Quantitative data collection occurred during a community based, longitudinal, randomized controlled trial. Six perceived common stressors were: lack of basic needs, issues involving childbirth, marital conflict and violence, other violence and conflict, inadequate health care, and issues involving children. Parents responded to stress by contacting leaders/authorities, talking to others, healthy coping skills, and unhealthy coping skills. Participants perceived the community could organizing community discussions, leadership, economic opportunities, recreational opportunities, and counseling. Breastfeeding barriers included: knowledge, physical, socioeconomic, and psychosocial. Beliefs and knowledge about breastfeeding benefits, support from husband/father, the community, and non-governmental organizations were facilitators of breastfeeding. During pregnancy, 70.3% of mothers had depressive symptoms and 19.9% had antenatal depression. Nearly a quarter (23.5%) had postpartum depression and 62.3% reported depressive symptoms. Over half (66.6%) breastfed within one hour of birth and 55.5% exclusively breastfed their infants. Among infants, 11.9% were underweight, 12.8% were stunted, and 7.1% were wasted. No association was determined between antenatal depression and breastfeeding practices or undernutrition. In adjusted analyses, mothers who met the criteria for postpartum depression were less likely to breastfeed within an hour of birth and less likely to exclusively breastfeed. Initiating breastfeeding within an hour after delivery and exclusively breastfeeding both significantly reduced the odds of developing postpartum depression. Early postpartum depression symptoms predicted significantly lower weight-for-age scores and lower length-for-age scores. These results indicate a connection between postpartum depression, breastfeeding, and infant nutritional status. Screening and treatment for perinatal depression during antenatal and postnatal care is important. Interventions aiming to improve breastfeeding among refugees may also consider including initiatives to address postpartum depression.

## TABLE OF CONTENTS

Chapter	Page
I. INTRODUCTION.....	1
Background.....	1
Purpose and objectives.....	4
Significance of the study.....	4
Strengths and limitations.....	6
II. LITERATURE REVIEW.....	8
Refugees.....	8
Mental health.....	10
Child undernutrition.....	14
Breastfeeding.....	19
Perinatal depression and breastfeeding.....	23
Breastfeeding and postpartum depression.....	26
Perinatal depression and child undernutrition.....	27
Summary.....	29
III. METHODS.....	30
Research setting and study population.....	30
Qualitative methods.....	30
Quantitative methods.....	31
Ethical approvals.....	34

Chapter	Page
IV. “IT IS NOT GOOD TO EXPLAIN YOUR STRESS TO ANYONE”: A QUALITATIVE STUDY OF HOW SOUTH SUDANESE REFUGEES COPE WITH STRESS IN ADJUMANI DISTRICT, UGANDA .....	40
Abstract .....	40
Introduction.....	41
Methods.....	43
Results.....	46
Discussion .....	53
Conclusion .....	62
Tables .....	63
References.....	81
V. BREASTFEEDING AMONG SOUTH SUDANESE REFUGEES IN POST EMERGENCY SETTLEMENTS IN ADJUMANI DISTRICT, UGANDA: FACILITATORS AND BARRIERS.....	88
Abstract .....	88
Introduction.....	89
Methods.....	92
Results.....	94
Discussion .....	99
Conclusion .....	106
Tables .....	108
References .....	119
VI. PERINATAL DEPRESSION AND BREASTFEEDING: A MIXED METHODS STUDY AMONG SOUTH SUDANESE REFUGEES IN THE WEST NILE REGION IN UGANDA.....	126
Abstract.....	126
Introduction.....	127
Methods.....	130
Results.....	135
Discussion .....	142
Conclusion .....	154
Tables.....	155
References.....	179

Chapter	Page
VII. PERINATAL DEPRESSION AND INFANT NUTRITIONAL STATUS AMONG SOUTH SUDANESE REFUGEES IN THE WEST NILE REGION IN UGANDA.....	188
Abstract.....	188
Introduction.....	189
Methods.....	192
Results.....	195
Discussion.....	196
Conclusion.....	202
Tables.....	203
References.....	208
VIII. CONCLUSION.....	215
Key findings.....	218
Implications and recommendations.....	222
Future research.....	223
REFERENCES.....	225
APPENDICES.....	243

## LIST OF TABLES

Table	Page
IV.1: Guides for focus group discussions and key informant interviews .....	63
IV.2: Descriptive characteristics of mothers and fathers (n = 115) .....	64
IV.3: Perceptions of how mothers and fathers cope with stress .....	65
IV.4: Perceptions of how the community can help mothers and fathers .....	74
V.1: Discussion guides for mothers' and fathers' focus group discussions .....	108
V.2: Descriptive characteristics of study participants (n = 95).....	109
V.3: Facilitators of breastfeeding.....	110
V.4: Barriers to breastfeeding .....	114
VI.1: Guides for focus group discussions and key informant interviews .....	155
VI.2: Descriptive characteristics of parents in the qualitative study (n = 115).....	156
VI.3: Perceived common stressors among parents in the settlements .....	157
VI.4: Quantitative study maternal and infant characteristics .....	174
VI.5: Breastfeeding practices and perinatal depression among participants .....	176

Table	Page
VI.6: Associations between perinatal depression and breastfeeding practices.....	177
VI.7: Associations between breastfeeding practices and postpartum depression...	178
VI.4: Quantitative study maternal and infant characteristics .....	174
VII.1: Maternal, infant, and household characteristics .....	203
VII.2: Associations between perinatal depression and z-scores among infants 4-9 months of age.....	205
VII.3: Associations between perinatal depression and undernutrition among infants 4-9 months of age.....	206
VII.4: Associations between perinatal depression and z-scores adjusted for covariates (n=337).....	207



## CHAPTER I

### INTRODUCTION

Most displaced individuals resettle in resource limited countries, including those in sub-Saharan Africa, where over one-fourth of the world's refugee population resides [1]. South Sudan, a country located in Eastern Africa, struggles to recover from decades long of war with Sudan, as well as a devastating civil war in recent years [2]. Globally, South Sudanese are the third largest group of refugees and the largest refugee population in Africa [3]. Many South Sudanese refugees have sought refuge in neighboring countries, including Uganda, where an estimated one million South Sudanese refugees temporarily reside [3].

After resettling into a new country, refugees often face many challenges and difficulties. Populations that have been affected by conflict, such as refugees, have a heightened risk for suffering from mental health illnesses and increased levels of psychological stress [4-7]. Despite estimates that approximately 20% of refugees develop

a mental health illness, mental health is often overlooked and untreated during resettlement [4]. Studies estimate high rates of mental health illness among South Sudanese refugees in Uganda and attempted suicide and suicide remain an issue [8-10]. However, gathering accurate data on mental health issues among South Sudanese refugees has reportedly been difficult [9, 10]. Despite quantitative estimates on the prevalence of mental health issues, the perspectives of South Sudanese refugees on their experience related to stress and mental health has not been assessed and is key information for programs and interventions seeking to improve the mental health of refugees.

In addition to a heightened risk for stress and mental health illnesses, refugees also face issues related to hunger and undernutrition, especially among children under 5 years old, which has been previously reported among South Sudanese in Uganda [8, 11]. Undernutrition has been connected with approximately 45% of all deaths of young children and consequently, optimal nutrition in the first 1,000 days is considered critical [12, 13]. A key component of infant and child nutrition is breastfeeding because of the numerous benefits, including decreased risk of infectious diseases and infant mortality [13].

Therefore, recommendations are for breastfeeding within one hour of birth, exclusive breastfeeding for the first six months, and continued breastfeeding for up to two years and beyond [14]. However, evidence suggests forced migration may adversely impact breastfeeding choices among refugees [15-18]. Across settlements in Uganda, breastfeeding practices among refugees have been on a downward trend since 2014 [11]. A recent report noted exclusive breastfeeding rates across all settlements was 62.3%, a significant decrease since 2014 when exclusive breastfeeding rates were 90.7% [11]. Despite the downward trend

in breastfeeding practices, the specific barriers and facilitators of breastfeeding among refugees in the settlements in Uganda have not been investigated and remain unknown.

One of the potential barriers to optimal breastfeeding practices is maternal mental health illnesses [19, 20]. Among common mental health issues faced by mothers is perinatal depression, which refers to depression that occurs during pregnancy (antenatal) and up to one year after delivery (postpartum) [21]. While research seems conclusive that perinatal depression predicts shorter duration of breastfeeding [19, 20, 22-26], mixed evidence exists between perinatal depression and early initiation of breastfeeding and exclusive breastfeeding. Previous research also suggests the relation between postpartum depression and breastfeeding may be bidirectional, indicating breastfeeding may be a protective factor against the development of postpartum depression [19]. Despite some evidence being available, most studies have been conducted in high income countries and data on the prevalence of perinatal depression among refugees is lacking. Thus, forced migration adds to the breastfeeding challenges of refugees and they face an increased risk of perinatal depression. Further, the association between perinatal depression and breastfeeding among refugees remains unknown.

In addition to perinatal depression having a potential effect on breastfeeding practices, perinatal depression may be negatively associated with child growth and nutritional status [27, 28]. However, this association appears to vary by country and timing of the assessment of perinatal depression and nutritional status. Most studies have focused primarily on postpartum depression and data on antenatal depression and nutritional status are scant. Exact reasons for the varying results across countries remains unclear [29] and limited research has been conducted among refugees.

## **Purpose and objectives**

Therefore, the overall purpose of the study was to investigate perinatal depression, breastfeeding, and infant nutritional status among South Sudanese refugees in the West Nile Region of Uganda. The specific objectives of the mixed-methods study were:

- To identify perceived common stressors among parents in the refugee community.
- To assess perceptions of how mothers and fathers respond to stress.
- To assess perceptions of how the community can help mothers and fathers cope with stress.
- To identify barriers and facilitators of breastfeeding.
- To analyze associations between perinatal depression and early initiation of breastfeeding.
- To analyze associations between perinatal depression and exclusive breastfeeding.
- To investigate if breastfeeding practices lower the likelihood of postpartum depression.
- To analyze associations between perinatal depression and infant nutritional status.

## **Significance of the study**

Despite the quantitative estimates of mental health illness among refugees, qualitative data are lacking. Qualitative data on mental health and stress among refugees aids in understanding the experiences of refugees. Data including their perceived common stressors and how they currently cope will be helpful for programs and interventions that seek to improve mental health of refugees. Furthermore, data on their perceptions of how the community could help them will be informative to key leaders who may be able to help decrease stress among refugees in the settlements.

Despite the breadth of knowledge on barriers and facilitators of breastfeeding globally, limited research has been conducted among refugees who may face unique, additional challenges to breastfeeding. Therefore, this study bridges the evidence gap and provides data on these barriers and facilitators among refugees. The knowledge of these barriers and facilitators will be useful for informing future interventions and programs that aim at improving breastfeeding among refugees.

The scope of the issue of perinatal depression among refugees in Uganda is currently unknown due to the lack of data. Additionally, while previous research provides evidence of the association between perinatal depression and breastfeeding, discrepancies exist. Understanding the association between perinatal depression and breastfeeding among refugees is important to consider for the design of effective breastfeeding interventions and policies. Additionally, investigating if breastfeeding may decrease the risk of postpartum depression is important as breastfeeding may be a cost-effective method of reducing the prevalence and severity of postpartum depression in a resource limited setting. Although maternal characteristics have previously been studied and identified as determinants of infant nutrition, the influence of perinatal depression on infant nutritional status remains understudied among refugees. Understanding the association of perinatal depression and infant nutritional status is key information that will be useful in designing interventions and programs that aim to reduce infant undernutrition among refugees.

Overall, the evidence on perinatal depression, breastfeeding, and infant nutritional status shows that the associations remain unclear. Furthermore, limited research has been conducted among mothers and infants living as refugees in low-income countries. The data

from this mixed-methods study bridges the evidence gap that exists as well as provides useful data that can inform the design of future interventions, programs, and policies that aim to improve perinatal depression, promote breastfeeding, and improve infant nutritional status among refugees.

### **Strengths and limitations**

A key strength of the study was the mixed-methods approach which allowed for a more comprehensive investigation and in-depth assessment of mental health and breastfeeding. Qualitative data related to mental health included key informants in addition to refugees to improve reliability of the results. Another strength of this study was the longitudinal nature, which allowed for multiple assessments of perinatal depression which aided in understanding the directional nature of the association between perinatal depression and undernutrition. In quantitative analyses, the adjusted models controlled for multiple covariates that are known to strongly influence breastfeeding and undernutrition, thus strengthening the findings.

Nevertheless, the study had a few limitations. Given the fact that resources are limited, a questionnaire was administered to assess perinatal depression symptoms but a definitive depression diagnosis requires the use of a professional clinician. Self-reporting limitations, including possible recall bias, social desirability bias, and stigma around mental health may have led some participants to limit their sharing in discussions. Participants were all from South Sudan and may not be representative of other refugee populations; therefore, results may not be generalizable across refugee populations. However, participants from

different settlements and ethnic backgrounds were included to increase representativeness and generalizability to refugees living in the West Nile Region of Uganda.

Lastly, participants were sampled from a larger community-based, randomized controlled trial that included breastfeeding education and therefore, it is possible that participants in the intervention arm were positively influenced by the education and encouragement to breastfeed. Additionally, the intervention utilized a Care Group model which likely increased social support which may have influenced perinatal depression rates. However, the statistical models accounted for these potential variables by controlling for the study arms in analyses.

## CHAPTER II

### LITERATURE REVIEW

#### **Refugees**

Globally, in 2021, over 80 million individuals were forcibly displaced individuals, many of whom found refuge in low- and middle-income countries where there are limited resources [1]. As of 2021, 26.6 million individuals were residing in other countries as refugees, those who have been forced to flee their country of origin due to war, violence, or persecution [30]. The 1951 Refugee Convention, a significant legal document, defines a refugee as: “someone who is unable or unwilling to return to their country of origin owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion” [31]. Globally, over two-thirds of refugees come from just five countries: Syria, Venezuela, Afghanistan, Myanmar, and South Sudan [30].

#### *South Sudan*

The South Sudanese refugee crisis is the largest refugee crisis in Africa and the third largest globally [3]. In 2011, after a devastating civil war, South Sudan declared independence from Sudan and became its own country [32].



However, shortly after achieving independence, in 2013, armed conflict broke out leading to more years of violence, disease, and hunger [32]. Decades of violence and armed conflict left an estimated 400,000 people dead [33] and caused 2.3 million South Sudanese to flee their home country and find refuge in neighboring countries [3]. Over 80% of those fleeing are women and children and over half are children [3].

Conflict and violence persists in South Sudan. As a result, the current conditions in South Sudan are not conducive to promoting refugees return to their homeland due to continued armed conflict and human rights violations [32]. Long-standing conflict and violence such as the situation in South Sudan can displace refugees for many years and the estimated average duration of stay for all refugees is estimated to be 26 years [34]. Most of the South Sudanese refugees, 2.2 million, have been residing in neighboring countries of Sudan, Ethiopia, Kenya, and Democratic Republic of Congo, and Uganda [3].

#### *Refugees in Uganda*

Uganda is the world's third largest refugee host country [32]. The 2006 Refugees Act and the 2010 Refugee Regulations in Uganda were important legislations that aimed to provide a favorable environment for refugees in Uganda [32]. As a result, refugees were entitled to similar freedoms of Uganda citizens including freedom of movement, right to employment, land and business ownership, education, and health care [32]. Refugees tend to stay in Uganda for decades as a result of on-going conflict and violence in their country of origin [35]. Most refugees in Uganda live in settlements and more than half of the refugees reside in northern Uganda or West Nile [32].

### *South Sudanese refugees in Uganda*

Uganda hosts more South Sudanese refugees than any other country and an estimated 65% of all the refugees in Uganda are from South Sudan [32]. At the end of 2020, Uganda hosted 889,000 South Sudanese refugees [32]. Despite the rights provided to them, refugees still struggle to thrive because services are unavailable to them due to lack of assistance, underdevelopment of the settlements, or differing interpretations and implementation of the legislation intended to help them [36]. Not surprisingly, South Sudanese refugees in Uganda face many difficulties and challenges. A recent study identified common challenges and issues among South Sudanese refugees in Uganda that lead to distress: violence, daily life stressors, loss of assets and economic opportunities, loss of hope for future peace, eroding social connections, alcohol misuse, and failing to secure children's education and wellbeing [8].

### **Mental health**

Mental health is “a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community” [37]. Mental health is an integral part of health and is determined by a variety of biological, environmental, and socioeconomic factors [37]. In 2017, the WHO estimated over 300 million individuals suffered from depression, one of the most common mental health disorders globally. The WHO also reported the occurrence of depression is increasing, especially in low-income countries including those in the African region where reported cases of depression are 16% of the population [38]. Furthermore, since mental health issues are commonly underreported it is likely these occurrences are higher than estimated.

### *Mental health of refugees*

Refugees are at an increased risk for mental health challenges because of their history of living in conflict affected areas [7]. Prior to migration, refugees often experienced trauma, such as violence, political oppression, torture, loss of loved ones, and other traumatic experiences [39]. In addition to stressful events before migration, refugees often face difficulties from the breakdown of their social support and community networks, as well as cultural and language barriers they encounter when they arrive in a new country [40]. Despite recent estimates that over 20% of individuals in conflict-affected populations suffer from mental health illnesses, during emergency or humanitarian crises, mental health is very often overlooked [4]. Previous research reveals that refugees have increased vulnerability to mental health conditions, such as depression, anxiety, and post-traumatic stress disorder [5-7].

### *Maternal mental health*

Maternal mental health can be defined as “a state of well-being in which a mother realizes her own abilities, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to her community” [41]. Maternal mental health is proposed to be “the missing ‘m’ in the global maternal and child health agenda” and the “neglected ‘m’” in maternal and child health [42] specifically in low and middle-income countries [43]. Maternal mental health has reportedly been a low healthcare priority in these countries and is only slowly capturing the attention of global health stakeholders [41].

Among the common mental health issues concerning mothers is perinatal mental illness, which refers to “psychiatric disorders that are prevalent during pregnancy and as

long as 1 year after delivery” [21]. Two of the most common perinatal mental illnesses are antenatal and postpartum depression; antenatal depression refers to depression experience during pregnancy, and postpartum depression is depression experienced by mothers after delivery up to one year [21]. A recent systematic review of low- and middle-income countries found the pooled prevalence of antenatal depression to be 25.3% and postpartum depression was 19% [44].

### *Perinatal depression and refugees*

Despite the common occurrence of mental health and psychosocial issues faced by refugees and the combined challenges of perinatal mental health, scant research has been conducted on perinatal depression among refugees. Mothers who are refugees are at an increased risk of developing perinatal depression due to their exposure to stressors prior, during, and post-migration [45]. Additionally, access to healthcare including antenatal and postpartum care is sometimes difficult for refugees further exacerbating issues related to perinatal mental health [46]. A systematic review and meta-analysis on migration and perinatal mental health among refugees, asylum-seekers and economic migrants revealed that one in three from low- and middle-income countries experienced perinatal depression [45]. However, this study noted that most studies have focused on women from low and middle-income countries (LMICs) who relocate to high-income countries and there is an evidence gap on perinatal mental health and women who migrate from LMIC to another low-income country. A recent study among migrant and refugee women on the Thai-Myanmar border found the prevalence of perinatal depression among refugees was 47.3% [45]. Data on perinatal mental health conditions, including antenatal and postpartum depression among refugees who relocate to LMICs

remains severely lacking. In order to effectively address maternal mental health among refugees, understanding the scope of the issue and the prevalence of antenatal and postpartum depression is imperative.

#### *Mental health of South Sudanese refugees in Uganda*

In 2018, 22% of refugee households in Uganda reported that at least one member was in psychological distress [32]. It is likely the number is even higher due to underreporting and stigma around mental health. Furthermore, 40% of refugee households raised the issue that a household member in need of psychosocial services was unable to access psychosocial care [32]. A recent study among 387 refugees from Uganda revealed a high prevalence of psychiatric disorders: generalized anxiety (73%), post-traumatic stress disorder (67%), and major depressive disorder (58%) [47]. Attempted suicide and suicide remains an issue among refugees in Uganda and the refugee community reported that stress of daily life, violence, trauma during displacement, loss of family and eroded social connectivity, alcohol and drug abuse, lack of basic needs, inadequate access to livelihoods opportunities, and lack of hope for their future were among key contributing factors of suicide [8].

Few recent studies have documented occurrence of mental health and psychosocial difficulties among South Sudanese refugees living in Uganda. While epidemiological studies suggest high prevalence of mental health issues among South Sudanese refugees, it has been acknowledged that accurate occurrence of psychological distress and mental health issues among South Sudanese in Uganda are challenging to estimate from the existing studies [9, 10]. In a qualitative study, refugees mentioned mental health and psychological concerns in response to the question on general

problems they face in the settlements [9]. Among South Sudanese refugees in Uganda, only 29% who identified as being in need of psychosocial support were able to receive care and support [32]. The lack of coordinated effort to obtain accurate data on the mental health of refugees in Uganda is detrimental to the health of refugees. Current available data, for example as presented in the Refugee Health and Nutrition Report, reportedly only relies on monthly health service reports obtained from health facilities, which may only reflect mental health illness among refugees who are seeking help [48].

Despite the stress levels and mental health concerns among refugees, limited research has been conducted on how refugees cope and respond to stress. Thus, to further understand stress and mental health among refugees in settlements, it's important to investigate their perceptions of common stressors they face and how they currently cope with stress. Additionally, exploring the perceptions of how the community can assist parents who are facing stress would be informative for mental health and psychosocial initiatives.

### **Child undernutrition**

In addition to the mental health issues faced by refugees, they also face issues of hunger, food insecurity, and consequently, undernutrition. Infants and young children are among the most vulnerable victims of emergencies and forced migration and not surprisingly, it is not uncommon they suffer from undernutrition. Undernutrition results when the nutritional needs are not met and can be classified into two categories: 1) growth faltering and 2) micronutrient deficiencies [12]. Growth faltering is typically assessed by making comparisons between the child's length/height and weight to a reference population [49]. Differences between the child's anthropometric measurements and median of the reference population, adjusted for age and sex, is the calculated z-score

for that child [49]. Three common z-scores used in the assessment of child undernutrition are length/height-for-age z-score (LAZ or HAZ), weight-for-age z-score (WAZ), and weight-for length/height z-scores (WLZ) and correspond to stunting, underweight, and wasting for any z-scores below -2 [49].

### *Global child undernutrition*

Worldwide, approximately 45% of all child deaths are related to undernutrition [12]. The 2018 Global Nutrition report stated, “The problem of malnutrition remains severe: the world is not on track to achieve the targets it has set itself. Malnutrition in all its forms remains unacceptably high” [50]. In 2018, nearly 149 million children were stunted, 50 million were wasted, 149 million were stunted, and an estimated 12.6% were underweight [51, 52]. Children can experience multiple forms of undernutrition and nearly 16 million children suffer from wasting and stunting. Most of the childhood undernutrition, especially stunting and wasting, occurs in low- and middle-income countries [13].

### *Consequences of child undernutrition*

In the absence of proper treatment and care, undernutrition can lead to severe negative consequences. Undernourished children have an increased risk of morbidity and mortality [53]. In the short-term, children suffering from undernutrition are at a higher risk for infectious diseases due lower immunity and also have an increased risk of suffering health complications from diarrhea [54]. Infections often worsen the nutritional status of children because nutrients are required to restore health and are spared from being used for growth [55, 56]. Furthermore, undernutrition negatively impacts

neurodevelopment which can lead to lower cognitive abilities [54]. Specifically, stunting is a risk factor for impaired child development and has been associated with lower academic performance [57]. Not surprisingly, the negative consequences of undernutrition during childhood can persist into adulthood, including lower productivity, lower wages, and increased risk of chronic disease [53, 58, 59]. Additionally, negative consequences of child undernutrition may impact the next generation as maternal nutritional status is known to be an important factor during pregnancy and may impact the risk of infants being low birth weight and stunted [58]. Consequently, the intergenerational impact of childhood undernutrition may also reinforce the cycle of poverty.

#### *Causes of child undernutrition*

In 2020, the United Nations Children's Fund (UNICEF) released “Conceptual Framework on the Determinants of Maternal and Child Nutrition, 2020” which built upon the previous 1990 conceptual framework and describes causes of undernutrition [60]. In the framework, determinants of undernutrition are categorized as: immediate, underlying, and enabling. The immediate determinants comprise of diet and care, which may influence each other. The underlying determinants include food, practices, and services available in their households, communities, and environments that provide opportunities to access good nutrition. Enabling determinants refer to governance, resources, and norms that influence the broader environment (political, financial, social, and cultural). The causes of childhood undernutrition are multifactorial and determinants may vary across populations.



### *Undernutrition among refugees*

Refugees living in settlements are at risk for facing hunger, food insecurity, and undernutrition [61]. Not surprising, a report of over 7,000 refugee children from 7 countries cited issues of stunting, wasting, and underweight among refugee children under 5 years old [62]. Refugees are often confined to settlements while remaining exclusively dependent on humanitarian assistance for food [62]. They routinely have daily challenges in meeting their basic needs, including adequate amounts of food and clean water [63]. Undernutrition among refugee children is a critical public health issue and will likely require multi-sectoral approaches to alleviate it.

### *Undernutrition among South Sudanese refugees in Uganda*

Among South Sudanese children, rates of child undernutrition are particularly high; 30.6% were stunted, 27.7% were underweight, and 22.7% were underweight [52]. Research indicates exposure to conflict has a negative impact on many measures of child health outcomes, including nutritional status and growth [64, 65]. Research among refugees in Uganda indicates hunger and food insecurity are among the challenging issues they regularly face [8]. Among South Sudanese children living in Uganda, stunting rates across settlements were as high as 48.7% and up to 10.7% were underweight [11].

## **Breastfeeding**

### *Breastmilk*

Breastmilk, a complex, nutritious biofluid is produced to nourish infants and protect them from disease. The composition of breastmilk changes in response to variables, matching the infant's nutritional requirements according to age and other

characteristics [66-68]. Breastmilk composition may vary by the time of day, stage of lactation, and other factors that may influence components found in breastmilk [69].

Lipids provides the main source of energy in breastmilk, including over 200 fatty acids [70]. Short-chain fatty acids are an important source of energy for infants and are critical for normal development of the maturing gastrointestinal tract [71, 72]. Breastmilk has over 400 different proteins that function in a variety of ways, including antimicrobial and immunomodulatory functions, important nutrition, and stimulate the absorption of nutrients [73, 74]. Breastmilk contains a variety of complex carbohydrates due to the high energy requirements of the developing human brain with lactose as the most abundant carbohydrates found in breastmilk [75].

Human milk oligosaccharides (HMO), an important constituent of breastmilk, make-up the third largest component of breastmilk [75]. Over 200 HMOs are found in breastmilk and function as prebiotics and immune modulators [76, 77]. Breastmilk also contains immunoglobulins, often referred to as antibodies, in high concentrations early in breastfeeding but decrease over time as the infant's immune system develops [78].

### *Benefits of breastfeeding*

Breastmilk is a valuable component of optimal nutrition for the first 1,000 days because of its nutrient contents and the benefits breastmilk provides. Breastfeeding has been linked with decreased risk of infectious diseases and infant mortality while also promoting optimal neurodevelopment [13]. Breastmilk contains antimicrobial and immunomodulatory components that support the developing neonatal immune system and impair the ability of pathogens to infect the gastrointestinal tract [79]. Breastmilk

contains bioactive factors that inactivate a host of pathogens as well as inhibit inflammation [79].

#### *Short-term benefits of breastfeeding*

Previous research has identified numerous short-term benefits of breastfeeding for the child. Additionally, a systematic review found that infants who were exclusively breastfed had significantly lower risk of all-cause mortality compared to predominantly, partially, and non-breastfed infants [80]. Furthermore, the risk of infection-related deaths in infants was significantly higher in the predominantly, partially, and non-breastfed infants compared to exclusively breastfed infants [80]. The breadth of current evidence, also observed in a systematic review, suggests that breastfeeding significantly reduces the risk of respiratory infections and diarrhea [81]. These results corroborate earlier findings from low- and middle-income countries that discovered breastfeeding substantially lowered morbidity from infectious disease and exclusive breastfeeding decreased morbidity from gastrointestinal and allergic diseases [82]

#### *Long-term benefits of breastfeeding*

In addition to short-term benefits, research has identified long-term benefit of breastfeeding for the child, specifically a reduction in the risk of chronic diseases. There is a general consensus due to the evidence available that breastfeeding provides a protective effect against obesity during childhood and into adulthood [67, 81, 83]. One of the proposed mechanisms of how breastfeeding prevents obesity is breastmilk's ability to establish the microbiome of the infant, as the gut microbiome has been linked to obesity [84]. Additionally, a systematic review and meta-analysis revealed that breastfeeding

has been associated with a decreased risk for Type II diabetes in adults [81]. Another long-term benefit of breastfeeding is the promotion of cognitive development and an increased intelligence quotient (IQ) in infants who are breastfed for longer than six months [81, 85].

The long-term benefits of breastfeeding are not just limited to the child as research has discovered that mothers also experience decreased health risks. The Women's Health Initiative study which included 139,681 participants revealed that a lifetime history of more than 12 months of lactation reduces the risk of hypertension, Type II diabetes, hyperlipidemia, and cardiovascular disease among mothers [86, 87]. This is consistent with previous studies where breastfeeding was linked to a reduced risk in Type II diabetes and obesity in breastfeeding mothers [88, 89]. Lastly, the European Investigation into Cancer and Nutrition prospective cohort study which included 322,972 participants discovered that breastfeeding was linked to a reduced risk of cancer and mortality [90].

#### *Breastfeeding recommendations*

Given the vast benefits of breastfeeding, the World Health Organization (WHO) recommends infants be breastfed within the first hour of birth and be exclusively breastfed until they reach six months [91]. Exclusive breastfeeding, defined as, “the infant receives only breast milk. No other liquids or solids are given – not even water – except for oral rehydration solution, or drops/syrups of vitamins, minerals or medicines,” is recommended for the first six months of life. Additionally, the WHO recommends that breastfeeding be continued at least until the first birthday and up to two years or beyond.

### *Breastfeeding globally*

In 2018, the WHO and UNICEF published the Global Breastfeeding Scorecard which set targets for breastfeeding rates to be achieved by 2030: early initiation of breastfeeding at 70%, exclusive breastfeeding at 70% and continued breastfeeding at 80% [92]. Yet, despite the known benefits and recommendations, global breastfeeding rates remain below what is recommended to protect and promote the health of mothers and their children [93]. In 2021, the global breastfeeding rate for early initiation of breastfeeding was 48%, exclusive breastfeeding at 44% and only 44% of children were being breastfeeding until two years of age [93].

### *Breastfeeding among refugees*

Forced migration adversely impacts refugee mothers' breastfeeding choices [15]. One factor that may hinder a mothers' breastfeeding are misconceptions related to a mother's ability to breastfeeding combined with uncontrolled donations of breastmilk substitutes [15, 94]. Unregulated distribution of breastmilk substitutes in refugees' settlements can lead to the cessation of breastfeeding, increasing the risk of undernutrition, mortality, and morbidity among infants and children [94, 95].

Current evidence is consistent with the concerns that forced migration negatively impacts breastfeeding choices of refugees. A meta-ethnographic analysis concluded that refugees and migrant women who did not have access to traditional postpartum practices in a new country were more likely to cease breastfeeding [17]. Furthermore, in Sahrawi refugee camps in Algeria, while 65% of refugee mothers initiated breastfeeding within an hour of delivery, only 11.7% exclusively breastfed their infants for the first six months [18]. In Turkey among Syrian refugees, forced migration was negatively associated with

the choice to breastfeed as Syrian refugees were less likely to breastfeed than native Turkish mothers [16]. In Rwanda, a study among refugees revealed only 34.4% of infants were exclusively breastfed for the first six months of life, despite 74.4% of mothers demonstrating knowledge of and having a positive attitudes towards exclusive breastfeeding [96].

#### *Breastfeeding among refugees in Adjumani, Uganda*

In 2020, the Food Security and Nutrition Assessment in Refugee Settlements and Kampala revealed exclusive breastfeeding rates across all settlements was 62.3%, a significant decrease since 2014 when exclusive breastfeeding rates were 90.7% [11]. Early initiation of breastfeeding rates ranged from 58%-84.4% across refugee settlements. Across settlements in Adjumani, exclusive breastfeeding occurred among only 42.3% of mothers and infants, nearly 20 percentage points lower than the average across all settlements. A recent study in Adjumani revealed that among 561 mothers in post-emergency settlements, just over half (57%) breastfed their infants within one hour of birth [97]. Lastly, compared to other regions in the report, refugees in the West Nile region, where Adjumani District resides, breastfeeding rates were lowest compared to the other regions [11].

Limited research has been conducted among South Sudanese and breastfeeding in their home country, and even less research has been conducted on breastfeeding among South Sudanese refugees in Uganda. A recent study of South Sudanese living in South Sudan discovered that pre-lacteal feeding, the practice of giving newborns liquids or foods other than breastmilk before breastfeeding has begun, was practiced by over half (53%) of the mothers [98]. The common pre-lacteal feeds given by South Sudanese

mothers to their infants were sugar solution, plain water, and infant formula. Given suboptimal rates of exclusive breastfeeding in Adjumani and the practice of giving pre-lacteal feeds by South Sudanese mothers, it's imperative for interventions, programs, and policies that aim to promote breastfeeding to uncover the barriers to and facilitators of breastfeeding among South Sudanese refugees in post-emergency settlements.

### **Perinatal depression and breastfeeding practices**

For interventions and programs to be effective in their goals to improve breastfeeding practices, understanding the underlying barriers faced by mothers is imperative. One of the studied maternal characteristics is maternal mental health, including perinatal depression, on breastfeeding practices but findings are mixed and association appears inconclusive. A study from Maldives concluded antenatal depression at 36 weeks of pregnancy was not significantly associated with a shorter duration of breastfeeding [23]. Evidence from a prospective cohort study in Malaysia showed depressive symptoms during the third trimester predicted breastfeeding cessation at three months after delivery [22]. On the contrary, a prospective study conducted among a low-income population in the United States found no significant association between antenatal depressive symptoms and breastfeeding at 12 weeks after delivery [99].

While the association between antenatal depression and breastfeeding remains unclear, study findings seem to corroborate that postpartum depressive symptoms are significantly associated with breastfeeding cessation across many populations [23, 25, 26]. Furthermore, a systematic review that included 48 studies concluded that postpartum depression predicted shorter breastfeeding duration [19]. Overall, the evidence on the association between postpartum depression and shorter duration of breastfeeding seems

consistent but most studies have not been conducted in low-income countries nor among refugees. Additionally, research is limited on perinatal depression on specific breastfeeding practices, such as early initiation and exclusive breastfeeding.

#### *Perinatal depression and early initiation of breastfeeding*

Previous research indicates the association between antenatal depression and early initiation of breastfeeding appears equivocal and few studies have been conducted [19]. A recent study from Ethiopia determined depression during the second or third trimester was a predictor of late initiation of breastfeeding [100]. However, these results contradict findings from a systematic review of primarily high income countries that concluded depression during pregnancy was not significantly associated with early initiation of breastfeeding [19]. One of the hypothesized explanations for how antenatal depression may lead to delayed initiation of breastfeeding is that antenatal depressive symptoms such as fatigue and loss of interest may cause a delay in early skin to skin contact between a mother and her infant [101]. The hypothesis continues to suggest that the delay in mother-infant bonding in turns lead to a delayed initiation of breastfeeding. This may be even more pronounced in resource limited areas where mothers do not have access or treatment for antenatal depressive. Mothers with antenatal depression are also more likely to request elective Caesarean sections for non-obstetrical reasons than mothers with no depressive symptoms, which also may in turn delay early initiation of breastfeeding [102].

#### *Perinatal depression and exclusive breastfeeding*

While research on the association between perinatal depression and early initiation of breastfeeding is limited, there are much more studies that have investigated



its' association with exclusive breastfeeding. However, the evidence on the association between perinatal depression and exclusive breastfeeding is mixed. In Pakistan, mothers with antenatal depression exclusively breastfed for significantly fewer days compared to mothers without depression [103]. The results from Pakistan corroborate with findings from two systematic reviews that both concluded depression during pregnancy predicts early cessation of exclusive breastfeeding [19, 104]. However, findings from population-based cohort study in Ghana revealed antenatal depression was not associated with exclusive breastfeeding [105]. While the association between antenatal depression and exclusive breastfeeding is less clear, a systematic review concluded findings from multiples studies showed that postpartum depression is significantly associated with shorter duration of exclusive breastfeeding [19].

### **Breastfeeding and postpartum depression**

Breastfeeding has been suggested to have a protective effect on mental health due to its role in moderating maternal stress levels [106]. Breastfeeding has always been suggested to be a factor in modulating maternal inflammatory response [106] and previous studies have shown lower levels of biomarkers of stress among breastfeeding mothers [107-109]. Consequently, evidence suggests breastfeeding appears to be a protective against development of mental health conditions, specifically during the postpartum period. Prior results from a systematic review indicates mothers who breastfeed are less likely to develop postpartum depression [19]. However, most studies have focused on differences between breastfeeding and non-breastfeeding mothers and specific breastfeeding practices such as early initiation of breastfeeding or exclusive breastfeeding have been less researched, and therefore, are not well-understood.

Mixed evidence exists on the association between early initiation of breastfeeding and postpartum depression. Studies have found that lack of breastfeeding initiation predicted a higher likelihood of postpartum depression and initiation of breastfeeding predicted lower rates of postpartum depression [110, 111]. On the contrary, some studies have revealed no significant association between breastfeeding initiation and lower risk of developing postpartum depression [112, 113]. One hypothesis for the possibility that early initiation of breastfeeding may reduce the risk of postpartum depression is the skin-to-skin contact associated with the secretion of the oxytocin hormone which in turn may increase positive maternal feelings and reduce stress in breastfeeding mothers [114].

Previous research from among Sudanese mothers showed that mothers who exclusively breastfed had an 80% lower odds of experiencing postpartum depression [115]. Additionally, a recent study in Bangladesh reported that mothers who did not exclusively breastfeed had a 7.58-fold higher likelihood to develop postpartum depression compared to mothers who exclusively breastfed [116]. Lastly, similar findings were discovered in Iran where depression scores during the postpartum period were significantly lower among mothers who were exclusively breastfeeding compared to those who were not [117]. Adding to the hypothesis presented above, perhaps the impact of breastfeeding on lowering maternal stress is more impactful among exclusive breastfeeding mothers who may experience the effect more frequently than non-exclusive breastfeeding mothers.

## **Perinatal depression and undernutrition**

In addition to the evidence between perinatal depression and breastfeeding, evidence suggests an association between maternal mental health and infant and child nutritional status. In India, children whose mothers had high maternal depressive symptoms had lower height-for-age, weight-for-age, and weight-for-height z-scores compared to those whose mothers had low maternal depressive symptoms [118]. Additionally, children whose mothers had high maternal depressive symptoms were nearly two times more likely to be underweight and stunted [118]. Despite this evidence suggesting a connection between maternal mental health symptoms and child nutritional status, it appears the association may vary by country and growth indicator and few studies have specifically analyzed the role of perinatal depression. Previous research has reported mixed and inconsistent results on the association between perinatal depression and undernutrition among children under five.

A recent systematic review and meta-analysis of LMICs concluded postpartum depression was significantly associated with an increased risk of stunting and underweight among children 0-59 months [27]. In Pakistan, infants of mothers with antenatal depression symptoms showed significantly greater risk for being underweight and stunted at both 6 and 12 months of age [119]. Infants of mothers with postpartum depression had statistically significantly poorer growth, both weight and length scoring below the 5<sup>th</sup> percentile, at 3<sup>rd</sup> and 6<sup>th</sup> months after birth in Nigeria [120]. Children of mothers with postpartum depression were more likely to be stunted in India [121]. Additional studies reported that postpartum depression has been associated with an increased risk of stunting [121-123].

On the contrary, postpartum depression was not significantly associated with poor infant nutritional status at 9 months of age in Nigeria [120](Adewuya, Ola, Aloba). A community-based study analyzed data from four low-income countries and reported significant associations in Vietnam and in India, but no associations were found in Peru and Ethiopia [124]. Lastly, a population based cohort study in Ethiopia reported that antenatal and postpartum depression were not significantly associated with underweight or stunting in infants at six or twelve months [29].

Despite some studies reporting significant findings, the association between perinatal depression and undernutrition across countries in sub-Saharan Africa remain unclear and few studies have assessed the association among refugees. It is widely acknowledged that the mechanisms between depression and child nutritional status remain unclear and may vary among different populations [28]. It has been suggested that the symptoms associated with depression, including fatigue, impaired concentration, and feelings of hopelessness may lead to increased difficulty with infant care and non-responsive caregiving practices [125-127]. However, few studies have analyzed the association between antenatal depression and infant growth. Furthermore, most studies have assessed postpartum depression and undernutrition at the same time, thus limiting the ability to assess the direction of the association. As such, there has been debate about the directional nature between the association of maternal depression and child undernutrition [126]; does undernutrition lead to maternal depression or does maternal depression lead to undernutrition?

## **Summary**

Refugees are at a heightened risk for developing mental health illnesses. Rates of perinatal depression among refugees are estimated to be high but there is a lack of data on the prevalence of perinatal depression among refugees in LMICs. Issues of child undernutrition are prevalent among refugees and are detrimental to the short and long-term health of the child. Breastfeeding is an important nutritional component for young children, especially in combatting the effects of undernutrition, yet refugee mothers often face additional barriers to breastfeeding when living in settlements. Most studies on perinatal depression and breastfeeding and undernutrition have been conducted in high income countries and may not be generalizable to refugees living in settlements in LMICs. Studies suggest breastfeeding may have a protective effect against the development of postpartum depression but the association of specific breastfeeding practices has been scantily assessed among refugee populations.

## CHAPTER III

### METHODS

This study utilized a mixed-methods approach. Qualitative data were collected as a part of formative research through focus group discussions and in-depth individual interviews. Quantitative data collection occurred during a community based, longitudinal, randomized controlled trial (RCT) in settlements in the West Nile Region of Uganda. The RCT implemented a peer-led integrated nutrition education intervention using the Care Group model that aimed to improve infant and young child feeding practices and growth. Quantitative data were collected at multiple data collection phases through questionnaires and anthropometric measurements.

#### **Research setting and study population**

##### *West Nile region*

The West Nile region is located in Northwestern part of Uganda. Approximately one million South Sudanese refugees reside in the West Nile region. The region houses a large number of community based organizations as well as international, and domestic non-governmental organizations.

Most (80%) of the population living in the West Nile region are living in rural areas. The West Nile consist of ten districts, including Adjumani district [128].

#### *Adjumani district*

In Adjumani district, over 230,000 refugees live in settlements, of whom almost all (99.0%) are South Sudanese. Among the 32,464 households in Adjumani, 85% of the population is women and children and only 18.1% of individuals are employed.

Adjumani district hosts the largest number of refugee settlements in Uganda [32].

### **Qualitative methods**

The study was conducted in settlements located in Adjumani district, in the West Nile region of Uganda in July 2019. Agojo, Ayilo-I, and Nyumanzi were randomly selected among the main refugee settlements in Adjumani to collect the qualitative data related to breastfeeding. Agojo, Boroli, Pagirinya, and Ayilo-I were randomly selected settlements in Adjumani for the collection of qualitative data related to stress and mental health.

#### *Focus group discussions among mothers and fathers*

Focus group discussions (FGDs) were used to collect data on both breastfeeding and topics related to stress and mental health. Participants were South Sudanese refugees living in the settlements and were parents of a child or children less than 24 months of age. With the assistance of Lutheran World Federation (LWF) community service officers, health care workers, and the Village Health Teams (VHTs), whom routinely interact with parents, a list of potential participants was prepared. From the prepared lists, participants were selected at random, and prospective participants were mobilized with the help of the VHTs for the FGDs. Fathers and mothers were recruited from different households. For breastfeeding data collection, participants included mothers (n= 63) and

fathers (n= 32) and participants formed six FGDs, four FGDs for mothers and two FGDs for fathers, with each FGD having 15-16 participants. For stress and mental health data collection, participants included mothers (n = 66) and fathers (n = 49) and formed a total of eight focus groups: four mothers FGDs, two fathers FGDs, and two FGDs with both mothers and fathers.

*Focus group discussion among Village Health Teams and in-depth individual interviews*

To add perspective to the stress and mental health data collection from the FGDs among parents, researchers conducted two FGDs with individuals who served on the Village Health Teams (VHTs). VHTs were established by the Ministry of Health as a community-based system to promote health and well-being in local communities, including refugee settlements [129]. VHTs are responsible for conducting home visits, promoting health, providing health education, and following-up with mothers during antenatal and postnatal care [130]. The key informants (KIs) comprised of one official from the Office of the Prime Minister and five settlement commandants. Settlement commandants serve as the highest ranking, appointed officers who work to ensure refugees have access to services provided by United Nations High Commissioner for Refugees (UNHCR) and other partner agencies in the settlements [131]. Both VHTs and these KIs were included in the study because of the frequent interaction and communication with mothers and fathers in the settlements; therefore, they were able to offer informative and important perceptions.

*Focus group questions and interview guide*

Questions used in the FGDs (Table 1) and KI interviews (KIIs) (Table 2) were developed based on previous research and were reviewed by the research team. Prior to data collection, the questions were examined by research translators who were hired for



their proficiency in English and Arabic, Dinka, or Madi, as well as experience in field work. Translated FGD questions were cross-checked with two additional research translators and were pre-tested among mothers and fathers in the settlements. After adjustments following pre-testing, the final FGD guide was reviewed and approved by the research team prior to data collection.

#### *Data collection*

FGDs were conducted by the research team along with enumerators, who were hired based on their prior experience in bridging communication gaps between humanitarian organizations and refugees. FGDs among mothers and fathers were held in community centers, conducted in Arabic, Dinka, or Madi, languages spoken by participants and were audio-recorded. FGDs with VHTs were conducted in Arabic and English and KIIs were conducted in English. Probing questions were implemented throughout the FGDs and KIIs and saturation was considered to be achieved when participants contributed no new information.

#### *Data analysis*

FGD audio recordings were transcribed verbatim by research translators, who were proficient in both English, Arabic, Dinka, and Madi, and then transcriptions were back-translated into English. Data were coded by the research team using NVivo, v. 12 prior to the cleaning of codes, which was completed by the primary investigator and agreed upon by the research team. Thematic analysis was used and codes with similarities were identified to form themes that answered the research questions. When very few discrepancies in analysis occurred, they were resolved as a team and minimal disagreement occurred among researchers during the data analysis.

### *Trustworthiness/reliability*

Data were collected from participants living in different settlements which allowed for multiple perspectives, and likely enhanced data reliability. The data triangulation method of collecting data from varying sources (mothers, fathers, key informants, and VHTs) and different collection methods (FGDs and in-depth individual interviews) was used to increase the validity and trustworthiness of the data. Probing questions were used to assist in the achievement of saturation. The involvement of multiple research team members during coding and thematic analysis reinforced trustworthiness and reliability.

### **Quantitative methods**

#### *Sample size and study participants*

Based on reported exclusive breastfeeding rates of 62.3% across settlements in Uganda [11] and a margin error of 0.05, 360 participants were estimated to be needed [132]. After adjustment for prospective loss to follow-up, 390 participants were enrolled in the study. Inclusion criteria required the participants to be of South Sudanese origin, in their third trimester of pregnancy, and living in the randomly selected settlements. Mothers who gave birth to premature infants or other congenital abnormalities that may have influenced breastfeeding practices or infant growth were eligible to remain in the study; however, their data were not included in the analyses. Recruitment of participants was conducted by the research team with the help of the VHTs and midwife assistant from the nearest health center in each settlement. Third trimester pregnancy was verified by three methods: self-reported by the pregnant women, cross-checked using each

woman's antenatal booklet, and confirmed by the midwife assistant and their antenatal register records.

### *Data collection*

Prior to data collection, the questionnaire, developed based upon previous research and literature, was pre-tested among refugees in the settlements. After minor adjustments were made, the final questionnaire was reviewed and agreed upon by the research team. Data collectors, of South Sudanese origin whom held a minimum of an associate degree in a social science or related field, were hired and trained to interview participants. Questionnaires were translated from English and administered verbally in the languages primarily spoke by participants, Arabic, Dinka, and Madi. Responses were recorded by data collectors using Qualtrics accessed through an iPad. Questions related to sociodemographic information and other participant characteristics were adapted from standardized questionnaires.

### *Perinatal Depression*

The Patient Health Questionnaire, nine-item version (PHQ-9) was used to assess perinatal depression [133]. The PHQ-9 has been reported to be a valid screening tool for perinatal depression and a recent study among South Sudanese refugees in Uganda reported a Cronbach's Alpha ( $\alpha = 0.75$ ) for the PHQ-9 [134, 135]. Scores for the PHQ-9 range from 0-27 and are classified into categories: none-minimal (0-4), mild (5-9), moderate (10-14), moderately severe (15-19), and severe ( $\geq 20$ ). A score of  $\geq 10$  or being in the moderate or severe category is considered suggestive for depression. To assess both antenatal and postpartum depression, the PHQ-9 was administered to study participants during the 3<sup>rd</sup> trimester and twice during the postpartum period. Explanatory

variables for antenatal depression and postpartum depression included continuous PHQ-9 scores and a categorical variable for meeting the criteria for depression (PHQ-9 score  $\geq 10$ ).

### *Breastfeeding*

Breastfeeding practices, early initiation of breastfeeding and exclusive breastfeeding were evaluated using the WHO guidelines [14]. Participants were asked how soon after birth they breastfed. Early initiation of breastfeeding was calculated as the proportion of infants who were breastfed within 1 hour after delivery. Guided by the WHO IYCF assessment protocol, a sequence of yes/no questions about liquids and foods given in the last 24 hours were used to assess exclusive breastfeeding. Exclusive breastfeeding was measured as the proportion of infants fed exclusively breastmilk in the preceding 24 hours. Both early initiation of breastfeeding and exclusive breastfeeding were assessed at less than 6 months postpartum.

### *Anthropometric measurements*

Infant anthropometrics, height and weight, were measured by the lead research team member when infants were 4-9 months old. A standardized SECA infantometer was used to measure recumbent length in centimeters and a digital scale (SECA 874) was used to measure weight in kilograms. Measurements were recorded to the nearest decimal (0.1) and the average of two measurements was used to improve accuracy of anthropometrics. Length and weight were converted into the standardized z-scores, which refer to the difference between the median reference population and the anthropometric measurement and are adjusted for sex and age [49] The z-scores used in this study included weight-for-age (WAZ), length-for-age (LAZ), and weight-for-length (WLZ) z-

scores and were calculated using ENA for SMART 2011. WAZ, LAZ, and WLZ were also converted into categorical variables according to the WHO growth standards: stunted if LAZ was less than -2, underweight if WAZ was -2, and wasted if WLZ was less than -2 [49]. In analyses, continuous z-scores: WAZ, LAZ, and WHZ as well categorical variables for undernutrition, including underweight, stunting, and wasting were used as an indicator for infant nutritional status.

### *Statistical analyses*

Participant characteristics, perinatal depression, early initiation of breastfeeding, exclusive breastfeeding, and the occurrence of stunting, underweight, and wasting were calculated using descriptive statistics. Logistic regressions were used to analyze associations between perinatal depression, both antenatal and postpartum depression, and breastfeeding practices. Multivariable models assessing perinatal depression and breastfeeding were adjusted for study arm, child age, child sex, maternal mid-upper arm circumference (MUAC), maternal fever or diarrhea in the last 24 hours, maternal age, maternal education, antenatal visits, postnatal visits, place of delivery, and type of delivery. Multivariable models investigating whether breastfeeding was associated with lower odds of developing postpartum depression were adjusted for study arm, child age, child sex, maternal age, maternal social support, maternal education, antenatal visits, postnatal visits, place of delivery, type of delivery, and maternal MUAC.

Linear regressions were conducted to analyze associations between perinatal depression and infant z-scores: WAZ, LAZ, and WHZ. Logistic regression analyses determined the associations between perinatal depression and growth indicators; underweight, stunting, and wasting. Variables with a significance of  $p < 0.05$  in bivariate

analyses were analyzed using multivariable regression analyses which adjusted for the following covariates: study arm, household food insecurity, maternal education, maternal mid-upper arm circumference, maternal short stature, maternal age, infant sex, infant low birth weight, infant diarrhea in the last month, and exclusive breastfeeding since birth. SAS, v. 9.4 was used for all analyses and the tolerance test and variance inflation factor indicated collinearity between variables was not present.

### **Ethical approvals**

Approval was obtained from the Makerere University School of Health Sciences Research and Ethics Committee in Uganda (SHSREC REF: 2019-020), the Uganda National Council of Science and Technology (SS 5038) and the Institutional Review Board at Oklahoma State University (HS-19-2). Local permission was acquired from the Ugandan Office of the Prime Minister (OPM/R/107). Eligible participants were made aware of the purpose of the study and were provided the opportunity to ask questions. Participants were informed that study participation was voluntary and informed consent was obtained at each data collection phase. Compensation for participation at each data collection phase was provided to participants in the form of household and food items (bar of soap, iodized salt, sugar, Vitamin A fortified cooking oil) that had an estimated value of 7,600 Ugandan Schilling (approximately \$1.50 USD).

## CHAPTER IV

### “IT IS NOT GOOD TO EXPLAIN YOUR STRESS TO ANYONE”: A QUALITATIVE STUDY OF HOW SOUTH SUDANESE REFUGEES COPE WITH STRESS IN ADJUMANI DISTRICT, UGANDA

#### **Abstract**

South Sudanese in Uganda face many challenges, including mental health illnesses and attempted suicide. Refugee parents face unique difficulties in a new country. Limited research has been conducted among South Sudanese refugee parents regarding the stress they face. Therefore, the purpose of this study was to investigate how refugee parents cope with stress and their perceptions of how the community can better help them manage stress in Adjumani district, Uganda. This study was conducted in July, 2019, among South Sudanese refugees living in settlements in Adjumani District, Uganda. Participants included mothers (n= 66) and fathers (n= 49) of children younger than 24 months. Agojo, Boroli, Pagirinya, and Ayilo-I were randomly selected settlements. Participants formed eight focus group discussions (FGDs), each consisting of 15-16 participants: four FGDs for mothers, two FGDs for fathers, and two FGDs of mothers and fathers. Two additional FGDs with members of the Village Health Team and six individual interviews with key informants were conducted.

Data were audio recorded, transcribed verbatim, and back-translated into English. NVivo, v. 12, was used for thematic analysis. Among parents, 69.7% of mothers and 69.4% of fathers were aware of mental health and psychosocial support resources available. However, only 40.9% of mothers and 42.9% of fathers reported utilizing those resources to help them cope with stress. Four major themes related to how parents coped included: contacting leaders/authorities, talking to others, healthy coping skills, and unhealthy coping skills. Perceptions of how parents felt the community could help them cope with stress included: community discussions, leadership, economic opportunities, recreational opportunities, and counseling. South Sudanese refugees in Uganda coped with stress in both healthy and unhealthy ways. Social networks, recreational opportunities, and accessing mental health and psychosocial support MHPSS services were important in helping parents cope in healthy ways. Alcohol misuse, intimate partner violence (IPV), child mistreatment, and suicide were unhealthy coping mechanisms. Counseling, leadership, and engaged involvement were discussed as strategies for how the community might help with stress management. Improvements in areas of addressing substance abuse, support for victims of IPV, and prevention of suicide are critical to the health and well-being of South Sudanese refugees in Uganda.

## **Introduction**

Globally, as of 2021, over 80 million individuals have been forcibly displaced and more than 30% were refugees in another country [1]. Most displaced individuals find refuge in low- and middle-income countries with limited resources, such as countries in sub-Saharan Africa, which hosts more than 26% of the global refugee population [1]. Globally, the South Sudanese refugee population is the third largest and is the largest in



Africa [2]. Over 80% of the South Sudanese refugees are women and children [2]. Many reside in neighboring countries, including over nearly one million living in Uganda [2].

Refugees and conflict-affected populations have an increased propensity for high levels of psychological stress and mental health illnesses, including post-traumatic stress disorder, anxiety, and depression [3-6]. Refugees have commonly experienced armed conflict, violence, torture, grief from loss of livelihoods and loved ones, as well as other traumatic experiences prior to migration [7]. Additionally, refugees often face additional difficulties after migration due to the collapse of their social connections and the challenges of language and cultural obstacles in a new country [8]. During the resettlement process of refugees, psychological stress and mental health are often overlooked, despite estimates that approximately 20% develop mental health illnesses [3].

Not surprisingly, despite finding temporary refuge, South Sudanese in Uganda face many challenges and difficulties. In 2018, nearly a quarter of South Sudanese refugee households self-reported that at least one household member experienced psychological distress [9]. High prevalence of mental health illnesses, anxiety (73%), post-traumatic stress disorder (67%), and major depressive disorder (58%) have been documented among refugees in Uganda and attempted suicide and suicide remain an issue among South Sudanese [9, 10]. Epidemiological studies suggest high prevalence of mental health issues among South Sudanese refugees, however, accurate data on psychological distress and mental health issues among the South Sudanese are difficult to obtain [11, 12]. Furthermore, only 29% of South Sudanese refugees who self-identified as needing psychosocial help were able to receive care [9].

Stress among parents is known to have negative effects on children and most of the adult refugees in the settlements are parents [13]. Previous research among refugees reveals that parents' psychological distress as well as post-migration living challenges were significantly associated with less school engagement among their children [14]. Additionally, children of refugee parents who had post-traumatic stress disorder were at a heightened risk of developing a mental health illness [15].

Despite their unique challenges faced as parents and their increased risk of stress and mental illness, limited research has been conducted among South Sudanese refugee parents. To enhance understanding of stress and mental health among these refugees, it is crucial to explore how they cope with stress. Furthermore, investigating perceptions of how the community can support stressed refugee parents will help inform mental health and psychosocial initiatives that aim to support South Sudanese refugees in Uganda. Therefore, the purpose of this study was to investigate perceptions related to stress among refugees living in Adjumani district, in the West Nile region of Uganda. The primary research questions in this qualitative study were: 1) how do mothers and fathers cope with stress? And 2) how can the community help mothers and fathers cope with stress? The findings will be useful for informing interventions, programs, and policies aimed at decreasing stress and improving mental health among refugees.

## **Methods**

### **Participants**

The study was conducted in Adjumani district, in the West Nile region of Uganda in July 2019. Agojo, Boroli, Pagirinya, and Ayilo-I were randomly selected among the nineteen refugee settlements in Adjumani. Participants included refugee mothers (n = 66)

and fathers (n = 49), originally from South Sudan, with children younger than 24 months of age who were living in these post-emergency settlements. Participants were selected with assistance from community leaders and formed a total of eight focus groups; four mother's focus group discussions (FGDs), two fathers FGDs, and two FGDs with both mothers and fathers.

Additionally, researchers conducted two FGDs with individuals who served on the Village Health Teams (VHTs), as well as six individual interviews with key informants (KIs), to add perspective to the data collected from mothers and fathers. VHTs, established by the Ministry of Health, are throughout Uganda as a community-based system to promote health and well-being in the local community [16]. Their responsibilities include visiting homes, health promotion and education, and follow-up with mothers during pregnancy and postnatal care [17]. The KIs were comprised of five settlement commandants and one official from the Office of the Prime Minister-Uganda. Settlement commandants, the highest-ranking Office of the Prime Minister-Uganda officers in the settlements, were appointed to ensure refugees have access to services provided by United Nations High Commissioner for Refugees (UNHCR) and partner agencies [18]. Because VHTs and settlement commandants interacted with mothers and fathers within the community frequently, they were able to provide valuable community perceptions.

### **Data collection**

The FGD and key informant interview (KII) guides were developed based on previous literature and reviewed by the research team (Table 1). Before data collection, the questions were examined by research translators who were hired based on their

experience in field work and their proficiency in English and the local languages. The translated guides were reviewed by two other research translators and pre-tested among mothers and fathers in the settlements. The research team agreed upon the final translated FGD guide. The FGDs for mothers and fathers were conducted in Arabic, Dinka, or Madi, the languages primarily spoken by the participants, and were audio-recorded. The FGDs with VHTs were conducted in Arabic and English, while the KIIs were all conducted in English. Probing questions were used during the FGDs and KIIs and saturation was considered to be established when no new information was added by participants.

### **Data analysis**

Audio recordings of the FGDs were transcribed verbatim by the research translators. Transcriptions were back-translated to English by research translators proficient in English and the local languages. The research team coded the data using NVivo, v. 12. Cleaning of codes was completed by the primary investigator and reviewed by the research team. Thematic analysis was used and the few discrepancies that occurred during analysis were resolved as a team.

### **Trustworthiness/ reliability**

Data were collected among participants from four different post-emergency settlements to provide multiple perspectives, which likely increased data reliability. The use of probing questions helped to achieve saturation. The involvement of the research team during coding and thematic analysis assisted in reinforcing trustworthiness and reliability.

## **Ethical Approvals**

The study was approved by the Makerere University School of Health Sciences Research and Ethics Committee in Uganda, the Uganda National Council of Science and Technology, and the Oklahoma State University Institutional Review Board. Eligible participants were informed of the study's purpose and were provided opportunities to ask questions. Participation was voluntary and informed consent was obtained from all participants prior to data collection. Compensation for participation was provided in the form of food and household items that were worth approximately 7,600 Uganda Schilling.

## **Results**

### **Descriptive characteristics**

Key descriptive characteristics of mothers and fathers are summarized in Table 2. The mean age of fathers (38.1 y) was higher than that of mothers (28.2 y). Fewer mothers reported working outside the home (7.6%) compared to fathers (44.9%). Most fathers (71.4%) and mothers (78.8%) reported completing some level of formal education. Many of the mothers (75.7%) had been living as refugees in the West Nile region for 2-3 years. Nearly a quarter of the fathers (24.5%) reported being in the West Nile region as refugees for longer than 5 years, while 38.8% had been there 2-3 years and 36.7% for 4-5 years. More than two-thirds of mothers (69.7%) and fathers (69.4%) were aware of mental health resources, such as psychosocial counseling, available to them. A lower percentage of mothers (40.9%) and fathers (42.9%) reported utilizing these available psychosocial services in the settlements.

## **Perceptions of how mothers and fathers cope with stress**

Four themes of how mothers and fathers coped with stress included: contacting leaders or authorities, talking to others, healthy coping skills, and unhealthy coping skills (Table 3). Official authorities included the Office of the Prime Minister, UNHCR, and the police. Additionally, participants and interviewees mentioned that parents go to community leaders, including block leaders and the Refugee Women's Council. Mothers, fathers, and VHTs also noted that parents go to church leaders when they are stressed.

*“When the stress is too much, they [parents] take it to the leaders and Office of the Prime Minister, and then the police.” – KII #1*

*“They [parents] talk to the opinion leaders to really guide them on what they are supposed to do because these are non-recognized counselors; like the village lawyers, when they talk to you, they counsel you, and that's what we call a community activist.” – KII #4*

*“They [parents] go to the block leaders and ask for help. Sometimes you can talk to the chairman and he will give you an idea.” – Mothers FGD (Boroli) and*

*Fathers FGD (Ayilo)*

Mothers, fathers, VHTs, and KIs noted that fathers and mothers talked to others when they are stressed. Friends, neighbors, and those they consider to be trustworthy were all mentioned as people who parents turn to in times of stress.

*“When I go and share with the friends in discussion then I feel relieved.” –  
Fathers FGD (Ayilo)*

*“You, as a man, if you have a problem at your heart you should first go to the  
neighbors.”- Mothers and Fathers FGD (Pagirinya)*

*“The neighbor will come and talk if the person has stress.” –KII #3*

*“For me when I do not feel well or I am stressed, I can go to the person whom I  
trust to explain my stress.” – Mothers FGD (Agojo)*

Additionally, relatives and elders, as well as spouses, were discussed by mothers, fathers, VHTs, and KIIs as people who parents talk to when they are stressed.

*“Because of culture, the fathers normally go to the elders.” – Fathers FGD  
(Ayilo)*

*“When the mother is very stressed she can go to the relatives of the husband for  
advice so she can solve the issue.” – VHT FGD (Boroli)*

*“This is what I do when I am totally stressed, I normally talk to my wife and  
when she advises me, I easily forget it.” – Fathers FGD (Ayilo)*

*“You tell your problems to your husband.” VHT FGD (Boroli)*

In addition to talking to others, healthy coping skills discussed included mothers expressing through crying, as well as recreation such as mothers and fathers playing and mothers singing. Interestingly, accessing resources that were available to help address psychosocial concerns was mentioned only by mothers and KIIs.

*“They [mothers] respond by crying.” – KII #6*

*“Sometimes they [parents] can go to the place of playing to release their stress.”*

*– Mothers and Fathers FGD (Pagirinya)*

*“I would go to the people of Lutheran World Federation who do counseling.”*

*Mothers FGD (Agojo)*

Unhealthy coping skills included suicide, which was mentioned by fathers and KIIs as how both fathers and mothers may handle stress. Alcohol consumption was mentioned by mothers, fathers, VHTs, and KIIs as a way fathers handle their stress.

*“There are cases where parents opt for suicide.” – Fathers FGD (Ayilo)*

*“Stress can make someone angry and sometimes alcohol is the solution to the problem.” – Fathers FGD (Boroli)*

Violence committed by both mothers and fathers was discussed as a way that parents cope with stress, as well as taking the stress out on their spouse and causing marital issues. Both KIIs and VHTs, but not mothers or fathers, reported that mothers and fathers abuse or neglect a child during times of stress.

*“Men can stay in their problems and stress, drinking all the time, and end up beating the wife.” Mothers and Fathers FGD (Pagirinya)*

*“A mother will want to stir up that same problem so that they end up fighting or quarreling.” – VHT FGD (Boroli)*

*“They [parents] beat children when stressed.” – KII #5*



Lastly, it was mentioned that staying quiet and not talking to others, as well as even leaving the family or home, was how parents coped with stress.

*“They [men] suffer silently.” – Fathers FGD (Ayilo)*

*“For me when I feel stress I do not explain to anybody. It is not good to explain your stress to anyone.” Mothers FGD (Agojo)*

*“Some men walk away from the family, without informing the wife where he is going.” – KII #5*

### **Perceptions of how the community can help mothers and fathers**

Community discussions, leadership, economic development, recreational opportunities, and counseling were the five themes related to perceptions of how the community can help mothers and fathers cope with stress (Table 4). Community discussions were mentioned by mothers, fathers, VHTs, and KIIs as an important way the community can help parents. Within this theme, participants discussed the need to form groups, hold meetings, and organize community dialogues.

*“We can be in the group, sharing a common understanding.” – Mothers and Fathers FGD (Pagirinya)*

*“By calling a community dialogue because in the community dialogue you find that somebody who is stressed will be mentored.” – VHT FGD (Boroli)*

Only the VHTs and KIIs described the need for leadership including community sensitization and the need for church leaders to be more involved. They also noted the

importance of raising awareness of existing resources. Lastly, mothers and fathers discussed the importance of rules and regulations within the community as a way to help decrease the stress among parents.

*“The church leaders have to play a role.”- KII #1*

*“I think there needs to be education, constant trainings, community sensitization, and the importance of getting psychosocial help needs to be taught to the people. Talking about the dangers of sexual gender-based violence and fighting needs to be there. Those are the ways of reducing stress in the community.” – KII #4*

Parents and VHTs mentioned several ideas related to the theme of economic development. First, they described the need to encourage work, as well as increasing the availability of vocational schooling and training within the community. They discussed the need for start-up money for business, as well as land on which they could labor in the fields.

*“Parents who have that stress with financial issues, the community would advise that person, ‘If you are suffering to support your child, you better go and work.’”*  
– VHT FGD (Boroli)

*“We are asking for vocational school so that we can ease our stress away.” –*  
*Mothers and Fathers FGD (Pagirinya)*

*“For women, give them a little money for them to start business.” – VHT FGD*  
*(Boroli)*

Recreational opportunities were mentioned by fathers and VHTs as a way of keeping parents busy and helping them ease their stress. These activities included organizing dramas and encouraging recreational play, such as football, for both mothers and fathers. Opportunities related to tradition included traditional cultural dances and cooking traditional food as a way to help relieve their stress.

*“Organizing drama in the community because drama tells them other things.” – VHT FGD (Boroli)*

*“Traditional food has to be cooked for the older people especially so that they can remove their stress away from them easily.” - VHT FGD (Boroli)*

Counseling was a theme noted by parents and KIIs as a way to help support mothers and fathers. Within this theme, the need to provide direct counseling and training, as well as providing advice to parents, were mentioned as important ways to help mothers and fathers manage their stress.

*“I think counseling is a must in community services.” – KII #4*

*“The community can also help us by training us on how to handle problems.” - Mothers and Fathers (Pagirinya)*

*“The community can help us by giving us good advice that are important for our daily life and this can help us to reduce our heart pain or stress.” - Mothers and Fathers FGD (Pagirinya)*

## **Discussion**

### **Perceptions of how mothers and fathers cope with stress**

Interestingly, accessing mental health and psychosocial support (MHPSS) resources that are available to help address psychosocial concerns was verbalized only by mothers and KIIs. However, in the descriptive data, 40.9% of mothers and 42.9% of fathers reported utilizing MHPSS services. Possibly fathers felt uncomfortable disclosing among their peers that they had utilized MHPSS services, as stigma regarding mental health problems has been documented among refugees[19], and specifically among the South Sudanese population [20]. Additionally, limited use of available MHPSS services has been reported with the suggestion that help-seeking patterns among South Sudanese refugees reflected their tendency to rely on cultural or religious leaders in times of stress rather than accessing MHPSS at the local health center [12, 21]. Future research may consider assessing the barriers that fathers and mothers face in accessing MHPSS resources available to them, as well as help-seeking behaviors regarding stress and mental health issues.

There were mixed findings on the role of social support and networks in how parents cope with stress. On one hand, all participants noted that fathers and mothers talked to others when they are stressed. They noted that parents may talk to: community leaders, religious leaders, friends, neighbors, relatives, elders, spouses, and other individuals they consider to be trustworthy during times of stress. These responses were consistent with a study among South Sudanese refugees that noted the importance of connectedness to their tribe, social networks, and seeking advice from leaders [12]. On the contrary, it was also mentioned by participants that staying quiet and not talking to others, as well as even leaving the family or home, was how parents coped with stress. Possibly choosing to stay quiet and not talk to others was out of a fear of being

stigmatized, as mental health stigma remains an issue among South Sudanese [20].

Addressing the existing stigma around mental health may be a critical factor to increase help-seeking behavior among stressed parents.

Suicide was also mentioned as how some mothers and fathers deal with stress.

Suicide has been reported as the leading cause of mortality among individuals aged 15-29 years living in refugee settings [22, 23]. The rate of suicide attempts and deaths by suicide among South Sudanese refugees in Uganda more than doubled in 2019 compared to the previous year and nearly 20% of refugee households reported incidences of suicidal ideation [24]. A variety of factors that may be impacting suicidal ideation and attempts may contribute to increased stress among the refugees; the stress of daily life, violence, loss of livelihoods, loss of hope, eroded social connectivity, alcohol misuse, and inability to secure children's education and wellbeing [10]. These results highlight the importance of suicide prevention initiatives in the settlements.

Alcohol consumption was mentioned by mothers, fathers, VHTs, and KIIs as a way fathers may handle their stress. Previous studies have noted the issue of alcohol misuse among refugees in Uganda [25, 26]. Data from a study on substance use among displaced individuals in Uganda reported that alcohol was readily available and there were no rules regarding its use [26]. Alcohol use was considered a public health concern, especially among men, and was associated with a wide number of issues, including mental health illness, suicide, dependence, violence, and financial constraints [26]. Furthermore, alcohol use among men has been shown to interfere with the responsibilities of fathers, including a compromised ability to provide the basic needs for their families [27]. Despite the public health concern of alcohol misuse, the monitoring,

prevention, and treatment of substance use among conflict-affected populations in low- and middle-income countries is limited [28]. A review of interventions used to address alcohol use among refugees noted that implementing existing community-based and peer-delivered interventions may be useful [29].

Violence towards spouses and children was mentioned as a response of parents to stress. Previous studies have documented the occurrence of intimate partner violence (IPV) and violence towards children among refugees in Uganda [12, 25, 30]. In 2019, a field research report among these refugees noted that seeking help for IPV issues was difficult [30]. Among barriers to receiving care was the fear of stigma surrounding IPV, victims' pre-conceived beliefs about receiving poor quality care, lack of information about where to access care, and logistical challenges for accessing help [30]. Additionally, service providers reported that they lacked needed resources to provide effective services for IPV victims in the refugee settlements [30].

### **Perceptions of how the community can help mothers and fathers**

Community activities, such as forming groups, and holding meetings and community dialogues were discussed by participants as strategies by which the community could help parents. Additionally, VHTs and KIIs described the need for more leadership, including community sensitization and the need for church leaders to be more involved. These results coincide with the fact that participants mentioned they turn to the community and religious leaders in times of stress, further indicating the key role such leaders can play in helping stressed parents. Previous findings among South Sudanese refugees also indicated the importance of social networks and seeking advice from

leaders to overcome stress and resolve conflicts [12]. The involvement of these key leaders will be important for interventions seeking to decrease stress and improve the mental health of parents.

KIIs noted the importance of raising awareness of existing resources available to parents when they are in need. KIIs indicated that there may be refugees who do not know of resources available to them and suggested all should be educated about services available when they enter the settlement. Interestingly, in the realm of MHPSS services, nearly one-third of both mothers and fathers were unaware these services were available. UNHCR's Uganda Mental Health and Psychosocial Support Strategy, 2019-2021 also has indicated the need for awareness of MHPSS interventions and the importance that interventions may have for the mental and psychosocial wellbeing of refugees [31].

Parents and VHTs mentioned several ideas related to the theme of economic development, including the need to work, access to vocational schooling, start-up money for businesses, and access to land. These results are consistent with findings that refugees had a desired to work and go to school but did not have access to those opportunities [32]. Participants also mentioned that staying busy with working or schooling reduced their stress [32]; yet, only 5% of refugees in Uganda had received skills or job training [33]. Previous findings from Uganda noted that the majority of refugees continue to rely on humanitarian aid [18]. While access to land provides economic benefits, the limited availability of land remains a problem.

Not surprisingly, opportunities related to culture and tradition, including traditional cultural dances and cooking traditional food, were mentioned as ways that

help relieve stress among parents. Migration can lead to cultural bereavement, or grief related to the loss of one's social structure and culture [34], and cultural bereavement among refugees has been identified as a factor among the complex causes of their mental health issues [35]. Therefore, opportunities to express cultural and traditional practices may help preserve culture, as well as decrease stress among refugees. Artistic activities such as dancing, as mentioned by participants, may decrease stress and support health among refugees, as well as help to preserve cultural heritage that can be passed on to children in the settlements [36].

Counseling was mentioned by parents and KIIs as a way to support mothers and fathers. However, as previously discussed, nearly one-third of both mothers and fathers were unaware of MHPSS resources available to them and KIIs indicated the need to raise awareness of existing services. According to the UNHCR's Uganda Mental Health and Psychosocial Support Strategy, 2019-2021, insufficient visibility and awareness of MHPSS services was a barrier for refugees [31]. UNHCR planned to work with existing community structures, including traditional and religious leaders and the VHTs, to raise awareness on mental health, as well as to identify refugees in need of MHPSS services.

One promising intervention receiving attention is the use of the World Health Organization's (WHO) Self-Help Plus among South Sudanese refugees [37]. Self-Help Plus utilizes group-based psychoeducational interventions as well as guided self-help strategies that address stress management skills that could be utilized by individuals with a broad range of stress and mental health challenges. It also seeks to reduce the burden of health care workers while increasing access by delivery in groups of 20-30 people.



Findings from a recent randomized controlled trial among South Sudanese refugees in Uganda indicate that the implementation of Self-Help Plus might be a feasible and effective first-line intervention for refugees who are exposed to stress [11]. The study revealed that individuals who had access to Self-Help Plus compared to individuals receiving enhanced usual care had greater improvements in psychological distress, post-traumatic stress disorder and depression symptoms, explosive anger, functional impairment, and subjective wellbeing at 3 months post intervention [11]. Enhanced usual care was defined as psychoeducation provided by a trained community health worker during a 30 minute individual meeting as well as information on how to access existing mental health services [11]. Utilization of the Self-Help Plus intervention has the potential to decrease stress levels and improve mental health of South Sudanese refugees as well as increase the capacity of the informal community to care for individuals facing stress and mental health issues.

### **Recommendations**

First, the existing stigma surrounding mental health among South Sudanese needs to be addressed; the use of advocacy leaders in the communities may be an effective avenue toward decreasing stigma and increasing reliance on social support networks and utilization of MHPSS services [20]. Programs seeking to decrease stress and improve the mental health of parents should consider the involvement of key community leaders whom the parents rely on in times of stress. Participants noted that counseling would be important for stressed parents which indicates the importance of implementing UNHCR's Uganda Mental Health and Psychosocial Support Strategy. More awareness of all services available to refugees is needed, so they know where they can access the help

available to them, especially when they are feeling stressed. Additionally, working to scale-up the utilization of the Self-Help Plus may be an effective way of helping stressed parents in the refugee settlements.

Additionally, results indicate the importance of suicide prevention initiatives. A need to strengthen surveillance of suicidal ideations and attempts among refugees in the West Nile region of Uganda has previously been noted and the results from our study corroborate this need [21]. In addition to surveillance, training refugees, community leaders, and VHTs on how to respond to suicidal ideations and attempts may be helpful. Furthermore, because parents mentioned they rely on a variety of people in times of stress, it would be important to raise awareness in the communities to ensure individuals can identify early indications of suicidal behavior [31].

A study evaluating a suicide prevention intervention in India among Sri Lankan refugees reported that the intervention was feasible and reduced suicidal behavior among refugees [38]. The intervention involved community volunteers making visits to provide emotional support to refugees who were suicidal or depressed. At the visits, individuals with the help of the community volunteers developed a safety planning card that included the warning signs of suicidal behavior, a personalized list of coping strategies, and a list of support available. Individuals were encouraged to utilize the safety planning card when in distress. The safety planning cards also included contact information for individuals who could be contacted during a suicidal crisis [38]. This type of intervention may be effective among South Sudanese refugees, and future research may consider assessing the feasibility and receptiveness of this type of intervention for implementation in Uganda.

Due to the public health concern of alcohol misuse among refugees, the monitoring, prevention, and treatment of substance use is imperative. A review of interventions used to address alcohol use among refugees noted that implementing existing community-based and peer-delivered interventions may be useful [29]. Additionally, substance-use training for primary healthcare workers is needed to increase the ability of providers to identify such problems, as well as provide any necessary treatment and care [29]. For interventions seeking to reduce alcohol misuse among fathers, the issue should not be seen in isolation; rather, substance use interventions should be considered essential aspects of general health care and MHPSS services [26]. Lastly, alcohol use among refugees needs the attention, support, and collaboration of policymakers and the government to address this important public health concern with effective measures [39].

Study results highlight the need to strengthen the capacity of communities to respond to intimate partner violence (IPV) and child protection issues such as child abuse. As previously mentioned, the use of a treatment delivered by non-specialist refugee workers improved outcomes for IPV victims in a refugee setting [40]. However, issues of violence often fall under the realm of protective services, instead of the health sector. Therefore, integrated interventions that involve both health and protection services are likely to be more effective in ensuring IPV victims receive the care they need. Additional considerations should be made towards raising awareness among refugees of how neighbors, friends, family members, and the community can help and support IPV victims. A study that involved Sudanese refugees in Kenya noted that some male refugees were mistrustful of how agencies respond to IPV issues, as well as noting that

only extreme cases require the attention of UNHCR or other agencies [41]. Research indicated that IPV programs currently in place may not result in the protection of women and the use of social support networks that are closer to the IPV victims may be a more effective approach to addressing the issues involving IPV [41].

Previous recommendations have been made that indicate economic opportunities for refugees should also include non-agricultural income-generating opportunities [18, 32]. Recommendations from the World Bank corroborate the importance of evaluating existing policies related to refugees' economic opportunities and of revisions to policies to increase opportunities for refugees to become self-reliant [33]. If such opportunities cannot be provided in the settlements, the Government of Uganda may need to consider the feasibility of allowing refugees to move freely out of the settlement to pursue livelihoods elsewhere without losing refugee status or access to humanitarian aid [18, 32].

### **Limitations**

Participants were all from South Sudan and may not be representative of other refugee populations; therefore, results may not be generalizable across refugee populations. Social desirability bias may have been present due to the nature of qualitative research, and stigma around stress and mental health may have led some participants to limit their sharing in discussions. Finally, non-governmental organization workers and other health care providers involved in MHPSS were not interviewed as KIs but may have added additional useful information.

### **Conclusion**

South Sudanese refugees living in post-emergency settlements in Adjumani district in the West Nile region of Uganda coped with stress in both healthy and unhealthy ways. Social networks, recreational opportunities, and accessing MHPSS services were mentioned as important aspects of helping parents deal with stress in healthy ways. Alcohol misuse, IPV, child mistreatment, and suicide were unhealthy coping mechanisms and concerning issues within the settlements. Counseling, leadership, and more engaged involvement were discussed as ways the community could help stressed parents. Economic development opportunities, such as access to work, schooling, and land for agriculture, were also mentioned and would likely be best addressed at the administrative and policy level of the host country and UNHCR.

**Table 1.** Guides for focus group discussions and key informant interviews

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**Focus group discussion questions: Mothers**

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- Who do mothers talk to when they feel stressed?
- Is it common to talk to others when you feel stressed?
- How do mothers in the community respond to problems or stress?
- Where would mothers in your community get help when they are stressed?
- What ways do you think the community can help mothers feel less stressed?

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**Focus group discussion questions: Fathers**

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- Who do fathers talk to when they feel stressed?
- Is it common to talk to others when you feel stressed?
- How do fathers in the community respond to problems or stress?
- Where would fathers in your community get help when they are stressed?
- What ways do you think the community can help fathers feel less stressed?

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**Focus group discussion and interview questions: Village Health Team & Key Informants**

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- Who do mothers talk to when they feel stressed?
  - Who do fathers talk to when they feel stressed?
  - Is it common to talk to others when they feel stressed?
  - How do mothers in the community respond to problems or stress?
  - How do fathers in the community respond to problems or stress?
  - Where would mothers in your community get help when they are stressed?
  - Where would fathers in your community get help when they are stressed?
  - Would mothers be willing to ask for help when they are stressed?
  - Would fathers be willing to ask for help when they are stressed?
  - What resources are in your community to help parents when they are stressed?
  - What ways do you think the community can help parents feel less stressed?
  - What do you see as your role in helping community members overcome stress?
- 

**Table 2.** Descriptive characteristics of mothers and fathers (n = 115)

Characteristics	Mothers (n = 66)	Fathers (n= 49)
	<u>Mean</u>	<u>Mean</u>
Respondent age (years)	28.2	38.1
Child's age (months)	13.2	16.1
Household size	6.6	8.5
	<u>%</u>	<u>%</u>
Occupation		
No occupation	92.4	55.1
Farmer	0	26.5
Office work	7.6	16.3
Other	0	2.1
Ethnicity		
Dinka	3.0	59.2
Madi	66.6	30.6
Acholi	7.6	0
Other	22.8	10.2
Education level		
Illiterate	18.2	24.5
Informal education	3.0	4.1
Formal education	78.8	71.4
Duration as refugee in West Nile, Uganda		
2 - 3 years	75.7	38.8
4 - 5 years	18.2	36.7
> 5 years	6.1	24.5
Aware of available MHPSS <sup>1</sup> services		
Yes	69.7	69.4
No	30.3	30.6
Utilized available MHPSS <sup>1</sup> services		
Yes	40.9	42.9
No	59.1	57.1

<sup>1</sup>Mental health and psychosocial support

**Table 3.** Perceptions of how mothers and fathers cope with stress

<b>Themes</b>	<b>Codes</b>	<b>Quotations</b>	<b>Data Source (# times mentioned)</b>
<b>Contacting leaders or authorities</b>	Official authorities	<p>“If the case is concerning police, you refer to police.” – KII #2</p> <p>“If it’s big issues then you call in the authorities and the United Nations High Commissioner for Refugees too.” – Mothers FGD (Boroli)</p>	<p>KII (2)</p> <p>Mothers FGD (1)</p>
	Community leaders	<p>“If a man was having problem, he should go to the respected big person like the leader for more advice.” – VHT FGD (Boroli)</p> <p>“You go to the women leader and if the problem was big she can refer to the Refugee Welfare Council.” – VHT FGD (Boroli)</p> <p>“The block leader can be able to advise, that’s what he is supposed to do.” – KII #4</p> <p>“You go to the block leader and report the issue chairman of the camp.” Mothers’ FGD (Boroli)</p> <p>“It’s easy for block leaders to be able to solve.” Mothers’ FGD (Boroli)</p> <p>“I will call community leaders and we are going to solve the problem peacefully.” – Mothers’ FGD (Boroli)</p>	<p>KII (7)</p> <p>Mothers FGD (1)</p> <p>Mothers and Fathers FGD (3)</p> <p>VHT FGD (3)</p>



		<p>“I can also involve the camp leader in if the problem persists.” Mothers’ FGD (Boroli)</p> <p>“Sometimes I just go to the community leaders.” – Mothers’ FGD (Agojo)</p> <p>“You have to go to community leader for more advice.” – Mothers’ and Fathers’ FGD (Pagirinya)</p>	
	Religious leaders	<p>“You can talk to trusted elders in the community and the churches.” – Fathers’ FGD (Ayilo)</p> <p>“Go to churches.” – Mothers’ FGD (Agojo)</p> <p>“They go to the church leaders.” – VHT FGD (Boroli)</p>	<p>Fathers FGD (2)</p> <p>Mothers and Fathers FGD (1)</p> <p>VHT FGD (1)</p>
<b>Talking to others</b>	Friends	<p>“When they have that stress, instead of staying lonely, they join their fellow men, they share, and become open to people.” – KII #4</p> <p>“They talk to their friends and they will stop there.” –KII #1</p> <p>“Trusted friends whom you know, you share with them and they will advise you.” – Fathers FGD (Ayilo)</p>	<p>Fathers FGD (3)</p> <p>KII (3)</p> <p>Mothers FGD (1)</p> <p>VHT FGD (5)</p>

		“When a mother feels stress she’ll first talk to the best friend.” Mothers’ FGD (Boroli)	
	Neighbors	<p>“The neighbor will talk to them so that they can solve these things.” – KII #3</p> <p>“It depends on the husband if he decides to talk to the relatives or to the neighbors”. – Fathers FGD (Ayilo)</p> <p>“I will call my neighbors and we are going to solve the problem.” Mothers FGD (Boroli)</p> <p>“If he doesn’t have brothers he should call the neighbors and the neighbors will come and sit for a meeting and they find out on how to get a solution.” – Mothers and Fathers FGD (Pagirinya)</p> <p>“Maybe with the neighbors, they go together to watch football if they’re stressed. A person that maybe you notice their face has changed, they look different, and you ask what’s wrong?”– Fathers FGD (Boroli)</p> <p>“The neighbors whom they trust.” VHT FGD (Boroli)</p>	<p>Fathers FGD (1)</p> <p>KII (3)</p> <p>Mothers FGD (1)</p> <p>Mothers and Fathers FGD (2)</p> <p>VHT (2)</p>
	Someone trustworthy	“Always go to the trusted people.”– Fathers FGD (Ayilo)	<p>Fathers FGD (1)</p> <p>Mothers FGD (1)</p> <p>Mothers and Fathers FGD (1)</p>

		<p>“He has to go to the person who he trusted.”- Mothers and Fathers FGD (Pagirinya)</p>	
	<p>Relatives or elders</p>	<p>“They [men] typically go to elder people for advice.” – KII #5</p> <p>“Like grandfather, if they [men] have a grandfather there they can talk to them.” – KII #3</p> <p>“Even the man who is stressed, he can talk to the relatives and say ‘I have a problem’.” – KII #3</p> <p>“The wife can talk to the relatives of the husband first.” – KII #3</p> <p>“The fathers seek the psychosocial support from the relatives.” - Fathers FGD (Ayilo)</p> <p>“You call your family members and you pray together.” Fathers FGD (Ayilo)</p> <p>“That thing depends on the husband, if he decides to talk to the relatives or to the neighbors.” – Fathers FGD (Ayilo)</p> <p>“You can talk to trusted elders in the community.” – Fathers FGD (Ayilo)</p> <p>“To the concerned person in community like the elder.” Mothers FGD (Agojo)</p>	<p>Fathers FGD (5)</p> <p>KII (8)</p> <p>Mothers and Father FGD (3)</p> <p>VHT FGD (3)</p>

		<p>“Sometimes she can talk to the sister-in-law or brother-in-law.” - Mothers and Fathers FGD (Pagirinya)</p> <p>“Some talk to uncles and others would talk to father in laws.” – VHT FGD (Boroli)</p>	
	Spouse	<p>“By the way he can even talk to them, to the wife first. My wife, he says my wife, I have think about this and this and I didn’t get what way forward can we do it? Then the wife, if the wife is very skill in mind, she said okay if that is the worry why don’t we sit a bit and think, we leave it for today then think for the tomorrow things.” –KII #3</p> <p>“Sometimes as a woman I ask my husband if there is a problem that I have done to him that might be paining him. By doing so, it will reduce tension us.” - Mothers and Fathers FGD (Pagirinya)</p>	<p>Fathers FGD (1) KII (3) Mothers and Fathers FGD (1) VHT FGD (1)</p>
<b>Healthy coping skills</b>	Crying	<p>“They [women] shout, they [women] cry.” – KII #5</p> <p>“With tears, when I have problems with my husband.” – Mothers FGD (Agojo)</p> <p>“I only carry with tears.” – Mothers FGD (Agojo)</p>	<p>KII (2) Mothers FGD (1)</p>

	Recreation	<p>“You go to the playing ground to refresh your mind.” Mothers FGD (Agojo)</p> <p>“Always for me in the home I keep on singing songs.” –Mothers FGD (Agojo)</p>	<p>Mothers FGD (2)</p> <p>Mothers and Fathers FGD (1)</p>
	Access available resources	<p>“In the community, like our community now, we have these people called the group of psychosocial. The psychosocial are the people to help your problem and you explain your problem. The psychosocial person can even move around in the community to go and call you and sit and talk with you.” – KII #3</p> <p>“They come to the focal person of psychosocial of Lutheran World Federation.” – KII #5</p>	<p>KII (4)</p> <p>Mothers FGD (2)</p>
<b>Unhealthy coping skills</b>	Suicide	<p>“She can kill herself or when people are not there and she is alone at home, she can even get a sharp thing, like a knife, and kill herself, which is a knife.” – KII #3</p> <p>“She is going to hide and hang herself.” – KII #3</p> <p>“He went and killed himself because of the stress.” –KII #3</p> <p>“Suicide among men because of stress.” –KII #6</p>	<p>Fathers FGD (1)</p> <p>KII (5)</p>
	Drink alcohol	<p>“He’ll make sure every day he’s drunk.” –VHT FGD (Boroli)</p>	<p>Fathers FGD (1)</p> <p>KII (1)</p>

		<p>“They go and drink.” – KII (Ayilo Jumo)</p> <p>“The man takes from ration money and drinks alcohol with it.” – Mothers FGD (Boroli)</p> <p>“Too much drinking alcohol.” – Mothers FGD (Agojo)</p> <p>“Men will drink alcohol.” – VHT FGD (Boroli)</p> <p>“Every day he’s drunk.” – VHT FGD (Boroli)</p>	<p>Mothers FGD (2)</p> <p>Mothers and Fathers FGD (1)</p> <p>VHT FGD (3)</p>
	Commit violence	<p>“Most of them [mothers] they are aggressive.” – KII #5</p> <p>“They [mothers] respond by retaliating violence on that person.” – KII #6</p> <p>“For men, they beat.” – KII #1</p> <p>“Some fathers when they have problems with the wife they will drink alcohol and end up being violent.” VHT FGD (Boroli)</p>	<p>KII (5)</p> <p>Mothers and Fathers FGD (1)</p> <p>VHT (1)</p>
	Cause marital issues	<p>“You know there are so many ways, sometimes by not giving support to the wife. Secondly by not even eating what the wife cooked.” VHT FGD (Boroli)</p>	<p>VHT FGD (5)</p>

		“Just by not talking to the husband.” – VHT FGD (Boroli)	
	Abuse or neglect child	<p>“Some women when they’re stressed, they will respond to the problem by beating a child and start slapping a child.” –VHT FGD (Boroli)</p> <p>“You’ll find the mother may start insulting the child.” VHT FGD (Boroli)</p> <p>“They [mothers and fathers] extend their anger to the children.” – KII (Pagirinya 2)</p>	<p>KII (3)</p> <p>VHT FGD (4)</p>
	Stay quiet and not talk to others	<p>“They are always reserved. For men they are reserved, they are not open.” –KII #5</p> <p>“She keeps it in her heart, she doesn’t want to tell to anyone.” – KII #3</p> <p>“I think fathers have no other people who normally care for them.” – Fathers FGD (Ayilo)</p> <p>“For me, I am just sitting quiet and hold my mouth.” – Mothers FGD (Agojo)</p> <p>“In the community I keep silent, I do not talk.” – Mothers FGD (Agojo)</p> <p>“The man will feel ashamed to open up to people, it sounds shameful for them so they keep quiet.” VHT FGD (Boroli)</p>	<p>Fathers FGD (3)</p> <p>KII (3)</p> <p>Mothers FGD (4)</p> <p>VHT FGD (1)</p>

	Leaving the family	<p>“Packing, going away, leaving the place.” – KII #6</p> <p>“Leaves the home and goes to stay with the relatives to avoid those problems.” -Fathers FGD (Ayilo)</p> <p>“I took my journey I went away I stay for one month and I came back and no more problem, the problem solved.” – VHT FGD (Boroli)</p>	<p>Fathers FGD (1)</p> <p>KII (3)</p> <p>VHT FGD (1)</p>

Abbreviations in Table 3:

FGD: Focus Group Discussion

KII: Key Informant Interview

VHT: Village Health Team

**Table 4.** Perceptions of how the community can help mothers and fathers

<b>Themes</b>	<b>Codes</b>	<b>Quotations</b>	<b>Data Source (# times mentioned)</b>
<b>Community discussions</b>	Form groups	“Group the fathers and even have them elect their own leaders to attend to their	<p>Fathers FGD (1)</p> <p>Mothers &amp; Fathers FGD (1)</p>



		problems.” – Fathers FGD (Ayilo)	
	Hold meetings	“The only way I think the community should help the stressed fathers is call them for a meeting and ask them about their difficulties that are hard to solve then they support them.” – Fathers FGD (Ayilo)	Fathers FGD (1)
	Organize community dialogues	“The other community members, when they see that person very stressed, they call that person and talk to him. They used to come every morning, in the midday, and even in the evening, they used to come as a group and counsel. That is the work for the community. “ – KII #2	KII (1) VHT FGD (1)

<b>Leadership</b>	Community sensitization	“By community sensitization, you sensitize the community on what is going on. Now when the community has been sensitized they settle the fact that their issues have been solved.” –VHT FGD (Boroli)	VHT FGD (1)
	Church leaders be more involved	“You know the church leaders can also help by telling a person to analyze his condition, pull themselves out from that condition. So the church leaders can help.” – VHT FGD (Boroli)	KII (1) VHT FGD (1)
	Raise awareness of existing resources	“By coming to them trying to make them aware of the channels of getting assistance. For those who may not know, those who might be new to the settlement, they have to be educated right from the entry point about what other services	KII (2)

		are provided. In case they need something, tell them this is the area to go in case you are lacking and tell them where to go to get those things.” – KII #6	
	Make rules and regulations	“Rules and regulations have to be set correct to address what goes wrong in your community.” – Mothers and Fathers FGD (Pagirinya)	Mothers & Fathers FGD (1)
<b>Economic development</b>	Encourage working	“Like when they are making money from cutting charcoal, they’ll be advised to go and work on charcoal or laying bricks for making money, it would be go to work on laying bricks.” – VHT FGD (Boroli)	VHT FGD (1)
	Vocational schooling	“Vocational school should be put in our community like	Mothers & Fathers FGD (1)

		hairdressing or carpentry.” – VHT FGD (Boroli)	VHT FGD (1)
	Provide money for businesses	“Support for cash grant for business.” –Mothers and Fathers FGD (Pagirinya)	Mothers & Fathers FGD (1) VHT FGD (1)
	Provide land	“If we have agriculture land, men can go in the field.” – Mothers and Fathers FGD (Pagirinya)	Mothers & Fathers FGD (1)
<b>Recreational opportunities</b>	Keep parents busy	“Another way is to support them since an idle mind is a devil workshop so when they have anything to do they will forget about their stress and continue with their activities. – Fathers FGD (Ayilo)	Fathers FGD (1)

	Organize dramas	“Organizing dramas and you have solutions you see physically what they are doing to help you pick some point out from it.”- VHT FGD (Boroli)	VHT FGD (1)
	Recreational play	“Football playing both for women and men.”- VHT FGD (Boroli)	VHT FGD (1)
	Traditional activities	“Traditional cultural dances in the community so that they learn.”- VHT FGD (Boroli)	VHT FGD (1)
<b>Counselling</b>	Provide counseling/training	<p>“The church leaders can provide counseling.”- KII #1</p> <p>“LWF psychosocial section can also provide training on conflict management this may help or reduce our heart pain</p>	<p>KII (3)</p> <p>Mothers &amp; Fathers FGD (2)</p>

		or problems.” – Mothers and Fathers (Pagirinya)	
	Advise and visit with parents	<p>“Like here in Boroli, people who have problems, we need to give them ideas and share with them so that their problem will be solved.” – Mothers FGD (Boroli)</p> <p>“I will advise them in good way if they can understand me.” – Mothers FGD (Boroli)</p> <p>“Sometime mothers and fathers get advice from leaders of the community such as chairman or block leaders if they have heart pain or problems.” – Mothers and Fathers FGD (Pagirinya)</p> <p>“By advising them.” – KII #6</p>	<p>KII (1)</p> <p>Mothers FGD (2)</p> <p>Mothers &amp; Fathers FGD (2)</p>

		<p>“Visit, every day, whether in the morning or in the afternoon you go and visit them.”– KII #3</p>	
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Abbreviations in Table 4:

FGD: Focus Group Discussion

KII: Key Informant Interview

VHT: Village Health Team

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CHAPTER V  
BREASTFEEDING AMONG SOUTH SUDANESE REFUGEES IN POST  
EMERGENCY SETTLEMENTS IN ADJUMANI DISTRICT, UGANDA:  
FACILITATORS AND BARRIERS

**Abstract**

Evidence suggests that forced migration and refugee status may adversely impact mothers' breastfeeding choices. Furthermore, suboptimal breastfeeding practices have been reported among vulnerable populations including those living in refugee settlements. Therefore, this study investigated the barriers and facilitators of breastfeeding in post-emergency settlements in Adjumani district, in the West Nile region in Uganda. This study was conducted among refugees living in post-emergency settlements located in Uganda in July 2019. Participants, originally from South Sudan, included mothers (n= 63) and fathers (n= 32) of children less than 24 months of age. Agojo, Ayilo-I, and Nyumanzi were randomly selected among the 17 refugee settlements in Adjumani. Participants formed a total of six focus group discussions (FGDs); four FGDs for mothers and two FGDs for fathers. Each FGD consisted of 15-16 participants. Data were transcribed verbatim and back-translated into English. Thematic analysis was used and data were analyzed using NVivo, v. 12.

Facilitators of breastfeeding included knowledge of breastfeeding benefits, support from husband/father, support from the community, and support from non-governmental organizations. Mothers and fathers noted that breastfeeding protected children from diseases and breastfed children grew well. Four themes were identified as barriers to breastfeeding: physical, socioeconomic, knowledge, and psychosocial. Mothers and fathers described physical barriers such as mothers stop breastfeeding when they are sick or they feel they are not producing enough breastmilk. Fathers described psychosocial barriers such as mothers' fear of pain during breastfeeding and maternal mental health issues. Interventions and policies that aim to improve breastfeeding in post-emergency settlements should consider addressing the barriers to breastfeeding at each level: physical, socioeconomic, knowledge, and psychosocial. Involving and encouraging support from husbands/fathers, relatives, and the community may increase adherence to breastfeeding recommendations.

## **Introduction**

Optimal nutrition is important for healthy infant growth and development [1]. Breastmilk is considered a key component of adequate nutrition because it contributes to decreased risk of infectious diseases and infant mortality, while also promoting optimal neurodevelopment [1, 2]. Additionally, breastfeeding has long-term benefits including reduction in the risk of chronic diseases such as cardiovascular disease, diabetes and obesity [3]. The risks of undernutrition, infectious disease, and mortality are significantly increased among refugee children less than 24 months of age who are not breastfed and in infants less than six months of age who are not exclusively breastfed [4]. The World Health Organization (WHO) recommends that mothers breastfeed within the first hour of birth, exclusively breastfeed until the infant is six months of age and continue

breastfeeding to two years or beyond [5]. The Global Breastfeeding Scorecard has breastfeeding targets to be reached by 2030 including early initiation of breastfeeding (70%), exclusive breastfeeding (70%), and continued breastfeeding (80%) [6].

Despite the WHO breastfeeding recommendations, global breastfeeding rates remain low, especially in vulnerable populations, such as those who have been displaced or are refugees living in another country. Globally, over 80 million individuals have been forcibly displaced, with 26.3 million of those individuals being refugees in another country [7]. The South Sudanese refugee population is the third largest globally and is the largest refugee crisis in Africa [8]. In 2011, after a distressing civil war, South Sudan declared independence and became the youngest country in the world [9]. However, since 2013 when armed conflict broke out, over 2.3 million South Sudanese have fled their home country to find refuge [8, 9]. Over 80% of South Sudanese refugees are women and children [8]. Most of these refugees have fled to neighboring countries of Sudan, Ethiopia, Kenya, Democratic Republic of Congo, and Uganda [8]. Uganda hosts more South Sudanese refugees than any other country and nearly 65% of all the refugees in Uganda have fled South Sudan [9]. Most refugees in Uganda live in settlements and more than half of the refugees reside in northern Uganda or West Nile [9]. Adjumani district is located in the West Nile region of Uganda and hosts over 200,000 refugees in settlements, among whom 60% are children [10]. In 2020, the three leading morbidities among children under 5 were malaria (41%), respiratory tract infections (23%), and acute watery diarrhea (12.7%) [10].

Limited research has been conducted on breastfeeding in post-emergency settlements in Uganda; however, a recent study in Adjumani district reported that among 561 mothers



in these settlements, just over half (57%) breastfed their infants within one hour of birth [11]. In 2020, early initiation of breastfeeding rates ranged from 58%-84.4% across refugee settlements. Exclusive breastfeeding rates across all settlements was 62.3%, a considerable decrease from the previous exclusive breastfeeding rate of 90.7% reported in 2014. Across settlements in Adjumani, the exclusive breastfeeding rate was 42.3%, nearly 20 percentage points lower than the average across all settlements. Compared to other districts in the West Nile region, breastfeeding rates of refugees were the lowest in Adjumani [10].

Recent studies are consistent with the WHO's concern that forced migration and refugee status may adversely impact mothers' breastfeeding choices [12]. In Rwanda, a study among refugees revealed only 34.4% of infants were exclusively breastfed for the first six months of life, despite 74.4% of mothers demonstrating knowledge of and having positive attitudes towards exclusive breastfeeding [13]. In refugee camps in Algeria, while 65% of refugee mothers initiated breastfeeding within one hour of birth, only 11.7% exclusively breastfed and 21.6% predominantly breastfed their infants to the age of six months [14]. Furthermore, a study in Turkey reported that Syrian refugees were less likely to breastfeed than native Turkish mothers and observed that forced migration and refugee status were negatively associated with the choice to breastfeed [15]. A meta-ethnographic study of refugee and migrant women's experiences of breastfeeding concluded that mothers who did not have access to traditional postpartum practices and who experienced tension with breastfeeding in a new country were more likely to cease breastfeeding [16].

Therefore, the barriers and facilitators of breastfeeding were investigated among refugees living in post-emergency settlements in the West Nile region of Uganda. The two main research questions for this qualitative study were: 1) what are the facilitators of breastfeeding among women living in post-emergency settlements? And 2) what are the barriers to breastfeeding among women living in these settlements? The data will be useful for informing policies and interventions aimed at improving breastfeeding among refugees.

## **Methods**

### **Participants**

This study was conducted in post-emergency settlements located in Uganda in July 2019. Participants, who were originally from South Sudan and living as refugees in the settlements, included mothers (n= 63) and fathers (n= 32) of children less than 24 months of age. Agojo, Ayilo-I, and Nyumanzi were randomly selected among the main refugee settlements in Adjumani. Along with Lutheran World Federation community service officers and health care workers in the randomly selected settlements, the research team coordinated with the Village Health Teams, who routinely interact with parents, to prepare lists of mothers and fathers of children under 2 years of age living within the villages where they operate. From those lists, participants were selected randomly, and with the help of the VHTs, prospective participants were mobilized for the FGDs. Mothers and fathers were recruited from different households. There were a total of six focus group discussions (FGDs): four FGDs for mothers and two FGDs for fathers and each FGD had 15-16 participants.

## **Data collection**

Questions used in the FGDs (Table 1) were developed based on previous research and were reviewed by the research team and doctoral committee. Before data collection, the questions were examined by research translators who were hired for their proficiency in English as well as in at least one of the three local languages. The translated documents were cross-checked by two other translators and pre-tested among parents in the settlements. The final translated FGD guide was agreed upon by the research team. FGDs were conducted by the research team along with enumerators, who were hired based on their prior experience in bridging communication gaps between humanitarian organizations and refugees. FGDs were held in community centers and were conducted in Arabic, Dinka, or Madi, the languages primarily spoken by the participants and were audio-recorded. Probing questions were used during the FGDs and saturation was considered to be achieved when no new information was contributed by participants.

## **Data analysis**

Audio recordings of the FGDs were transcribed verbatim by native speakers of Arabic, Dinka, and Madi. Next transcriptions were back-translated to English by native speakers who were also proficient in English. Data were coded by the research team using NVivo, v. 12. Cleaning of codes was completed by the primary investigator and reviewed by the research team. The research team identified codes with similarities to form themes that appeared to answer the research questions using thematic analysis. When discrepancies in analysis occurred among the researchers, they were resolved as a team during coding and thematic analysis. However, due to the nature of the participants' responses, there was minimal disagreement among researchers during the data analysis.

## **Trustworthiness/reliability**

Data were collected from participants living in three different post-emergency settlements which allowed for multiple perspectives and which likely increased data reliability. Probing questions used during the FGDs helped achieve saturation.

Furthermore, during the formation of codes and themes, the involvement of the research team further reinforced trustworthiness and reliability.

## **Ethics**

The study was approved by the Makerere University School of Health Sciences Research and Ethics Committee in Uganda, the Uganda National Council of Science and Technology, and the Oklahoma State University Institutional Review Board. Eligible participants were made aware of the purpose of the study and were provided the opportunity to ask questions. Participation in the study was voluntary and all participants signed informed consent before data collection began. Compensation for participation was provided to all participants in the form of household and food items that were worth approximately 1.5 USD.

## **Results**

### **Demographics of Participants**

Key descriptive characteristics of the participants are summarized in Table 2. The mean age of fathers (39.7 years) was higher than that of mothers (27.1 years). Fewer mothers reported working outside the home (14.3%) compared to fathers (50%). A higher

percentage of mothers were illiterate (36.5%) than fathers (18.8%). Many mothers (71.5%) reported attending four or more antenatal sessions.

### **Facilitators**

Beliefs and knowledge about breastfeeding benefits, support from husband/father, support from the community, and support from non-governmental organizations (NGOs) were identified facilitators of breastfeeding (Table 3). Many mothers and fathers mentioned that breastmilk was nutritious and would protect against disease as well as help the child grow strong and well.

*“An infant fed with breastmilk grows well and will be strongly protected from the diseases.” - Mother (FGD Nyumanzi)*

*“Breastmilk makes the baby strong and sometimes protect the baby from diseases.” - Father (FGD Ayilo-I)*

*“An infant fed with breastmilk will grow well.” – Mother (FGD Nyumanzi)*

*“Breastmilk makes the baby strong.” – Father (FGD Ayilo-I)*

Many fathers mentioned different ways that they support breastfeeding mothers including providing food and emotional support. Fathers said that they should make sure the breastfeeding mother has something to eat and that she feels happy. They also reported that they can assist with household chores that are typically considered the role of the wife such as helping clean the home and cultivating the garden as a way to support breastfeeding.

*“Your role is to provide the food for the mother who is breastfeeding, when you increase the diet for the wife the baby will breastfeed very well.”*

*- Father (FGD Ayilo-I)*

*“Make her feel happy and loved.” - Father (FGD Ayilo-I)*

*“A husband is supposed to help his wife by taking part in cleanliness of home.” - Father (FGD Ayilo-I)*

Additionally, participants mentioned community support and support from other organizations as facilitators of breastfeeding. Community support included help from relatives, such as grandmothers, and also from neighbors. Medical Teams International (MTI) and Plan International, partner agencies of the United Nations High Commissioner for Refugees (UNHCR), were mentioned as the NGOs providing support to breastfeeding mothers in the area.

*“In our homes grandmothers do provide mothers with food for cooking so that she produce more breastmilk for the child.” – Mother (FGD Agojo)*

*“And also some neighbors do support mother with providing them firewood and drinking water.” - Mother (FGD Agojo)*

*“They were being supported by the partners MTI and Plan International who were giving out flour for porridge.” - Mother (FGD Agojo)*

## **Barriers**

Identified barriers were organized into four themes: knowledge, physical, socioeconomic, and psychosocial (Table 4). Both mothers and fathers reported that

infants under six months could be fed supplemental feedings that include powdered milk diluted with water, cow's milk, juice or formula. Also, some mothers discussed that breastmilk is not sufficient for sick infants and therefore, breastfeeding should be supplemented with other liquids.

*“When the baby is sick and has become very weak and although has not reached the required age, breastfeeding should be supplemented with other liquids such as milks and drinks.” - Mother (FGD Nyumanzi)*

*“It is to sustain the baby until 6 months and that is why the baby is given milk and blueband [margarine].” - Mother (FGD Nyumanzi)*

*“A baby is given cow's milk before reaching 6 months.” - Nyumanzi (Mothers FGD)*

*“Other supplements are juices.” - Mother (FGD Nyumanzi)*

*“A baby is given infant formula such as Nan1 and Nan2 for their feeding.” - Father (FGD Ayilo-I)*

*“When you have cow's milk, other parts of the milk is skimmed for butter and ghee and should be the supplement for the feeding of the baby.” – Father (FGD Ayilo-I)*

Many participants identified that when the mother is sick, there will be a disruption in breastfeeding. Mothers and fathers reported that sick mothers may have been advised to stop breastfeeding or believe that the disease may transmit through breastmilk.

*“When you are not healthy, you will not be allowed to breastfeed your baby.” - Mother (FGD Nyumanzi)*

*“When the mother is sick, the baby is supposed to stop breastfeeding so not to transmit the disease from the mother to the child.” - Father (FGD Ayilo-I)*

Mothers and fathers both reported that mothers may not produce enough breastmilk and experience other breastfeeding difficulties that lead them to stop breastfeeding. They stated that sometimes if a mother does not initiate breastfeeding early, she has difficulties breastfeeding or that a child may not breastfeed well.

*“Sometimes the breastmilk is not coming.” – Mother (FGD Agojo)*

*“It’s because the mother may lack enough breastmilk.” - Father (FGD Ayilo-I)*

*“The reason might be the mother have started to give breastmilk late after she has given birth.” – Mother (FGD Agojo)*

*“When a baby is born and refuses to breastfeed from the mother that child is given the supplementary feeding.” - Father (FGD Ayilo-I)*

Only a few mothers discussed barriers related to socioeconomic factors, such as working status and education. Working outside the home or higher levels of education were identified as being factors that hinder breastfeeding.

*“Other mothers are working class.” – Mother (FGD Agojo)*

*“For educated mothers they said they will not feed their child on breastmilk and they will use other milk.” - Mother (FGD Agojo)*

A few fathers mentioned psychosocial barriers such as marital conflict, mothers’ fear of pain during breastfeeding, and maternal mental health issues. Marital conflicts



may lead to the mother temporarily leaving the home without her child, thus she stops breastfeeding.

*“Some women when they fight with the husband at home, they may decide to go to their mother’s home and leave the child with the husband.” -*

*Father (FGD Ayilo-I)*

*“The young woman who has just started giving birth may fear to breastfeed the baby and she may feel pain while breastfeeding.” - Father*

*(FGD Ayilo-I)*

*“When the mother is not normal like she is mad, then the baby should be fed with alternative feeding because she may even harm the baby so it is*

*better to stop the baby from breastfeeding.” - Father (FGD Ayilo-I)*

## **Discussion**

### ***Facilitators***

Both mothers and fathers mentioned beliefs and knowledge about breastfeeding benefits that were identified facilitators of breastfeeding. Participants discussed that breastmilk was nutritious, would make the baby grow to be smart, and would protect against disease as well as promote healthy growth. These findings are consistent with previous qualitative studies in Nigeria [17], Ghana [18], and Zimbabwe [19] which found that beliefs or knowledge about breastfeeding were facilitators of breastfeeding.

Knowledge is an important part of behavior change and is an aspect of social and behavior change communication (SBCC) interventions [20]. The use of SBCC for improving breastfeeding practices has been widely shown to be effective across many

countries [20]; however, evidence of the effectiveness of SBCC in post-emergency settlements and among refugees is limited. Because beliefs and knowledge were facilitators of breastfeeding in this study, it is important that interventions aiming to improve breastfeeding consider these two individual factors. Furthermore, training healthcare staff and community health workers to provide and communicate the benefits of breastfeeding to mothers during their antenatal and postnatal visits would be beneficial.

Fathers described different ways that they support breastfeeding mothers including contributing to household chores, procuring food, and providing emotional support. Likewise, in Zimbabwe, the presence of a spouse who assisted with chores was a facilitator of breastfeeding [19] and in Ethiopia, fathers supported breastfeeding mothers by providing and contributing to meal preparation [21]. Among refugee Syrian mothers, those who did not receive social support from their spouse were more likely to stop breastfeeding [22]. A recent systematic review revealed different ways fathers' were involved in supporting breastfeeding mothers, including verbal encouragement and helping with household and child care responsibilities [23].

However, none of these studies were conducted among refugees in post-emergency settlements where fathers may not be present in the household for a variety of reasons including working in their home country or death during conflict. Additionally, a review of 28 projects in 20 low- and middle-income countries did not find consistent associations between male engagement and increases in breastfeeding and noted that there is currently a lack of evidence to make broad recommendations about targeting male engagement to improve breastfeeding [24]. Additionally, there is scant research

available on the role of South Sudanese fathers' in childcare and domestic housework. However, reported defined gender roles among South Sudanese indicate that fathers are responsible for financially providing for their families while the mothers are responsible for household chores [25]. Therefore, future research may consider a more in-depth analysis of local gender norms, fathers' presence in the post-emergency settlements, the level of influence they have in breastfeeding decisions, and the type of support they can offer. This information could inform whether father involvement would be an effective factor in supporting breastfeeding.

A few participants mentioned community support as a facilitator of breastfeeding. Participants discussed how breastfeeding mothers receive help from relatives, such as grandmothers, and from neighbors. Interestingly, the type of support mentioned included material support such as food, firewood, and drinking water. Similar results have been found among refugee mothers in Syria; those who did not receive social support from relatives stopped breastfeeding [22]. Furthermore, in Ethiopia, breastfeeding mothers received support from grandmothers; however, the support differed in that grandmothers in Ethiopia also provided childcare and housework assistance for breastfeeding mothers [21]. A systematic review that assessed grandmothers' roles in breastfeeding found that grandmothers can be influential in breastfeeding decisions and recommended that interventions aiming to improve breastfeeding should consider including grandmothers [26]. Future research might explore the family dynamics among refugees living in post-emergency settlements to better understand the role and influence of grandmothers on breastfeeding in a new environment.

Organizations such as Medical Teams International (MTI) and Plan International were cited as the NGOs providing support to breastfeeding mothers. Plan International provided breastfeeding education and both MTI and Plan International gave flour for porridge for breastfeeding mothers. While NGOs have generally not been mentioned as facilitators of breastfeeding in previous literature, in the context of post-emergency settlements, the presence of partners and NGOs with breastfeeding initiatives may be more common and might be an important avenue for improving breastfeeding practices among refugees.

Interestingly, participants did not mention support from community health workers, medical staff, or peers as facilitators to breastfeeding. Support from peers has been shown to be an effective way to promote breastfeeding [27]. A systematic review and meta-analysis of the effectiveness of community-based peer support for mothers to improve breastfeeding practices, reported that in low- and middle-income countries, community-based peer support increased exclusive breastfeeding, compared to the standard care [28]. Interventions, facilitated by NGOs, or in partnership with the local health care system, involving the use of peers may provide efficient, cost-effective, and sustainable ways to improve breastfeeding among refugees living in post-emergency settlements.

### ***Barriers***

While knowledge of breastfeeding benefits was an identified facilitator, the lack of knowledge of breastfeeding recommendations was a barrier. Many participants, both mothers and fathers, stated that infants under six months could receive supplemental feedings that included items such as powdered milk diluted with water, cow's milk, juice,

formula, or margarine. Introducing complementary feedings before six months and poor rates of exclusive breastfeeding have been reported previously in this area [10]. These results highlight the need for continued emphasis on education about infant and young child feeding practices at antenatal care, place of delivery, and postnatal care.

Breastfeeding difficulties and inadequate breastmilk supply were among the two main physical barriers preventing mothers from breastfeeding. Both mothers and fathers reported that mothers may not be producing enough breastmilk or may experience issues where the child is not breastfeeding well. While perceived low milk supply has been documented in many different contexts and is a common barrier to breastfeeding [19, 21, 29] it is uncertain if maternal perception of inadequate breastmilk is accurate. In order to overcome this barrier, it would be important for mothers to receive education about maternal factors that influence breastmilk supply and how to support breastmilk production. Ideally, such discussions would be best during antenatal care so that mothers are equipped to identify these issues early in their breastfeeding experience. Furthermore, hospitals and other places of delivery may consider training their staff on solutions to common lactation issues that mothers may face during the postnatal period, as well as expansion of community-based support for mothers who lack access to healthcare facilities.

Socioeconomic factors such as working status and education level were barriers mentioned by a few mothers. Despite only 14.3% of mothers working outside the home, this factor was identified as being a barrier to breastfeeding. A systematic review of factors influencing breastfeeding that included 25 studies from 19 countries found that in the majority of the studies, maternal employment outside the home was negatively

associated with exclusive breastfeeding [30] which also is consistent with findings in more recent studies [19, 21, 29]. Overcoming this barrier may be very challenging, depending upon the type of the mother's work outside the home. More information is needed from breastfeeding mothers about their specific barriers to work outside the home. Policies for working mothers may need to be implemented in both formal and informal settings, to allow them to bring their child to work and to allow time throughout the day for breastfeeding. Implementing policies for breastfeeding mothers in informal sectors may be more difficult and may require the influence of strong governmental policies.

The finding that mothers who have more education will chose other milk for their infants is consistent with a recent study in Uganda where mothers felt that if they have enough money, they should not allow their babies to breastfeed [31]. However, other studies have reported that higher education levels are often positively linked to breastfeeding [32-34], and low maternal education has been identified as a risk factor for suboptimal breastfeeding practices [35, 36]. Furthermore, a recent systematic review of 81 low- and middle-income countries found that compared to women with primary, secondary or higher education, women with no formal education had poorer adherence to breastfeeding indicators [37] The inconsistent findings and variations across countries in the association between education level and breastfeeding may highlight specific cultural or societal beliefs influencing mothers. In a recent study in Uganda, participants reported a belief that breastfeeding was for poor women who could not afford an alternative [31].

In the context of refugees in settlements, formula is often one of the first donations to arrive in settlements and its' donations remain unregulated. It has been noted

that mothers who receive donations of formula may perceive it to be superior to breastmilk, and thus formula donations may serve as an impediment to exclusive breastfeeding among refugees in settlements. This reemphasizes the need for policies to regulate and control wide-spread donations of formula in refugee settlements, as well as provide information and support to breastfeeding mothers [38]. Combined with improvement in policies, future research is needed to better understand why mothers with presumably more knowledge about the benefits of breastfeeding may prefer breastmilk substitutes over breastfeeding. Further understanding of these beliefs would inform interventions designed to improve breastfeeding among mothers regardless of their educational level.

Only a few fathers discussed psychosocial barriers such as marital conflict, mothers' fear of pain during breastfeeding, and maternal mental health issues. Marital conflict, in the form of intimate partner violence (IPV) [39-41] and maternal mental health issues, including perinatal depression [42-44] have shown to have a negative influence on breastfeeding among some populations. Refugees are at increased risk for mental health issues [45] and refugees living in Uganda's post-emergency settlements often suffer from psychosocial difficulties [46].

Interestingly, none of these psychosocial barriers were reported by the mothers in the FGDs. Possibly the mothers felt uncomfortable disclosing marital conflict or mental health issues as stigma regarding mental health problems has been documented among refugees [47] and specifically, among the South Sudanese population [46]. These results highlight the importance of including FGDs for fathers as well as mothers because both parents may provide additional insights essential to improving breastfeeding practices.

Furthermore, screening for IPV and maternal mental health during antenatal and postnatal care may be imperative to improve breastfeeding among mothers living in these post-emergency settlements. However, for maternal mental health issues to be addressed adequately, reducing the stigma around these types of issues will be necessary so that individuals are willing to access available resources.

A psychosocial factor not mentioned by fathers or mothers is self-efficacy or the confidence in ability to breastfeed which is reportedly a known facilitator of breastfeeding [48-51]. A systematic review and meta-analysis that included 24 randomized controlled trials from 14 countries found that theory-based educational interventions have been effective in improving breastfeeding self-efficacy and breastfeeding rates at 6 months [52]. Assessing self-efficacy concerns of refugee women could inform the design of effective breastfeeding interventions among this population.

### **Limitations**

Although participants from different post-emergency settlements were included, the results may not be generalizable across all refugees from other districts. Furthermore, parents who were willing to participate may not be representative of the population. Lastly, limitations arising from social desirability bias were possible due to the nature of qualitative research and may explain some of the differences between the responses of mothers and fathers.

### **Conclusion**

This study revealed the complexity of the barriers to breastfeeding faced by mothers living in post-emergency situations. Barriers included individual knowledge of breastfeeding recommendations, physical challenges, socioeconomic status, and



education level, as well as psychosocial barriers. To tackle these wide-ranging barriers, interventions and policies guided by the socioecological model may best address the concerns discussed by participants. Furthermore, because facilitators of breastfeeding included beliefs and knowledge about benefits, antenatal staff should continue to deliver messaging about the benefits of breastfeeding. Support from fathers, the community, and NGOs were facilitators; therefore, these support networks are likely key aspects of an effective strategy to improve breastfeeding among mothers in post-emergency settlements.

**Table 1.** Discussion guides for mothers' and fathers' focus group discussions

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<b>Mothers' focus group discussion guide</b>
What do you think are the benefits of breastfeeding?
At what age should children stop breastfeeding?
What might a parent give a child to eat before they are 6 months old?
How does your community support breastfeeding mothers?
What are some reasons why mothers do not breastfeed their children?
What are some reasons children are given food before six months old?

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<b>Fathers' focus group discussion guide</b>
What do you think are the benefits of breastfeeding?
At what age should children stop being breastfed?
What might a parent give a child to eat before they are six months old?
How does your community support breastfeeding mothers?
What are some reasons why mothers do not breastfeed their children?
What are some reasons children are given food before they are six months old?
What do you feel is your role in supporting your wife who is breastfeeding?

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**Table 2.** Descriptive characteristics of study participants (n = 95)

Characteristics	Mothers (n = 63)	Fathers (n= 32)
	<u>Mean</u>	<u>Mean</u>
Respondent age (years)	27.1	39.7
Child's age (months)	13.2	16.5
Household size	7.3	8.8
Number of living children	3.5	5.7
	<u>%</u>	<u>%</u>
Occupation		
No occupation	85.7	50.0
Farmer	0	12.5
Office work	6.3	0
Other	8.7	37.5
Ethnicity		
Dinka	49.2	84.3
Madi	44.4	9.4
Other	6.4	6.3
Education level		
Illiterate	36.5	18.8
Informal education	1.6	6.3
Formal education	61.9	74.9
Duration as refugee in West Nile, Uganda		
2 - 3 years	75.7	38.8
4 - 5 years	18.2	36.7
> 5 years	6.1	24.5
Antenatal visit attendance		
Less than four	28.5	-
Four or more	71.5	-

**Table 3.** Facilitators of breastfeeding

Themes	Codes	Quotations	Data source (# of times mentioned)
<b>Beliefs and knowledge about breastfeeding benefits</b>	Child will be bright	<p>“Breastmilk develops a clever mind or brain of the baby.” - Mother (FGD Agojo)</p> <p>“The child will be bright.” - Mother (FGD Agojo)</p>	Mothers FGD (2)
	Child will grow well and strong	<p>“Breastmilk makes the baby fat. So when other people come visit, they feel happy when they see the baby.” - Mother (FGD Nyumanzi)</p> <p>“When a baby is fed on breastmilk, the baby becomes very strong.” - Mother (FGD Nyumanzi)</p> <p>“Breastmilk makes the baby feel strong.” – Mother (FGD Nyumanzi)</p> <p>“Breastmilk makes a child grow stronger.” - Mother (FGD Agojo)</p> <p>“The child will be very strong.” - Mother (FGD Agojo)</p>	Fathers FGD (2) Mothers FGD (7)

		<p>“The child will be strong.” - Mother (FGD Agojo)</p> <p>“A child breastfeeding makes them strong.” - Father (FGD Ayilo-I)</p> <p>“Breastmilk builds the baby’s body.” - Father (FGD Ayilo-I)</p> <p>“Breastmilk makes the baby grow strong and healthy.” - Father (FGD Ayilo-I)</p>	
	Breastmilk is nutritious and protects from disease	<p>“Breastmilk protects the baby.” - Mother (FGD Nyumanzi)</p> <p>“Breastmilk protects the baby from diseases.” - Mother (FGD Nyumanzi)</p> <p>“Breastmilk makes the baby strong and sometimes protects the baby from diseases.” - Father (FGD Ayilo-I)</p>	Fathers FGD (1) Mothers FGD (3)
<b>Support from husband/father</b>	Provides food	<p>“The husband should come up with the money to buy food such as meat so that the lactating mother gets soup.” - Mother (FGD Nyumanzi)</p> <p>“You try to maintain your wife through feeding so that she</p>	Fathers FGD (4) Mothers FGD (1)

		<p>can't be weak." - Father (FGD Ayilo-I)</p> <p>"You ensure that the mother has eaten." - Father (FGD Ayilo-I)</p> <p>"We help out wife in some ways like providing food." - Father (FGD Ayilo-I)</p>	
	Provides emotional support	<p>"The husband makes sure she's happy." - Father (FGD Ayilo-I)</p> <p>"The love we have for them that is how we help them with breastfeeding." - Father (FGD Ayilo-I)</p>	Fathers FGD (3)
	Do household chores	"When it is rainy season the man has to cultivate in the garden at home." - Father (FGD Ayilo-I)	Fathers FGD (2)
<b>Support from community</b>	Grandmother provides food	"In our homes, grandmothers provide breastfeeding mothers with food for cooking so that she can produce more breastmilk for the child." - Mother (FGD Agojo)	Mothers FGD (1)
	Neighbors provide materials	"And also some neighbors support the breastfeeding mother with providing them firewood and drinking water." - Mother (FGD Agojo)	Fathers FGD (1) Mothers FGD (1)

		“Also when the man is poor to provide for the baby and the breastfeeding mother it is his role to borrow from the neighbors.” - Father (FGD Ayilo-I)	
<b>Support from non-governmental organizations (NGO)</b>	NGO provides education	“And also Plan International was educating mothers about breastfeeding.” - Mother (FGD Agojo)	Mothers FGD (1)
	NGO provides food	“They were being supported by the partners giving out flour for porridge MTI and Plan International.” - Mother (FGD Agojo)	Mothers FGD (2)

Abbreviations in Table 3:

FGD: Focus Group Discussion

**Table 4.** Barriers to breastfeeding

Themes	Codes	Quotations	Data Source (# times mentioned)
<p><b>Physical barriers</b></p>	<p>Mother is sick</p>	<p>“Sometime the mother was sick and stop breastfeeding.” - Mother (FGD Agojo)</p> <p>“When the mother is sick and has been advised to stop the baby from breastfeeding.” - Mother (FGD Nyumanzi)</p> <p>“When the mother is sick, the baby will not be allowed to breastfeed.” - Mother (FGD Nyumanzi)</p> <p>“Another reason is when the mother has developed breast cancer a baby is not supposed to breastfeed.” - Father (FGD Ayilo-I)</p> <p>“Also when the mother is infected with HIV/AIDS then the baby is not supposed to be breastfed that is why the baby may not be given breastmilk.” - Father (FGD Ayilo-I)</p>	<p>Fathers FGD (5) Mothers FGD (4)</p>



		<p>If the mother is sick then she cannot breastfeed the kid.” - Father (FGD Ayilo-I)</p> <p>“If the mother is sick she will not breastfeed.” - Father (FGD Ayilo-I)</p>	
	Mother has died	<p>“Sometimes the biological mother died.” - Mother (FGD Agojo)</p> <p>“The mother the baby might have died and therefore the alternative is supplementary feeding.” - Father (FGD Ayilo-I)</p>	<p>Fathers FGD (1) Mothers FGD (1)</p>
Perceived milk insufficiency	<p>“Sometimes there is no breastmilk for the baby.” - Mother (FGD Agojo)</p> <p>“There will be no breastmilk.” - Mother (FGD Agojo)</p> <p>“When a baby is four months old and the mother does not produce enough milk they should be given other feedings.” - Mother (FGD Nyumanzi)</p> <p>“When the wife has produced twins extra feeding should be added on top of breastmilk</p>	<p>Fathers FGD (2) Mothers FGD (4)</p>	<p>Fathers FGD (2) Mothers FGD (4)</p>

	because the milk from the mother is not enough for the two babies.” – Father (FGD Ayilo-I)		
Breastfeeding difficulties	<p>“They did not start giving breastfeeding on time that is why no breastmilk is coming.” - Mother (FGD Agojo)</p> <p>“When the baby doesn’t breastfeed well he or she should be given extra feedings.” - Father (FGD Ayilo-I)</p> <p>“When a baby is born and refuses to breastfeed that child is given the supplementary feeding.” - Father (FGD Ayilo-I)</p>	Fathers FGD (2) Mothers FGD (2)	Fathers FGD (2) Mothers FGD (2)
<b>Socioeconomic barriers</b>	Mother is working	“Other mothers are working class.” - Mother (FGD Agojo)	Mothers FGD (1)
	Educated mother uses other milk	“For educated mothers they can say they will not feed their child on breastmilk they will use other milk.” - Mother (FGD Agojo)	Mothers FGD (1)
<b>Knowledge barriers</b>	Breastfeeding should stop at 3 months	“Weaning a baby can sometime reach 3 months if the baby has no access to supplementary feedings and when it is naturally weak.” - Mother (FGD Nyumanzi)	Mothers FGD (1)

	<p>Infant under 6 months should eat and drink items other than breastmilk</p>	<p>“When the mother produces less milk, then the parent buys the powder milk and dilute it with the water and give it to the baby they also buy Blueband [margarine] for the baby.” - Mother (FGD Nyumanzi)</p> <p>“The parent buys the powder milk and dilute it with the water.” - Mother (FGD Nyumanzi)</p> <p>“It can be after 3 months.” - Father (FGD Ayilo-I)</p>	<p>Fathers FGD (3) Mothers FGD (5)</p>
	<p>Sick baby needs more than breastmilk</p>	<p>“You try to feed a sick baby with milk.” - Mother (FGD Nyumanzi)</p> <p>“I can provide porridge for the sick baby.” - Mother (FGD Nyumanzi)</p> <p>“I can give a sick child some soft drinks the ones that he might want.” - Mother (FGD Nyumanzi)</p>	<p>Mothers FGD (4)</p>
<p><b>Psychosocial barriers</b></p>	<p>Fighting with husband</p>	<p>“When the wife is not happy at home for example she might have fought with the husband and she may refuse to</p>	<p>Fathers FGD (2)</p>

		breastfeed the child.” - Father (FGD Ayilo-I)	
	Fear of pain	“The other young woman who has just started giving birth may fear to breastfeed the baby she may feel painful to breastfeed.” - Father (FGD Ayilo-I)	Fathers FGD (1)
	Mother has mental health issues	“The mother is mentally challenged.” - Father (FGD Ayilo-I)	Fathers FGD (2)

Abbreviations in Table 4:

FGD: Focus Group Discussion

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## CHAPTER VI

### PERINATAL DEPRESSION AND BREASTFEEDING: A MIXED METHODS STUDY AMONG SOUTH SUDANESE REFUGEES IN THE WEST NILE REGION IN UGANDA

#### **Abstract**

Refugees face an increased risk of developing mental health illnesses and mothers living in settlements have unique challenges and barriers to breastfeeding. The purpose of this mixed methods study was to 1) identify perceived common stressors among parents in refugee settlements and 2) explore the association between perinatal depression and breastfeeding practices. Qualitative study participants were mothers (n= 66) and fathers (n=49) who compromised eight focus group discussions (FGDs): four mothers FGDs, two fathers FGDs, two mothers and fathers FGDs. Two FGDs with Village Health Team and six individual interviews with key informants also were conducted. Thematic analysis was used in NVivo, v. 12. Quantitative study participants (n=390) were pregnant mothers who were enrolled in a community-based randomized control study. Perinatal depression was measured using Patient Health Questionnaire-9 during 3rd trimester and postpartum.

Early initiation and exclusive breastfeeding were assessed using WHO guidelines. SAS, v. 9.4, was used to conduct logistic regressions to analyze perinatal depression and breastfeeding and models were adjusted for confounders. Six themes related to perceived common stressors among refugees were identified: lack of basic needs, issues involving childbirth, marital conflict and violence, other violence and conflict, inadequate health care, and issues involving children. Over two-thirds (66.3%) of mothers breastfed within one hour after birth and 55.5% exclusively breastfed. Antenatal depression occurred in 19.9% of participants and 23.5% had postpartum depression. Antenatal depression was not significantly associated with early initiation of breastfeeding or exclusive breastfeeding. Postpartum depression was associated with significantly lower odds of breastfeeding within an hour after birth and of exclusive breastfeeding. Early initiation of breastfeeding and exclusive breastfeeding were associated with a significant reduction in odds of developing postpartum depression. Screening and treatment for perinatal depression during antenatal and postnatal care is important for refugee mothers. Interventions aiming to improve breastfeeding among refugees may also consider including initiatives to address postpartum depression.

## **Introduction**

South Sudanese are the largest group of refugees in Africa; armed conflict and violence has forced an estimated 2.3 million to flee and find refuge [1, 2]. Many South Sudanese refugees settled in the neighboring countries, including Uganda [1]. Uganda hosts more South Sudanese refugees than any other country and over 2/3 of the refugees in Uganda are from South Sudan [3]. Despite finding temporary refuge, South Sudanese refugees in Uganda face difficulties and challenges including hunger, loss of economic opportunities, violence, and degradation of social networks [4].

Refugees have a higher risk for developing mental health illnesses, and it is estimated that over 20% of conflict-affected populations face such illnesses [3, 5, 6]. Stressors surrounding forced migration put pregnant women and mothers in refugee populations at risk of facing perinatal mental health challenges [7]. A systematic review investigating mental health among refugees revealed that over 30% of refugee mothers from low- and middle-income countries (LMICs) developed perinatal depression [7]. However, most studies, including this meta-analysis included refugees who relocated to high-income countries from LMICs. Despite the common psychosocial issues faced by refugees and the increased risk of perinatal depression, scant research has investigated perinatal depression among refugees who flee to nearby countries and thus, data on antenatal and postpartum depression among refugees in LMICs is severely lacking. To better address perinatal mental health issues among refugees, understanding the scope of antenatal and postpartum depression is critical.

In addition to facing perinatal mental health issues, evidence implies that refugee mothers have unique challenges when making breastfeeding choices [8]. Current evidence suggests forced migration negatively impacts breastfeeding decisions among refugees [9-12]. As a key component of optimal nutrition for the first 1,000 days, early initiation of breastfeeding lowers the risk of morbidity and mortality among infants [13]. Furthermore, according to a systematic review, exclusively breastfed infants had significantly lower risk of infection-related deaths and all-cause mortality compared to predominantly, partially, and non-breastfed infants [14]. The World Health Organization (WHO) recommends breastfeeding within the first hour after birth and exclusive breastfeeding (EBF) until the infant is six months old [15].

A recent report showed early initiation of breastfeeding across refugee settlements in Uganda ranged from 58%-84.4%. Exclusive breastfeeding rates among South Sudanese refugees in Uganda have decreased dramatically since 2014 when 90.7% of mothers were exclusively breastfeeding as opposed to 62.3% mothers in 2020. Compared to other regions, breastfeeding rates were the lowest in the West Nile region, where Adjumani District is located. Across settlements in Adjumani, only 42.3% of infants were EBF, which was 20% below the average across settlements [16]. However, breastfeeding practices among South Sudanese are not well-understood as limited research has been reported among South Sudanese women in their home country, and even less research has been conducted on breastfeeding among South Sudanese refugees in Uganda.

Mixed evidence exists on the association between perinatal depression, including antenatal and postpartum depression, and breastfeeding. A systematic review of studies primarily from high income countries concluded that antenatal depression was not associated with breastfeeding within one hour after birth [17]. These findings oppose results from Ethiopia that found antenatal depression was a predictor of late initiation of breastfeeding [18]. Some researchers have concluded that the association of perinatal depression and early initiation of breastfeeding is equivocal and requires further investigation [17].

Associations between perinatal depression and EBF also are inconclusive. Findings from multiple studies, including a systematic review of mostly high-income countries [17], showed a significant negative association between depression during pregnancy and EBF [19-21]. However, results from a population-based study in Ghana revealed that antenatal depression had no significant association with EBF [22].

However, many studies corroborate findings that postpartum depression is significantly associated with shorter duration of breastfeeding exclusively [17, 20, 23, 24].

Furthermore, research also indicates that the relationship between perinatal mental health, especially postpartum depression, and breastfeeding may be a bidirectional relationship. Evidence from a systematic review suggests breastfeeding may be a protective factor against the development of postpartum depression [17].

Most studies on perinatal depression and breastfeeding have not been conducted in LMICs. To better understand the situation regarding mental health among refugees, it is important to know the common stressors parents face in the settlements. Thus, the purpose of this study was to explore perinatal mental health and breastfeeding among South Sudanese refugees in the West Nile region in Uganda. The specific objectives were: 1) to identify perceived common stressors among refugees in the refugee settlements, 2) to analyze the associations of perinatal depression with early initiation of breastfeeding 3) to analyze the associations between perinatal depression and exclusive breastfeeding, and 4) to investigate if breastfeeding is associated with the development of postpartum depression. The data will be useful for informing interventions, programs, and policies aimed at improving perinatal mental health and breastfeeding practices among refugees.

## **Methods**

### **Qualitative methods**

Qualitative data were collected in July 2019 in the West Nile region of Uganda in Agojo, Boroli, Pagirinya, and Ayilo-I which were randomly selected refugee settlements in Adjumani district. Participants included South Sudanese mothers (n = 66) and fathers



(n = 49), with children less than 24 months of age who were living as refugees in Uganda. Participants, randomly selected from a list of potential participants prepared with the assistance of Village Health Teams (VHTs) formed eight focus groups; four mothers' focus group discussions (FGDs), two fathers' FGDs, and two FGDs with both mothers and fathers.

Additionally, six individual interviews with key informants (KIs) and two FGDs with Village Health Teams (VHTs), were conducted to add perspective to the data collected from parents' FGDs. VHTs are responsible for conducting home visits, promoting health, and following up with mothers during pregnancy and postpartum and were established as a community-based system to promote health in Uganda [25, 26]. Among the KIs were five settlement commandants and one official from the Office of the Prime Minister-Uganda. Settlement commandants serve in an appointed position to ensure refugees have access to services offered by United Nations High Commissioner for Refugees (UNHCR) and partner agencies [27]. Since VHTs and settlement commandants interact and communicate frequently with mothers and fathers in the settlements, they added informative and valuable community perceptions.

### **Data collection**

The questions used in FGD and key informant interview (KII) guides to assess perceptions of common stressors faced by refugees are outlined in Table 1. Prior to data collection, questions were reviewed by research translators, proficient in English and the local languages, who were hired based on their field work experience. Translated FGD and KII guides were examined by two additional research translators followed by pre-testing among mothers and fathers in the settlements. After making changes based on pre-testing, the final translated guides were reviewed and agreed upon by the research team.

FGDs and KIIs were audio recorded; FGD for mothers and fathers were conducted in Arabic, Dinka, or Madi, the primary languages spoken by participants. FGDs with VHTs were conducted in Arabic and English and the KIIs were conducted in English. Probing questions were used and saturation was considered established when no new data was provided by participants.

### **Data analysis**

Audio recordings of FGDs were transcribed verbatim. Transcription was conducted by research translators, proficient in English and the local languages, who back-translated the data to English. Data were cleaned and coded by the research team using NVivo, v. 12. Thematic analysis was conducted by three researchers and themes among similar codes were identified.

### **Trustworthiness/ reliability**

The data represents perspectives from participants from four different post-emergency settlements as well as from VHTs and KIIs, which increased data reliability. Probing questions helped to achieve saturation. Involvement of multiple researchers during coding and thematic analysis assisted in reinforcement of trustworthiness and reliability.

### **Quantitative methods**

Quantitative data were collected in 2020 as a part of a community-based, longitudinal, randomized controlled trial in Adjumani District that utilized a peer-led nutrition education intervention using the Care Group model. Based on breastfeeding rates across settlements in Uganda [16] and a margin error of 0.05, 360 participants were estimated to be needed [28]. After adjustment for potential loss to follow-up, 390 women

were enrolled in the study. Participants were South Sudanese refugees and were in their 3<sup>rd</sup> trimester of pregnancy.

### **Data collection**

The research team hired and trained data collectors who interviewed participants. Data collectors were South Sudanese and individually administered questionnaires in the local languages of the participants. The questionnaire was developed based on previous research and was pre-tested. After adjustments were made, the final questionnaire was reviewed and approved by the research team prior to data collection. Questions related to sociodemographic characteristics were adapted from Demographic and Health Surveys.

### **Variables**

Early initiation of breastfeeding and exclusive breastfeeding were assessed using WHO infant and young child feeding practice guidelines [15]. Mothers were asked how soon after birth they breastfed, and early initiation of breastfeeding was measured as the proportion of infants who were breastfed within 1 hour after birth. A series of yes/no questions guided by the WHO infant and young child feeding (IYCF) assessment protocol about liquids and foods given to the infant in the last 24 hours was used to assess exclusive breastfeeding which was calculated as the proportion of infants who were fed exclusively with breastmilk in the previous 24 hours.

Perinatal depression was measured using the Patient Health Questionnaire, nine-item version (PHQ-9) that has a four point scale [29]. A systematic review and meta-analysis concluded the PHQ-9 is a valid screening tool for perinatal depression [30]. A recent study among South Sudanese refugees in Uganda assessed psychometric properties

and reported a Cronbach's Alpha ( $\alpha = 0.75$ ) for the PHQ-9 [31]. Scores range from 0-27 and are organized into the following categories: none-minimal (0–4), mild (5–9), moderate (10–14), moderately severe (15-19), and severe ( $\geq 20$ ). A PHQ-9 score of  $\geq 10$  (moderate or severe category) is suggestive of depression [29]. The PHQ-9 was administered to participants during the 3<sup>rd</sup> trimester and less than 6 months postpartum.

### **Data analyses**

Bivariate logistic regressions were used to analyze associations between perinatal depression and breastfeeding. Multivariable models assessing the association between perinatal depression and breastfeeding were adjusted for study arm, child age, child sex, maternal MUAC, maternal fever or diarrhea in the last 24 hours, maternal age, maternal education, antenatal visits, postnatal visits, place of delivery, and type of delivery. Multivariable models investigating whether breastfeeding was associated with odds of developing postpartum depression were adjusted for study arm, child age, child sex, maternal age, maternal social support, maternal education, antenatal visits, postnatal visits, place of delivery, type of delivery, and maternal MUAC. Multicollinearity was tested using variance inflation factor and the tolerance test and SAS, v. 9.4 was used for analyses.

### **Ethical Approvals**

Ethical approval was obtained from the Makerere University School of Health Sciences Research and Ethics Committee in Uganda, the Uganda National Council of Science and Technology, and the Oklahoma State University Institutional Review Board. Eligible participants were informed of the purpose of the study and were provided opportunities to ask questions. Informed consent was obtained from all participants prior

to data collection and participation was voluntary. Participant compensation was provided at each data collection point in the form of food and household items worth 7,600 Uganda Shillings.

## **Results**

### **Qualitative findings**

Most mothers (93.9%) and over 3/4 of fathers (75.5%) in the qualitative study reported they had been living in the West Nile region of Uganda as refugees for 2-5 years (Table 2). High levels of unemployment were reported by both fathers (55.1%) and mothers (92.4%). Most participants reported the completion of some level of formal education; fathers (71.4%) and mothers (78.8%). More than two-thirds of participants were aware of available mental health and psychosocial support resources.

Six themes related to perceived common stressors among refugees included: lack of basic needs, issues involving childbirth, marital conflict and violence, other violence and conflict, inadequate health care, and issues involving children (Table 3). Mothers, fathers, and key informants all reported the lack of basic needs as a common stressor among refugees. Participants discussed poverty, lack of employment, inadequate food and water among the difficulties that they face. Additionally, the lack of land for agriculture, lack of household and building materials, lack of fire wood for cooking were also reported by participants.

*“There is a struggle of basic needs such as food, clothes, education, and medication. There are a lot of challenges we have but the major struggle is we need money for education and other needs.” – Fathers FGD (Ayilo)*

*“The men have no jobs.” – Mothers FGD (Boroli)*

*“I think generally we struggle after one year for food issues because the ration given does not last for a month and people are trying to make sure that their children have something to eat.” – Fathers FGD (Ayilo)*

*“We struggle to look for food and it is very hard to find. The little the United Nations High Commissioner for Refugees (UNHCR) gives us only lasts for two weeks and not the full month.” – Fathers FGD (Ayilo)*

*“We struggle to look for grass to build our homes. Getting this grass for building the house is very hard because the host community does not allow the grass to be cut.” – Fathers FGD (Ayilo)*

Mothers, fathers, KIIs, and VHTs also expressed concerns regarding issues related to childbirth including maternal bleeding during delivery and the death of the mother or infant during delivery. They also described other common childbirth issues such as maternal pain, delivering at home or on the roadside, and inadequate breastmilk production.

*“Sometimes the midwives in the health facilities do not pay attention to the mothers. You will find that they [the mothers] struggle alone until they delivered the baby.” – VHT FGD (Boroli)*

*“There are difficulties when they give birth at the health center. They fail to get the support they need and during the delivery, they need support.” – KII #2*

*“They [refugees] have difficulties getting items needed for childbirth. The non-governmental organizations (NGOs) and the health facility used to*

*give delivery kits but those things have been cut off. And now, it is difficult after giving birth. It costs money and getting those mother kits is difficult and most of the mothers are vulnerable.” – KII #4*

*“After the delivery, you undergo severe pain and too much bleeding.” – KII #5*

*“You have been taught that some women die during delivery and you may start to think you may not be alive to take care of children at home.” – Mothers FGD (Agojo)*

*“Sometimes the far distance of health facilities makes mothers deliver at home and the baby will die due to no proper care.” – Mothers FGD (Agojo)*

*“There is pain in the womb after you deliver the baby.” – Mothers FGD (Agojo)*

Mothers, fathers, and key informants all discussed different types of intimate partner violence (IPV) such as emotional, economic, physical, and sexual violence that occurs among refugees in the settlements. In addition to violence, other marital conflicts such as infidelity, arguments, and the lack of physical presence of the husband/father were also reported by participants.

*“It [domestic violence] is common because you don’t have something to sustain the family and therefore, the tension will increase over the resources and the wife will blame the husband for not providing to the family.” – Fathers FGD (Ayilo)*

*“There is emotional violence, psychological torture, this form of using frightening language.” – KII #5*

*“A man, who is family head, after receiving money, uses much of the money for alcohol. The money that is supposed to be used for school fees and food is less and the money for alcohol is greater. You’ll find that kind of economic violence.” – VHT FGD (Boroli)*

*“We have been seeing marital rape where the wife is not interested in having sex and the husband forces her.” – KII #4*

*“The wife will start blaming the husband and that will bring a lot of problems.” – KII #2*

In addition to marital conflict and violence, participants cited other conflict and violence among refugees. Mothers and key informants described community and intertribal violence, gender-based violence and conflict, and issues among neighbors. Participants in the mothers and fathers FGDs also reported issues among neighbors as a source of conflict among refugees.

*“Last year there was violence in the community. Refugees divided themselves in the settlement last year and that one was very bad. They divided themselves and fought and that case had been settled by the Office of the Prime Minister.” – KII #3*

*“We have a good number of gender-based violence conflicts.” KII #7*



*“The only thing that can make it hard to live with neighbors is if my neighbors fight with my husband. The neighbors sometimes will feel my husband wants to take the neighbors’ wife and it will bring problems between neighbors.”– Mothers and Fathers FGD (Pagirinya)*

Mothers and key informants discussed inadequate health care as a common stressor. They reported issues at the health centers and with midwives as their concerns related to inadequate health care. Additionally, they raised the issue that the distance to the health centers is too far which makes accessing health care difficult.

*“If my wife, starts to deliver at home and the health center is very far, when I take my wife to the health center, those people they refuse to see her. They say, “Why did you let you wife deliver at home while we already told you to bring your wife to deliver at the health center.” They refuse to even give support at the health center. So they start blaming you and that is something which I want to raise. If possible, if your wife delivers at home, they [health center] can accept them and even treat the mother. Some children pass away because of the refusal of the health center to treat them if they delivered at home.” – KII #2*

*“At the health center there are gaps in all the sectors. Not that partners are not doing their part because they’re trying their best, but the services are not there yet.”– KII #7*

*“The health center is very far. Sometimes when the person is sick and has no transport, you can carry the sick person very far but sometimes the person passes away on the way there.” – VHT FGD (Boroli)*

Many issues involving children were also described by participants. KIIs noted the issue of child labor and early or forced marriages. Mothers, fathers, KIIs, and VHTs all raised the issue of parental abuse and neglect in the settlements. Fathers and key informants raised the issue of inadequate education for the children living in the settlements. They stated there were not enough schools and classrooms for the number of children. They also reported that the school fees were unaffordable for most refugees.

*“She [the mother] will not pay attention to the baby’s cries.” – Mothers and Fathers FGD (Pagirinya)*

*“There is beating of children, it is violence.” – KII #3*

*“You’ll find that some women abandon the child or throw the child away in the rubbish pit or in the bush.” – VHT FGD (Boroli)*

*“The community is struggling for better education for their children. Nursery schools are very few here compared to the host community population. More primary schools should be added, maybe an extra 2– 3. When the number of primary schools is increased it will be okay but now the one classroom has 200– 300 pupils which is very hard to control.” – Fathers FGD (Ayilo)*

*“There are an inadequate number of schools for children.” – VHT FGD (Boroli)*

*“Refugees still need a lot of help in various sectors. If you consider education, one of the primary schools in my settlement has one classroom with 400 pupils with 2 or 3 teachers. The classroom is so congested. There are not classrooms just because the funds are not enough to build more classrooms.” –KII #7*

### **Quantitative findings**

Maternal and infant characteristics are presented in Table 4. A fifth (19.9%) of mothers met the PHQ-9 depression criteria for antenatal depression (Table 5). Occurrence of depression increased among participants after birth as 23.5% of the mothers met criteria for postpartum depression. During pregnancy, only 29.7% mothers had no or minimal symptoms of depression and half of the mothers (50.4%) had mild symptoms. Two-thirds (66.6%) of mothers initiated breastfeeding within one hour of birth and 55.5% exclusively breastfed their infants. Nearly all (98.3%) of mothers were breastfeeding and only 10% of those not exclusively breastfeeding were formula feeding (data not shown).

PHQ-9 scores during the third trimester (Table 6) were not associated with early initiation of breastfeeding in bivariate analyses [OR 0.99 (0.92-1.06)]. Similarly, there was not a significant association between meeting the PHQ-9 criterion for antenatal depression and breastfeeding within an hour of birth [OR 0.81 (0.44-1.41)]. However, there was a significant association between higher postpartum PHQ-9 scores and a lower likelihood of early initiation of breastfeeding which remained significant in the adjusted model [AOR 0.92 (0.87-0.98),  $p < 0.01$ ]. Postpartum mothers who met the PHQ-9 depression criterion were less likely to breastfeed within an hour of birth [AOR 0.35 (0.21-0.61),  $p < 0.001$ ]. In bivariate analyses, antenatal and postpartum PHQ-9 scores were

not associated with exclusive breastfeeding [OR 0.98 (0.92-1.05)], [OR 0.98 (0.93-1.03)]. No significant association was detected between meeting the criteria for antenatal depression and exclusive breastfeeding [OR 0.73 (0.40-1.34)]. However, mothers who were classified as depressed by their PHQ-9 scores during the postpartum period were less likely to exclusive breastfeed [AOR 0.43 (0.25-0.73),  $p < 0.001$ ]. Initiating breastfeeding within an hour after delivery and exclusively breastfeeding both were significantly associated with reduced the odds of developing postpartum depression; [AOR 0.35 (0.20-0.59),  $p < 0.001$ ], [AOR 0.45 (0.26-0.79),  $p < 0.01$ ] as illustrated in Table 7.

## **Discussion**

### **Qualitative**

Six themes described the common stressors among refugees: lack of basic needs, issues involving childbirth, marital conflict and violence, other violence and conflict, inadequate health care, and issues involving children. Lack of basic needs, issues involving childbirth, marital conflict and violence, and inadequate health care particularly may influence breastfeeding practices among refugees in the settlements.

Participants mentioned various stressors related to basic needs: poverty, unemployment, inadequate food and water, lack of land for agriculture as well as lack of household and building materials and firewood. Previous findings from Uganda noted most refugees rely exclusively on humanitarian aid [27]. Additionally, a study reported that South Sudanese refugees in Adjumani had a desire to work and go to school but lacked access to such opportunities [32]. Only 5% of refugees in Uganda reportedly received skills or job training [33], yet refugees have expressed that engaging in work or

education is a critical way to help reduce their stress [32]. Refugees in Uganda have reported a lack of access to agricultural property despite their desires to cultivate land, but the limited availability of land remains a problematic barrier [27].

Another investigation among South Sudanese in Uganda found that lack of economic opportunities was one of the contributing factors to despair and suicidal-related behaviors among refugees [4] further highlighting the pressing issues of lacking basic needs in the settlements. Recommendations have previously indicated that income-generating opportunities for refugees should also include non-agricultural labor due to the limited land [27, 32]. The World Bank has emphasized that evaluation and revision of existing policies related to refugees' economic opportunities in Uganda are necessary to increase chances for refugees to grow in self-reliance [33].

Participants noted many issues related to childbirth including physical issues such as maternal bleeding, maternal pain, and sickness or death of mother or newborn. They also mentioned issues related to midwives and staff not being attentive or supportive during the childbirth process. These findings corroborate previous findings among refugees in Uganda that found refugees experience significant challenges to accessing adequate delivery care [34]. Additionally, mothers reported corruption, discrimination, and language barriers as struggles they faced during the childbirth process and experience [34]. Many of these concerns raised by participants may negatively influence the childbirth experience for refugees, which in turn likely negatively influences breastfeeding practices and perinatal mental health. Pregnancy complications and trauma during childbirth are associated with poorer mental health outcomes for mothers [35]. Future research may consider assessing the quality of delivery care at health centers and

hospitals in refugee settlements and how complications during childbirth may be an underlying factor impacting both early initiation of breastfeeding and perinatal depression among refugees.

Participants reported several types of intimate partner violence (IPV) as common stressors among parents in the settlements. Previous studies have documented the occurrence of IPV among refugees in Uganda [36, 37]. A field research report revealed barriers refugees face in seeking help for IPV issues including: stigma, victims' beliefs about receiving poor care, not knowing where to access care, and challenges for accessing help [38]. Even if victims were able to access care, service providers stated they lacked necessary resources to administer effective care for IPV victims in the settlements [38]. Furthermore, a study among Sudanese refugees in Kenya reported male refugees tend to be mistrustful of how agencies in the settlements respond to IPV issues, and sometimes refugees reported only extreme cases that they felt needed the attention of UNHCR or other agencies [39]. Not surprisingly, it has been reported that current IPV programs may not result in protection of victims and the use of social support networks may be a more effective approach to addressing IPV issues [39]

Experience of IPV has been negatively associated with breastfeeding practices [40] and mental health outcomes for women [41], and therefore addressing the IPV, both prevention and treatment, may be a key component of improving breastfeeding and mental health outcomes among refugees. However, issues of IPV tend to be overseen by protective services in the settlements, and not health services. Therefore, collaborative initiatives that involve both protection and health services may be more effective to

provide support and care for IPV victims. Future studies may consider assessing the feasibility of using an IPV screening tool during antenatal and postnatal care.

Participants noted issues related to inadequate health care including the issues of not providing care for women who deliver their newborn at home. Furthermore, participants raised the issue of health centers not being open on weekends and lack of emergency services for adults. Lack of transport and far distance to health centers were also among the issues raised by participants. Additionally, participants reported that midwives at the health centers were not supportive or attentive. Similar results were found in a recent study among Congolese refugees in Uganda [34]. These concerns indicate it may be helpful to conduct a comprehensive assessment of health care provided to refugees in the settlements. The issues being faced by health centers to provide the appropriate level of care for refugees may need to be assessed. The difficulties mothers are reporting in relation to midwives may make them more reluctant to seek help when they are in need, which could contribute to breastfeeding difficulties or perinatal depression [42]. Assessing barriers faced by health care workers in the settlements to providing adequate care and addressing any potential language or cultural barriers between health care providers and South Sudanese refugees may be needed.

### **Quantitative**

Although less than a quarter (19.9%) of participants met the PHQ-9 criteria for antenatal depression in the third trimester of pregnancy, depression was still higher than the global prevalence of 15.0% estimated by a systematic review and meta-analysis [43]. Depression symptoms increased after childbirth as 23.5% of mothers had moderate or severe postpartum depression. These rates are higher than the global prevalence of 17.2%

estimated from the largest systematic review and meta-analysis of postpartum depression [30]. During the perinatal period, there is typically an increase in frequency of contact between pregnant women and health care workers. Not surprisingly, current recommendations in many high income countries suggest that all pregnant women be assessed for perinatal depression. However, currently the feasibility of screening for perinatal depression in refugee settlements in low income countries is limited. Therefore, developing and validating a perinatal depression screening tool to be used by health care workers, non-specialist workers or the Village Health Team during antenatal and postnatal care in refugee settlements might be an important beginning to address this problem.

However, once the feasibility of screening for perinatal depression is evaluated, having effective treatment available for mothers struggling with perinatal depression is also important. One promising mental health intervention is use of the World Health Organization's (WHO) Self-Help Plus among South Sudanese refugees [44]. Self-Help Plus is a group-based intervention that provides mental health education and self-help strategies that aim to improve coping skills of individuals with a wide range of stress and mental health conditions. Results from a recent randomized controlled trial using Self-Help Plus among South Sudanese in Uganda revealed that refugees who utilized Self-Help Plus had greater improvements in psychological distress and depression symptoms at three months post-intervention compared to those who received enhanced usual care [45]. The authors concluded Self-Help Plus is an effective and feasible first-line intervention among refugees [45]. However, the use of the intervention has not been evaluated among mothers with perinatal depression. Future research may consider the



effectiveness and feasibility of using the Self-Help Plus for the prevention and treatment of perinatal depression among refugees.

Over half (66.6%) of participants initiated breastfeeding within one hour of birth. These findings were slightly higher than results from a recent study among other refugees in Adjumani in which 57% of infants were breastfed within one hour of birth [46]. Previous reports show early initiation of breastfeeding rates across all settlements was 58%-84.4%, and breastfeeding rates were lowest in the West Nile region compared to other regions in Uganda where refugees reside [16]. A study in South Sudan noted that delivery by C-section, discarding of colostrum (believing it was dirty and bad), and exposure to infant formula marketing and advertisements were factors associated with delayed initiation of breastfeeding [47]. While those findings provide insight into barriers South Sudanese women may face to initiate breastfeeding early, those living in settlements in Uganda may face additional or different barriers, such as sporadic infant formula donations. Therefore, assessment of specific factors inhibiting breastfeeding within one hour of birth among South Sudanese refugees in Uganda may be useful in developing appropriate interventions.

Our finding that 55.5% of infants were exclusively breastfed was higher than the previously reported 42.3% in Adjumani, but still remains below the average of 62.3% across all settlements. More concerning, since 2014 exclusive breastfeeding declined significantly from 90.7% among refugees in Uganda [16]. However, almost all (98.3%) mothers were breastfeeding to some extent but not exclusively. Among those not breastfeeding exclusively to six months, 10% were formula feeding, and 90% were giving their infants other liquids and foods. A study in South Sudan reported that 53% of

mothers provided their infants with pre-lacteal feeds, giving solid or liquid foods other than breast milk during the first three days after birth [48]. The study revealed that the common pre-lacteal feeds among South Sudanese mothers were glucose solution, water, or formula [48]. The practice of pre-lacteal feedings among South Sudanese refugees as well as additional barriers they face to exclusive breastfeeding may merit investigation. Such findings highlight the need for continued emphasis on breastfeeding education and support at antenatal care, after delivery, and in conjunction with postnatal care. Hospitals and health centers may consider training selected staff to support breastfeeding mothers who face lactation issues, as well as expansion of community-based support for breastfeeding mothers who have barriers to accessing healthcare facilities.

Another challenge is that formula and breastmilk substitutes are often among the first donations to arrive in settlements. Mothers who receive such donations may perceive the formula to be superior to breastmilk; thus, donations may act as an impediment to exclusive breastfeeding among refugees. Furthermore, if formula donations run out, mothers who have ceased breastfeeding will have difficulty feeding their infants. In this study, 10% of participants who were not exclusively breastfeeding were formula feeding. Combined with policies regulating formula donations in settlements, future research may explore factors associated with formula use in a setting where access to formula supply is inconsistent and supplies of bottles and clean water are limited.

### **Perinatal depression and early initiation of breastfeeding**

Previous studies on antenatal depression and breastfeeding primarily have been conducted in high income countries and not among refugees in low-income countries. In this study, antenatal depression measured in the 3<sup>rd</sup> trimester, was not significantly

associated with early initiation of breastfeeding. These results add to the findings of a systematic review of studies from largely high income countries that concluded depression during pregnancy was not associated with early initiation of breastfeeding [17]. However, it contradicts evidence from a study in Ethiopia that determined depression measured during the second or third trimester was a predictor of late initiation of breastfeeding [18]. Research on the association between antenatal depression and early initiation of breastfeeding remains equivocal [17].

However, higher postpartum PHQ-9 scores were associated with a significant lower likelihood of early initiation of breastfeeding and postpartum mothers who met the criteria for postpartum depression had 65% lower odds of breastfeeding within an hour after birth. These results may point to depression that occurred in proximity to the time of delivery and soon after childbirth that persisted into postpartum depression. Difficulties during childbirth may negatively impact perinatal mental health, and therefore this association also may be reflective of mothers who had a traumatic child birth experience and developed depression that resulted in not breastfeeding within an hour. Strategies such as Childbirth-Related Post Traumatic Stress Disorder assessment [35] and its association with depression in the days following childbirth may be useful.

### **Perinatal depression and exclusive breastfeeding**

Additionally, there was no significant association between antenatal depression scores and exclusive breastfeeding. Similar findings were discovered in Ghana in a population-based cohort study (n= 20,679) where antenatal depression was not associated with breastfeeding exclusively [22]. A prospective study conducted among Mexican-Americans also found no significant association between depressive symptoms during

pregnancy and breastfeeding at 12 weeks postpartum [49]. On the contrary, findings from other studies reveal evidence of a significant negative association between antenatal depression and exclusive breastfeeding [19-21]. Furthermore, a systematic review of primarily high-income countries concluded depression during pregnancy predicted shorter breastfeeding duration [17].

However, mothers who met criteria for postpartum depression had 55% lower odds of exclusively breastfeeding. These findings corroborate findings from a systematic review that reported postpartum depression had a significantly negative association with exclusive breastfeeding practices [17]. Additionally, the results correlate with previous studies findings that showed significant associations between postpartum depression and early cessation of exclusive breastfeeding [20, 23, 24].

### **Breastfeeding and postpartum depression**

Several studies have concluded that breastfeeding appears to be a protective factor against development of adverse mental health conditions, specifically during the postpartum period. However, most studies have focused on breastfeeding vs. not breastfeeding [17]; early initiation or exclusivity of breastfeeding have been scanty investigated. In this study, early initiation of breastfeeding was significantly associated with lower likelihood of postpartum depression among refugee mothers. Mothers who initiated breastfeeding within the first hour after delivery had 65% lower odds of developing postpartum depression. Previous study findings concluded that that early breastfeeding initiation predicted lower rates of postpartum depression [50]. Furthermore, other investigators showed that no or delayed breastfeeding initiation predicted postpartum depression [51]. Despite the associations, the mechanisms of how

early initiation of breastfeeding lowers the risk of postpartum depression are not well-understood. Breastfeeding may have a protective effect on mental health because of its role in mitigating maternal stress. Also breastfeeding may be a key factor in modulating the inflammatory response [52]; studies have shown breastfeeding mothers to have lower levels of biomarkers of stress [53-55]. Therefore, it's possible that early initiation of breastfeeding mitigates the risk of developing perinatal depression amidst stress and trauma from childbirth. Given these findings, understanding the full scope of barriers to early initiation of breastfeeding among refugees is important so that interventions and programs aiming to improve early initiation of breastfeeding rates are effective and in turn, may positively influence the postpartum mental health of refugee mothers.

Additionally, mothers who exclusively breastfed their infants had 65% lower odds of having postpartum depression. These odds ratios corroborate previous findings among Sudanese mothers that showed exclusive breast feeding was associated with 80% lower odds in developing postpartum depression [56]. Furthermore, a study in Bangladesh revealed that non-exclusively breastfeeding mothers were 7.58-fold more likely to experience postpartum depression than exclusively breastfeeding mothers [57]. And in Iran postpartum depression symptoms were significantly lower among exclusively breastfeeding mothers compared to non-breastfeeding mothers [58]. Researchers have suggested the continued skin-to-skin contact associated with breastfeeding may be associated with an increase in secretion of oxytocin which in turn may increase positive maternal feelings and reduction in stress [59]; this impact may be more pronounced in mothers who are exclusively breastfeeding as their skin-to-skin contact may be more frequent.

## **Recommendations**

Efforts towards decreasing complications during childbirth, as well as improving the quality of care received by refugees are important considerations. Previous studies among refugees in Uganda have recommended increasing training for healthcare staff, ensuring compliance with anti-corruption policies, and enhancing maternity care provided to refugees, as well as efforts towards overcoming language and cultural barriers between health care workers and refugees [34]. Implementing screening and treatment for IPV victims, especially during the perinatal period would be beneficial to help mitigate any potential negative effects of IPV on breastfeeding and mental health outcomes among refugee mothers. An integrated intervention was assessed among Congolese refugees in Tanzania that included evidence-based interventions for IPV psychological distress delivered by non-specialist refugee workers improved awareness, skills, and overall well-being of victims [60]. This type of intervention may be feasible and effective in refugee settlements in Uganda and could potentially be delivered by the VHTs.

In addition to screening for perinatal depression during antenatal and postnatal care, addressing stigma and involving social networks and key leaders may be important for programs and interventions aiming to improve perinatal depression. Since current research has shown promising effects of the Self-Help Plus compared to usual MHPSS care among South Sudanese refugees, this may be an effective tool to consider using during antenatal and postnatal care. Since it can be delivered by a non-specialist, such as the VHT, it works to reduce the burden of health care workers while increasing access as it can be provided in a group setting. Implementation and adoption of the principles set

forth by the Baby Friendly Hospitals Initiative [61] in refugee settlements may be an appropriate next step for improving breastfeeding, as well as improving other newborn practices that have been found to be inadequate in settlements in Uganda [46].

Furthermore, the use of formula among participants reemphasizes the need for policies to regulate the wide-spread donations of formula in settlements, as well as ensure that breastfeeding information and support is provided to refugees [62].

### **Limitations**

Recall bias or social desirability bias may have influenced breastfeeding data and stigma around depression may have influenced responses during data collection.

Antenatal depression was measured during the 3<sup>rd</sup> trimester; however, multiple measurements of assessing depression symptomology throughout pregnancy may be more informative. Due to pandemic related delays, of the 390 participants enrolled at baseline, 115 participants delivered before data collection began. Thus antenatal depression data were not available for these participants, significantly reducing the sample size available for analyses. Also, there are limitations in comparing results to other studies as a wide array of measurement tools have been used to assess perinatal depression and breastfeeding in different populations.

### **Conclusion**

Data from this study provided insight into the childbirth experience, as well as potential issues influencing both breastfeeding practices and perinatal depression among refugees. Nearly one-quarter of mothers experienced perinatal depression and breastfeeding practices were below global targets. Continued communication of breastfeeding recommendations and benefits during antenatal and postnatal visits will

likely aid in improved breastfeeding rates. Postpartum depression was significantly associated with poorer breastfeeding practices, and early initiation of breastfeeding and exclusive breastfeeding were linked to significantly lower odds of development of postpartum depression. Screening for and providing treatment for postpartum depression will be important for interventions aiming to improve breastfeeding among South Sudanese refugees in Uganda.



**Table 1.** Guides for focus group discussions and key informant interviews

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<b>Focus group discussion questions: Mothers</b>
1. Sometimes mothers have struggles after giving birth. <ol style="list-style-type: none"><li>What struggles do mothers in your community have after giving birth?</li><li>What struggles have you had before and after birth?</li></ol>
2. Sometimes mothers do not feel safe. <ol style="list-style-type: none"><li>How safe do you feel where you live?</li><li>Do you feel safer or less safe than where you lived before?</li><li>What is it like for you to live here?</li></ol>
3. What other struggles are common in your community?
4. What types of violence exists in your community and in families? <ol style="list-style-type: none"><li>Is violence between husband and wives common?</li></ol>

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<b>Focus group discussion questions: Fathers</b>
1. Sometimes fathers have struggles after a new child is born. <ol style="list-style-type: none"><li>What struggles do fathers in your community have after a child is born?</li><li>What struggles have you had before and after the birth of a child?</li></ol>
2. How safe do you feel where you live? <ol style="list-style-type: none"><li>Do you feel safer or less safe than where you lived before?</li><li>What is it like for you to live here?</li></ol>
3. What struggles are common in your community?
4. What types of violence exists in your community and in families? <ol style="list-style-type: none"><li>Is violence between husband and wives common?</li></ol>

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<b>Focus group discussion and interview questions: Village Health Team &amp; Key Informants</b>
1. What struggles do mothers have after giving birth?
2. What struggles do fathers have after giving birth?
3. How safe do mothers and fathers feel living in the community?
4. What struggles are common in your community?
5. What types of violence exists in the community and in families? <ol style="list-style-type: none"><li>Is violence between husband and wives common?</li></ol>

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**Table 2.** Descriptive characteristics of parents in the qualitative study (n = 115)

Characteristics	Mothers (n = 66)	Fathers (n= 49)
	<u>Mean</u>	<u>Mean</u>
Respondent age (years)	28.2	38.1
Child's age (months)	13.2	16.1
Household size	6.6	8.5
	<u>%</u>	<u>%</u>
Occupation		
No occupation	92.4	55.1
Ethnicity		
Dinka	3.0	59.2
Madi	66.6	30.6
Other	30.4	10.2
Education level		
Illiterate/no formal education	21.2	28.6
Formal education	78.8	71.4
Duration as refugee in West Nile, Uganda		
2 - 5 years	93.9	75.5
> 5 years	6.1	24.5
Aware of available MHPSS <sup>1</sup> services	69.7	69.4

<sup>1</sup>Mental health and psychosocial support

**Table 3.** Perceived common stressors among parents in the settlements

Themes	Codes	Quotations	Data source (# times mentioned)
Lack of basic needs	Poverty	<p>“I am staying here just to sustain my life and there is nothing to kill me. Everything we are doing here will end. The type of education which is given to our children here is not standard and the food does not even last 5 days. As you know very well a budget of 31,000 UGS per a month is not enough to satisfy someone’s hunger. “ – Fathers FGD (Ayilo-I)</p> <p>“A husband has to try all the ways to get money to fulfill the needs of the child.” Fathers FGD (Ayilo-I)</p> <p>“We are not doing well because sometimes the food ration will not come. This is why we are not happy, we have no money.”– Mothers FGD (Boroli)</p> <p>“Money has become the first obstacle in the community.” – VHT FGD (Boroli)</p>	<p>Fathers FGD (5)            Mothers FGD (6)            Mothers and Fathers FGD (1)            VHT FGD (2)</p>

	<p>Inadequate food and water</p>	<p>“The father struggles to provide all the nutritional values to make the baby grow and be healthy.” – Fathers FGD (Ayilo-I)</p> <p>“We have only one problem and it is all about food.” – Mothers FGD (Boroli)</p> <p>“We have no money for buying food.” – Mothers FGD (Boroli)</p> <p>“There is inadequate drinking water.” Boroli VHT</p> <p>“There are inadequate food items in our household to feed children.” – VHT FGD (Boroli)</p> <p>“The food ration we are getting it will not last a full month. We shall eat it in three weeks so generally we struggle to get food to eat.” VHT FGD (Boroli)</p> <p>“The issue is receiving food. The distance there is too long, like it is the policy of WFP, they combine settlements. It is</p>	<p>Fathers FGD (4) KII (7) Mothers FGD (3) Mothers and Fathers FGD (2) VHT FGD (3)</p>
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		<p>more than 4-5 kilometers to get food. Now, people become tired, stressful, so people begin thinking of those things. There's no means of carrying food, you are supposed to go and get food. You see, when you don't go, you don't have something to eat. See, that's the stressful situation we are seeing." – KII #4</p> <p>"For us as a community we actually don't have food, so we don't have any support." – KII #3</p> <p>"The time we came, our ration was 100% but with time, our ration was reduced to 50%, so now, if you are receiving cash, you get 31,000 Ugx, and that 31,000 Ugx cannot support you for treatment or buying food." – KII #2</p> <p>"They [refugees] struggle to find good nutritious foods. They [refugees] can eat for two days and there is no food left." – KII #1</p>	
	Lack of land for agriculture	"There is no land. They get a small place and don't have any	KII (3)

		support or seed for farming. That's what they are facing." KII #3	
	Lack of household and building materials	"Generally they are struggling for the grasses for building the houses." VHT FGD (Boroli)	Fathers FGD (1) KII (1) VHT FGD (2)
	Lack of firewood for cooking	"We struggle to get firewood, it is difficult to get." Fathers FGD (Ayilo-I)  "There's not enough firewood here and sometimes they cross to the village which is another struggle." – VHT FGD (Boroli)	Fathers FGD (1) VHT FGD (1)
	Lack of employment	"We struggle to look for a job." Fathers FGD (Ayilo-I)  "Having no job, this is our big problem." –VHT FGD (Boroli)  "There's no work for the men, that's common in the community." – VHT FGD (Boroli)	Fathers FGD (1) KII (4) Mothers FGD (1) VHT FGD (3)
<b>Issues involving childbirth</b>	Lack of items needed for childbirth and post-delivery	"The wife is pregnant and we struggle to meet the needs of the child. When the time comes for delivery and we do not have the items we need. Also, the mother needs to be fed a balanced diet to keep her healthy which requires a lot of	Fathers FGD (2) KII (4)

		<p>money. You also need to care for the health of baby which involves taking the baby to the health center.” – Fathers FGD (Ayilo-I)</p> <p>“Before the baby is born you have to be sure to get the nursing materials. You get them ready so that when the wife delivers everything you need should be in place such as bathing room and other things. After the wife delivers you need to equip yourself with money such that you will be able to provide for the baby and delivered mother. – Fathers FGD (Ayilo-I)</p>	
	<p>Maternal bleeding</p>	<p>“Sometimes you will bleed while waiting to receive a baby.” – Mothers FGD (Boroli)</p> <p>“Sometimes the blood runs nonstop from the mother’s body.” – Mothers FGD (Agojo)</p> <p>“Blood will run nonstop from the body of the mother.” – Mothers and Fathers FGD (Pagirinya)</p>	<p>KII (3)  Mothers FGD (4)  Mothers and Fathers FGD (2)  VHT FGD (3)</p>

	<p>Death of mother or newborn</p>	<p>“You may thinking of giving birth as life or death. – Agojo Moms FGD</p> <p>“Sometime you feels the pains of the baby for two days but you can’t deliver and you may think of operation where you may die.”– Mothers FGD (Agojo)</p> <p>“Sometimes the baby will die.” – Mothers FGD (Agojo)</p> <p>“Something like umbilical cord if remains in the stomach of the mother, it causes her a lot of pain and it will lead to her death.” –KII #7</p> <p>“Sometime the baby or the mother will die.” – VHT FGD (Boroli)</p> <p>“After the delivery, you undergo severe pain and too much bleeding not controlled in the hospital can lead to the loss of the life of the mother.”– KII #5</p> <p>“Like if your wife delivers at the health center, during</p>	<p>KII (4)  Mothers FGD (4)  Mothers and Fathers FGD (1)  VHT FGD (1)</p>
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		<p>delivery, there is a small connection between the child and the mother and when they cut the connection, the baby shall die. We have very many babies who are dying because of that in the health center.”– KII #2</p> <p>“What goes wrong is when the mother is unable to deliver unfortunately issues in terms of most cases umbilical cord is tied around the neck of the baby making it difficult and those are the dangerous things that make death and life can be seen there you are not rushed to get help first either you or the baby of the two or both of you can lose lives so it’s bit difficult scenario that need to be handled with care and proper monitoring and that requires both the father and mother to be around.” –KII #5</p>	
	Problems with delivery	<p>“Sometimes the baby will not be pushed out or the baby may sleep across in the womb.” – Mothers FGD (Agojo)</p>	<p>KII (1) Mothers FGD (3) Mothers and Fathers FGD (2)</p>

		<p>“The baby will push their hand out first.” – Mothers FGD (Agojo)</p> <p>“The umbilical cord may get damaged.”– Mothers FGD (Agojo)</p> <p>“If the umbilical cord remains in the stomach of the mother, it causes her a lot of pain.”– Mothers and Fathers FGD (Pagirinya)</p> <p>“Sometimes, the mother does not deliver.”– Mothers and Fathers FGD (Pagirinya)</p>	
	<p>Mother or newborn are sick</p>	<p>“When a mother has a newborn baby, there may be some problems like if the baby was sick or the mother is sick.”– Mothers and Fathers FGD (Pagirinya)</p> <p>“Caring for the child because of sickness and taking the child for the treatment is a struggle.” – VHT FGD (Boroli)</p> <p>“If the mother has a problem or disease or malaria, meaning that there is sickness in the</p>	<p>KII (1)  Mothers and Fathers FGD (1)  VHT FGD (1)</p>

		body and that malaria is disturbing that child.” – KII #3	
	Delivers at home or roadside	“During the delivery process, there should be razorblades in case she should deliver on the way to the health facility.” – VHT FGD (Boroli)	KII (4) VHT FGD (1)
	Pain	“Before giving birth mothers have back pain.” – Mothers FGD (Boroli)  “When you have pain, you need to go to the hospital.” – Mothers FGD (Boroli)	KII (1) Mothers FGD (5) Mothers and Fathers FGD (1)
	Perceived inadequate breastmilk	“Pregnant mothers may not afford to buy the nutritious food daily in order to produce more breastmilk.” – Mothers FGD (Agojo)  “She [the mother] does not have enough milk.” – Mothers FGD (Boroli)  “There is no breastmilk coming out.” – Mothers FGD (Agojo)  “Sometimes there is no breastmilk for the baby.” – Mothers FGD (Agojo)	KII (2) Mothers FGD (4) Mothers and Fathers FGD (1) VHT FGD (2)

		<p>“She [the mother] will feel very weak and there is no breastmilk.” – Mothers and Fathers FGD (Pagirinya)</p>	
<p><b>Marital conflict and violence</b></p>	<p>Domestic violence</p>	<p>“The violence between husband the wife is so common because of the disagreement on family issues. A man may decide and the woman rejects and therefore, violence may occur.” – Fathers FGD (Ayilo-I)</p> <p>“I think the common one is domestic [violence] and this one is happening due to little resources because like the other men who want refreshment with drinking and maybe when you are drunk the wife will accuse you of having money therefore it may result into violence in the community and family.” – Fathers FGD (Ayilo-I)</p> <p>“Men can stay in their problems and stress and all the time drinking and end up in beating wife.” – Mothers and Fathers FGD (Pagirinya)</p>	<p>KII (3) Fathers FGD (4) VHT FGD (2)</p>

	<p>“Domestic violence is common in the community and in the family.” – VHT FGD (Boroli)</p> <p>“Domestic violence is very, very common.” – KII #5</p> <p>“Using money in the household in bad manners will cause fights because a woman may decide to take control of the money in the household.” – VHT FGD (Boroli)</p>	
Emotional Violence	<p>“There is emotional violence.” – KII #2</p>	KII (4)
Economic Violence	<p>I am a man and my wife has been identified as a vulnerable individual in my household. Therefore, the partner is trying to support that vulnerable person. The woman is not given any money in order to have something. They [the men] basically grab that money from the women to go and drink. This woman would wish that the husband will give them some money so that they can budget and buy things but the money will not be there. It causes violence. KII #5</p>	KII (2) VHT FGD (1)

	Physical Violence	<p>“If he beats you, dash to the nearest neighborhood for help.” – Mothers FGD (Boroli)</p> <p>“There is physical violence.” – VHT FGD (Boroli)</p> <p>“It’s possible sometimes you can be beaten.” – Mothers FGD (Agojo)</p>	<p>KII (3) Mothers FGD (2) VHT FGD (1)</p>
	Sexual Violence	<p>“Men sometimes rape their wife and it creates more issues of gender based violence.” – Mothers FGD (Agojo)</p> <p>“They [men] forcing sex with their wives in the house.” – Mothers FGD (Agojo)</p> <p>“There is rape and sexual violence. The sexual violence is because of the fighting between the husband and the wife.” – KII #3</p>	<p>KII (2) Mothers FGD (2)</p>
	Infidelity	<p>“It [infidelity] is because a man can get his sugar mommy outside the home.” – Mothers and Fathers FGD (Pagirinya)</p>	<p>Mothers and Fathers FGD (1)</p>
	Arguments	<p>“If something is paining in your heart, you talk to the wife. If you as a man do not talk to her, she will die.” –</p>	<p>KII (1) Mothers and Fathers FGD (1)</p>

		Mothers and Fathers FGD (Pagirinya)	
	Husband/father not around	“It happens such that some men also neglect the wife after impregnating her. You’ll find that the man will refuse to take the full responsibility of the wife. Now it’s a single mother who will feel bad because now she has nothing. Even when she gives birth she has nothing she needs to care for the child.” – VHT FGD (Boroli)	VHT FGD (3)
<b>Other violence and conflict</b>	Community and Intertribal violence	“There are intertribal conflicts and conflicts between refugees and nationals.” – KII #1  “We have these issues like the areas of community violence.” – VHT FGD (Boroli)	KII (3) VHT FGD (1)
	Gender-based violence and conflict	“There is gender based violence.” – VHT FGD (Boroli)  “There is sexual violence.” – VHT FGD (Boroli) “We have sexual violence and they [the perpetrator] says ‘I did it because influence of alcohol which is not true.’” – KII #5	KII (6) Mothers FGD (1) VHT FGD (2)
	Issues with neighbors	“Some problems do happen with neighbors. If your goat	Mothers and Fathers FGD (2)

		went and ate maize in the neighbors' garden and if the neighbor is a bad person, it will be very hard to have peace with your neighbors.” – Pagirinya M/F FGD	
<b>Inadequate health care</b>	Health center issues	“One stressful situation is that the long distance in getting to the health unit and it’s rare that it opens on weekends. It’s rare that it operates over weekends, Saturdays and Sundays. Emergencies are only done for children, but not for adults.– KII #4	KII (7)
	Health centers are far	“There is an issue with transport to health facilities because of the long distance.”– Mothers FGD (Agojo)  “There is a far distance of the health facilities.” – Agojo Mothers FGD	Mothers FGD (3) VHT FGD (1)
	Issues with midwives	“The midwife in the health center, their heart is not good with mothers.” –Mothers FGD (Agojo)  “When the midwife is not around, there will be a sickness because the midwife is not there. If possible, we need to add more midwives, like today	KII (1) Mothers FGD (2) VHT FGD (1)



		is Saturday, if you take your wife today, they will say, there is no work today, because it is a weekend.” – KII #2	
<b>Issues involving children</b>	Child labor	“We have issues of overworking women and there is child labor. – KII #6	KII (1)
	Early or forced marriage	“There is early marriage and forced marriage.” – KII #6	KII (2)
	Parental abuse or neglect	<p>“Another violence is when a husband does not provide for the children.” – Fathers FGD (Ayilo-I)</p> <p>“There is child abuse and child neglect.” –KII #7</p> <p>“You’ll find some scenarios where you find that the mother abandons the child after delivery.”– VHT FGD (Boroli)</p>	<p>Fathers FGD (2)</p> <p>Mothers and Fathers FGD (1)</p> <p>KII (2)</p> <p>VHT (2)</p>
	Children fight	<p>“The children also fight when they come back from the school and if a parent may intervene, the other parents also intervene and violence erupts in the community.” – Father FGD (Ayilo-I)</p> <p>“Children cause problems in the settlement. They go play and they fight. They may break someone’s hand and the fight</p>	<p>Fathers FGD (1)</p> <p>KII (1)</p>

		will attract many people.” KII #1	
	Not enough schools	<p>“It is hard to get a secondary school to be built in Ayilo-I. It is being disputed by the OPM.” – Fathers FGD (Ayilo-I)</p> <p>“Children stay at home without schools.” – VHT FGD (Boroli)</p> <p>“The school is very far and when you see all the children just within the camp sometimes they’re not going to the school because of that distance and that’s a big concern.” – VHT FGD (Boroli)</p>	Fathers FGD (3) KII (4) VHT FGD (4)
	Unaffordable school fees	<p>“Generally there’s no money coming from anywhere for school development fund and school fees. It is you, the father or the mother to struggle to get a development fund for their government school. After they finish the primary and when they’re going to the next level and you to pay school fees, then you have to struggle and get fees to send your child to secondary school.”– VHT FGD (Boroli)</p>	Fathers FGD (1) VHT FGD (1)

		<p>“To get access to education is what the community is struggling for and the secondary school is very hard to afford.” – Fathers FGD (Ayilo-I)</p>	
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Abbreviations in Table 3:

FGD: Focus Group Discussion

KII: Key Informant Interview

VHT: Village Health Team

**Table 4.** Quantitative study maternal and infant characteristics

<b>Maternal Characteristics</b>	<b>n</b>	<b>Frequency (%)</b>	<b>Mean ± SD</b>
<b>Age (years)</b>	362		27.7 (5.1)
<b>Education</b>			
None or informal	171	47.2	
Some primary	160	44.2	
Secondary or higher	31	8.6	
<b>Occupation</b>			
Not employed	320	88.4	
Farming/Agriculture	22	6.1	
Other work or business	20	5.5	
<b>Marital status</b>			
Married	355	98.1	
Never married or widowed	7	1.9	
<b>Number of antenatal visits</b>	362		5.4 (1.8)
<b>Type of delivery</b>			
<i>Caesarean section</i>	22	6.1	
Vaginal	340	93.9	
<b>Place of delivery</b>			
Home or roadside	10	2.8	
Health center	267	73.8	
Hospital	85	23.4	
<b>Number of postnatal visits</b>	362		2.7 (1.2)

<b>Mid-upper arm circumference</b>			27.0 (3.7)
<b>Sickness in last 24 hours</b>			
No sickness	323		89.2
Fever or diarrhea	39		10.8
<b>Infant Characteristics</b>	<b>n</b>	<b>Frequency (%)</b>	<b>Mean ± SD</b>
<b>Age (months)</b>			2.9 (1.3)
<b>Sex</b>			
Male	185		51.1
Female	177		48.9
<b>Sickness in last 24 hours</b>			
No sickness	330		91.2
Fever or diarrhea	32		8.8

**Table 5.** Breastfeeding practices and perinatal depression among participants

<b>Breastfeeding</b>	<b>n</b>	<b>Frequency (%)</b>
Early initiation	240/362	66.3
Exclusive breastfeeding	200/362	55.5
<b>Perinatal depression</b>		
Met criteria for prenatal depression	53/266	19.9
Met criteria for postpartum depression	85/362	23.5
<b>Prenatal depression symptom categories<sup>1</sup></b>	<b>n = 266</b>	
None-minimal	79	29.7
Mild	134	50.4
Moderate	46	17.3
Moderately severe	7	2.6
<b>Postpartum depression symptom categories<sup>1</sup></b>	<b>n = 362</b>	
None-minimal	136	37.6
Mild	141	38.9
Moderate	76	21.0
Moderately severe	9	2.5

<sup>1</sup> PHQ-9 scores: None-minimal: 0-4, Mild: 5-9, Moderate: 10-14, Moderately severe 15-19

**Table 6.** Associations between perinatal depression and breastfeeding practices

<b>Perinatal depression</b>	<b>Early Initiation of breastfeeding</b>		<b>Exclusive breastfeeding</b>	
	<b>OR</b>	<b>AOR<sup>1</sup></b>	<b>OR</b>	<b>AOR<sup>1</sup></b>
<b>Prenatal Depression (n=266)</b>				
Prenatal PHQ-9 score	0.99 (0.92-1.06)	-	0.98 (0.92-1.05)	-
Met criteria for prenatal depression <sup>2</sup>	0.81 (0.44-1.41)	-	0.73 (0.40-1.34)	-
<b>Postpartum Depression (n=362)</b>				
Postpartum PHQ-9 score	0.93 (0.88-0.98)**	0.92 (0.87-0.98)**	0.98 (0.93-1.03)	-
Met criteria for postpartum depression <sup>2</sup>	0.42 (0.25-0.68)***	0.35 (0.21-0.61)***	0.53 (0.33-0.87)*	0.43 (0.25-0.73)***

Results expressed as OR/AOR (95% CI)

\*p-value < 0.05, \*\*p-value < 0.01, \*\*\*p-value < 0.001

<sup>1</sup>Models adjusted for study arm, child age, child sex, maternal MUAC, maternal fever or diarrhea in the last 24 hours, maternal age, maternal education, antenatal visits, postnatal visits, place of delivery, and type of delivery

**Table 7.** Associations between breastfeeding practices and postpartum depression

Breastfeeding practices (n=362)	Postpartum Depression <sup>1</sup>	
	OR	AOR <sup>2</sup>
Early initiation of breastfeeding	0.42 (0.25-0.68)***	0.35 (0.20-0.59)***
Exclusive breastfeeding	0.53 (0.35-0.87)*	0.45 (0.26-0.79)**

Results expressed as OR/AOR (95% CI)

\*p-value < 0.05, \*\*p-value < 0.01, \*\*\*p-value < 0.001

<sup>1</sup> PHQ-9 score of 10 or higher (category of moderate or higher)

<sup>2</sup> Models adjusted for study arm, child age, child sex, maternal age, maternal social support, maternal education, antenatal visits, postnatal visits, place of delivery, type of delivery, and maternal MUAC



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## CHAPTER VII

### PERINATAL DEPRESSION AND INFANT NUTRITIONAL STATUS AMONG SOUTH SUDANESE REFUGEES IN THE WEST NILE REGION IN UGANDA

#### **Abstract**

Globally, nearly 45% of young child deaths are linked to undernutrition. Refugee children in resource-limited areas have increased vulnerability to food insecurity and hunger after relocating to a new country. Additionally, refugee mothers have a heightened risk for developing perinatal depression. Prior research indicates an association between perinatal mental illnesses and undernutrition in infants among different populations. Quantitative study participants (n=390) were pregnant mothers who were enrolled in a community-based randomized control study. Perinatal depression was measured using Patient Health Questionnaire-9 during 3rd trimester and twice during postpartum. Infant anthropometrics were collected for infants between 4-9 months of age. SAS, v. 9.4, was used to conduct linear and logistic regressions to analyze perinatal depression and infant nutritional status and models were adjusted for confounders.

Among infants, 11.9% were underweight, 12.8% were stunted, and 7.1% were wasted. One-fifth (20.0%) of mothers met the criteria for antenatal depression and 24.6% for postpartum depression. Many (71.9%) had symptoms of antenatal depression; antenatal depressive symptoms were not significantly associated with infant z-scores or undernutrition. However, early postpartum depression symptoms predicted significantly lower weight-for-age z-scores and lower length-for-age scores. Higher concurrent postpartum depression symptoms were significantly associated with increased odds of infants being underweight. Screening and treatment for perinatal depression during antenatal and postnatal care is a key step in supporting mothers. Interventions seeking to alleviate undernutrition in refugee settlements may consider strategies that include helping mothers mitigate the effects of perinatal depression.

## **Introduction**

Globally, undernutrition is linked to approximately 45% of all-cause mortality among children under five years old [1]. In 2019, nearly 50 million children under five were wasted, 149 million were stunted, and an estimated 12.6% were underweight [2, 3]. Suboptimal growth during the first 1,000 days is known to have long-term effects, including potentially irreversible damage to immune function, physical growth, and cognitive development [4]. Furthermore, underweight (low weight for age) and wasting (low weight for length/height) have been associated with increased risk of death from infectious diseases among children under 5 [5]. Stunting is also associated with increased morbidity and mortality from infectious diseases, as well as decreased cognitive abilities, impaired neurodevelopmental and heightened risk of chronic diseases in adulthood [6, 7].

High rates of undernutrition commonly occur in low- and middle-income countries and the risk of death increased among children as undernutrition z-scores decreased [8].

Rates of child undernutrition are particularly high among children in South Sudan; 30.6% were stunted, 27.7% were underweight, and 22.7% were wasted [3]. Due to years of armed conflict and a devastating civil war, South Sudanese comprised the largest refugee population in Africa [9]. Evidence indicates exposure to conflict has a negative impact on child health outcomes, including nutritional status [10, 11]. Over 2.3 million South Sudanese, of which over 50% are children, have been forced to flee their home country and most have found refuge in the neighboring country of Uganda [9]. Among South Sudanese children living in Uganda, stunting rates across settlements were as high as 48.7% and up to 10.7% were underweight [12].

Investigation to uncover the causes of infant and child undernutrition has indicated poor maternal mental health is a factor [13, 14]. Maternal mental health problems are estimated to be three times more prevalent in low- and middle-income countries (LMICs) where mental health has reportedly been a neglected and low healthcare priority [15, 16]. Included in maternal mental health concerns is perinatal depression, a term used to encompass both antenatal and postpartum depression [17]. Approximately 19% of women living in LMICs experience perinatal depression and nearly 33% of migrants and refugees from LMICs suffer from perinatal depression [18, 19]. However, studies on perinatal depression among refugees from LMICs have focused on women who have relocated to high income countries. Data on antenatal and postpartum depression among refugees who migrate to LMICs remains severely lacking and the prevalence of perinatal depression among refugees living in LMICs is unknown.

However, perinatal depression is linked to a variety of negative maternal and infant health consequences [20]. In order to effectively prevent, screen, and treat perinatal depression among refugees, an understanding of antenatal and postpartum depression is imperative.

Mixed and inconsistent results have been reported on associations between perinatal depression and undernutrition among children under five years of age. A prospective cohort study in Pakistan reported that infants of mothers with antenatal depression had a higher risk of being underweight and stunted at six and twelve months of age [21]. A recent systematic review and meta-analysis of studies from LMICs concluded postpartum depression was significantly associated with an increased risk of stunting and underweight among children 0-59 months [14]. Additional studies also have reported associations between postpartum depression and an increased risk of stunting [22-24].

Apparently these associations may vary by country, growth indicator, and time of assessment for perinatal depression and infant nutritional status. In Nigeria, infants of mothers with postpartum depression had significantly poorer growth, both weight and length, scoring below the 5<sup>th</sup> percentile at 3 and 6 months but not at 9 months after birth [25]. A community-based study analyzed data from four low-income countries and reported that maternal common mental disorders during 6-18 months postpartum were associated with underweight in Vietnam, and stunting in India, but no associations were found in Peru and Ethiopia [26]. Lastly, a population-based cohort study in Ethiopia reported that antenatal and postpartum depression were not significantly associated with underweight or stunting in infants at six or twelve months[27]. Why perinatal depression

is associated with infant nutritional status in some countries and not in others also continues to be unknown [27]. Most studies have focused on postpartum depression and data on antenatal depression and infant nutritional status is scant. Furthermore, the association between perinatal depression and infant nutritional status has not been studied among refugees in LMICs. Therefore, the purpose of this study was to investigate perinatal depression and infant nutritional status among South Sudanese refugees in the West Nile region in Uganda. The specific objectives were to: 1) assess the occurrence of antenatal and postpartum depression 2) analyze associations between antenatal depression and infant nutritional status, and 3) analyze associations between postpartum depression and infant nutritional status.

## **Methods**

Data collection occurred during a longitudinal, community-based, randomized controlled trial (RCT) in Adjumani District, in the West Nile Region of Uganda in 2020. The RCT study utilized a peer-led nutrition education intervention using the Care Group model compared to the standard of care in refugee settlements. The study enrolled 390 women who were South Sudanese refugees in their 3<sup>rd</sup> trimester of pregnancy. The research team hired and trained South Sudanese data collectors who verbally administered a questionnaire in the languages primarily spoken by each refugee: Arabic, Madi, or Dinka. This questionnaire was developed based on prior research and was pre-tested before data collection. Data collection for each participant in this study occurred at three time points: the 3<sup>rd</sup> trimester of pregnancy, 0-5 months and 4-9 months postpartum. The two data collection points occurring after delivery were approximately three months apart for each participant.

## Variables

Antenatal and postpartum depression were measured using the Patient Health Questionnaire, nine-item version (PHQ-9) [28]. The PHQ-9 has been reported as a valid screening tool for perinatal depression [29] and has a reported Cronbach's Alpha ( $\alpha = 0.75$ ) among South Sudanese refugees in Uganda [30]. PHQ-9 scores (scale from 0-3) range from 0-27 and a total score for number of depression symptoms is summated: none-minimal (0-4), mild (5-9), moderate (10-14), moderately severe (15-19), and severe ( $\geq 20$ ). A PHQ-9 score  $\geq 10$  indicates moderate or severe symptoms and is suggestive of depression. The PHQ-9 was administered to participants during the 3<sup>rd</sup> trimester and twice during the postpartum period.

Infant anthropometrics were collected for all infants by the lead research team member. A standardized infanometer was used to measure recumbent length in centimeters and a digital scale (SECA 874) was used to measure weight in kilograms. Measurements were recorded to the nearest decimal (0.1) and the average of two measurements was used to improve precision of anthropometrics. Length and weight were converted to length-for-age (LAZ), weight-for-age (WAZ), and weight-for-length (WLZ) z-scores according to the WHO growth standards [31] using a software called Emergency Nutrition Assessment for Standardized Monitoring and Assessment of Relief and Transitions (ENA for SMART 2011). Z-scores were converted into categorical variables to measure undernutrition: stunted if LAZ was less than -2, underweight if WAZ was -2, and wasted if WLZ was less than -2. Anthropometrics were collected when infants were between four to nine months old.

## **Data analyses**

Linear regressions were conducted to analyze associations between perinatal depression and z-scores. Logistic regression analyses were performed to determine associations between perinatal depression and child growth indicators; underweight, stunting, and wasting. Explanatory variables for antenatal depression and early and current postpartum depression included continuous PHQ-9 scores as well as the categorical variable for whether or not the mother had met the criteria for depression (PHQ-9 score  $\geq 10$ ). Outcome variables include continuous z-scores: WAZ, LAZ, and WHZ as well as categorical indicators for undernutrition, including underweight, stunting, and wasting. Variables that reached a significance of  $p < 0.05$  in bivariate analyses were analyzed using multivariable regression analyses which adjusted for covariates. Covariates were selected based on prior research of determinants of undernutrition among refugee children [32-35] and the United Nations Children's Fund conceptual framework [36] and included study arm, household food insecurity, maternal education, mid-upper arm circumference, short stature, and age, as well as infant sex, low birth weight, diarrhea in the last month, and exclusive breastfeeding since birth. SAS, v. 9.4 was used for analyses and multicollinearity was assessed using the tolerance test and variance inflation factor and no collinearity issues were detected.

## **Ethical approvals**

Approvals were obtained from the Makerere University School of Health Sciences Research and Ethics Committee in Uganda, the Uganda National Council of Science and Technology, and the Oklahoma State University Institutional Review Board. Participants were informed participation was voluntary, received explanation of the



study's purpose and were provided an opportunity to ask questions. Informed consent was received from each participant prior to data collection. Compensation for their time was provided to participants in the form of food and household items including soap, iodized salt, sugar, and Vitamin A fortified cooking oil, worth approximately 7,600 Uganda Schillings. Participants received compensation at each data collection point.

## **Results**

### **Descriptive characteristics of mothers and infants**

Over half of mothers had been living in the West Nile region of Uganda as refugees for 6 years or more. Mean maternal age was 28.4 years and mean infant age was 6.5 months. Almost half (46.7%) of mothers had received no formal education. Mean maternal mid-upper arm circumference was 27.2 mm and mean maternal height was 167.3 cm. Over one-third (32.9%) of infants had diarrhea in the last month. Most (85.6%) households faced severe food insecurity and only 1.6% were food secure.

### **Occurrence of perinatal depression and undernutrition**

One-fifth (20.0%) of participants had a PHQ-9  $\geq$  10 during pregnancy, which is suggestive of antenatal depression. Many (71.9%) had symptoms of antenatal depression; 51.9% had mild symptoms, 17.0% had moderate symptoms, and 3.0% had moderately severely symptoms. Nearly two-thirds (62.9%) had symptoms of early postpartum depression; 38.3% had mild symptoms, 21.7% had moderate symptoms, 2.9% had moderately severe symptoms and 24.6% met the criteria for postpartum depression. Postpartum depression declined over time to 12.6% and just over half (52.2%) had postpartum depression symptoms when measured 4-9 months after delivery. For infants,

the occurrence of underweight (11.9%) and stunting (12.8%) were similar, and 7.1% were wasted.

### **Associations between perinatal depression and nutritional status**

Antenatal PHQ-9 scores were not significantly associated with WAZ, LAZ, or WHZ (Table 2). Additionally, there were no significant associations detected between antenatal depression and undernutrition (Table 3). In bivariate analyses, higher maternal early postpartum scores predicted significantly lower infant WAZ and LAZ scores ( $\beta = -0.04$ ,  $p < 0.05$ ;  $\beta = -0.06$ ,  $p < 0.01$ ). Infants whose mothers had early postpartum depression had significantly lower LAZ scores ( $\beta = -0.46$ ,  $p < 0.05$ ). Higher concurrent postpartum depression scores were significantly associated with a higher odds of the infant being underweight (OR 1.09 [1.01-1.19],  $p < 0.05$ ). In the adjusted models, early postpartum depression scores predicted significantly lower WAZ scores ( $\beta = -0.03$ ,  $p < 0.05$ ) and lower LAZ scores ( $\beta = -0.06$ ,  $p < 0.05$ ). However, early postpartum depression did not remain significantly associated with lower LAZ scores ( $\beta = -0.40$ ,  $p = 0.07$ ) in adjusted models [data not shown]. Higher concurrent postpartum depression scores remained significantly associated with increased odds of infants being underweight (OR 1.11 [1.02-1.21],  $p < 0.05$ ) when accounting for covariates [data not shown].

## **Discussion**

### **Perinatal depression**

To the best of our knowledge, this is the first study to report perinatal depression rates among refugees in settlements in Uganda. Many (71.9%) participants reported antenatal depression symptoms and 20.0% had antenatal depression [data not shown]

which is higher than the estimated global prevalence of 15.0% [37]. Similarly, over two-thirds faced symptoms of early postpartum depression and 24.6% had early postpartum depression which is also higher than the global prevalence of 17.2% depression [29]. The occurrence of postpartum depression decreased over time as 52.2% reported symptoms and 12.6% met the postpartum depression criteria when measured between 4-9 months after delivery. Current recommendations in many high-income countries suggest perinatal depression screening for all pregnant women. Given the prevalence of perinatal depression and symptoms in this study, it is important to implement screening for antenatal and postpartum depression among refugees in the settlements. Future research should evaluate and validate the feasibility of a screening tool in resource-poor areas that could be administered by health care workers, or non-specialist workers such as the Village Health Team during antenatal and postnatal care in settlements.

In addition to screening for perinatal depression, providing effective treatment for refugees is critical. Recent evidence suggests there may be affordable and effective treatments that could be offered in LMICs [38]. A variety of interventions including the use of group therapy, home visits, and social support often delivered by community workers have been effective in reducing depressive symptoms among mothers in resource-limited countries [39-43].

Although its use has not been tested in the context of perinatal depression, the World Health Organization's (WHO) Self-Help Plus program [44] has been effective in improving mental health among South Sudanese refugees and has been recommended as a feasible and effective first line strategy[45]. As a group-based intervention, Self-Help Plus enhances the opportunity to increase refugees' access to care and could be

administered by non-specialists, such as the Village Health Team, which may reduce the burden on health care workers.

### **Undernutrition**

Among infants, 11.9% were underweight, 12.8% were stunted, and 7.1% were wasted. These stunting rates were similar to those recently reported from elsewhere in Adjumani district where 11.5% of children under 5 years were stunted [45]. That report concluded that stunting across settlements in Uganda was more common among Congolese refugees compared to those from South Sudan and noted the tall stature of South Sudanese may diminish stunting [12]. The occurrence of underweight (11.9%) in our study was nearly twice as high as the previously reported rate of 5.7% in Adjumani and wasting rates (8.3%) were similar. Underweight, stunting, and wasting remain classified as a “medium” level public health issue for children under 5 years in the settlements across Uganda [12]. However, rates from this study should be viewed with caution as women were enrolled in a RCT aiming to improve feeding practices and growth among children 0-9 months old. Future analyses from these studies will report on the effectiveness of the RCT on supporting infant growth, and differences in growth between control and intervention groups.

### **Perinatal depression and undernutrition**

Antenatal depression was not associated with infant z-scores or underweight, stunting, and wasting. While robust evidence exists to conclude antenatal depression is a risk factor for low birthweight, few studies have analyzed the association between antenatal depression and infant growth. Similar findings were reported in Ethiopia from a

population-based cohort study that concluded antenatal depression was not significantly associated with stunting or underweight at six or twelve months of age [27].

On the contrary, a prospective cohort study in Pakistan found infants of mothers with antenatal depression to be at higher risk for underweight and stunting at both 6 and 12 months of age [21]. However, Rahman and colleagues noted that comparing their findings with results from LMICs should be done cautiously, especially in poor populations where severe food insecurity may be a key driver of undernutrition [21]. Additionally, various methodological tools used to assess antenatal depression make it difficult to compare results across studies and countries [27]. Future research may consider assessing antenatal depression at multiple time points throughout pregnancy to gather a more accurate understanding of the scope of antenatal depression and its impacts on infant nutritional status.

Interestingly, the associations in the adjusted models for postpartum depression were significant when analyzing the PHQ-9 depression scores as continuous variables as opposed to the specified cut-off criteria for a depression diagnosis. Our study results indicated that maternal depressive symptoms, even if scores did not meet the diagnostic cut-off, were negatively associated with infant WAZ, HAZ, and the odds of being underweight. In this study, the standard cut-off of  $\geq 10$  was used [28]; however, evidence from a meta-analysis suggests that there were no significant differences in pooled specific cut-off scores between 8 and 11 [46]. Future research may undertake a validation study to determine whether or not a cut-off of  $\geq 10$  is the most appropriate among populations such as refugees [47] and South Sudanese [48] among whom stigma in disclosing mental health issues remains high. Determining the most applicable cut-off for depression could

be critical to guide the decision on implementing screening and effective treatment in areas where access to mental health professionals is limited. Based on estimates that reductions in the prevalence of perinatal depression could result in a reduction of infant growth deficits of up to 30% [21], appropriate screening and treatment are critical.

Early postpartum depression scores predicted significantly lower WAZ and LAZ scores, even after controlling for potentially confounding variables. Comparable findings from a study in Brazil reported that six-months-old infants of depressed mothers had significantly lower WAZ scores compared to infants of non-depressed mothers [49]. Most studies have assessed postpartum depression and undernutrition at the same time, which has limited the ability to assess the direction of the associations. As such, there has been debate about the directional nature between the association of maternal depression and child undernutrition [50]. However, based on the longitudinal nature of this study, early postpartum depression symptoms were assessed approximately three months prior to infant anthropometrics. Therefore, findings that early postpartum depression scores predicted significantly lower z-scores provides useful information regarding the potential direction of the association, suggesting depressive symptoms might precede lower z-scores. This indicates a window of opportunity to help mothers with depressive symptoms to not only better their own mental health, but also to help mitigate negative consequences on infant nutritional status and growth.

Higher concurrent postpartum depression scores were significantly associated with increased odds of underweight among infants. Similar findings in a systematic review and meta-analysis that included LMICs, reported that children of mothers with depressive symptoms were more likely to be underweight and estimated that 23% fewer

children would be underweight if maternal depression were alleviated [13]. However, it is widely acknowledged that the mechanisms between depression and child nutritional status remain unclear and may vary among different populations [13]. Perhaps the symptoms associated with depression, including fatigue, impaired concentration, and feelings of hopelessness may lead to increased difficulty with infant care and contribute to non-responsive caregiving practices [50-52]. Future research might explore factors mediating depression and the risk of infants being undernourished among refugees.

### **Strengths and limitations**

A key strength of the study was the longitudinal nature, allowing for multiple assessments of perinatal depression which aids in understanding the directional nature of the association between perinatal depression and undernutrition. Additionally, the adjusted models controlled for multiple covariates that are known to strongly influence undernutrition. Nevertheless, the study had limitations. Firstly, the PHQ-9 scale is based on assessment of depressive symptoms and does not indicate a definitive depression diagnosis which requires a professional clinician. However, given the fact that resources are limited in the settlements and refugees' access to clinicians would be difficult, this questionnaire served as an appropriate and accessible assessment. Secondly, undernutrition rates were not as high as expected among this sample size, possibly due to their participation in the larger study aiming to improve feeding practices and child growth. Even though the study arm was controlled for in analyses, low occurrence of undernutrition may have decreased study power to uncover additional effects of perinatal depression on infant nutritional status. Lastly, of the 390 enrolled in the study, almost

30% had delivered prior to data collection, significantly reducing the available sample size for antenatal depression analyses.

## **Conclusion**

This study exposed an estimate of the extent of perinatal depression among South Sudanese refugees in settlements in Uganda. Antenatal and early postpartum depression were higher than the global estimates. Implementing screening and treatment for perinatal depression during antenatal and postnatal care is a key step in helping mothers. Higher postpartum depression scores were significantly associated with lower WAZ, LAZ, and as well as higher odds of an infant being underweight at 4-9 months of age. Interventions seeking to improve undernutrition among infants in refugee settlements may need to include strategies that include help to mitigate negative effects of perinatal depression on their health and the health of the child.



**Table 1.** Maternal, infant, and household characteristics

<b>Maternal Characteristics</b>	<b>n</b>	<b>Frequency (%)</b>	<b>Mean ± SD</b>
<b>Age (years)</b>	337		28.4 (5.1)
<b>Education</b>			
None or informal	157	46.7	
Some primary	149	44.4	
Secondary or higher	31	8.9	
<b>Occupation</b>			
Not employed	294	87.5	
Farming/Agriculture	23	6.8	
Other work or business	20	5.7	
<b>Marital status</b>			
Married	330	98.2	
Never married or widowed	7	1.8	
<b>Number of antenatal visits</b>	337		5.4 (1.8)
<b>Type of delivery</b>			
<i>Caesarean section</i>	19	5.7	
Vaginal	317	94.3	
<b>Number of postnatal visits</b>	337		2.7 (1.1)
<b>Mid-upper arm circumference</b>			27.2 (3.3)
Less than or equal to 23 mm	21	6.2	
Greater than 23 mm	316	93.8	
<b>Height (cm)</b>			167.3 (7.4)
<b>Infant characteristics</b>	<b>n</b>	<b>Frequency (%)</b>	<b>Mean ± SD</b>
<b>Age (months)</b>			6.5 (1.3)
<b>Sex</b>			
Male	176	52.2	
Female	161	47.8	
<b>Diarrhea in last month</b>			
No diarrhea	226	67.1	
Diarrhea	111	32.9	

<b>Mean z-scores</b>		
Weight-for-age z-score		-0.7 (1.4)
Length-for-age z-score		-0.6 (1.8)
Weight-for-height z-score		-0.4 (1.4)
<b>Household characteristics</b>		
<b>Time in the West Nile (years)</b>		4.7 (1.6)
1-3 years	63	19.7
4-5 years	97	29.0
6+ years	177	51.3
<b>Food insecurity</b>		
Food secure	5	1.6
Mildly food insecure	12	3.9
Moderately food insecure	28	8.9
Severely food insecure	332	85.6

**Table 2.** Associations between perinatal depression and z-scores among infants 4-9 months of age

Perinatal depression	Infant nutritional status					
	WAZ		LAZ		WHZ	
	$\beta$	p-value	B	p-value	$\beta$	p-value
<b>Antenatal depression (n=235)</b>						
Antenatal depression score	0.02	0.34	0.01	0.92	0.03	0.19
Met criteria for antenatal depression	0.09	0.68	-0.25	0.40	0.38	0.11
<b>Early postpartum depression (n=337)</b>						
Postpartum depression score	<b>-0.04</b>	<b>0.04*</b>	<b>-0.06</b>	<b>0.006**</b>	0.02	0.98
Met criteria for postpartum depression	-0.21	0.22	<b>-0.46</b>	<b>0.03*</b>	0.07	0.67
<b>Concurrent postpartum depression (n=333)</b>						
Postpartum depression score	-0.01	0.78	0.02	0.64	-0.02	0.21
Met criteria for postpartum depression	0.07	0.75	0.20	0.50	-0.17	0.46

\*p<0.05, \*\*p<0.01

**Table 3.** Associations between perinatal depression and undernutrition among infants 4-9 months of age

Perinatal depression	Infant nutritional status					
	Underweight		Stunting		Wasting	
	OR	p-value	OR	p-value	OR	p-value
<b>Antenatal depression</b>						
Antenatal depression score	1.00 (0.89-1.12)	0.99	0.98 (0.88-1.09)	0.72	0.95 (0.82-1.10)	0.47
Met antenatal depression criteria	1.16 (0.44-3.07)	0.76	1.20 (0.48-2.97)	0.70	0.51 (0.11-2.32)	0.39
<b>Early postpartum depression</b>						
Postpartum depression score	1.03 (0.95-1.11)	0.46	1.06 (0.98-1.14)	0.16	1.01 (0.92-1.12)	0.81
Met postpartum depression criteria	1.18 (0.56-2.49)	0.65	1.34 (0.69-2.81)	0.36	1.02 (0.39-2.77)	0.97
<b>Concurrent postpartum depression</b>						
Postpartum depression score	<b>1.09 (1.01-1.19)</b>	<b>0.03*</b>	0.98 (0.91-1.07)	0.69	1.10 (0.96-1.22)	0.06
Met postpartum depression criteria	0.98 (0.36-2.68)	0.98	0.48 (0.14-1.64)	0.24	1.94 (0.68-5.49)	0.21

\*p<0.05, \*\*p<0.01

**Table 4.** Associations between perinatal depression and z-scores adjusted for covariates (n=337)

Predictor variables	Infant z-scores	
	WAZ	LAZ
	$\beta$	$\beta$
Early postpartum depression scores	-0.03*	-0.06*
<b>Covariates</b>		
Study arm	0.29**	0.20
Household food insecurity	0.43	0.24
Maternal education	-0.12	-0.41
Maternal mid-upper arm circumference	0.78*	0.76
Maternal short stature	-0.30	-1.19**
Maternal age	-0.01	-0.01
Infant sex	0.11	0.16
Infant low birth weight	-0.32	-0.28
Infant diarrhea in last month	-0.15	-0.23
Exclusive breastfeeding since birth	0.04	0.08

\*p<0.05, \*\*p<0.01

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## CHAPTER VIII

### CONCLUSION

This mixed methods study investigated perinatal depression, breastfeeding, and infant nutritional status among South Sudanese refugees in Uganda. Qualitative methods were used to collect data on perceived common stressors, how parents cope with stress, and perceptions of how the community can provide better support. Barriers to and facilitators of breastfeeding among refugees in the settlements were also identified. Additionally, the associations between antenatal and postpartum depression and breastfeeding practices, as well as infant nutritional status were analyzed.

#### **Key findings**

Six themes related to perceived common stressors among refugees included: lack of basic needs, issues involving childbirth, marital conflict and violence, other violence and conflict, inadequate health care, and issues involving children. Participants raised the issue of poverty, lack of employment, inadequate food and water, lack of land for agriculture, lack of household and building materials, and lack of fire wood for cooking. They also cited many stressors surrounding childbirth including maternal bleeding, death, pain, delivering at home or on the roadside, and inadequate breastmilk production. Intimate partner violence of varying types as well as other forms of community violence were stressors mentioned by refugees.

Stressors surrounding inadequate health care included issues at the health centers, long distances to health facilities, inattentive and unhelpful midwives, and lack of access to care on weekends. Child labor, early or forced marriages, abuse, neglect, and lack of adequate education for children were also stressful situations for parents.

The coping strategies of mothers and fathers in the settlements were summarized into four key themes: contacting leaders or authorities, talking to others, healthy coping skills, and unhealthy coping skills. Participants mentioned that parents in the settlements seek out a variety of people to talk to when they feel stressed, including: community leaders, block leaders, the Refugee Women's Council, church leaders, friends, neighbors, relatives, elders, spouses and others they consider to be trustworthy. Healthy coping skills included accessing mental health and psychosocial support resources and engaging in recreation. Unhealthy coping skills such as suicide, alcohol consumption, violence, child abuse and neglect, or isolating from others were reported.

Participants stated the community could help them cope with stress in the following ways: organizing community discussions, leadership, economic opportunities, recreational opportunities, and counseling. Specifically they mentioned the desire to form groups, hold meetings, and have community dialogues. Involvement of church leaders in community activities was important. Raising awareness of existing resources and establishing community rules and regulations were also noted. Refugees expressed the desire for work, vocational schooling, and training within the community as well as recreational opportunities to help ease their stress. They expressed a desire for cultural activities that would include cultural dancing and traditional cooking. Counseling and

providing advice to parents were mentioned as important ways to help mothers and fathers manage their stress.

Identified breastfeeding barriers were organized into four themes: knowledge, physical, socioeconomic, and psychosocial. Participants stated breastmilk is not sufficient for sick infants and breastfeeding should be supplemented with other liquids.

Additionally, they noted infants under six months could be fed supplemental feedings that include powdered milk diluted with water, cow's milk, juice or formula. Physical barriers included maternal sickness, perceived inadequate breastmilk production, and other breastfeeding difficulties for which mothers are unable to find help and support.

Working outside the home or higher levels of education were identified as barriers to breastfeeding. Marital conflict, fear of pain, and maternal mental health issues were also reported as factors that hinder breastfeeding.

Beliefs and knowledge about breastfeeding benefits, support from husband/father, support from the community, and support from non-governmental organizations were facilitators of breastfeeding. Participants stated breastmilk was nutritious, would help the child grow strong and well, and would protect against diseases. Fathers offered support to breastfeeding mothers by providing food, emotional support, and assisting with household chores. Community support from neighbors as well as other relatives including grandmothers was reported. Agencies provided support to breastfeeding mothers in the area by providing food and education.

During pregnancy, 70.3% of mothers had symptoms of depression, ranging from mild to moderately severe. Under a quarter (19.9%) of mothers met the criteria for

antenatal depression. Occurrence of depression increased from during pregnancy to after as 23.5% of the mothers met criteria on the PHQ-9 for postpartum depression and 62.3% reported depressive symptoms.

Over half (66.6%) of mothers breastfed within one hour of birth and only 55.5% of infants 0-5 months were exclusively breastfed. Nearly all (98.3%) mothers were breastfeeding and only 10% of those not exclusively breastfeeding were formula feeding. Among infants in the study, 11.9% were underweight, 12.8% were stunted, and 7.1% were wasted.

No significant association was determined between depressive symptoms or antenatal depression and breastfeeding practices. Antenatal depressive symptoms were not significantly associated with infant z-scores or with undernutrition. In analyses adjusted for covariates, there was a significant association between higher postpartum depressive symptoms and a lower likelihood of early initiation of breastfeeding. Mothers who met the criteria for postpartum depression were less likely to breastfeed within an hour of birth and less likely to exclusively breastfeed. Both initiating breastfeeding within an hour after delivery and exclusively breastfeeding significantly reduced the odds of developing postpartum depression. Early postpartum depression symptoms predicted significantly lower weight-for-age scores and lower length-for-age scores. Higher current postpartum depression symptoms were significantly associated with increased odds of infants being underweight.

## **Implications and recommendations**

The socio-ecological model [136] will be used to summarize how data from this mixed methods study can be used to improve the experience, health and well-being of South Sudanese refugees in Uganda. The following recommendations were driven by the findings of this study and may be important factors to consider when designing interventions, programs, initiatives, and policies aiming to help refugees in the settlements.

### **Individual level**

- Decrease stigma around mental health and improve knowledge/awareness.
- Increase awareness of early signs symptoms of depression/suicidal behavior.
- Enhance coping skills of refugees through administering the World Health Organization's (WHO) Self-Help Plus intervention.

### **Interpersonal level**

- Improve conflict resolution and management skills among couples to decrease the incidence of intimate partner violence.
- Promote the continued involvement of husbands/fathers in supporting breastfeeding mothers.

### **Organization level**

- Involve key community leaders in mental health and psychosocial support initiatives.



- Implement screening for intimate partner violence and perinatal depression during antenatal and postnatal care.
- Strengthen surveillance for suicidal ideations and attempts and consider implementation of a safety planning initiative that could be led by the Village Health Teams.
- Conduct assessments of the quality of delivery care at health centers and hospitals in settlements and ensure anti-corruption policies.
- Work towards overcoming any language and cultural barriers between health care workers and refugees or provide translators as needed.
- Provide substance abuse training for healthcare workers to increase the ability of providers to identify issues and provide care as needed.
- Implement and adopt the principles set forth by the Baby Friendly Hospitals Initiative by health care facilities and hospitals to promote breastfeeding support and education.
- Train of healthcare staff on solutions to common lactation issues and expanding community-based health care support for mothers who lack convenient access to healthcare facilities.
- Continue to emphasize education about infant and young child feeding practices at antenatal care, place of delivery, and during postnatal care.

### **Community level**

- Involve key refugee community leaders in important health initiatives in the settlements.

- Promote access to mental health and psychosocial resources available within the community.
- Work towards a decrease in community violence by promoting community dialogues across tribes.
- Organize cultural recreation opportunities that involve traditional cooking and dances.
- Provide informal advice and counseling to parents in distress.
- Promote the reduction of stigma around mental health.
- Assist health care workers in identification of individuals who are at risk for suicidal behavior.
- Continue to provide various types of support to breastfeeding mothers.

### **Policy level**

- Revisit current policies regarding refugees' rights and consider policies that allow them opportunities to expand beyond exclusive reliance on humanitarian assistance from agencies and thrive in the community.
- Consider the feasibility of allowing refugees to move freely out of the settlement to pursue livelihoods locally without losing refugee status or access to humanitarian aid.
- Strengthen policies that aim to prevent intimate partner violence, as well as violence against children.

- Implement collaboration between health and protective services to oversee issues of intimate partner violence and violence against children to more effectively provide support and care for victims.
- Consider the need to strengthen policies related to alcohol and substance abuse in the settlements.
- Ensure that current policies regarding health care standards in the settlements are being followed, especially during the childbirth and delivery process.
- Create policies that regulate formula donations and distributions in the settlements.

### **Future research**

Based on promising results among refugees, the feasibility of scaling up the use of the World Health Organization's Self-Help Plus should be assessed. Additionally, screening for intimate partner violence and perinatal depression during antenatal and postpartum care should be investigated. Future research may consider assessing barriers faced by health care workers in the settlements to provide adequate care and also addressing potential language or cultural barriers between health care providers and South Sudanese refugees. Additionally, the effectiveness and practicality of implementing a suicide prevention initiative that involves the use of Village Health Teams in identifying and working with individuals at risk could be investigated.

Assessing the barriers that fathers and mothers face in accessing mental health and psychosocial support resources available to them, as well as help-seeking behaviors among refugees is likely to improve livelihoods. Furthermore, a validation study to

determine if a cut-off  $\geq 10$  for the PHQ-9 is the most appropriate among populations where stigma in disclosing mental health issues remain high is important. Determining the most accurate cut-off for depression could be imperative for implementing effective screening and treatment in areas where access to mental health professionals limited.

Qualitative studies are needed to better understand why mothers with presumably more knowledge about the benefits of breastfeeding may prefer breastmilk substitutes over breastfeeding. Better understanding of these beliefs would inform interventions designed to improve breastfeeding practices. Future work may consider an in-depth analysis of local gender norms, fathers' presence in settlements, the level of influence fathers have in breastfeeding decisions, and the type of support they can offer that could inform whether father involvement would be an effective factor in supporting breastfeeding. Exploring the family dynamics among refugees living in settlements to better understand the role and influence of grandmothers on breastfeeding in a new environment may also be important information to inform breastfeeding initiatives. Future studies may consider assessing antenatal depression at multiple time points throughout pregnancy to develop a more accurate understanding of the scope of antenatal depression and its' association with breastfeeding practices and infant nutritional status. Lastly, future research may consider exploring mediating and moderating factors that may influence the association between perinatal depression and infant undernutrition among refugees.

## **Conclusion**

South Sudanese refugees face many stressors and difficulties in the settlements and they utilize both healthy and unhealthy coping strategies. They provided useful data on a variety of ways the community can better help them cope with their stress. Barriers to and facilitators of breastfeeding were wide-ranging, indicating the need for a multi-level intervention to support breastfeeding practices among refugees. Significant associations between postpartum depression and breastfeeding practices and infant nutritional status were detected. Early initiation of and exclusive breastfeeding were both associated with over 50% lower odds of developing postpartum depression. These results indicate an important connection between postpartum but not antenatal depression, breastfeeding, and infant nutritional status among South Sudanese refugees in Uganda.

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## APPENDICES

### Appendix 1. Focus Group Discussion Guides

#### Mothers

##### *Mental health*

5. Describe what it is like for a mother to give birth?
  - a. Where does it happen?
  - b. Who is present?
  - c. What types of things go wrong during childbirth?
6. Sometimes mothers have struggles after giving birth.
  - a. What struggles do mothers in your community have after giving birth?
  - b. What struggles have you had before and after birth?
7. Sometimes mothers do not feel safe.
  - a. How safe do you feel where you live?
  - b. Do you feel safer or less safe than where you lived before?
  - c. What is it like for you to live here?
8. What other struggles are common in your community?
9. What types of violence exists in your community and in families?
  - a. Is violence between husband and wives common?
10. Who do mothers talk to when they feel stressed?
11. Is it common to talk to others when you feel stressed?

12. How do mothers in the community respond to problems or stress?
13. Where would mothers in your community get help when they are stressed?
14. What ways do you think the community can help mothers feel less stressed?

## **Fathers**

### *Mental health*

5. Describe what it is like for fathers when a mother gives birth?
  - a. Are fathers present?
  - b. What is the father's role?
6. Sometimes fathers have struggles after a new child is born.
  - a. What struggles do fathers in your community have after a child is born?
  - b. What struggles have you had before and after the birth of a child?
7. How safe do you feel where you live?
  - a. Do you feel safer or less safe than where you lived before?
  - b. What is it like for you to live here?
8. What struggles are common in your community?
9. What types of violence exists in your community and in families?
  - a. Is violence between husband and wives common?
10. Who do fathers talk to when they feel stressed?
11. Is it common to talk to others when you feel stressed?
12. How do fathers in the community respond to problems or stress?
13. Where would fathers in your community get help when they are stressed?
14. What ways do you think the community can help fathers feel less stressed?



## **Mothers**

### *Breastfeeding*

1. What do you think are the benefits of breastfeeding?
2. At what age should children stop breastfeeding?
3. What might a parent give a child to eat before they are 6 months old?
4. How does your community support breastfeeding mothers?
5. What are some reasons why mothers do not breastfeed their children?
6. What are some reasons children are given food before six months old?

## **Fathers**

### *Breastfeeding*

1. What do you think are the benefits of breastfeeding?
2. At what age should children stop being breastfed?
3. What might a parent give a child to eat before they are six months old?
4. How does your community support breastfeeding mothers?
5. What are some reasons why mothers do not breastfeed their children?
6. What are some reasons children are given food before they are six months old?
7. What do you feel is your role in supporting your wife who is breastfeeding?

## **Appendix 2. Village Health Team Focus Group Discussion & Key Informant Interview Questions**

### *Mental health*

6. What struggles do mothers have after giving birth?
7. What struggles do fathers have after giving birth?
8. How safe do mothers and fathers feel living in the community?
9. What struggles are common in your community?
10. What types of violence exists in the community and in families?
  - a. Is violence between husband and wives common?
11. Who do mothers talk to when they feel stressed?
12. Who do fathers talk to when they feel stressed?
13. Is it common to talk to others when they feel stressed?
14. How do mothers in the community respond to problems or stress?
15. How do fathers in the community respond to problems or stress?
16. Where would mothers in your community get help when they are stressed?
17. Where would fathers in your community get help when they are stressed?
18. Would mothers be willing to ask for help when they are stressed?
19. Would mothers be willing to ask for help when they are stressed?
20. What resources are in your community to help parents when they are stressed?
21. What ways do you think the community can help parents feel less stressed?
22. What do you see as your role in helping community members overcome stress?

## Appendix 3. Questionnaire

### Section 1: SOCIODEMOGRAPHIC CHARACTERISTICS

Today's date (dd/mm/year)	
Data collection	<ul style="list-style-type: none"> <li>0. Baseline</li> <li>1. Midline I</li> <li>2. Midline II</li> <li>3. End line</li> </ul>
Enumerator initials	
Respondent's code	
Settlement name	
Village name	
Mother's name	
Father's name	
What is your age (in years)?	
For your most recent birth, how big was your baby?	<ul style="list-style-type: none"> <li>0. Very small</li> <li>1. Smaller than average</li> <li>2. Average</li> <li>3. Larger than average</li> <li>4. Very large</li> <li>5. I don't know</li> </ul>
Has your youngest child had diarrhea recently?	<ul style="list-style-type: none"> <li>0. No</li> <li>1. Yes, in the last 24 hours</li> <li>2. Yes, in the last 2-4 weeks</li> <li>3. I don't know</li> </ul>
Has your youngest child had cough recently?	<ul style="list-style-type: none"> <li>0. No</li> <li>1. Yes, in the last 24 hours</li> <li>2. Yes, in the last 2-4 weeks</li> <li>3. I don't know</li> </ul>
Has your youngest child had fever recently?	<ul style="list-style-type: none"> <li>0. No</li> <li>1. Yes, in the last 24 hours</li> <li>2. Yes, in the last 2-4 weeks</li> <li>3. I don't know</li> </ul>
Have you had a fever recently?	<ul style="list-style-type: none"> <li>4. No</li> <li>5. Yes, in the last 24 hours</li> <li>6. Yes, in the last 2-4 weeks</li> <li>I don't know</li> </ul>
Have you had diarrhea recently?	<ul style="list-style-type: none"> <li>0. No</li> <li>1. Yes, in the last 24 hours</li> <li>2. Yes, in the last 2-4 weeks</li> <li>3. I don't know</li> </ul>

How many antenatal visits have you attended for your most recent pregnancy?	
Where did you deliver your baby?	<ul style="list-style-type: none"> <li>0. Hospital</li> <li>1. Local public health center</li> <li>2. Private health center</li> <li>3. Home</li> <li>4. Other (specify): _____</li> </ul>
For how long do you plan to breastfeed your baby?	<ul style="list-style-type: none"> <li>0. Not at all</li> <li>1. For 3 months</li> <li>2. For 6 months</li> <li>3. For 1 year</li> <li>4. For 2 years</li> </ul>
What type of delivery did you have?	<ul style="list-style-type: none"> <li>1. Caesarean section</li> <li>2. Vaginal birth</li> </ul>
How many postnatal visits have you had after delivery?	
Has your child been immunized recently (past three months)?	<ul style="list-style-type: none"> <li>0. No</li> <li>1. Yes</li> <li>2. I don't know</li> </ul>

## Section 2: COMPLEMENTARY FEEDING PRACTICES

How soon after birth was your youngest child breastfed?	<ul style="list-style-type: none"> <li>0. Not at all</li> <li>1. After 24 hours</li> <li>2. After 1 hour</li> <li>3. Immediately</li> </ul>
Was your youngest child breastfed yesterday?	<ul style="list-style-type: none"> <li>0. No</li> <li>1. Yes</li> </ul>
Has your youngest child had anything to eat or drink other than breastmilk since birth?	<ul style="list-style-type: none"> <li>0. No</li> <li>1. Yes</li> </ul>
In the last 24 hours, has your youngest child had any of the following? (Circle all that apply).	<ul style="list-style-type: none"> <li>0. Infant formula such as NAN1, NAN2, Nutricia, Gallia, etc</li> <li>1. Juice or juice like drinks</li> <li>2. Tinned, powdered, or animal milk</li> <li>3. Water</li> <li>4. Any other liquids (specify): _____</li> <li>5. Porridge</li> <li>6. Yogurt</li> <li>7. Soda</li> <li>8. Clear broth</li> <li>9. Anything not listed other than breastmilk (specify): _____</li> </ul>

<p>Since birth, has your youngest child had any of the following? (Circle all that apply).</p>	<ol style="list-style-type: none"> <li>0. Infant formula such as NAN1, NAN2, Nutricia, Gallia, etc</li> <li>1. Juice or juice like drinks</li> <li>2. Tinned, powdered, or animal milk</li> <li>3. Water</li> <li>4. Any other liquids (specify): _____</li> <li>5. Porridge</li> <li>6. Yogurt</li> <li>7. Soda</li> <li>8. Clear broth</li> <li>9. Anything not listed other than breastmilk (specify): _____</li> </ol>
<p>At what age did your youngest child first drink anything other than breastmilk?</p>	<ol style="list-style-type: none"> <li>0. Before 3 months old</li> <li>1. Before 6 months old</li> <li>2. At 6 months old</li> <li>3. My youngest child has only had breastmilk</li> </ol>
<p>At what age did your youngest child first eat anything other than breastmilk?</p>	<ol style="list-style-type: none"> <li>0. Before 3 months old</li> <li>1. Before 6 months old</li> <li>2. At 6 months old</li> <li>3. My youngest child as only had breastmilk</li> </ol>
<p>Describe how often you are currently breastfeeding?</p>	<ol style="list-style-type: none"> <li>0. Not at all</li> <li>1. Every other day</li> <li>2. 1-2 times a day</li> <li>3. Multiple times a day</li> </ol>

**Section 3: MENTAL HEALTH**

Over the last 2 weeks, how often have you been bothered by any of the following problems? The answer choices for the next nine questions are: not at all, several days, more than half the days, or nearly every day.

<p>Little interest or pleasure in doing things?</p>	<ol style="list-style-type: none"> <li>0. Not at all</li> <li>1. Several days</li> <li>2. More than half the days</li> <li>3. Nearly every day</li> </ol>
<p>Feeling down, depressed, or hopeless?</p>	<ol style="list-style-type: none"> <li>0. Not at all</li> <li>1. Several days</li> <li>2. More than half the days</li> <li>3. Nearly every day</li> </ol>
<p>Trouble falling or staying asleep, or sleeping too much?</p>	<ol style="list-style-type: none"> <li>0. Not at all</li> <li>1. Several days</li> <li>2. More than half the days</li> <li>3. Nearly every day</li> </ol>

Feeling tired or having little energy?	<ul style="list-style-type: none"> <li>0. Not at all</li> <li>1. Several days</li> <li>2. More than half the days</li> <li>3. Nearly every day</li> </ul>
Poor appetite or overeating?	<ul style="list-style-type: none"> <li>0. Not at all</li> <li>1. Several days</li> <li>2. More than half the days</li> <li>3. Nearly every day</li> </ul>
Feeling bad about yourself or that you are a failure of have let yourself or your family down?	<ul style="list-style-type: none"> <li>0. Not at all</li> <li>1. Several days</li> <li>2. More than half the days</li> <li>3. Nearly every day</li> </ul>
Trouble concentrating on things such as reading the newspaper or watching television?	<ul style="list-style-type: none"> <li>0. Not at all</li> <li>1. Several days</li> <li>2. More than half the days</li> <li>3. Nearly every day</li> </ul>
Moving or speaking so slowly that other people could have noticed. Or the opposite- being so restless that you have been moving around a lot more than usual?	<ul style="list-style-type: none"> <li>0. Not at all</li> <li>1. Several days</li> <li>2. More than half the days</li> <li>3. Nearly every day</li> </ul>
Thoughts that you would be better off dead or of hurting yourself? (Note to enumerator: If respondent chooses several days, more than half the days, or nearly everyday, please follow research protocol for referrals for psycho-social support.)	<ul style="list-style-type: none"> <li>0. Not at all</li> <li>1. Several days</li> <li>2. More than half the days</li> <li>3. Nearly every day</li> </ul>
How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	<ul style="list-style-type: none"> <li>0. Not difficult at all</li> <li>1. Somewhat difficult</li> <li>2. Very difficult</li> <li>3. Extremely difficult</li> </ul>

**Section 4: MOTHERS ANTHROPOMETRICS**

Mother's MUAC Measurement 1 (mm)	
Mother's MUAC Measurement 2 (mm)	
Mother's height Measurement 1 (mm)	
Mother's height Measurement 2 (mm)	

## Section 5: INFANT ANTHROPOMETRICS

What is the child's birth date (dd/mm/year)?	
If the respondent does not know the exact birthdate, ask: Does he/she have a health/vaccination card with the birth date recorded? If the health/vaccination card/official document is shown and the respondent confirms the information is correct, record the date of birth as documented on the card.	
How many months old is your child? (Check consistency (calendar of events, birth card)	
Child's sex	0. Male 1. Female
Child's height (cm) measurement 1	
Child's height (cm) measurement 2	
Child's weight (kg) measurement 1	
Child's weight (kg) measurement 2	

## Appendix 4. Ethical Approvals



### Oklahoma State University Institutional Review Board

Date: 01/18/2019  
Application Number: HS-19-2  
Proposal Title: Peer groups to improve feeding practices and child nutrition in post-emergency settlements in Uganda

Principal Investigator: Joel Joshua Komakech  
Co-Investigator(s): Christine Walters, Hasina Rakotomanana  
Faculty Adviser: Deana Hildebrand  
Project Coordinator:  
Research Assistant(s):

Processed as: Expedited

**Status Recommended by Reviewer(s): Approved**

**Approval Date: 01/18/2019**

**Expiration Date: 01/17/2020**

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## Oklahoma State University Institutional Review Board

Date: 01/06/2020  
Application Number: HS-19-2  
Proposal Title: Peer groups to improve feeding practices and child nutrition in post-emergency settlements in Uganda

Principal Investigator: Joel Joshua Komakech  
Co-Investigator(s): Barbara Stoecker, Christine Walters, Hasina Rakotomanana  
Faculty Adviser: Deana Hildebrand  
Project Coordinator:  
Research Assistant(s):

Processed as: Expedited Continuation

**Status Recommended by Reviewer(s): Approved**

**Continuation Approval Date: 01/06/2020**



## Uganda National Council for Science and Technology

*(Established by Act of Parliament of the Republic of Uganda)*

Our Ref: SS 5038

6<sup>th</sup> August 2019

Mr. Joel Joshua Komakech  
Principal Investigator  
C/o Makerere University Kampala  
**Kampala**

Dear Mr. Komakech,

**Re: Research Approval: Peer Support Groups to Improve Infant and Young Child Feeding Practices (IYCF) and Child Nutrition in Post – Emergency Settlements in Uganda**

I am pleased to inform you that on **30/07/2019**, the Uganda National Council for Science and Technology (UNCST) approved the above referenced research project. The Approval of the research project is for the period of **30/07/2019 to 30/07/2020**.

Your research registration number with the UNCST is **SS 5038**. Please, cite this number in all your future correspondences with UNCST in respect of the above research project.

**MAKERERE**



**UNIVERSITY**

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**COLLEGE OF HEALTH SCIENCES  
SCHOOL OF HEALTH SCIENCES  
OFFICE OF THE DEAN**

May 02<sup>nd</sup>, 2019

**Mr. Joel Joshua Komakech**  
Department of Nutritional Sciences  
Oklahoma State University-USA

**Category of review**


- Initial review  
 Continuing review  
 Amendment  
 Termination of study  
 SAEs


Dear Mr. Komakech,

**Re: Approval of research protocol #SHSREC REF: 2019-020  
"Peer Groups to Improve Feeding Practices and Child Nutrition in Post Emergency  
Settlements in Uganda"**

Thank you for submitting an application for ethical review of the above referenced research protocol.  
The committee reviewed it and granted approval for **one (1) year**, effective **May 02<sup>nd</sup>, 2019**.  
Approval is valid until **May 01<sup>st</sup>, 2020**.

## Appendix 5. Local Permissions

  
THE REPUBLIC OF UGANDA

  
Uganda  
Vision 2040

**OFFICE OF THE PRIME MINISTER**  
PLOT 9-11 APOLLO KAGGWA ROAD. P.O. BOX 341, KAMPALA, UGANDA  
TELEPHONES: General Line 0417 770500, Web: www.opm.go.ug, E-mail: ps@opm.go.ug

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In any correspondence on this subject, please quote No: **OPM/R/107**

July 30, 2019

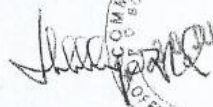
Mr. Jesse Kamstra,  
Country Representative,  
The Lutheran World Federation Uganda.

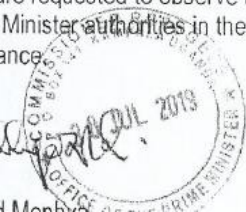
**RE: PERMISSION TO ACCESS REFUGEE SETTLEMENTS UNDER ADJUMANI AND MOYO DISTRICTS**

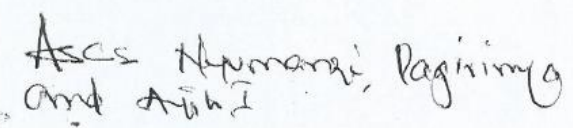
Reference is made to your letter dated July 26, 2019 in regard to the above subject matter.

This is to authorize Joel Joshua Komakech, Christine Walters and Hasina Rakotomana from Oklahoma State University to undertake a study titled "**Peer Groups to Improve Feeding Practices and Childhood Nutrition in Post Emergency Settlements in Uganda**", from August 1-31, 2019 in Refugee Settlements under Adjumani and Moyo Districts.

They are requested to observe the rules and regulations governing the settlements. Office of the Prime Minister authorities in the settlements are hereby requested to accord them the necessary assistance.

  
Jesse Kamstra  
Country Representative



  
ASCS Humana, Ragirima  
and Aki

## VITA

Christine Nicole Walters

Candidate for the Degree of

Doctor of Philosophy

Dissertation: INVESTIGATING PERINATAL DEPRESSION, BREASTFEEDING, AND  
INFANT NUTRITIONAL STATUS AMONG SOUTH SUDANESE REFUGEES IN  
UGANDA: A MIXED METHODS STUDY

Major Field: Nutritional Sciences

Biographical:

Education:

Completed the requirements for the Doctor of Philosophy in Nutritional Sciences at  
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Completed the requirements for the Master of Science in Nutritional Sciences at  
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Completed the requirements for the Bachelor of Science in Medical Dietetics at The  
Ohio State University, Columbus, Ohio, USA in 2013.

Experience:

Lead Instructor at Oklahoma State University-Oklahoma City  
August 2020 – Present (May 2022)

Graduate Research/Teaching/Extension Assistant at Oklahoma State University  
May 2015 – August 2020

Registered Dietitian at Crandall Corporate Dietitians  
March 2016 – November 2016

Clinical Dietitian at Aramark at Berger Health System  
July 2014 – May 2015

Professional Memberships: American Society for Nutrition