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**HIV and food systems: A mixed-  
methods study on the impacts of the  
human immunodeficiency virus on the  
local food system for small-scale female  
farmers in rural Malawi**

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## **Declaration**

I, Julie Therese Aamodt, declare that this thesis is a result of my research investigations and findings. Sources of information other than my own have been acknowledged and a reference list has been appended. This work has not been previously submitted to any other university for award of any type of academic degree.

Signature.....

Date.....27.05.2020...

## **Abstract**

HIV and food insecurity continue to be two of the leading causes of morbidity and mortality in Malawi, and throughout sub-Saharan Africa. Food insecurity threatens progress towards ending the HIV epidemic, and HIV threatens the ability of food systems to provide food security and incomes for rural populations in Malawi. Therefore, this study aims to identify the effects of HIV on the food system for small-scale female farmers in a resource-constrained setting in rural Malawi and to explore how informal and formal coping strategies influence this relationship. The study employs a mixed-methods approach using semi-structured interviews, focus groups, key informant interviews and statistical analysis. Findings from this study demonstrate that HIV impacts several components of the food system, including primary agricultural production, market access and consumer behaviors. Respondents were particularly concerned with the effect that HIV had on their strength, despite taking antiretrovirals. However, the data shows a slightly less dark picture of the impacts of HIV on the food system compared to previous studies, suggesting that the lives for women living with HIV in rural Malawi has slightly improved. Some women emphasized that other issues related to living in poverty were more challenging compared to HIV. Although there is a large diversity in experiences, there are two key pathways through which HIV affects the food system for small-scale farmers in rural Malawi: (1) the deterioration of livelihoods through impacting the ability of women to participate in agricultural work, or (2) positive behavioral changes in the form of changed diets and food safety practices through increasing access to health education, adherence to antiretroviral therapy and motivation amongst the women to improve their health and quality of life.

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# Table of Contents

<b>Declaration</b> .....	<b>II</b>
<b>Abstract</b> .....	<b>III</b>
<b>Acknowledgements</b> .....	<b>IV</b>
<b>Abbreviations List</b> .....	<b>VII</b>
<b>List of figures</b> .....	<b>VIII</b>
<b>List of tables</b> .....	<b>VIII</b>
<b>1. Introduction</b> .....	<b>1</b>
<b>2. Research aims and questions</b> .....	<b>5</b>
<b>3. Background</b> .....	<b>6</b>
3.1. Socioeconomic profile of Malawi.....	6
3.2. Population health in Malawi.....	6
3.3. HIV/AIDS in Malawi.....	7
3.4. HIV and nutrition.....	8
3.5. Food systems in Malawi.....	9
3.6. Agricultural development in Malawi .....	11
3.7. Social Security in Malawi.....	12
<b>4. Theoretical Framework</b> .....	<b>13</b>
4.1. Food system framework.....	13
4.2. Food system activities.....	16
4.2.1. Food supply chain.....	16
4.2.2. Consumer behavior.....	19
4.3. Food system outcomes .....	19
4.3.1 HIV effects on income and expenditures.....	19
4.3.2. HIV effects on food security and health outcomes.....	20
4.4. Coping mechanisms.....	24
4.4.1. Informal coping strategies.....	24
4.4.2. Formal coping strategies.....	25
<b>5. Research design</b> .....	<b>30</b>
5.2. Study design.....	30
5.2. Study setting.....	31
5.3. Sampling.....	32
5.4. Data collection .....	34
5.4.1. Qualitative data .....	34
5.4.2. Quantitative data .....	36

5.5.	Data Analysis .....	36
5.5.1.	Content analysis.....	36
5.5.2.	Statistical analysis.....	37
5.6.	Ethical considerations, challenges and limitations.....	40
5.6.1.	Ethical considerations.....	40
5.6.2.	Reflexivity, reactivity and researcher bias.....	41
5.6.3.	Response bias.....	43
5.6.4.	Interpretation.....	44
5.6.5.	Other challenges .....	45
<b>6.</b>	<b>Findings.....</b>	<b>45</b>
6.1.	Participant characteristics.....	46
6.2.	Challenges.....	49
6.2.1.	Poor quality diet.....	50
6.2.2.	Loss of strength.....	50
6.2.3.	Side-effects of anti-retroviral therapy.....	51
6.2.4.	Discrimination.....	52
6.2.5.	Psychological challenges.....	53
6.2.6.	Other .....	53
6.2.7.	No challenges.....	54
6.3.	Food System activities .....	54
6.3.1.	Effect of HIV on food supply chain .....	54
6.3.2.	Effect of HIV on consumer behavior.....	61
6.4.	Coping strategies .....	65
6.4.1.	Informal coping strategies.....	65
6.4.2.	Formal support.....	69
6.4.3.	Discrimination in access to support.....	73
6.5.	Impact of HIV on food systems outcomes .....	75
6.5.1.	Impact of HIV on income and expenditures.....	75
6.5.2.	Impact of HIV on food security.....	76
6.6.	How should policies and programs be implemented and what should be implemented?.....	82
6.7.1.	Suggestions for how to implement programs and policies .....	82
6.7.2.	Help wanted.....	83
<b>7.</b>	<b>Discussion .....</b>	<b>86</b>
7.1.	Summary of findings .....	86
7.2.	Impact of HIV on food security.....	91
7.3.	Explaining differences in behavioral changes and coping abilities.....	95
7.3.1.	Economic coping capacity.....	95
7.3.2.	Self-efficacy.....	96
7.3.3.	Increased social capital from CBOs and counselling.....	97
7.3.4.	General positive trends in development.....	98
7.3.5.	Social and cultural norms influence food choices .....	98
<b>8.</b>	<b>Conclusion.....</b>	<b>100</b>
<b>9.</b>	<b>References.....</b>	<b>102</b>

## Abbreviations List

ART	Antiretroviral Therapy
EPA	Extension Planning Area
FAO	Food and Agricultural Organization of the United Nations
FCS	Food Consumption Score
FIRP	Food Insecurity Response Plan
FISP	Farm Input Subsidy Program
GoM	Government of Malawi
HLPE	The High Level Panel of Experts on Food Security and Nutrition
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immunodeficiency Virus
HSA	Health Surveillance Assistant
IHS4	Fourth Integrated Household Survey
MASAF	Malawi Social Action Fund
NGO	Nongovernmental Organization
NSO	National Statistics Office
PLHIV	People Living with HIV
rCSI	Reduced Coping Strategies Index
SCT	Social Cognitive Theory
SCTP	Social Cash Transfer Program
SD	Standard Deviation
SSA	Sub-Saharan Africa
SSN	Social Security Net
WHO	World Health Organization
WLHIV	Women Living with HIV



## List of figures

**Figure 1:** The relationship between nutrition and HIV infection

**Figure 2:** Analytical framework for the relationship between HIV and food systems

**Figure 3:** The occurrence of challenges experienced by women living with HIV.

**Figure 4:** The occurrence of the impacts of HIV on the food supply chain.

**Figure 5:** Changes to crop diversity following HIV diagnosis

**Figure 6:** A causal pathways model of the impact of HIV on the food supply chain for women living with HIV in rural Malawi

**Figure 7:** The effect of HIV on the four pillars of food security.

**Figure 8:** Overview of support women living with HIV feel would improve their quality of life.

**Figure 9:** The impacts of HIV on a traditional food system for small-scale female farmers in rural Malawi

## List of tables

**Table 1:** Descriptive statistics of key demographic and socioeconomic indicators of secondary data sample

**Table 2:** Difference in consumption of food groups in HIV affected households - mean count of days in a week when household members consumed a particular food group

**Table 3:** Food and agricultural-related coping strategies

**Table 4:** Non-food related coping strategies

**Table 5:** Access to social security, extension services and FISP in HIV/AIDS affected and non-affected households

**Table 6:** Number of coupons and number of agricultural inputs that household received advice on.

**Table 7:** Food security status in HIV-affected and non-affected households, measured by FCS, rCSI and number of meals per day

**Table 8:** Food security in HIV-affected and non-affected households, measured using the reduced coping strategies index

**Table 9:** Results of estimation of HIV as a determinant of food security in female-headed agricultural households

## 1. Introduction

Many countries in sub-Saharan Africa (SSA) have made tremendous progress towards ending the HIV/AIDS epidemic. Antiretroviral therapy (ART) coverage is considered a success story in the region, with 78% ART coverage in Malawi, higher than the global average of 65% (UNAIDS 2019a). The increasing availability of ART and easy access to testing has led to an increase in the life expectancy for people living with HIV (PLHIV), the prevalence rates of HIV have decreased, and HIV/AIDS-related morbidity and mortality has been significantly reduced (Mutabazi-Mwesigire et al. 2014). The roll-out of ART has improved the health and physical functioning for PLHIV and thereby restored and improved social and economic health (Tsai, Bangsberg & Weiser 2013; Thomas et al. 2019). Consistent access to ART changed the discourse of the HIV epidemic from a “problem with a solution, not a hopeless crisis,” promising health improvements which would contribute to global development (Piot 2006; Rhodes, Bernays & Terzic 2009). HIV is said to no longer be a death sentence but a manageable chronic condition (Mutabazi-Mwesigire et al. 2014). These changes have brought new challenges as more people are living with chronic illness, and improving health outcomes and quality of life, defined broadly as the satisfaction with life in general, has become a key component of HIV care (Mutabazi-Mwesigire et al. 2014).

Despite these very positive developments, HIV remains one of the biggest threats to public health and overall development in SSA (Thomas et al. 2019). Although the relative burden has declined, more people than ever are living with HIV, and it still remains one of the leading causes of morbidity and mortality throughout SSA (UNAIDS 2019b). PLHIV report difficulties in managing living with HIV due to ongoing economic and social challenges, especially in settings with poverty and weak health systems (Russell & Seeley 2010; Mutabazi-Mwesigire et al. 2014). Although PLHIV are not a homogenous group, HIV-positive populations across SSA, in general, suffer socioeconomic disadvantage, often living in poverty facing high rates of food insecurity (Nakimuli-Mpungu et al. 2020). High levels of food insecurity among PLHIV is said to undermine the fight against HIV, and some researchers are questioning the efficacy of ART in food insecure individuals (Frega et al. 2010; Rodas-Moya et al. 2015; Masa, Chowa & Nyirenda 2017). Studies have documented that well-nourished individuals on ART are more likely to live

longer than malnourished individuals on the same treatment (Paton et al. 2006). Food insecurity is also a key determinant in reduced adherence to ART, often due to increased feelings of hunger and adverse side-effects of the drugs (Kalofonos 2010; Weiser et al. 2010; Young et al. 2014). However, in resource-constrained settings, where undernutrition is widespread, and low-quality monotonous diets are the norm, PLHIV are often unable to follow optimal food and nutrition recommendations (Weldegebreal et al. 2018).

In parts of SSA, including Malawi, high rates of HIV and food insecurity are often found in communities that are highly dependent on the food system for their income and food security, and usually affects those in the most productive phase of their life (Komwa, Jacobsen & Parker 2010). Food systems lie at the heart of the 2030 Agenda for Sustainable Development and can be defined as “all the elements (e.g. environment, people, inputs, processes, infrastructures and institutions) and activities that relate to the production, processing, distribution, preparation and consumption of food, and the outputs of these activities, including socioeconomic and environmental outcomes (HLPE 2019, p.11). Adequate human health is both the foundation and the expected outcome of a strong food system (Pinstrup-Andersen 2011; HLPE 2017). However, the current food system is failing to meet the food security needs of the population and failing to provide farmers with an adequate income, considering the fact that around 65% of those living in poverty are small-scale farmers (Nyuyen-Viet, Grace & McDermott 2019; Diao et al. 2019).

HIV has the potential to disrupt the food system by affecting agricultural production, market access and decisions regarding food consumption, and have economic and productivity implications that are particularly pronounced in rural areas (Pinstrup-Andersen 2011). In turn, these factors can have substantial negative impacts on the socioeconomic, nutritional and health status of the affected households and their communities (Komwa, Jacobsen & Parker 2010). A healthy population is central to human well-being and makes an essential contribution to economic development, as healthy populations live longer, are more productive, and require less investment in healthcare (WHO n.d.). The severity of the impacts of HIV upon the food system, however, is highly-context based dependent on several factors including the socioeconomic position of the household, individual factors (e.g. health and personality) and the availability of

support systems from non-governmental organizations (NGOs) or the government (Gill 2010; Peng, Dernini & Berry 2018).

One of the biggest challenges to HIV response remains unchanged since its outbreak: HIV disproportionately affects people in vulnerable populations (Frega et al. 2010). HIV usually thrives in situations of inequality, whether it be inequalities in education, gender or wealth (Frega et al. 2010). In Malawi, young girls and women continue to be disproportionately affected (UNAIDS 2019a). The Malawi Population-Based HIV Impact Assessment 2015-2016 found HIV prevalence among adult women (aged 15-64) to be 12.8% compared with 8.2% among adult men (MoH 2018). The difference is particularly pronounced in the age group 25-29 (13.6% in women and 4.7% in men) (MoH 2018). Although, this could be linked to the fact that women more frequently go for testing and are more aware of their status (MoH 2018). Figures also show that an estimated four in five new infections in SSA occur in girls aged 10-19 years old (UNAIDS 2019a; UNAIDS 2019b). HIV is gendered from the point of contraction and throughout the course of illness. The feminization of HIV reflects women's greater biological vulnerability, but also their socioeconomic vulnerability resulting from several interrelated economic, socio-cultural and legal factors (Chop et al. 2017).

Moreover, women farmers play an increasingly important role in the agriculture sector, which lies at the core of the food system, in many developing countries, including Malawi, a trend known as the 'feminization of agriculture,' (FAO 2017). In Malawi, a higher portion of female members of the household contributes to the agricultural labor force compared to male household members (95% vs 83%) (NSO 2017). Women are also more commonly becoming the head of the household as men are migrating to urban cities or neighboring countries for work (FAO 2017). Despite their importance, it is well documented that women in rural SSA in general, face barriers in terms of access to education, agricultural inputs, extension and advisory services (EAS), and have significant income and productivity gaps compared to men (Doss et al., 2018; FAO 2011). While this is not a study on gender issues, it is important to recognize these differences to understand the context for women living with HIV (WLHIV) in Malawi. Moreover, the abovementioned inequalities highlight the need to explore women's issues separate to that of men in the context of HIV and food systems, as it allows us to identify the

wide diversity between women's experiences, without assuming that all women's needs, thoughts and experiences are the same (Harding 1987 as cited in Landman 2006).

Although scholars have analyzed and described the HIV/AIDS epidemic in detail, past research will only provide a temporary description of the situation, as the HIV epidemic is “never static but is continuously evolving and in flux” (Frega et al. 2010, p.S295). Much of the previous literature on HIV, agriculture and food security has its roots in the two decades since its spread. A lot has changed since then with the roll-out of ART, bringing relief to many households and communities (Frega et al. 2010). Conclusions from studies dating back to the first decades of the epidemic must be drawn with caution to presume the situation and needs of rural households today (Murphy, Harvey & Silvestre 2005). To describe the changing nature of HIV/AIDS, USAID has coined the term “know your epidemic, know your response,” emphasizing the importance of an up-to-date understanding of each specific context (Wilson & Halperin 2008).

Against the foregoing background, this paper addresses the following aims: to identify the feelings, experiences and perceptions of WLHIV and how they perceive their positive status to affect the food system<sup>1</sup>, to assess the role of informal and formal support as coping strategies and to quantitatively assess the relationship between HIV status, food security and access to formal support. Several studies have quantitatively analyzed the relationship between HIV/AIDS and agriculture (e.g. Fox et al. 2004; Dorward & Mwale 2011). This study aims to complement such studies with a mixed-methods approach, using a food systems perspective. No studies, to my knowledge, have studied HIV through a holistic food systems lens. Malawi provides a highly relevant country to study these issues as it has one of the highest HIV prevalence rates in the world (10.6% in the population aged 15-64) (MoH 2018; UNAIDS 2019a). Also, most Malawians rely on farming as their primary livelihood and food source and thus, questions about the linkages among HIV and food systems is highly relevant. Understanding the links between HIV and food systems represents an opportunity to design strategies that can effectively alleviate

<sup>1</sup> The food system will hereby refer to the central components of the food system in rural Malawi, which is made up of the food supply chain, consumer behaviour, and the food system outcomes which includes food security (availability, access, utilization), income and health. See figure 1 for details. I recognize that there are other important outcomes in the food system, including environmental and social sustainability, but this is not included here.

food insecurity and improve the quality of life for PLHIV (Bukusuba, Kikafunda & Whitehead 2007). Theoretically, the research draws upon the food systems framework (HLPE 2017). Systems thinking can be used as a tool to address complex problems which consist due to several interdependent elements which interact with each another (Ericksen 2007). I also draw on social and behavioral theories related to health in the discussion of the findings.

The rest of the paper is organized as follows. The next section outlines the research aims and questions, followed by relevant background information on Malawi. This is followed by the theoretical framework that will be used to guide the research. Chapter four presents the research methodology, followed by the study findings in chapter five. The last section discusses the research findings and a conclusion.

## **2. Research aims and questions**

1. To identify the effects of HIV on the food system for small-scale female farmers in a resource-constrained setting in rural Malawi.
  - a) What are the major challenges for women with HIV when working in agriculture?
  - b) How do small-scale female farmers experience their positive HIV status to affect the food system?
2. To identify coping mechanisms that small-scale female farmers adopt to deal with the effects of HIV on the food system, what external support they rely on, and assess how formal support can be optimized to improve food security and health outcomes.
  - a) What informal and formal coping mechanisms do small-scale female farmers rely on to cope with the effects of HIV on the food system, and to what extent are these mechanisms perceived as effective?
  - b) What programs and policies do small-scale female farmers feel would benefit them, and how should these be implemented?
3. To quantitatively assess food insecurity in households affected by HIV compared to non-affected households and to determine the impact of HIV on food security and access to formal support programs for households affected by HIV.
  - a) Does HIV status impact food security in households affected by HIV, compared to non-affected households?
  - b) Is HIV status a predictor of household food security?

c) Does HIV status affect access to social security programs?

### **3. Background**

This section will present the necessary background information to understand the general context of Malawi and the relevance of this study. The demographic and socioeconomic profile of Malawi will be presented, in addition to a description of the characteristics of the Malawian food system and the current food security and population health<sup>2</sup> situation in Malawi.

#### **3.1. Socioeconomic profile of Malawi**

Malawi consistently ranks as one of the poorest countries in the world despite significant structural and economic reforms to support economic growth (World Bank 2020a). In recent years, Malawi has made progress in several non-monetary indicators of human development, such as health and education, but little change has been seen in reducing poverty which has largely stagnated, especially in rural areas (IMF 2017; UNDP 2019). The World Bank (2018) describes Malawi as a country with weak governance, poor institutions, limited ability to implement policy, with a high level of dependence on international aid. Based on World Bank estimates using a poverty line of US\$1.90 per day, 70.3% of the population lived under the poverty line in 2016 (World Bank 2020b). During the past decades, Malawi has been negatively affected by both climate-related and political shocks, which combined have contributed to economic stagnation and limited poverty reduction leaving the country vulnerable to future shocks (IMF 2017).

#### **3.2. Population health in Malawi**

Large investments in the health sector in Malawi, one of the highest in SSA, has led to improvements in several key health indicators (Chansa & Pattnaik 2018; World Bank 2020c). For example, Malawi was one of 11 countries in Africa to reach the MDG target of reducing under-five mortality, one of eight countries in SSA where female life expectancy increased by more than ten years from 1990 to 2015, largely due to a decrease in AIDS-related mortality (Chansa & Pattnaik 2018). Malawi has kept out-of-pocket spending on healthcare much lower

<sup>2</sup> The health outcomes of the population as a whole

than its neighboring countries due to its free healthcare policy, while also making improvements towards the goal of universal healthcare (Chansa & Pattnaik 2018).

However, Malawi still has a long way to go in terms of improving population health. The Malawian health system suffers from many challenges; key among these issues is a severe shortage of skilled healthcare workers and lack of healthcare facilities (Chansa & Pattnaik 2018). Malawi has a severe crisis regarding the shortage of trained healthcare workers, with the lowest physician-to-population ratio at 2:100 000 and second lowest nurse to population ratio at 28:100 000 in SSA (Avert 2020a). With economic stagnation and low salaries, many healthcare workers are migrating out of the country. Access to health facilities is a major challenge, especially in rural areas, where the majority of the population live (around 80-85%) (Chansa & Pattnaik 2018). While healthcare is supposed to be free at all government facilities, the above-mentioned challenges, in addition to a lack of medicines and supplies, necessitates out-of-pocket spending at private health facilities or transportation costs to facilities far away (Chansa & Pattnaik 2018).

### **3.3. HIV/AIDS in Malawi**

HIV/AIDS is a range of conditions caused by infection with the human immunodeficiency virus. The virus targets the immune system and weakens its ability to fight infection (WHO 2020). There are three stages of HIV infection: (1) acute HIV infection, (2) chronic HIV infection/asymptomatic stage and (3) Acquired Immunodeficiency Syndrome (AIDS) (WHO 2020). The severity of HIV/AIDS and its effects are highly dependent on the stage of the disease. Before and right after initial infection, viral loads are high, and the individual may feel flu-like symptoms (e.g. fever, headache, muscle pain, rash), as the body is responding to HIV infection and producing antibodies to attack the virus, a process known as seroconversion and can last for several months (Avert 2020b). Once a person has been through the seroconversion process, they often start to get better. Asymptomatic HIV infection is the second stage of HIV/AIDS. In an ideal situation, there are no symptoms of HIV infection during this stage, but this is dependent on age, background, ART adherence and general health. During this stage, the virus is multiplying in the body, and the immune system is slowly weakening. This stage may last for several years (10-15 years), even if a person is not yet taking ART (Avert 2020b). With effective treatment, a person can live with chronic HIV infection for decades. Without proper treatment, HIV infection advances in stages, worsening with time, increasing damaging the immune system (WHO 2020).



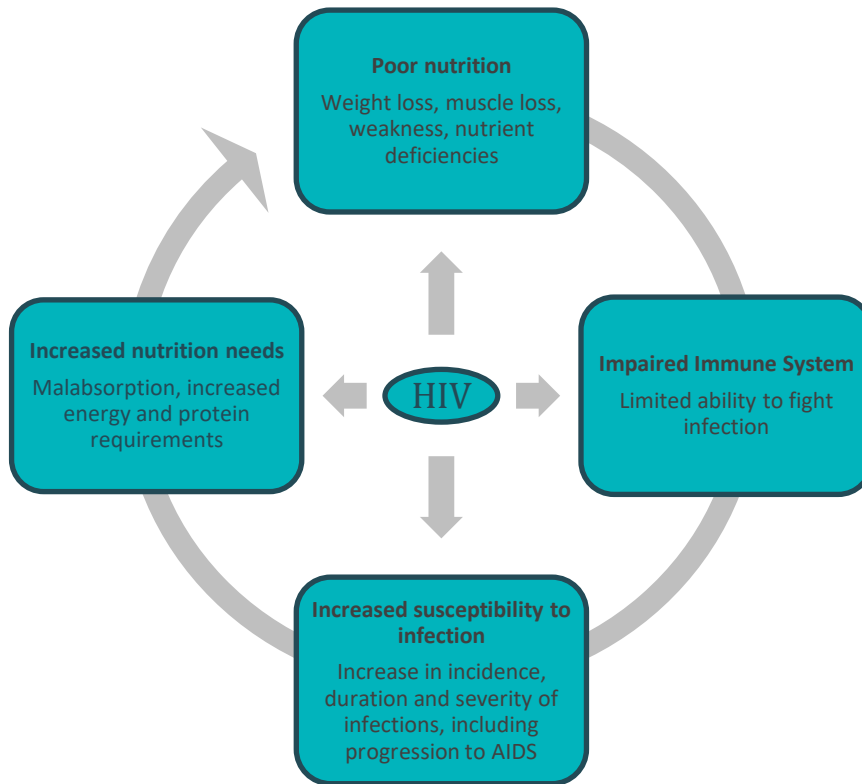
ART and good nutrition are essential parts of HIV treatment (WHO 2020). With effective treatment HIV has become a manageable chronic health condition, which in theory should enable PLHIV to live a healthy and productive life (WHO 2019).

Malawi has made remarkable progress in controlling the HIV epidemic in recent years, as one of few countries in SSA being close to achieving the 2020 UNAIDS 90-90-90 targets (UNAIDS 2019a). This means that 90% of people with HIV know their status, 90% of these are on ART and 90% of those on treatment are being virally suppressed (UNAIDS 2019a). In Malawi, in 2018, 90% of PLHIV were aware of their status, of whom 87% were on treatments, and of these 89% were virally suppressed (UNAIDS 2019a). Key to this success is investments in prevention work, HIV testing and counselling services, including nutrition counselling, expanding access to ART and maintaining high levels of adherence to ART through public education and engagement and the use of community support groups (GoM 2015). However, HIV/AIDS continues to be one of the biggest contributors to the burden of disease in Malawi and contributes to the low life expectancy of 61 years for men and 67 years for women (UNAIDS 2019a; NSO 2017; Chansa & Pattnaik 2018). The HIV response is hampered by several factors including stigma and discrimination, which prevents people from seeking healthcare, overall weak health systems and low levels of health education (Avert 2020a).

### **3.4. HIV and nutrition**

Good nutrition is essential for PLHIV to increase drug efficacy and adherence, reduce negative side-effects, delay opportunistic infections, slow disease progression, and to limit further negative impacts of HIV on nutritional status (WHO 2003; Asenso-Okyere et al. 2011). The relationship between HIV infection and nutrition is outlined in figure 1. According to international guidelines, PLHIV should increase energy intake by 10–30% depending on disease stage and meet standard protein and micronutrient requirements (WHO 2003). Due to the relationship between HIV infection and nutrition, NGOs and the Government of Malawi (GoM) are specifically aiming to target food insecurity in programming and policies (MoH 2017). The GoM has issued nutritional guidelines for PLHIV, which aims to boost the immune system with a diverse diet consisting of food from the six food groups, including vegetables, fruits, legumes and nuts, animal foods, staples and fats (MOH 2017). However, limited resources and reliance

on a monotonous diet often prevent the ability of PLHIV to consume a nutritious diet (Weldegebreal et al. 2018).



**Figure 1:** The relationship between nutrition and HIV infection

*Source: Author, adapted from Fanta 2003*

### 3.5. Food systems in Malawi

The agriculture sector is at the heart of the food system and drives the livelihoods<sup>3</sup> for up to 90% of the population in rural areas (NSO 2017; GoM 2017). Despite the importance of food systems for livelihoods and overall development of Malawi, the agricultural sector is characterized by low productivity, limited technology, small farms and as being vulnerable to shocks such as poor health and climate extremes (FAO 2015, World Bank 2020). 99% of households in Malawi,

<sup>3</sup> “The capabilities, assets (stores, resources, claims and access) and activities required for a means of living” (Chambers & Conway 1992:7)

report experiencing at least one type of shock, most commonly high food prices, irregular rains, unusually high costs of inputs, unusually low prices for outputs and serious illness (NSO 2017).

The food system in rural Malawi can be characterized as what the HLPE refer to as a traditional food system (HLPE 2017). Some of the key characteristics of a traditional food system are as follows (HLPE 2017; NSO 2017; Ericksen 2007):

- Food is mainly produced by smallholder farmers and most of the food available for consumption is local and seasonal
- Farmers typically rely on small parcels of land - average land size in Malawi is 1.5 acres (1.2 acres for females)
- Dependency on a few types of crops or monocropping. 53% of plots were intercropped consisting of mainly two or three crops; the rest use monocropping techniques.
- Limited access to agricultural inputs
- Short and local food supply chains
- Basic processing techniques are used such as drying fruit, milling flour or processing dairy.
- High density of local informal markets and limited access to formal markets
- Food purchasing typically makes up a large portion of the household expenditure

In light of this, an analysis of the Malawian food system entails a focus on primary food production, agricultural productivity and market access (HLPE 2017; Haug & Westengen 2020). Diets in Malawi typically consist of staple grains, and often do not contain adequate amounts of protein and micronutrients (Gilbert, Benson & Ecker 2019). Dietary diversity across households in Malawi is improving slightly, however, households still rely on a small number of food groups, with lower levels of dietary diversity found in rural areas (Gilbert, Benson & Ecker 2019). Maize is the main staple, as well as cassava in some regions (Gilbert, Benson & Ecker 2019). Tobacco is the main cash crop (NSO 2017). People in rural areas also depend on food purchases from local wet markets and small kiosks to purchase food items which they do not produce themselves if money is available (HLPE 2017).

The food system is related to human health and nutrition in a multitude of ways, perhaps the most obvious is the way in which the food systems makes food available to meet people's energy and dietary needs (Kanter et al. 2015). Traditional food systems are currently associated with low levels of dietary diversity, higher levels of malnutrition and the highest prevalence of under-five mortality (HLPE 2017). Food insecurity is high in Malawi as measured using several indicators of food security: 34% of women aged 15-49 have anemia; 26% of the overall population are undernourished; 29% of children are stunted and 6% are wasted (FAO et al. 2019). 64% of Malawians feel they have less than adequate food security (NSO 2017). These figures mean that Malawian diets are lacking in terms of both the quantity and quality of food, as both enough calories and nutrient-rich foods are lacking (Harris, Meerman & Aberman 2018).

### **3.6. Agricultural development in Malawi**

Due to Malawi's reliance on agriculture, it is in this sector that improvements can be made to enhance economic development and thus also the food security and health situation of the population (GoM 2017). In recognition of this, the GoM has since the 2005/06 farming season implemented a large-scale Farm Input Subsidy Program (FISP). The intention of the program is to target resource poor agricultural households who are unable to afford the full market price of fertilizer, hybrid maize seeds and legume seeds (Chirwa et al. 2015). Two main criteria are used in selection of beneficiaries: households that own a piece of land and female- or child-headed households (Duchoslav & Kenamu 2018). The budget for FISP accounts for 3-6% of Malawi's GDP and accounted for 50% of agricultural spending in 2016/2017 (MOAIWD 2017). The targeting of beneficiaries used to be carried out by traditional leaders, but since allegations of interference by traditional leaders the process changed during the 2016/2017 farming season, when the Ministry of Agriculture, Irrigation and Water Development started to randomly select FISP beneficiaries from registers of farming households compiled by extension workers (Chirwa et al. 2015).

Extension and advisory services (EAS) are another important source of support within the agricultural sector. EAS is defined as "all the activities that provide the information and advisory services that are needed and demanded by farmers and other actors in agri-food systems and rural development" (Christoplos 2010, p.2). EAS in Malawi is pluralistic, meaning many actors are involved (e.g. GoM, NGOs, multilateral organizations, farmer clubs, private sector), although

the government remains the most common source of EAS (Khaila et al. 2015). Malawi is divided into eight agricultural development divisions, which is further divided into 30 rural development projects (RDPs). The rural development projects are further divided into 173 extension planning areas (EPA). Each EPA has a number of extension workers, which are required to work with farmers in their area. The ratio of extension workers to farmers is low in Malawi (1:1848), indicating a shortage of staff (Khaila et al. 2015). EAS in Malawi mainly follows the lead farmer model, which means that farmers are picked by the community to participate in trainings to address agriculture techniques that aim to improve small farmers' productivity (Khaila et al. 2015; Andersen 2019). The lead farmer is responsible for disseminating the teachings to a number of follower farmers. Coverage of EAS is high in Malawi, with 77% of households receiving some form of training in 2017/2018 (Ragasa et al. 2019).

### **3.7. Social Security in Malawi**

In recent decades, social safety nets (SSNs) have expanded across Malawi, becoming a key strategy to address poverty (World Bank 2018). SSN are one of the several priority poverty and relief responses that currently exist in Malawi, alongside FISP<sup>4</sup> and humanitarian aid (World Bank 2018). Malawi's SSNs that are most relevant to this study, include the Food Insecurity Response Plan (FIRP), which provides food assistance and direct cash transfers to vulnerable households during the lean season; the Social Cash Transfer Program (SCTP), which provides unconditional cash transfers to poor and labor constrained households; the Malawi Social Action Fund (MASAF), a public work program which provides subsidized employment through various cash-for-work, food-for-work and input-for-work programs (Duchoslav & Kenamu 2018). Targeting of FIRP and SCTP is based on satisfying one or more of the following criteria: child, elderly or female-headed households or households caring for orphaned children; household with chronically ill or HIV/AIDS affected members, households repeatedly experiencing crop failure and households with children receiving supplementary or therapeutic feeding (Duchoslav & Kenamu 2018). Currently, 5% of Malawians benefit from cash transfers, around 21% benefit from free maize distribution programs, and a further 16% benefit from other free food programs

<sup>4</sup> FISP can be considered a SSN, but I separate FISP and other SSN here.

(NSO 2017). The SCTP has had a consistent and strong positive impact on livelihood and education outcomes (World Bank 2018a).

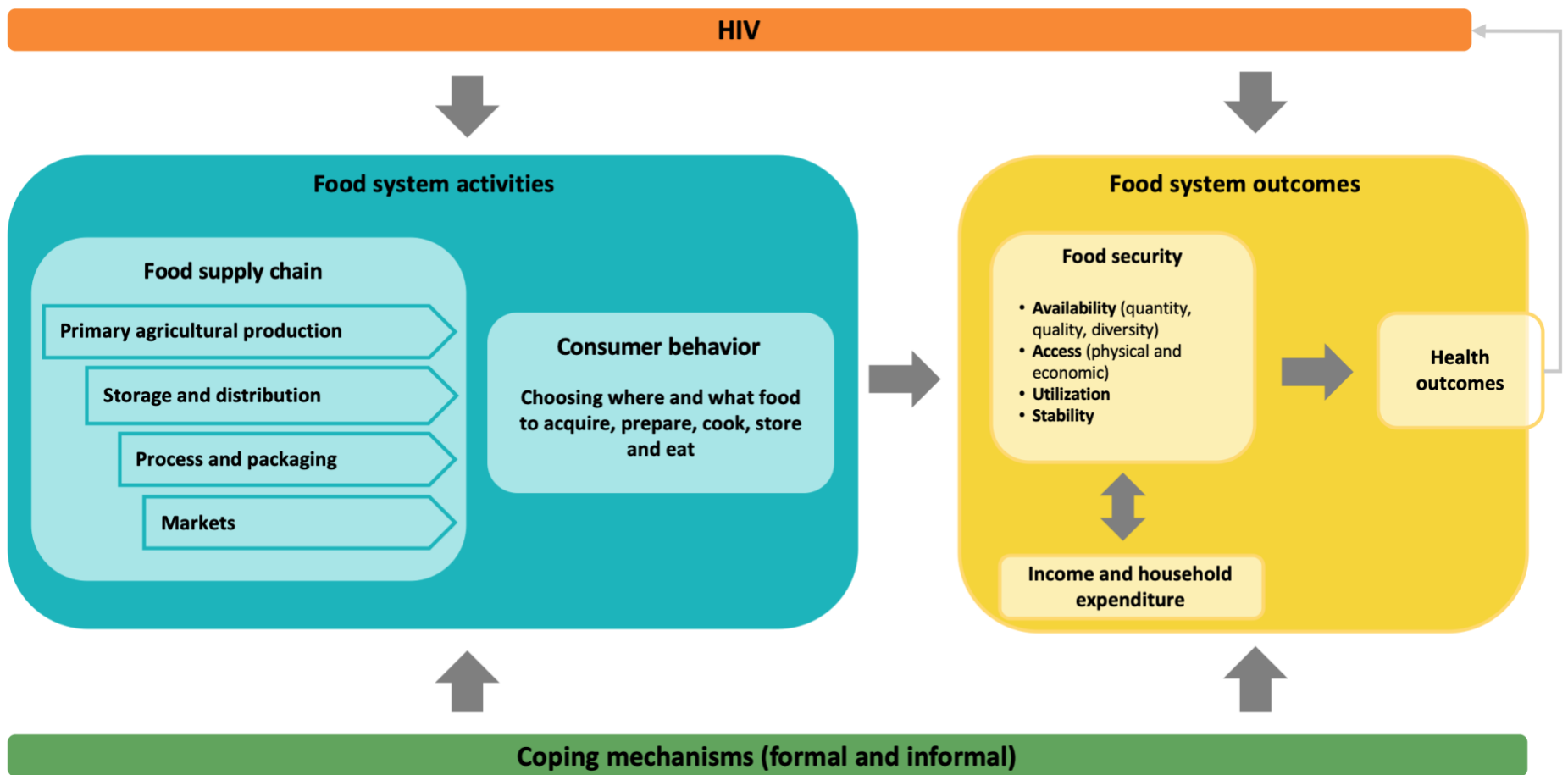
#### **4. Theoretical Framework**

The following section will outline key concepts, and the core elements of the food system, which will be used as an analytical tool in this study. Relevant literature and ongoing debates regarding HIV, food security and agriculture will be reviewed. Literature carried out in urban areas, studies focusing on macro-level impacts and studies that focus solely on the effects of AIDS-related mortality on households are excluded.

##### **4.1. Food system framework**

Recent research has emphasized the impacts of climate change and environmental degradation on food systems as a result of factors such as population growth, urbanization, changing consumption patterns, land use change and increased fertilizer and irrigation use (HLPE 2017 and 2019; UNEP 2016; IPCC 2019). While these factors cannot be overlooked, understanding the challenges food systems in Malawi face also requires significant attention to HIV and its connection to the food system, considering its large disease burden and Malawi's reliance on the agricultural sector. An analysis of the food system enables researcher to identify where the most important issues lie regarding HIV and the food system and identify intervention points for enhancing food security and health outcomes, and thus the overall sustainability of the food system (UNEP 2016). Analyzing the whole food system is more appropriate given its holistic nature than an approach focused on agriculture, markets, nutrition and health separately (Ericksen 2007; van Berkum, Dengerik & Ruben 2018). There is a tradition in both social and natural sciences to use a systems approach "to help in addressing complex problems with multi-causality resulting from interactions among interdependent components" (Ericksen 2007, p.4). The impact of HIV can be the death of a household member, chronic illness or having to support orphans following AIDS-related deaths (O'Donnell (2004). Here, the focus is on the result of chronic illness as this is most relevant to today's context as fewer people are dying from AIDS as a result of treatment.

The framework outlined in figure 2, was developed based on the literature on food systems (e.g. Ericksen 2007; HLPE 2017; UNEP 2016; van Berkum, Dengerik & Ruben 2018; Pinstруп-Andersen 2011) and the literature on health and agriculture (e.g. Hawkes & Ruel 2006; Aberman, Meerman & Benson 2015). A theoretical framework is useful for researchers to understand and explain a phenomenon. The framework describes the components of the food system and how these components interact. The framework relies heavily on the conceptual framework of food systems for diets and nutrition developed by the High-Level Panel of Experts on Food Security and Nutrition (HLPE 2017). However, it has been adapted and simplified to focus on the local context of Malawi and to include HIV as the driver of food system change, and health and food security as the final outcome of the food system. Health is defined here using the widely accepted WHO definition as “a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity (WHO 1946, p.1)”. The concept of food security is defined and discussed in section 4.3 on food system outcomes.



**Figure 2:** Analytical framework for the relationship between HIV and food systems

*Source: Author, adapted from Eriksen 2007; UNEP 2016; HLPE 2017; van Berkum, Dengerik & Rueb 2018*



## **4.2. Food system activities**

The food system consists of several activities whose primary aim is to increase food security (van Berkum, Dengerik & Ruben 2018). There are two core components of the food system: the food supply chain and consumer behavior (HLPE 2017).

### **4.2.1. Food supply chain**

The food supply chain is made up of primary agricultural production, storage and distribution of food, processing and packaging of food, retail and markets (HLPE 2017). Here, I limit the focus to primary agricultural production, storage and informal market participation as those are the most relevant aspects to the Malawian context.

#### **Primary agriculture production**

Primary agricultural production, defined as all the activities involved in the production of food, is at the center of the food system in Malawi, given that 85-90% of the rural population work in agriculture (NSO 2017; van Berkum, Dengerik & Ruben 2018). Agricultural production requires high inputs of physical labor, and poor health can affect the availability and quality of the agricultural labor force (Pinstrup-Andersen, 2011; Parker, Jacobsen & Komwa 2009). Much of research to date is from before 2005, when ART was less accessible, and generally shows that fatigue and illness related to HIV has a negative effect on the availability and quality of labor (e.g. ILO 2000; Backman & Booyesen 2003; Fox et al. 2004). For example, a review by researchers from IFPRI, based on studies from several countries in SSA dated between 1995-2005, found that HIV led to large labor reductions (Asenso-Okyere et al. 2011). However, as argued by Murphy, Harvey and Silvestre (2005), one must be careful to draw conclusions from studies dating back to the first decades of the epidemic to “presume the situation and needs of rural households in the future” (p. 272). Conclusions must be interpreted with caution as a majority of studies on HIV and labor availability and productivity were conducted before 2010 when ART was less accessible and focus on the (nowadays) small and nonrepresentative group of PLHIV in the final years before death or who are living with AIDS (Thomas et al. 2019). Therefore, there is a need for up-to-date research from populations where ART adherence is high.

Studies from Kenya and Uganda have shown how labor availability and productivity increases when PLHIV initiate ART (Thirumurthy, Zivin & Goldstein 2008; Larson et al. 2008; Larson et al. 2013). The literature usually illustrates a V-shaped pattern in which labor participation and productivity decline sharply immediately following diagnosis and before initiating ART and recover within a few months following initiation of ART to similar levels experienced before becoming symptomatic (Gill 2010; Thomas et al. 2019). For example, Larson et al. (2013) found that HIV-positive workers reported significant reductions in productivity and income before and immediately after starting ART treatment and as time on ART increased, these reductions dropped noticeably, although not to the same level as HIV-negative individuals. In Zambia and South Africa, PLHIV lost an average of 1.70 and 0.30 days due to illness, respectively, over a three-month period compared to HIV-negative individuals (Thomas et al. 2019). Thomas et al. (2019) argue that their estimates are significantly lower than those from eight older studies where the median days lost was 5.1 over three months. In Nigeria, researchers found that the level of involvement in agricultural activities, such as land clearing, weeding, planting, harvesting and storage, was significantly lower following HIV diagnosis (Nwugo & Abiodun 2017). However, a large portion of the study participants were still highly involved in agriculture following HIV diagnosis (47% pre-infection vs. 41% post-infection) (Nwugo & Abiodun 2017). In Uganda, there were no significant differences in work hours between HIV-positive and HIV-negative individuals health (Komwa, Jacobsen & Parker 2010). However, the research emphasizes how 93% of the sample believed that PLHIV should work less to save energy, but the economic situation of the household does not allow for a relatively-healthy person with HIV to significantly cut back on work to rest more, which could have negative consequences in terms of health (Komwa, Jacobsen & Parker 2010).

Reduction in labor has previously been found to lead to a range of changes in households' cropping patterns, use of land and agricultural resources. Land area may be reduced or left fallow to deal with changes in labor productivity (Parker, Jacobsen & Komwa 2009; Masuku & Sithole 2009; Gill 2010; Akrofi, Price & Struik 2012). In Uganda, HIV-affected households, especially female-headed households, reduced the total cultivated land due to labor shortages with negative effects on household food supply (Gill 2010). Such findings highlight the difference in impacts

depending on whether the HIV-positive individual is a male or female-household head. Similar findings are found in Western Kenya where the reduction in female on-farm labor severely undermined production compared to reductions in male labor (Gill 2010). Affected households are also frequently forced to reduce the diversity of crops grown or reduce their reliance on labor or input-intensive crops (Asenso-Okyere et al. 2011; Dorward & Mwale 2011). For example, research from Rwanda showed that reductions in labor availability as a result of illness in women led to a decline in production of beer bananas, a cash crop and an important source of income for women, and an increase in sweet potato, a food crop, which allows for a more flexible schedule but no income (Donovan and Bailey 2006).

### **Processing and storage**

Processing and storage are other important aspects of the food supply chain, particularly in countries like Malawi where crop production is seasonal. An adequate crop processing and food storage system is required to ensure a stable supply of food throughout the year (HLPE 2017). At this stage in the supply chain, food may lose its quality or food may be lost due to inadequate processing and storage facilities (HLPE 2017). No studies identified have focused on whether HIV may affect this part of the food supply chain. However, due to the reported effects on primary production, it is not unlikely that there will be less output that needs to be stored.

### **Market access**

A household's participation and access to markets is important for food security and health as it provides farmers with an income and a place to purchase nutritious food that they do not produce themselves (Aberman, Meerman & Benson 2015). Evidence from several countries, including Malawi, suggests that market participation has a significant impact on dietary diversity, more so than the diversity of the crops they produce themselves (Koppmair, Kassie & Qaim 2017; Sibhatu et al. 2015). Changes in labor productivity and declining yields can affect a household's ability to sell produce at markets, which in turn affects their ability to generate income and their purchasing power to buy agricultural inputs and food (Parker, Jacobsen & Komwa 2009; Kaler et al. 2010). Kaler et al. (2010) found that HIV did not affect household's involvement in market transactions in a straightforward linear fashion. Some households were forced to sell their livestock due to HIV-related expenses, and therefore no longer had anything to sell, others could

no longer afford the opportunity cost of time spent selling, while some no longer had the strength to participate (Kaler et al. 2010). In contrast, some households intensified their involvement in market exchanges to meet increased needs for money (Kaler et al. 2010). In Uganda, researchers found that affected households were unable to transport goods to market further away, such as those near the Kenya-Uganda border, where they could sell for a higher price. As a result, they sold their products to middlemen who come to the village to buy produce cheap and thus losing important income (Parker, Jacobsen & Komwa 2009).

#### **4.2.2. Consumer behavior**

Consumer behavior refers to “the choices made by the consumer, at household or individual level, on what food to acquire, store, prepare and eat, and on the allocation of food within the household (HLPE 2017, p.11). Behavior is a complex issue shaped by a number of factors “including food prices, income, knowledge and skills, time and equipment, and social and cultural norms” (HLPE 2017, p.31). Several theories aim to understand the complexity of human behavior. Here, I draw upon social cognitive theory (SCT), which is commonly used in health research. SCT explains “human behavior as a dynamic, reciprocal and continuous interaction between the individual and the environment” (Bandura 1988, p.276).

#### **4.3. Food system outcomes**

Food system activities give rise to a variety of outcomes. Here the focus will be on outcomes in terms of income, food security and health (van Berkum, Dengerik & Ruben 2018).

##### **4.3.1 HIV effects on income and expenditures**

Illness through its impacts on food system activities can lead to changes in household expenditures and income (HLPE 2017). Despite free public healthcare in many countries in SSA, including Malawi, research shows that PLHIV experience a host of expenses following diagnosis, at a time when income is often reduced since production has declined (Parker, Jacobsen & Komwa 2009; Asenso-Okyere et al. 2011). Increased expenditures include money for medication, healthcare at private clinics, transportation costs and recommended nutritious food (Parker, Jacobsen & Komwa 2009). In Nigeria, a study found that there was a 30% rise in medical expenditure and a 30% fall in annual income for HIV-positive farmers (Nmadu &

Nwawulu 2015). Gill (2010) found that reductions in available labor due to HIV was directly related to reductions in household income. Similar findings are found in Zimbabwe and Swaziland, where studies show that households are forced to sell assets or re-allocate cash resources from agriculture to increased medical expenses. These changes have led to a decline in farm productivity and food insecurity (Masuku & Sithole 2009; Muzari et al. 2014; Masuku, Singh & Kibirige 2015).

Again, it is important to highlight the role of ART in reducing HIV's social and economic impacts. In Uganda, ART enabled PLHIV to regain "control" over daily activities and family life, achieve economic and social goals such as investing in agriculture and small business (Kaler et al. 2010). Better health and returning to agricultural work improved the economic situation for all study participants, as well being important for household food security and poverty reduction (Kaler et al. 2010; Russel & Seeley 2010). Feulefack et al. (2013) showed that since participants started taking ART the health conditions of all participants improved, and all household incomes increased by approximately 30% to 40%. However, improvements in incomes were dependent on several factors, including age, education and household size (Feulefack et al. 2013).

#### **4.3.2. HIV effects on food security and health outcomes**

Food security is a term that has caused controversy and debates since its introduction, and around 200 definitions and 450 indicators are found in the literature (Pinstrup-Andersen 2009; Anema et al. 2014). The current definition used by many multilateral agencies, originally evolving from the World Bank in 1986, and the one which I apply here, was affirmed by the 1996 World Food Summit, which states that "food security exist when all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life" (World Food Summit 1996). Nutrition is inherent in this definition. This definition is a multidimensional concept that includes several dimensions, compared to when it was first introduced in the 1970s.

Food security is often characterized as consisting of four broad and intersecting dimensions: availability, access, utilization and stability. These dimensions are complex and are defined differently in the literature (Anema et al. 2014). Here, food availability refers to the ability of a

household to produce enough food of sufficient quantity and quality. Food access refers to physical and economic access to enough food (FAO et al. 2019). Food utilization refers to whether or not the household makes use of the various nutrients in the food (FAO et al. 2019). Food utilization is dependent on a balanced diet, clear water and sanitation, nutritional knowledge and health (Frega et al. 2010). Food safety is an important aspect of utilization, referring to an individual's ability to prepare, consume and biologically utilize safe food, ensuring that poor food or hygiene, which can cause infections, are minimized (Anema et al. 2014). Stability is the condition in which the dimensions of availability, access and utilization are met, ensuring food security at all times (FAO et al. 2019).

Food security depends on the adequate functioning of the food system (HLPE 2017). Changes to food system activities and income can impact on food security. The negative impacts of HIV on food security are widely reported in the literature in several rural settings throughout SSA, including Senegal (Benzekri et al. 2015), South Africa (Ncube et al. 2016), Ghana (Akrofi, Price & Struik 2012), Ethiopia (Weldegebreal et al. 2018); Kenya (Ngata et al. 2012), Zambia (Masa, Chowa & Nyirenda 2017) Uganda (Tsai et al. 2012; Palermo et al. 2013) and Malawi (Rodas-Moya et al. 2015). Although food insecurity is generally high in SSA (24.4% of total population severely food insecure) (FAO et al. 2019), studies often reveal higher levels among PLHIV (Masa, Chowa & Nyirenda 2017). HIV/AIDS can compromise food security through the many pathways already discussed, including affecting the ability to participate in agricultural work, reductions in income and increased expenditure on health-related expenses, which affects the ability to purchase food or agricultural inputs. These pathways can comprise an already vulnerable situation as PLHIV are biologically more susceptible to food insecurity (Frega et al. 2010).

The issue of food security and HIV/AIDS has led to the development of a new hypothesis - the "New Variant Famine" hypothesis (de waal & Whiteside 2003; Arrehag, de waal & Whiteside 2006), a hypothesis that is widely referred to in the literature. The New Variant Famine is a famine characterized by more households becoming vulnerable, quicker, with limited ability to cope, eroding the health and economic situation of the household. This happens through four main pathways: labor loss, asset and skill loss, increasing burden of care for the sick and

orphans, and malnutrition (de Waal & Whiteside, 2003). The hypothesis appears to be the “common assumption” regarding the impacts of HIV on agrarian communities.

Almost two decades later, empirical research continues to support the “New Variant Famine” hypothesis, suggesting little has been done to improve the food security situation for PLHIV in SSA. A study from Western Kenya shows that in all the households studied food security, was negatively affected in terms of both quantity and quality of food (Gill 2010). Declines in food production were directly related to the loss of labor. However, the severity of the effects was highly dependent on who in the household was infected, the resources available to the household and the stage of HIV of the infected household member (Gill 2010). Differences in gender roles means that food security is more severely affected when women are infected due to differences in gender roles. Women in a household often have primary control over food crops and are primarily responsible for food preparation and cooking and collecting water, fuels and other necessary items to feed the household (Gill 2010).

Dietary diversity is often the first part of food security to be affected as households will often prioritize staple grains over vegetables and legumes in an effort to supply enough calories for the household, thus leaving households on diets high in carbohydrates, but low in many essential vitamins and nutrients that are essential to support the immune system (Gill 2010). In South Africa, Ncube et al. (2016) show that there was no difference in daily calorie intake between HIV-affected and non-affected households, but the dietary diversity was lower in households affected by HIV. Ncube and colleagues (2016) argue that this may be because non-affected households are able to spend more money of food, while affected households are likely to have less income due to decreased labor supply and increased expenses, and thus have lower purchasing power (Ncube et al. 2016). In Ethiopia, Weldegebreal and colleagues (2018) studied dietary diversity amongst PLHIV on ART and found low dietary diversity (less than 4 food groups) in 30% of the participants.

While the general picture regarding HIV and food security is dark, a few studies shows, in a very limited sample, that HIV can function as a mechanism to drive behavioral changes. In a cross-country study, including Malawi, researchers found that HIV has led to positive changes in diet

(Makoae et al. 2008). Komwa, Jacobsen and Parker (2010) show that people with HIV infection report eating more nutritious and diverse food, particularly higher levels of fruit and vegetables compared to other participants. However, the majority of the sample could not translate beliefs and knowledge regarding nutrition into practice due to financial constraints (Komwa, Jacobsen and Parker 2010).

In terms of food security, the impact and role of ART is highly relevant. While there is increased availability of ART that has improved immune system functioning and overall health, food insecurity shapes the efficacy of these medications (Rodas-Moya et al. 2015; Nyantakyi-Frimpong et al. 2016). Research has shown that food insecurity has been a considerable barrier to using ART to manage HIV because ART requires not only adequate but also nutritious food (Nyantakyi-Frimpong et al. 2016). In addition, ART is well-known for its side-effects. These side-effects are relatively frequent and sometimes so severe that people are unable to leave the home or care for themselves or others (Renju et al. 2017). Several studies, from Uganda, Senegal, Mozambique and Kenya, discuss how ART creates more hunger as one of the side-effects (Kalofonas 2010; Groh et al. 2011; Ngata et al. 2012; Benzekri et al. 2015; Renju et al. 2017). PLHIV have reported fear or actual feelings of increased hunger since initiating ART, and especially when taking ART on an empty stomach, which has subsequently led to non-adherence to the medication (Ngata et al. 2012; Young et al. 2014). When taking the ART without food, feelings of nausea, headaches, dizziness, shivers, fainting, loss of energy, rapid heartbeat, vomiting and stomach pain were experienced by PLHIV (Young et al. 2014). In a study in Senegal, 17% of the study sample did not take ART due to hunger, and 60% missed meals due to ART side-effects (Benzekri et al. 2015). Similarly, in Rwanda, researchers found that 76% of participants stated that having an increased appetite reduced adherence (Au 2006). ART side-effects can negatively impact food security, for example nausea, appetite loss and taste changes, may reduce food consumption, while diarrhea and vomiting may increase nutrient loss (Weldegebreal et al. 2018). Kalofonas (2010) argues that although coverage of ART increases, overall quality of life does not improve if the underlying problems of food insecurity are not addressed (Kalofonas 2010).



Food security is an important determinant of health and is crucial for individuals to reach their physical and mental potential, maintain their health, and ensure economic productivity (IFPRI, n.d.). The nutritional status of an individual is crucial to the outcome of the HIV infection and progression to AIDS, and the co-existence of HIV infection and malnutrition may lead to increased mortality, as well as lower quality of life (Palermo et al. 2013; Mulu, Hamza & Alemseged 2016; Tesfaye et al. 2016). Food insecurity has also been associated with depression in PLHIV, which contributes to worsened HIV-related outcomes (Tsai et al. 2012).

#### **4.4. Coping mechanisms**

To cope with the shocks and added stress of living with HIV, farmers have adopted a range of coping mechanisms. Coping refers to the behavioral and psychological strategies that people employ to master, tolerate, reduce or minimize stressful events (Lazarus & Folkman 1991). In general, the literature distinguishes between problem-solving strategies and emotion-focused coping strategies. Emotional coping strategies involve managing feelings and emotions, and problem-solving strategies are those that directly address the problem (Lazarus & Folkman 1991). Households can cope using informal mechanisms or formal support from the government and NGOs, however formal support is often limited in resource-constrained settings (Christiaensen, Nikoloski & Hill 2018). The ability to cope with added stress is determined by several factors including individual factors (e.g. physical health, mental health, personality, life philosophy), relationships (e.g. interactions with family, friends) and context-specific factors (e.g. education, employment, socioeconomic position) (Peng, Dernini & Berry 2018). The success with which PLHIV cope with the stress of living with HIV has direct impacts on their quality of life and health (Makoae et al. 2008).

##### **4.4.1. Informal coping strategies**

Existing studies on coping strategies find that PLHIV adopt a range of different coping strategies: intra-household labor substitution to compensate for production losses (Bignami-Van Assche et al. 2011); diversification of income sources (Masuku, Kibirige & Singh 2015); acquiring more knowledge (Makoae et al. 2008).; eating more wild foods (Kaschula 2011); begging (Laar et al. 2015); migrating to find work; seeking loans (UNAIDS 1999); and if resources allow hiring labor and draught power to meet production requirement are common, as

is receiving support from family (Masuku & Sithole 2009). Emotional coping strategies such as rationalization, seeing oneself as being okay, turning to God, hoping and humor have also been identified as coping strategies in PLHIV (Makoae et al. 2008).

Studies also highlight how many of the adopted strategies are often undesired, harmful and irreversible (Akrofi, Price & Struik 2012). For example, HIV-affected households may compromise their ability to cope in the long term by selling assets such as livestock or land to buy food or pay for increased medical expenditures (Wagner et al. 2009; Masuku, Kibirige & Singh 2015); women may engage in unsafe sexual behavior to acquire money for food (Chop et al. 2017); withdrawing children from school to save money and to have additional labor (UNAIDS, 1999); and shifting cultivation practices towards less profitable, more labor-efficient crops (Dorward & Mwale 2011; Talman et al. 2013; Masuku, Kibirige & Singh 2015). Food-related coping strategies include substituting food for cheaper food alternative (e.g. porridge instead of bread) (Muzari et al. 2014); cultivating fewer crop species (Akrofi, Price & Struik 2012); skipping meals and reducing portion size (Benzekri et al. 2015; Peinaar, Rooyen & Walsh 2017); decreasing cultivated area, harvesting immature crops and relying on less expensive foods (Laar et al. 2015). These strategies may improve food security in the short-term, however, over time, they have the potential to cause long-term deterioration of livelihoods (Laar et al. 2015).

#### **4.4.2. Formal coping strategies**

In addition to the informal coping mechanisms, households often rely on formal support from social protection systems, in the form of cash, food, skills, education and other assets, from the government or NGOs (World Bank 2018). In this context, social protection is defined as a set of measures that support vulnerable populations (Holzmann & Jorgensen 1999). An NGO is broadly defined here as any nonprofit, non-governmental organization that works in the development, humanitarian, advocacy, or civil society sector. They can be international, regional, national, or local (Brass et al. 2018).

Not surprisingly, the health sector lies at the core of support in which PLHIV rely on. HIV care in Malawi is decentralized with a focus on delivering support at the community level through

community healthcare workers<sup>5</sup>, as well as nurses and doctors, a strategy recommended by the WHO due to the shortage of highly trained workers (Bemelmans et al. 2010; Smith et al. 2014). The decentralization of HIV services has improved equity in access to care for rural populations, as well as being highly successful in scaling up ART coverage (Massaquoi et al. 2009). Health Surveillance Assistants (HSAs) are at the heart of the community's response and play an important role in providing healthcare and connecting the community with the formal health sector, both out in the villages and at the health clinic (Smith et al. 2014). Despite positive developments in light of decentralization, HSAs in Malawi state that there are issues related to high workloads, lack of adequate training, remuneration and supervision, which makes delivering good services challenging (Smith et al. 2014). At the patient side, there are issues related to travel times and transportation costs, which has important implications for those who live far away from the health clinics (Pinto et al. 2013). It is also widely reported in the literature that PLHIV experience stigma and discrimination in healthcare access in Malawi, with women reporting higher levels of discrimination at healthcare facilities (e.g. Neuman et al. 2013).

In recent years, the global health community has recognized that addressing food insecurity is critical for successful HIV care in resource-limited settings, where PLHIV lack access to sufficient nutritious foods (Yager, Kadiyala & Weiser 2011; Gebremicheal et al. 2018). As a result, there have been significant movements “on the ground” to jointly address food insecurity and HIV (Yager, Kadiyala & Weiser 2011). A large-scale study including 336 HIV treatment sites, serving 470 000 patients in nine different countries in SSA found that the availability of nutritional supplementation and food assistance is high (90%). However, the extent that these support services are implemented, and their effectiveness is unclear (Anema et al. 2011). Other studies show that food assistance can, in some contexts, improve food security, quality of life and adherence to ART (Aberman et al. 2014; Young et al. 2014; Hong, Budhathoki & Farley 2018). However, there are significant limitations to food supplementation programs as they do not tackle the underlying determinants of food insecurity, in addition to being unsustainable (Yager, Kadiyala & Weiser 2011).

<sup>5</sup> A community member chosen by the community or an organization to provide basic healthcare within their community.

Access to nutritional counseling is crucial in HIV treatment, particularly in areas where health education is low and poverty is high. It then becomes essential to find cost-efficient ways to add more nutritious foods to the diet (Weldegebreal et al. 2018). In Uganda and Tanzania, nutrition education and counseling services have been found to have a positive effect on food consumption patterns, such as the adoption of more food groups (Bakusuba, Kikafunda & Whitehead 2010; Hudayani & Sartika 2016). The relationship between nutrition knowledge and the number of meals consumed in a day, the frequency of which fruits, vegetables, legumes, animal products and cereals consumed was positive and significant in a study done on nutritional knowledge amongst PLHIV in Kenya (Muthamia 2014). Consumption of a diverse diets is significantly associated with access to food aid, possibly because food aid frees of resources for other important foods (Bukusuba, Kikafunda & Whitehead 2010). Food support must also be carefully designed and implemented, research from Kenya and Malawi, on therapeutic feeding, found that although the patients were enthusiastic about weight gain and the rapid return to work, the taste of the product, diet monotony and inability to carry the 12kg bag home from the clinic made it difficult for many of the patients to consume the daily prescription (Dibari et al. 2011; Rodas-Moya et al. 2015).

The agricultural sector has the potential to play an important role in the lives of HIV-positive farmers (Mandumbu & Mariga 2017). FAO has called for a “mainstreaming” of HIV/AIDS into EAS (FAO 2002). No studies have explicitly focused on EAS and PLHIV, however, in general, EAS are recognized as an important contributor to agricultural productivity (Christoplos 2010). In turn, this can lead to increased incomes, empowerment, increased food security and reductions in workloads (Andersen 2019). Lead farmers help increase farmer knowledge and enhance the exchange of knowledge and experiences, as well as providing motivation and an encouraging environment to adopt new technologies, as well as providing a focal point for both the community and other service providers (Khaila et al. 2015).

However, a common assumption regarding EAS is that the improved technologies promoted by extension workers are productive and profitable, when in fact, various studies highlight that this may not always be the case (Ragasa & Mazuna 2018). For example, ‘improved’ technologies have been found to increase time spent on agricultural work, and often reduces a woman's time

spent on feeding and cooking, which may have negative consequences for food security (Johnston et al. 2018). This is particularly challenging in the context of HIV. Research from Malawi has found that there is, in general, a low awareness and low adoption of the technologies promoted by extension workers, however, food and health related technologies have relatively high adoption rates, because they are relatively cost-efficient and simple compared to production-related technologies (Ragasa & Nui 2017). Ragasa and Mazuna (2018) found some of the reasons for farmers dissatisfaction with extension advice to be: extension workers are not providing advice on what the farmers need, and do not consult the community about their demands and preferences; different extension workers from different organizations provide conflicting advice, and the farmers, therefore, do not trust the knowledge and expertise of the workers; some farmers experienced that because the inputs, services or equipment required to implement the teaching were not provided or locally available, farmer were not able to implement the teachings. Gender is also an issue regarding access to EAS. EAS have been found to be mostly directed at male heads and also often overlooks the fact that women have different roles, resources and constraints (Netsayi et al. 2016). Within the EAS system, institutional biases can reproduce gender inequality by reinforcing stereotypical gender norms (Mudege et al. 2016).

On a more general basis, the GoM has responded to the overall health, food security and poverty situation in the country by investing in and implementing a series of social security nets (SSNs) (Haug & Westengen 2020; NSO 2017). Some of the most common forms of social support that are relevant for this study are discussed below. There exists extensive literature on the impacts of these SSNs on various outcomes related to food security and overall poverty alleviation throughout SSA and Malawi, while a detailed review of literature is beyond the scope here, and a brief overview will be given. The FISP is the largest of the SSNs in Malawi. Some have recognized FISP as an effective strategy to bring about an ‘African Green Revolution,’ while others are highly critical (Ragasa & Mazunda 2018). FISP has been criticized for not being economically viable, distorting the market, poor targeting, leakage, not environmentally sustainable, and for crowding out other necessary measures related to longer-term resilience building (Haug & Westengen 2020). In Malawi, input subsidies have been found to have a varying impact on agricultural productivity and food security (Ragasa & Mazuna 2018). The program has boosted maize production and lowered maize prices, but its overall effects on food

consumption, dietary diversity and micronutrient deficiency is unclear (Verduzco-Gallo, Ecker & Pauw 2014). Also, the large allocation of funding to the FISP leaves minimal funding for other services in the public agricultural sectors, such as EAS (Ragasa & Mazuna 2018). This unequal funding raises concerns among experts who suggest that inadequate provision of information for farmers might account for some of FISP's varying impact (Lunduka, Ricket-Gilbert & Fisher 2013). The FISP has also been found to be poorly targeted, reaching mainly middle segments of the population (Chirwa et al. 2015; Duchoslav & Kenamu 2018). Although the targeting process is designed to accommodate decision-making by the community, traditional leaders emerge as key decision-makers on who gets coupons for subsidized inputs. As a result, recipients of subsidized farm inputs are all over the wealth distribution, with the poor being as likely as the rich to receive subsidized inputs (Chirwa et al. 2015).

The SCTP has emerged as a social protection strategy targeted to vulnerable populations, including PLHIV, which provides economic assistance when people are unable to work (Miller & Tsoka 2011). The SCTP has been found to have a positive impact on health, food security and economic well-being for PLHIV in Malawi (Miller & Tsoka 2011). However, Richter (2010) argues that although the SCTP has the potential to bring benefits to recipients, they can be “hijacked by local political and community self-interests and encourage perverse household and community adaptations to receive benefits” (p. 81). As with many of the government-run SSNs, research from Malawi shows that SCTP are poorly targeted to poor households, and often reach middle segments of the population (Duchoslav & Kenamu 2018; Christiaensen, Nikoloski & Hill 2018). The fact that malnutrition and poverty is rising in Malawi suggests that many of the SSNs are not effective, although it is not unlikely to assume that the situation would be worse without the current programs. There have also been found gendered differences in access to support. For example, in Uganda, research on gendered differences to support for PLHIV found that male households had better access to government SSNs, and women appear to have better access to community social networks and NGOs (Kanyamurwa & Ampek 2007).

NGOs have a large and increasingly important role in development work around the world and has the potential to play a positive role in individuals and the households' ability to cope with HIV (Werker & Ahmed 2008). Support groups for WLHIV, which are often run by NGOs, offer

a supportive environment and have found to decrease isolation and feelings of shame, increase networks, create mutually empathetic relationships, improve self-care behaviors, and decrease risk behavior of re-exposure to HIV (Paudel & Baral 2015). Despite the potential of NGOs in alleviating the challenges faced by PLHIV, there is widespread criticism surrounding the role of NGOs in development work. While this critique has many factors and is a complex issue - here I focus on the role of NGOs in sustaining inequalities and poor targeting of beneficiaries. Swidler & Watkins (2009) critique the role of NGOs in implementing HIV policies and programs, arguing “that projects for community mobilization frequently fail to achieve their goals and that resources are sometimes diverted from their intended beneficiaries” (p. 10). The authors also raised issues relating to project length, and how projects can be cut off abruptly when funding ends with negative consequences for those that are meant to benefit (Swidler & Watkins 2009). Moreover, NGOs have also attracted growing criticism for being unrepresentative of and unaccountable to the vulnerable people that they are meant to help (Bebbington 2004; Werker & Ahmed 2008). Bebbington (2004) argues that the strategies used by NGOs do not respond to the structural and economic dynamics of people's livelihoods and they do little to address the underlying processes of development that produce poverty and inequalities (Bebbington 2004).

## **5. Research design**

This chapter reviews and outlines the research approach. To begin, a review of the overall study design is presented, followed by a description of the study area. Then, the process of selecting informants is reviewed. In the remainder of the chapter, each subsection explains and discusses a fundamental procedure of methodology: data collection, data analysis, limitations, and ethical considerations. The main focus of the chapter is the data collection methods employed during the fieldwork in Malawi.

### **5.2. Study design**

As mentioned in the introduction, this thesis aims to generate a broad and comprehensive understanding of the consequences of HIV on food systems for small-scale female farmers in Malawi, therefore, a mixed-methods approach is employed. Primary data collection involved semi-structured interviews, focus group discussions and key informant interviews. The Malawi Fourth Integrated Household Assessment 2016/2017 (IHS4) was used for statistical analysis.

More specifically, the study design follows an exploratory sequential design, defined by Creswell, Clark and Garreth (2008) as a study “that begins by exploring the topic with qualitative methods and then builds to a second quantitative phase where the initial results may be tested or generalized” (p. 69). First, a qualitative study was used to explore the perceptions, feelings and experiences of WLHIV, followed by a quantitative phase, employing statistical methods. The quantitative phase provides supplementary and additional information and explores further some of the findings from the qualitative phase of the study. The rationale for mixing methods is grounded in the fact that neither methods are sufficient, by themselves, to capture the complexity of a multifaceted phenomenon such as health and food systems (Bryman 2016). In combination, quantitative and qualitative methods complement each other, which allows for a more robust analysis that takes advantage of the strengths of each strategy (Bryman 2016).

Qualitative research is preferable when the researcher aims to understand the subjective experiences, attitudes, meanings and perspectives of a phenomenon from a small group of individuals (Brockington & Sullivan 2003). Qualitative research also has the potential to give a voice to minorities and groups in society, which may not be heard elsewhere (McGrath, Palmgren & Liljedahl 2019). In contrast, quantitative research is strong at describing the ‘what’, but weak at explaining the why, it is good to gain a broad picture of patterns, predicting what will happen, the magnitude of changes and the relationship between variables and can be generalized to a wider population, but not why these things occur (Overton & van Diermen 2003). However, numbers cannot tell the full story and the experiences of those who it represents. Statistical analysis alone rarely takes on the system of meanings that qualitative methodologies seek to uncover (Brockington & Sullivan 2003). Therefore, when combined in a mixed-method approach one can understand the ‘what’ and the ‘why.’ A further motivation behind mixed-methods relates to complementarity and triangulation (Bryman 2016).

## **5.2. Study setting**

The research was carried out in Mzimba district and Nkhata Bay district in the northern region of Malawi during October and November 2019. Malawi was selected as a study country because it has a high prevalence of HIV and food insecurity and a substantial part of the population rely on the food system for their livelihoods. Sampling from two districts allows for a wider diversity



and representativeness to be included in the study. The data was collected from one EPA in each of the districts (Manyamula EPA in Mzimba and Nkhata Bay EPA in Nkhata Bay). The study site was chosen in collaboration with the Development Fund based on the following criteria: project site for Development Fund, an agricultural district and a district with a high HIV burden. Combined the districts have a population of 500 630. The livelihood strategies for women in the districts revolve around agriculture. Around 90% of households in these two districts are involved in agriculture, mainly subsistence agriculture<sup>6</sup> (NSO 2017). Around 40% of households are engaged in intercropping with primarily two crop species and the other 60% use monocropping (NSO 2017). The main crops grown include maize, pigeon peas, groundnuts, beans, soya beans, rice and tobacco. These crops are grown on small parcels of land (average 0.45 and 0.95 ha in Nkhata Bay and Mzimba, respectively) (NSO 2017). Official HIV prevalence rates are difficult to obtain, but the GoM estimates that about 17% of residents residing in Northern Malawi have HIV/AIDS. Food insecurity is high throughout the Northern region, with 58% of individuals reporting low levels of food security (NSO 2017). All study participants were accessing care at a public health clinic and were, in theory, part of a farmer-to-farmer lead extension program. The women had access to a primary health clinic, which offers counselling and ART, free of charge.

### **5.3. Sampling**

Purposeful sampling was carried out for the qualitative interviews, which means that selection is done based on certain criteria that are relevant to the study rather than random sampling or sampling based on convenience (Maxwell 2013). According to Maxwell (2013), purposeful sampling is a strategy whereby “particular settings, persons, or activities are selected deliberately to provide information that is particularly relevant to your questions and goals, and that can’t be gotten as well from other choices (p. 97).” Purposeful sampling was useful because it ensured a certain degree of representativeness, made it possible to select informants who could provide key information and enabled me to capture the heterogeneity within the sample (Maxwell 2013). In qualitative research, it is often more useful to carry out purposeful sampling rather than probability sampling as it allows for especially important members of the target population to be included in the sample (Maxwell 2013). According to Patton (1990 as cited in Masuku & Sithole

<sup>6</sup> Farming that involves production primarily for the needs of the farmers and his/her household

2009, p.207) “the power of purposive sampling lies in selecting cases with rich information for the study, such cases provide a great deal of insight into the issues of central importance to the research study”. Purposive sampling involves the researcher’s subjective judgement and allows for certain criteria and characteristics to be included in the study, thus increasing validity and reliable representation of the data (Bryman 2016).

Access to the participants was facilitated by a local extension worker and the translator.

Selection of the female farmers that participated in the semi-structured interviews and focus groups was based on the following criteria:

- Female household heads in their productive working-age 18-59 diagnosed with HIV (in stages before progression to AIDS)
- Main source of income from the agriculture
- Women of different ages with varying farm size, income level, and household size
- Women who are adhering to anti-retroviral therapy

Key informants were purposively selected, so their experience, point of view and knowledge could enhance the understanding of the research topic. The selected individuals were, directly and indirectly, involved with HIV treatment and care in the community. The key informants consisted of extension workers, lead farmers, traditional authority and community healthcare workers. Furthermore, purposive snowball sampling strategies played an important role in the sampling process. Initial interviewees directed me to more individuals who were relevant to the research. It is important to note that due to the sampling strategy used in the qualitative phase of the research, the findings are not generalizable to a wider population than the one being studied here. However, qualitative research aims to gain insight into complex social phenomena from a range of different perspectives and not generalizability (Bryman 2016). However, as most themes reached saturation, this indicates that the interview number were sufficient to draw conclusions from the sample (Bryman 2016).

## **5.4.Data collection**

### **5.4.1. Qualitative data**

Qualitative methods for data collection often rely on conducting interviews, which have the “purpose of obtaining descriptions of the life world of the interviewee in order to interpret the meaning of the described phenomena” (Brinkmann & Kvale 2015, p.6). Primary data was collected using a series of interview methods: semi-structured interviews, focus groups and key informant interviews. The use of several data collection methods was motivated by triangulation and to gain a deeper insight into the phenomenon from a diversity of viewpoints. Triangulation improves the validity and reliability of the research conducted, ensuring that the researchers’ interpretation of the data is valid (Bryman 2016). The researcher can cross-check the findings from the other methods to validate the findings and fill any data gaps, thus enabling “a better, more substantive picture of reality” (Berg & Lune 2012, p. 6). Although, many of the questions asked during the research involved the personal opinions and experience of respondents, which is difficult to triangulate. I conducted a total of 61 qualitative interviews in the field: 46 semi-structured interviews, seven focus groups and eight key informant interviews.

The purpose of a semi-structured interview is to obtain rich, in-depth and detailed answers on a certain topic. They give insights into what the interviewee thinks is important and provides an understanding of what she emphasizes within the research topic (Brinkmann 2018). The semi-structured style was considered most appropriate here as it ensures flexibility, while still allowing for the interviewer to guide the focus and obtain the relevant data (Bryman 2016). Such interviews are useful in knowledge production as they allow for leeway in terms of sliding off track or going back and forth between the topics and between topics that are perceived as important by both parties (Brinkmann 2018). The interviews lasted on average 40 minutes.

During the interviews, there were several interesting findings that I wanted to explore further, so I decided to carry out a series of focus group discussions with the same women to discuss these topics. I carried out seven focus groups with groups of three to seven participants. The focus groups lasted on average 70 minutes. Focus groups do not offer the same depth of information as an individual interview, however, focus groups are a good approach for investigating personal and group motivations, behaviors, attitudes and opinions regarding a specific topic (Berg & Lune

2012). Second, through interaction between participants, focus groups can be helpful to gain insight into how meaning is jointly constructed and to gather information on a variety of viewpoints (Bryman 2016). Finally, focus groups allow for the respondents perspectives to be revealed in a way that is different from individual interviews as it allows for discussion, participant questions and arguments (Bryman 2016).

The key informant interviews lasted on average 30 minutes. These interviews provided valuable insight into the research topic from a different perspective compared to the other interviews (Bryman 2016). I would have liked to interview more key informants, but given structural constraints, I was unable. For example, in Nkhata Bay, the FISP distribution program was happening at the time of the fieldwork and my contact person had limited time to arrange meetings. Also, traveling long distances to speak to some key informants was limited due to a lack of finances. There are likely other key persons whose insights would have been beneficial to the research, such as representatives from NGOs, government officials and academics.

Throughout my fieldwork, I also held several unstructured conversations (i.e., not planned interactions) in informal settings. As Maxwell (2013, p.88) points out, “hanging out, casual conversations, and incidental observations” are just as important as formal interviews in data collection. When a setting is informal, it can be easier to gain information as these types of conversations allow for spontaneity and naturalism (Bryman 2016). These interactions provided valuable insights into the culture of Malawi and helped to gain a deeper understanding of the research topic.

Three different interview guides were made, one for each of the data collection methods (Appendix 1). The questions were designed to capture the experiences of the WLHIV who rely on agriculture as their source of food security and income, their experiences with support services and their coping strategies. The interview guide for the focus groups was developed based on initial findings from the semi-structured interviews. A question guide strengthens the reliability and provides comparable data (Bryman 2016). The guide for the key informant interview was adjusted according to the role of the interviewee. The interview guide was pre-tested on two participants prior to data collection to assess language, content and clarity and revised accordingly by removing some questions and rephrasing others.

All interviews were conducted with informed consent. Effort was made to ensure that all interviews were carried out privately with no distractions or interruptions. Prior to starting each interview, the aims, procedures of data collection and confidentiality were explained (explained more in section 5.6.). The interviews were carried out with an interpreter and were recorded; however, some did not feel comfortable with recording. Extensive notes were taken during the interviews to assist transcription, which allowed for emerging categories and themes to be established during the data collection process. For the less structured conversations and other observations, I made time in the evening to write a summary of the information I had collected, any thoughts and ideas for the analysis.

#### **5.4.2. Quantitative data**

The quantitative analysis relies on data from the 2016/2017 Fourth Integrated Household Survey (IHS4), carried out by the National Statistical Office in Malawi (NSO 2017). Using a secondary data set has several benefits, according to Bryman (2016): it saves costs and times, the data is usually of high quality, large sample sizes yielding nationally representative results. The dataset was downloaded with permission from the World Bank Microdata Library. IHS4 is a nationally representative household survey that includes data on household characteristics, health, welfare and food security. The unit of analysis is the household. The IHS4 covers a total of 12,480 households across all districts in Malawi, sampled using a stratified two-stage sample design (NSO 2017). Households in rural districts where the female head is affected by HIV/AIDS and is involved in agriculture were included in the final sample.

### **5.5. Data Analysis**

#### **5.5.1. Content analysis**

The interviews were transcribed, and conventional content analysis was used to analyze the data, which involves coding of categories derived from the raw data (Berg & Lune 2012). Content analysis allows for “a careful, detailed, systematic examination and interpretation of a particular body of material in an effort to identify patterns, themes, biases and meanings” (Berg & Lune 2012, p.349-350). The analysis was conducted manually by using hand-coding, rather than relying on computer software. Codes were developed both inductively and deductively. An

inductive approach means that codes, categories and themes are drawn directly from the data, whereas in the deductive approach codes, categories and themes are based on existing theory (Bryman 2016). Most categories and themes were based on the analytical framework (fig. 2), but some were developed inductively to account for any themes that arose during the coding.

The first stage of content analysis involved open coding, where each line of data was attached with as many codes as relevant (using color-coding). Related codes were grouped and then sorted into different categories to identify similar phrases, patterns, relationships, commonalities and disparities. Categories were subsequently grouped together to form themes. To assess each theme's prominence, I also analyzed theme frequency and the number of participants who articulated a particular theme. During the coding process, I looked for repetitions, metaphors and analogies, linguistic connectors, similarities and differences and theory-related material as recommended by Ryan and Bernard (2003 as cited in Bryman 2016) Quotations were included in the results section based on their ability to capture the emergent themes.

### **5.5.2. Statistical analysis**

SPSS was used to transform and analyze the quantitative data. Descriptive and inferential statistics were performed to show associations between HIV and food security and several independent variables of interest. The type of variables included determined the choice of analysis. Descriptive statistics were calculated and included frequencies and percentages for categorical data and means and standards deviations (SDs) (for continuous variables). To test for differences in HIV-affected and non-HIV affected households regarding food security, food consumption groups, access to SSP, FISP and extension services, Pearson's chi-squared tests were used for categorical variables and Independent Samples t-test for continuous variables. To further investigate the effects of HIV status on food security, multiple linear regression using ordinary least squares was performed, controlling for several explanatory factors (explained below). Tests were also carried out to assure that the relevant statistical assumptions were met, e.g. in relation to, for example, a normal distribution, heteroscedastic, linearity, multicollinearity. Statistical significance was set at  $\alpha=0.5$  for all statistical tests.

### *Variables and measurements*

The key variables included are defined and measured as follows:

**Food security.** Food security will be measured using the following indicators (1) the number of meals per day, (2) food consumption score (FCS) and (3) reduced Coping Strategies Index (rCSI). Using several indicators gives a broader understanding of food security as the indicators measure different but equally important aspects of being food insecure, each with its own strengths and weaknesses. The number of meals per day is measured using a variable corresponding to the question: “how many meals, including breakfast are taken per day in your household?”. The FCS variable was calculated using the household’s frequency of consumption of different food in a seven-day reference period, with each food group having a different weighting reflecting its nutrient density. The household score can have a maximum value of 122, which means that each of the food groups was consumed every day for the last seven days. The household's food consumption status is based on the following thresholds: 0-21: Poor; 21.5-35: Borderline; >35: Acceptable (WFP 2008). The rCSI, a simple numeric value, indirectly captures food security, by measuring behaviors related to a shortfall in food consumption. The higher the sum, the lower the food security. The rCSI is a reduced version of the Coping Strategies Index, which counts the frequency and severity of coping behaviors that households adopt during food shortages (Maxwell & Caldwell 2008). The behaviors include limiting portion size at mealtimes, reducing the number of meals eaten per day, borrowing food or relying on help from relatives or friends, relying on less expensive food and restricting the consumption of food by an adult for a child. The respondents were asked to recall the number of days in the past seven days were they had to resort to one or more of the abovementioned strategies. Each strategy is given a different weighting. The indicators used here measure food security at the household level and have been previously validated. When using these types of indicators there could be limitations associated with retrospective memory, as respondents may not accurately recall information on food consumption.

**Farm Input Subsidy Program.** Access to farm inputs through FISP was measured as a dummy variable corresponding to the question, “Did you or anyone in your HH obtain any input coupons during the rainy season?” The variable captures the contribution of input subsidies to food security. The number of coupons received was also included as an explanatory variable.

**Access to extension services.** Access to agricultural extension and advisory services was measured here as a dummy variable corresponding to the question, “Did you or anyone in your household receive any advice on agricultural advice in the past 12 months?” The variable captures the contribution of extension services to food security. The number of inputs the household received advice was used as an explanatory variable.

**Social Security Nets.** Access to social security is measured here as a dummy variable, corresponding to the questions: “In the last 12 months, has any member of your household received cash, food, or other aid from any of the following programs?” SSNs that relate to income generation, cash transfer and food aid were included in the study: MASAF (public works program), free maize, free food, work for cash/food programs and social cash transfer for GoM or other sources (e.g. NGOs, development partners). SSNs related to education bursaries and school feeding are not included here. Although, FISP is also considered an SSN, here it is included as a separate variable as it is the largest of the programs in Malawi and is important in terms of the food system.

**Explanatory factors.** Explanatory factors are characteristics of the sample that are included that could potentially explain the differences seen in the dependent variable. Informed by the available literature, the following explanatory factors were included in the regression modeling: HIV status (positive/negative), age, education of female household head (measured as PSLC, JCE, MSCE<sup>7</sup> and higher education), marital status (married, widow, separated/divorced, never married, coded as a dummy variable with married as reference category) household size, livestock ownership (yes/no), land<sup>8</sup> and garden size<sup>9</sup>, use of organic and inorganic fertilizer (yes/no) and distance to nearest Agricultural Development and Marketing (ADMARC) outlet<sup>10</sup>,

<sup>7</sup> PLSC – Primary School Leaving Certificate; JCE – Junior Certificate of Education; MSCE – Malawi School Certificate of Education

<sup>8</sup> Defined as a continuous piece of land that is not split by a river or path wide enough to fit an ox-cart or vehicle (NSO 2017)

<sup>9</sup> Defined as a continuous piece of land on which a unique crop or a mixture of crops is grown, under a uniform, consistent, crop management system.

<sup>10</sup> ADMARC, through its markets, buys agricultural produce from traders and smallholder farmers.



agricultural market and nearest paved road (measured in km). The distance to the nearest place where food can be sold or bought as an indicator of market access. Wealth was measured using an asset index, which was created based on the ownership of select durable goods (e.g. bed, table, radio, tv, bicycle, motorbike) (yes/no). The number of goods owned were summed into one composite variable. The wealth index can have a maximum value of 14, implying that the household owned each of the goods included. Livestock ownership is also an indication of wealth.

## **5.6. Ethical considerations, challenges and limitations**

As with all research, this study has several limitations and ethical considerations to consider. As qualitative research relies on the researcher's judgement, it is more difficult to avoid biases, understood here "as any systematic error in the design, conduct or analysis of a study" (Althubaiti 2016, p.211). The majority of what is discussed below relates to the primary data collection.

### **5.6.1. Ethical considerations**

The right of the respondents requires particular consideration when carrying out research that involves people. Fieldwork in developing countries with vulnerable groups "can give rise to a plethora of ethical dilemmas, "many of which relate to power gradients between the researcher and the respondents" (Scheyvens, Noway & Scheyvens 2003, p.139). According to Bryman (2016), the following ethical principles should be considered when the research involves human subjects: whether there will be harm to participants, whether informants participate under informed consent, whether informants' privacy is assured, and whether deception is involved. I did my best to ensure the participants' dignity, privacy, safety and acted in a sensitive and respectful manner (Scheyvens, Noway & Scheyvens 2003). Several of the women expressed gratitude that we were there, and that being able to discuss their experiences and feelings was said to be beneficial by several of the women. The welfare of the participants takes precedence and during any interviews in which the participants appeared uncomfortable, we (myself and the translator) addressed this and reminded the respondent that they are free to stop the interview at any time. I also tried to be very careful not to give any false impressions or hopes to the respondent, making informants believe that I'm able to change anything about their situation.

Informed consent means that the informant is given the necessary information to “make an informed decision about whether or not they wish to participate in a study” (Bryman 2016, p.691). The participant should be informed about any risks or benefits from participation and should be fully informed about the background, procedures and purposes of the study (Brinkmann & Kvale 2015). Due to the context in which the research was carried out, written consent was deemed inappropriate, and therefore verbal consent was obtained. Verbal consent was documented on tape recordings in the local language, except in situations where the women did not want to be recorded. The participants were thoroughly informed of the research aims and how the data will be handled and stored. The translator repeatedly emphasized that participation was voluntary and that the same support services would be provided irrespective of participation. The participants were also provided with the ability to ask questions at any point and were informed about their right to withdraw from the study at any time or not to respond to questions. Another concern relates to anonymity and confidentiality. Anonymity can only be guaranteed where the researcher has no knowledge of the identity of the participants and is therefore not possible in this type of qualitative work (Banks & Scheyvens 2003). Therefore, pseudonyms will be used when analyzing the data to ensure participants' confidentiality.

### **5.6.2. Reflexivity, reactivity and researcher bias**

There are three important considerations in social science research that deals with the role of the researcher. These biases can threaten the validity of the findings, defined as “the correctness or credibility of a description, conclusion, explanation, interpretation, or other sort of account” (Maxwell 2013, p.122). Although it is impossible to completely eliminate our own beliefs and perceptions, it is important to be aware of them and be open to possible biases caused by these factors, as part of one’s research integrity.

First, it is important to be aware of the researcher’s reflexivity, which refers to “a researcher’s ongoing critique and critical reflection of his or her own biases and assumptions and how these have influenced all stages of the research process” (Mills, Durepos & Wiebe 2010, p.788). This entails sensitivity to the researchers’ cultural, political and social context and can be considered a process of becoming self-aware (Bryman 2016). Another consideration relates to reactivity, which is a term used to describe a situation that occurs when individuals alter their performance

or behavior due to the awareness that they are being observed (Bryman 2016). Reactivity can result in untypical behavior and is considered a threat to the external validity of the research (Bryman 2016). Such reactivity may result in, for example, the participants deliberately telling the researcher what he or she thinks the researcher wants to hear or the informant exaggerating certain aspects of the topics he or she is asked about, or the researcher's position unconsciously affecting the informants' answers (McKechnie 2008). The interviewee may change their responses based on the interviewer's reaction to the answer. For example, a smile, a nod in agreement, or a frown, may alter how the participant chooses to respond to subsequent questions (Lavrakas 2008).

In addition, there is a risk that due to my affiliation with the Development Fund of Norway (DF) and its partner in the field, Find Your Feet (FYF), the participants may give answers they believe the DF wants to hear or would be beneficial to their relationship with the organizations. The expectation of continued or more support from FYF could also contribute to bias. The interpreters I used during the interviews worked for FYF and could have influenced the women's responses. The presence of someone the participants were familiar with may also give the participants a sense of security and facilitate development of rapport. Moreover, characteristics of the researcher (e.g. ethnicity, age, gender, social background) that differ substantially from that of the participants are likely to cause more reactivity (McKechnie 2008). Therefore, in this research it is not unlikely that some of the informants adjusted their answers based on my presence. Triangulation, which is already discussed in section 5.4.1, can help to prevent reactivity. So can respondent validation, or "member checks," which means "systematically soliciting feedback about your data and conclusions from the people you are studying" (Maxwell 2013, p.126). However, this was not possible in this case due to time and financial constraints. The data would have to be translated back to the local language which would be costly, and as most of the analysis was done after returning from the field, it would be difficult to verify the data without access to the participants.

Finally, it is important to consider the possibility of researcher bias. Maxwell (2013) defines researcher bias as "the selection of data that fit the researcher's existing theory, goals, or preconceptions, and the selection of data that "stand out" to the researcher (p. 124)." I made a

conscious effort to try to avoid researcher bias by keeping an open mind. Since many of my reported findings and conclusions differ from the assumptions I had when I started, based on existing theory, indicating that I was able to explore other theories and avoid assumptions. Moreover, I made sure to have detailed and rich data, which eliminates the possibility of bias and misinterpretation, according to Maxwell (2013).

### **5.6.3. Response bias**

The abovementioned factors relate to my role as a researcher, here I discuss two forms of biases related to the participant's responses that could have distorted the data - social desirability bias and recall bias. Response bias is a wide term used to describe a situation in which participants respond inaccurately or falsely to questions, common in interviews (Furnham 1986). These types of biases also threaten the validity of the findings. It is important to be aware of these biases and the effects that they may have on the research to prevent any negative impacts on the research findings.

Social desirability bias has been defined as “a distortion of data that is caused by participants responding to data collection exercises in terms of socially desirable traits so that their account conforms to their perception of socially acceptable beliefs or behaviors” (Bryman 2016, p.695). This is a common issue when the study involves sensitive issues, such as HIV (Grimm 2010). For example, participants may not want to openly share unfavorable coping strategies that are frowned upon in some cultures (e.g. begging or transactional sex). In a face-to-face interview setting there is a heightened risk of social desirability bias (Bryman 2016). This is a difficult factor to control for when conducting interviews, but we (myself and the interpreter) tried to minimize this risk by establishing rapport with the respondents, while still maintaining distance - not being too friendly, and also not being judgmental of their responses, as advised by Bryman (2016). We aimed to build rapport by establishing comfortable interactions, approaching the participants in a friendly, open and curious manner and explained why we were interested in their specific point of view, as recommended by McGrath, Palmgren and Liljedahl (2019).

When research is dependent on the participant's ability to recall past events, there is a chance that this can be remembered incorrectly. In this case, the bias is often referred to as recall bias

and is the result of recall error (Althubaiti 2016). This is most common in health-related case-control designs and retrospective cohort study designs when asking about routine or frequent events (Althubaiti 2016). However, there is a chance that this type of bias happened here since the time since diagnosis was high for some of the women there is a chance that these women do not accurately recall the true effect of HIV. Ideally, it would have been beneficial to include participants who were diagnosed a certain number of years ago to reduce the recall period (Althubaiti 2016). However, finding participants that fit this criterion and who were willing to participate was challenging.

#### **5.6.4. Interpretation**

Language is perhaps the biggest and most significant barrier as I lack knowledge of local languages. The language barrier was mediated through the use of a qualified interpreter. Different interpreters were used in Nkhata Bay and Mzimba. The interpreters also functioned as valuable informants and research assistants, helping to interpret the interviews correctly, to build rapport with the participants, and helped in accessing participants, information and logistics. He also helped clarify anything that could be confusing or misleading to someone from a different background.

Using an interpreter has its own benefits and challenges. Using an interpreter gives the researcher an ability to understand and take notes during interviews, but has the disadvantage of receiving information second-hand, the possibility of information being lost or being misrepresented or that the initial meaning expressed by the participants is reframed. It also creates a significant distance between the interviewer and the interviewee and gives less flexibility and spontaneity compared to direct interviewing (Leslie & Storey 2003). Burja (2006) argues that interpreters are not merely translating what is being said but are “participant intermediaries making judgements which many transform the message received” (p.175). Interpreters may also filter out what they regard as less important, or place emphasis on particular elements in their translations. Furthermore, many concepts, words and ideas are not possible to translate from one language to another (Burja 2006).

To address, and hopefully avoid, some of the problems associated with interpreting I followed the advice of McLennan, Storey and Leslie (2003) who state that it is important to communicate carefully and clearly with the interpreter, ensuring they understand the research objectives and the reasons behind asking the particular questions. The interpreters I used had prior experience with interpretation work, and I continuously highlighted the importance of translating as much detail as possible instead of short summaries. Although I was given no reason to assume the data was affected by interpretation problems, I cannot rule out the possibility of bias due to interpretation.

### **5.6.5. Other challenges**

One of the hurdles in collecting information was to find enough women affected by HIV/AIDS that were willing to be interviewed, as it is a sensitive topic. Turner (2010) highlights the importance of acquiring participants who “will be willing to openly and honestly share information of their story (p. 757).” Stigma attached to being HIV-positive is high and people often feel reluctant to talk about it or share their experiences. I was told by key informants that young women are more likely not to disclose their status in the community, and therefore, the mean age is slightly skewed towards “older women.” This brings me to the next limitation, the fact that many women are not open about their status means that the sample is only representative for those women who chose to be open about their status and seek help from healthcare clinics. The situation could be very different for those who chose not to disclose their status, particularly in terms of access to ART, counseling and other support services. Thus, introducing a sampling bias, as these members of the population have no chance of being selected for inclusion in the sample (Bryman 2016).

## **6. Findings**

This chapter will present the findings from the interviews with the women and the key informants, supplemented and supported by statistical analysis, were appropriate. The framework in figure 2 is used to guide the analysis. The findings will be presented such that the effects on food system activities are presented first, followed by the coping strategies employed by WLHIV. The impacts on food security and income are presented throughout with a summary towards the end. The data is supported with quotes and life stories, using pseudonyms, to demonstrate typical examples of the effects of HIV on the food system. I use a few graphs to

support the qualitative findings to illustrate the occurrence of different themes and categories established from the analysis. I recognize that there is a debate regarding the use of numbers and quantitative presentation in qualitative research (Maxwell 2010). However, as argued by Maxwell (2010), the use of numbers is a “legitimate and valuable strategy for qualitative researchers when it is used as a complement to an overall process orientation to the research” (p. 480). Incorporating numbers in qualitative research has several benefits: (1) simple counts can make statements such as “some,” “usually,” and “most” more precise; (2) providing numerical data about the number of respondents who report a particular experience or statement provides valuable information on if the themes identified are a characteristic of the whole study sample or just a few (Maxwell 2010). Any differences in the two study sites, Mzimba and Nkhata Bay, are mentioned throughout the section. No generalization can be made from the qualitative data since the research sites and participants were purposively selected.

### **6.1. Participant characteristics**

The findings are introduced with a presentation of demographic and background information on the respondents that make up the qualitative sample and the quantitative sample. Regarding the primary data that constitutes the qualitative part of the study, the mean age of the 46 participants was 44,4. The majority of the women were widowed (44%) or married (44%) while the rest were divorced or not yet married. Even though the women were married several of the women reported that their husband had migrated to South Africa for work. All of the women reported having children; the average household size was 5,9. Participant’s range of awareness of their HIV status ranged from one year to 19 years (average 9,5 years ago). All participants were on ART and were, in theory, part of a farmer led extension program. The farmers interviewed were primarily subsistence farmers, supplementing their diet with purchasing food they did not grow themselves if money allowed. A few women sold crops such as tomatoes, onions and groundnuts and a few women were involved in casual labor and small-scale businesses.

The characteristics of the quantitative sample, which is based on data from the IHS4, are presented in table 1. Regardless of HIV status, the majority of the participants have no education, owned few assets and are widowed or separated/divorced. However, there are some differences between HIV-positive women and HIV-negative women. HIV-positive women have less land,

livestock and assets. HIV-positive women have a higher percentage of widowed women and lower levels of education. HIV-positive women use more inorganic fertilizer. Although some of these differences are not substantial.



**Table 1.** Descriptive statistics of key demographic and socioeconomic indicators of the secondary data sample.

	<b>Total sample</b> (N=2952)	<b>HIV-positive</b> (N=189)	<b>HIV-negative</b> (N=2763)
	<b>Percentage or mean (SD)</b>	<b>Percentage or mean (SD)</b>	<b>Percentage or mean (SD)</b>
<b>Age</b>	48.49 (17.75)	45.6 (10.83)	48.69 (18.11)
<b>Marital status</b>			
Married	19	11	19
Widow	42	50	41
Divorced/separated	38	37	38
Never married	2	2	2
Total	100	100	100
<b>Education*</b>			
None	53	60	53
PSLC	8	8	8
JCE	5	5	5
MSCE	1	0	1
Higher	1	0	1
Total	77	77	77
<b>Land size</b>	0.88 (.80)	.73 (.43)	.88 (.82)
<b>Garden size</b>	1.28 (1.28)	1.09 (.70)	1.29 (1.3)
<b>Household size</b>	3.8 (1.85)	3.78 (1.72)	3.80 (1.86)
<b>Asset index</b>	1.84 (1.82)	1.56 (1.59)	1.86 (1.83)
<b>Ownership of livestock</b>	34.9	28.6	35.4
Cattle and oxen	2	1.1	2.1
Sheep, pigs, goats	17.4	12.2	17.8
Poultry	22.5	20.1	22.7
<b>Fertilizer use</b>			
Organic	19.7	25.4	19.3
Inorganic	50.6	59.8	49.9

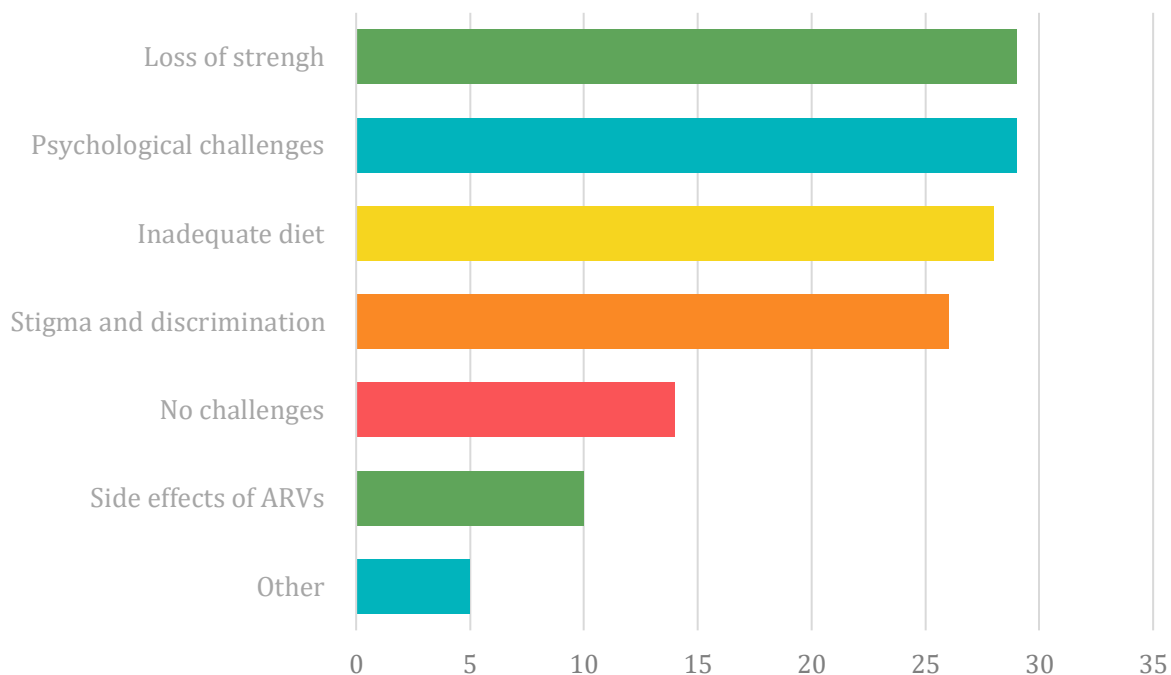
*\*Data missing for 23% of the sample*

*Raw data source: Malawi Integrated Household Survey 2016/2017*

## 6.2.Challenges

The interviews started with a question regarding what the women perceive to be the challenges of being HIV-positive when working as a farmer. Understanding these challenges will assist in understanding how HIV is affecting the food system. The women were asked to specifically focus on those challenges that had come in as a result of the diagnosis or pre-existing challenges that were made worse as a result of HIV. This was done to distinguish between challenges they are facing as a result of the HIV diagnosis and not challenges they face due to living in a setting with high levels of poverty. However, it is important to recognize that the respondents reported a range of equally challenging issues that co-exist with HIV infection, including migration of husbands and children to urban cities or neighboring countries (especially to South Africa), the introduction of market vendors into the community, poverty, death of a husband and lack of inputs (e.g. seeds and fertilizer).

The findings show that a large portion of WLHIV experience added challenges as a result of HIV, as illustrated in figure 3. The challenges that the women are facing are categorized around the following themes: (1) poor quality diets (2) weakness and loss of strength, (3) side-effects of ART, (4) discrimination (5) psychological challenges (6) others and (7) no challenges. The women experienced either one of these challenges or a combination of two or more. There is a large diversity in the experiences of WLHIV and some are struggling and experiencing more challenges than others. Without being able to say anything about causality, the findings show a pattern of which those who have received external support through cash transfers or coupons through FISP once or more, or engage in off-farm labor are those who more commonly stated that they did not experience any added challenges following the diagnosis. Moreover, some interviewees attribute their lack of challenges to the ART, which gives them the strength to “continue like before.” It is not possible to attribute any of these above-mentioned factors to why some women are not experiencing any challenges specifically related to HIV, while for others it has led to dramatic negative changes in their lives. This would require further research.



**Figure 3:** The occurrence of challenges experienced by women living with HIV.

*Source: Author*

### 6.2.1. Poor quality diet

A large majority of the participants felt that their diet was limited in terms of nutritional value. While this was a challenge before HIV, an inadequate diet become increasingly challenging in the context of HIV, considering the importance of adequate nutrition to fight the infection. The women explained that their diet is “simple” and “insufficient” to “be strong” and to “provide energy to fight the infection” and to provide “strength for work.” The key informants consistently agreed that the majority of WLHIV are food insecure, which is challenging when trying to stay healthy when living with an infection like HIV.

### 6.2.2. Loss of strength

Loss of strength or weakness emerged as a noticeable theme across a majority of the discussions. The women experienced that they more often feel ill and that their bodies were weaker compared to before, despite strictly adhering to ART. As a result, the farmers could not go to the farm as before: “because my body has been weakened, I am failing to do much work. This translates into low production because time and time again I am found sick.” Another woman said: “I often feel like my heart burns, and I also feel like my left leg and hand is paralyzed, which affects my

performance at the farm. When I am faced with this, I don't go to the farm." The health surveillance officers (HSA) also reported that in their meetings with the WLHIV, they often experienced that women would 'complain' about lack of strength.

### **6.2.3. Side-effects of anti-retroviral therapy**

The participants reported several side-effects of ART. Some women said that these side-effects affected their ability to farm but more so gave them an increased appetite and an increased feeling of hunger: "the problem is that we don't take any food [with the ARVs] when we are going to farm, which makes us feel bad and we cannot work like before." Another woman expressed that "when we take the ART in the morning and farm without having food, we are not able to farm like in the past." Taking the ART without food also worsened some of the other side-effects: "when I take the ARVs without food – I feel dizzy and pain in the stomach." The following excerpt explains the need for good nutrition to counter the side-effects of the ART and to stay healthy, which one woman expressed was difficult against a backdrop of high poverty levels:

Participant: "Because of high poverty levels in the village it is not easy to have breakfast, and we were told by the medical personal to not take the ARVs without having breakfast."

Interviewer: "Does not having breakfast have any effect on your body?"

Participant: "When I take the ARVs, I feel like I will vomit, my heart is beating fast, I do not get the strength I want. I don't feel normal because I don't have food to support the drug. The ART depends on food for me to be strong."

The following words and quotes were used to describe some of the other side-effects the women experienced: "dizzy," "sleepy," "tired," "vomiting," "skin rashes," "ulcers," "pain in the stomach," "my legs get frozen" and "pain in legs and my head." In one of the focus groups, the women explained that the side-effects often depend on the type of ART the women are on, so therefore some women are not experiencing any side-effects. Discussions with key informants also revealed that the ART quality varied, and so do side-effects.

#### **6.2.4. Discrimination**

Experiences of feeling discriminated against were common amongst the women. They felt that discrimination occurred in several settings, particularly in distribution and access to external support such as FISP, food aid, and extension services. Some women said that they felt they were not receiving any support because “they think [referring to actors involved in formal support services] that we are ‘already dead,’ so we are not worth helping.” In the same vein, another woman expressed: “some of the people that are HIV-negative regard HIV-positive people as already dead, they are not seeing us as human beings. So, when there is a chance of support or training, the ones who are supposed to get teachings or support are not the ones getting the support.” In relation to FISP, several women felt that “just because” they were HIV-positive; the village head or extension officers did not put their names on the list of those eligible for fertilizer coupons through FISP.

In terms of food aid, one participant in the focus groups explained her experience, with support from the rest of the group, in the following way: “when food support has come to the community, the ones targeted are those who are HIV-positive, but those who actually receive support are HIV negative. We feel worried, victimized and side-lined.” Several participants expressed that they felt discriminated against in terms of access to EAS: “sometimes when we are ill, we are not being picked into the programs [referring to EAS] that allow us to find fertilizer. I used to participate in agricultural training, but now I feel like I am not being picked anymore just because I am HIV-positive.” One woman also explained that she felt discriminated against in terms of market access: “I feel that when someone knows that there is someone positive in one house, they think that if they go there to buy something then maybe they will get the disease. Since people are not coming to the house [to buy produce], we have reduced income.”

Several of the Nkhata Bay respondents felt discriminated against at the health center, where they were meant to go to get food aid, which was specifically targeted towards PLHIV: “There are many things that are given at the hospital which are meant for those who are HIV-positive, but it is not given to us. Some of the medical personal are taking it home to feed their families or

selling them, for example, peanut butter, cooking oil and soya porridge. These things are being monopolized by the people working in the health sector.”

#### **6.2.5. Psychological challenges**

The majority of the women mentioned psychological issues as a challenge. Several women explained: “they were not at peace,” “had no peace in their life,” and were “more stressed” following their diagnosis. Another woman felt bitter that she has contracted the disease from her husband and blames the marriage for the disease: “if she weren’t married, there would be no disease.” The main reason for worry and stress was due to not being able to eat the diet that is recommended for PLHIV because of limited resources. The following two quotes summarizes the feelings of several of the women: “I worry about my health because we lack the six food groups. I feel that we are prone to many diseases because we lack important nutrients that keep out body strong” and “before I didn’t have much to worry about regarding my health, but now that I am ill, I think about and am concerned about needing the proper food to be strong.” Women’s feelings of worry and distress were also commonly linked with concerns regarding their ability to care for and the well-being of their children, particularly over not having enough food or enough money for school fees: “I don’t have much peace on how to survive, I am worried about the children. I don’t have peace because I don’t have the strength to farm, so I don’t know how to find money to educate the children.”

#### **6.2.6. Other**

Other challenges that were not mentioned as frequently during the discussions was the issue of distance to the health clinic, which made in very time-consuming and exhausting to visit the clinic. The key informants said that this prevented some of the women from collecting their medication and receiving counseling, however, none of the women mentioned this in the interviews or focus group discussion. Discussions with HSAs also revealed that the disease led to much disagreement between husband and wife, a finding which was supported by a few women in the interviews:

“There is not much agreement between the husband and wife, most of the time it is the women who take the first step in terms of medication. The man remains behind and does not take the ARV. Because men to not take much part in fighting for this disease, it is a

major challenge. We can come to teach the household, and the women will want to implement the teachings, but the husband will not want to implement, making it difficult to implement the teachings as a family.”

This quote also highlights the differing roles of women and men in responding to and changing behaviors following HIV diagnosis. The women said that the arguments with their husbands caused added stress to their life.

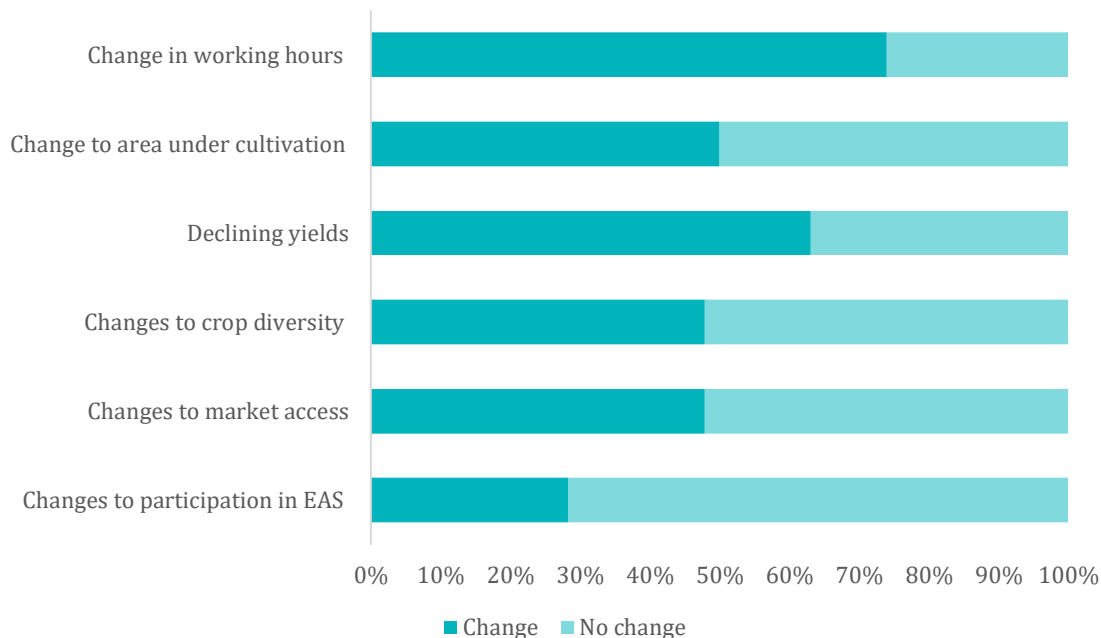
### **6.2.7. No challenges**

It is also important to note that over a quarter of the studied sample reported living a normal life with no dramatic changes or added challenges following the HIV diagnosis. One woman reported: “I live like anybody else, so to me, everything is just okay.” Similarly, another woman stated: “everything is the same, even though I am living with HIV.” While these women are not experiencing any added challenges, the diagnosis has still had effects on the food system, which will be discussed in the following sections.

## **6.3. Food System activities**

### **6.3.1. Effect of HIV on food supply chain**

The impacts of HIV on the food supply chain can be divided into the following categories: (1) changes in working hours and productivity; (2) reduction in the area of land under cultivation; (3) declining yields; (4) changes to crop diversity (5) changes to market access and (6) changes in participation in extension services. The occurrence of each effect is shown in the figure 4. The graph visualizes the occurrence of each category in comparison to the other categories and the sample as a whole. Again, there is a large diversity in experiences amongst the women. I recognize that some of these effects can also be considered coping strategies but are included here to align with the analytical framework.



**Figure 4:** The occurrence of the impacts of HIV on the food supply chain.

*Source: Author*

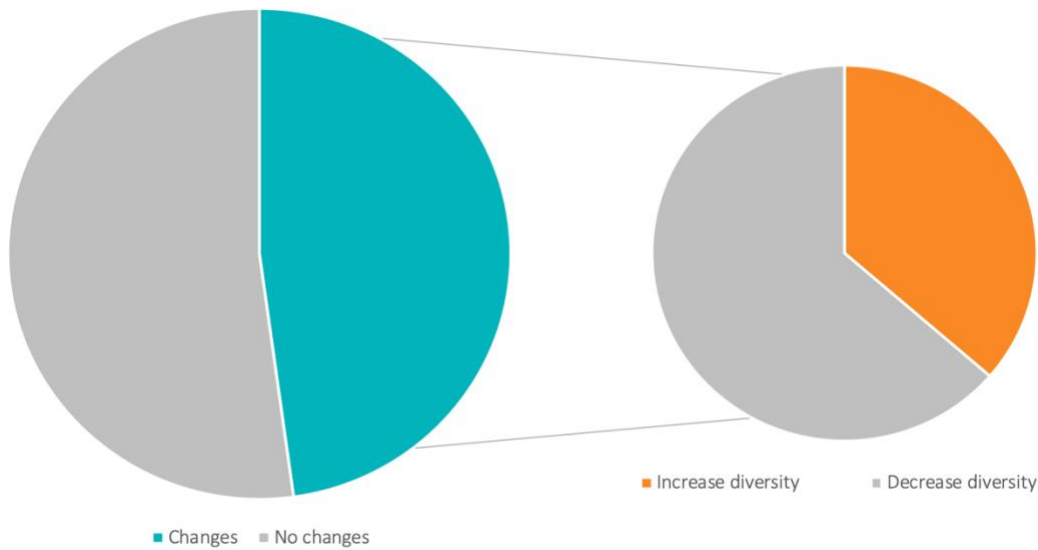
**Changes in working hours and productivity.** The most common effect of HIV was a change in working hours. A reduction in hours spent cultivating was a result of two main factors, either alone or in combination: (1) lack of strength and (2) being told by healthcare workers that they should not work the same amount as before to “keep our bodies strong and healthy.” The respondents stated that healthcare workers in the community advise PLHIV to reduce work hours and not to overexert themselves, even if they are feeling healthy. This HSAs confirmed this. A woman shared the following: “We are advised that we should not overwork and give the body time to rest. This has improved my health, because previously when I was working for a longer period of time, I was often ill, now the body is a bit healthier than before.” Moreover, some of the women expressed that they were not as productive as they used to be: “at first when I didn’t have HIV, I could finish one acre in three days, but now I can finish one acre in seven days.” The impact of changed working hours and productivity varied, and for some women it is a large burden, especially because many are the primary caregiver of the household, many of whom have lost their husband to AIDS, or live without their husbands as they have migrated to South Africa for work.



**Changes in area of land under cultivation.** Half of the women reported a reduction in area of land under cultivation, this was primarily caused by loss of strength, which resulted in the woman's inability to cultivate on all the land at their disposal. For example, one woman said the following, which summarized the feelings of many on the women: "just because I lack strength, I only have one and a half acres instead of two acres." Another farmer expressed that she found it to challenging too use the tools to prepare the land due to lack of strength, so now she is cultivating on less land: "the tools we use here in Malawi require a lot of strength, which I don't have." The other half of the respondents were able to continue farming on the same land, most often the ones that reported not experiencing any challenges or were able to employ laborers. One woman explained that she had increased the land she cultivated on to increase the amount of food she had, recognizing the importance of food and nutrition when HIV-positive.

**Declining yields, less storage and processing.** The respondents reported that yields had decreased as a result of HIV, due to its effects on several of the factors mentioned above (reduction in land areas, change in working hours and productivity). Declining yields resulted in lower food availability for several of the women. Some women expressed that they were no longer able to store food for future use. However, not all the women who experienced declining yields reported lower food availability, instead it manifested itself in less surplus to sell and lower income. Since agriculture is their main source of income, these changes leave some households in tough economic situations, with effects for food access. Moreover, two women mentioned that they changed how they processed the food after being found HIV-positive. One woman said she could no longer use the local way of pounding maize anymore due to lack of strength, so she now had to spend money to use the maize mill. Another woman said she had started to dry vegetables to preserve the food since her production has declined.

**Change to crop diversity.** To adapt to HIV, farmers have responded, in around half the cases, by changing their cropping patterns (fig. 5). The results show a mixed picture in terms of changing crop diversity, with the following scenarios most common:



**Figure 5: Changes to crop diversity following HIV diagnosis**

*Source: author*

- (a) Around half the participants reported that they made no changes to their crops. Respondents that said that they did not face any added challenges due to HIV were those that more frequently reported not making any changes to their crops. Although many women don't report making changes to their own farm, it is common for them to make other changes to the diet's nutritional quality by purchasing more nutritious food (discussed in section 6.4.2).
- (b) Over half of those that said they had made changes to crop diversity report a reduction in the number of crops cultivated. This is likely to have negative consequences for food security, especially food utilization. These changes are the result of a reduction in strength associated with HIV. Many of the women reported that they wanted to make changes to their crops but could not due to a lack of money.

One woman said the following about her experience:

Participant: "Since I was diagnosed, I have changed in terms of crops. At first, I used to have maize, groundnuts, beans, soya, but now I just have soya and maize. These changes have happened just because I am ill."

Interviewer: "Why?"

Participant 16: “I am failing to find work. Had I been strong, I would indulge in off-farm work on other people farm, so I am failing to find money to buy fertilizer.”

Others shared similar experiences: “Before I used to farm different types of crops, but now because of my strength I only farm maize,” “I do not have the strength to go to the farm and cultivate different types of crops. I used to farm sunflower, soya and tobacco. Now that I don’t have the strength, I am just farming maize,” and “I used to cultivate vegetables, but now I stopped because of my breathing [referring to her lacking strength and breathing hard] even though it is imperative, I am too tired.” The reduction in diversity often meant that the women were left with just maize and one other crop.

(c) A smaller number of women have done the opposite by increasing crop diversity at the farm, which is likely to have a positive impact on the diet’s nutritional quality. These changes were linked to a desire to improve the nutritional status and subsequently, their health and well-being: “after being diagnosed, I started farming tomatoes and soya just to produce more and to observe the six food groups”. Similarly, another woman said: “before I used to just farm maize and soya, now I am farming beans and tomatoes as well. I am doing so because I want to observe the six food groups”. A third woman said: “the doctors told me that I should add soya and groundnuts to my field, so I will pound groundnuts and soya together with maize so that I can be strong.” These quotes illustrate a certain degree of nutritional awareness amongst the WLHIV. Despite these positive changes, several of the women reported that they found it difficult to find the money for seeds to implement these changes.

**Changes in market access.** When asked about if and how HIV had affected their ability to access markets, around half the respondents said that they are still able to access markets, but due to lower production, they no longer sold their produce at markets, which had negative effects for their income. For example, one woman expressed: “I used to cultivate three ox carts, and I would sell it to buy household necessities (e.g. soap), now I don’t cultivate as much, and I just keep for food and storage.” Other women no longer had the strength to go to the markets, which are often

too far away: "before I used to take the produce to Mzimba<sup>11</sup> to sell my produce at a high price, now I go to cooperatives which are closer and sell at a lower price because I no longer have the ability to walk long distances because of the pain in my feet". As a result, the declines in yields and shortage of strength resulted in a reduction in income for many of the participants. Income, which otherwise would have been used to buy basic necessities such as soap, food and clothes or to hire occasional labor, or to purchase inputs such as seed and fertilizer.

### **Life story 1: The story of Violet.**

Violet, a 30-year-old farmer widow with four children, was diagnosed with HIV in 2015 and has since witnessed a dramatic change in circumstances and well-being. Violet was a productive farmer, cultivating on three acres of land where she grew maize, tomatoes, rapeseed, groundnuts, beans and soya. Most of the time she was able to produce enough food for the household and earn a small amount of cash. Since she was diagnosed, she often gets sick, she has lost much of her strength, her heartburns and her left hand and leg feels paralyzed. She is no longer able to perform on the farm the way she used to and was forced to reduce the land she cultivated on from three acres to two acres. She no longer has the strength to cultivate many different types of crops, and focuses on soya and maize, purely for household consumption. In periods of illness she relies on her young son to go to the farm. In the past Violet was able to produce seven ox carts during the harvesting season, but now she is only able to farm one ox cart. One ox cart is not enough to feed her household, and they are often faced with hunger and are only able to eat two meals per day compared to three in the past. Moreover, because she lacks strength, she is no longer able to take part in off-farm work on other people's farm, which would in the past have allowed her to find money to buy fertilizer.

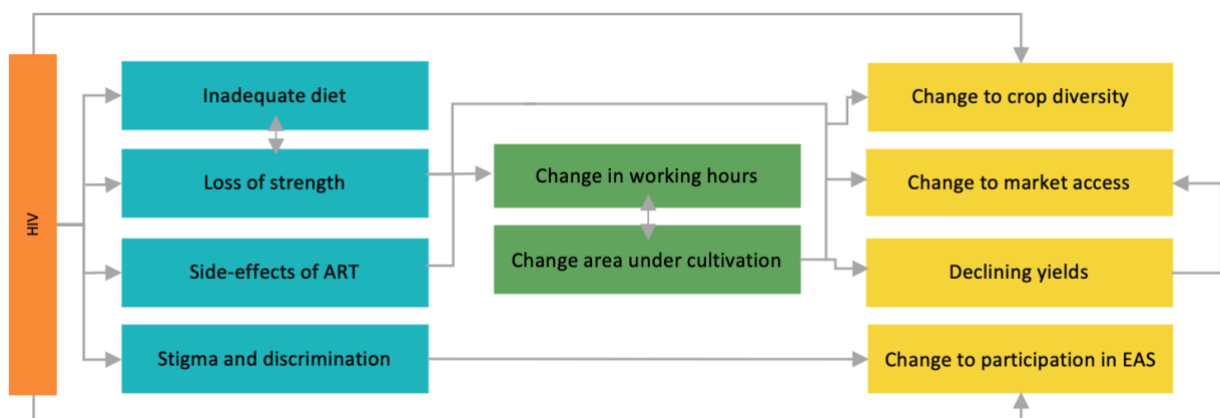
**Changes to participation in agricultural extension and advisory services.** The findings also reveal that living with HIV has changed the way they participate in EAS: some have started to participate in EAS while others are participating less. The main motivation for participating more in extension services was a wish to learn more about nutrition, and about how to change their farming practices now that they were ill and are not able to farm like in the past. The following quotes illustrate this point:

<sup>11</sup> Nearest trading center

- “Previously, we [the household] were relying much on fertilizer, now we want to reduce our expenditure because of our status, so we are taking part in agricultural training to learn about compost manure and conservation agriculture.”
- “Since I was diagnosed, I was told I should attend the training to learn about nutrition, so now I am attending”
- “After being diagnosed, I am now taking part in training, because I want to learn about farming the six food groups for me to maintain my diet and to increase my produce.”

The second reason was that the women often felt, as already mentioned, discriminated against due to their positive status. Lastly, some women felt they no longer had the strength to participate: “Previously, I used to indulge myself in agricultural training, but now because I lack strength I cannot move around as much. I used to go to Mzimba to do some activities, now that I am lacking strength I cannot go.” Another woman said the following about her experience: “I used to participate in many activities when I was wandering around. I used to be a wanderer, but now because I have lost some strength I cannot move around to participate in training.” Not participating in EAS could have a negative effect on food security as women are not exposed to new technologies or knowledge related to nutrition and health.

The impacts of HIV on primary agricultural activities, although a simplified version of reality, are summarized in the following figure:



**Figure 6:** A causal pathways model of the impact of HIV on the food supply chain for women living with HIV in rural Malawi

*Source: author*

### 6.3.2. Effect of HIV on consumer behavior

Consumer behavior here refers to changes in food related behaviors and lifestyle. Analysis of the interviews and focus group discussion identified two key themes regarding changes in behavior following diagnosis with HIV: (1) changes to dietary patterns, especially meal frequency, meal portions and nutritional diversity, and (2) food hygiene practices. No changes to intrahousehold food allocation were identified. The changes in consumer behavior can also be considered coping strategies but are included here to fit the analytical framework. These changes in behavior could either have positive or negative effects on individual and household food security (section 6).

#### Life story 2: The story of Grace

Grace, a widow, looks after five other household members in a small brick house. Grace was diagnosed with HIV six years ago but remains strong. She cultivates on the same amount of land and is farming the same number of hours, and therefore has the same amount of produce as before. Since receiving the diagnosis, she has made significant changes to her life, after receiving counseling and health education from the local clinic. She was told that she needed to be strong and to have a balanced and nutritious diet. Therefore, she added soya and groundnuts to her farm, which she pounds to combine with the maize to make porridge. She also farms maize, although this is very difficult due to lack of fertilizer. She has also started to prepare three meals for herself and the family and tries her best to consume food from each of the six food because she was told this was important. She has started to buy orange squash to get sugar, and stock and margarine to add to her porridge. However, finding money is difficult to buy such items. When she needs money, she goes to the forest to collect firewood to sell. Although she wishes she could generate enough capital to start a business.

**Dietary patterns.** A common response to the impact of HIV was to make changes to the frequency for meals, either reducing the number of meals or increasing the number of meals. For those women who had reduced the number of meals the main reason for this was lower production, and for because of reduced income. The motivation behind increasing number of meals was that the women had received nutritional counselling and now had more knowledge of the importance of eating frequently when HIV-positive in order to stay “strong”. For example, one woman said the following: “we are encouraged to eat three meals per day. I used to eat two meals, but now I have received advice that I should be eating more regularly.” Another said this: “At first [before diagnosis] I used to cook more food and eat only once a day, now I eat three meals per day, but less food at each times in order to have more meals because I was told it was important.” In addition, some women manage declining yields by reducing the size of their

meals, either in combination with a reduction in meal frequency or alone: “I used to give three pieces of nsima to children now only two” and “most of the time when we eat, we are more half full instead of full.”

**Nutritional diversity.** The consumption of highly nutritious food emerged as a noticeable theme throughout the interviews. All the women were focused on the “six food groups” and the importance of diversity in their diet and believed this was essential for PLHIV. The majority of women had made active choices to improve their diet by increasing the nutritional diversity of the food they prepare and eat. Some, as already mentioned, have added crops to their farm while others purchased such food from the market. Some participants did both. Purchasing of nutritious food often took priority over other HH necessities. The cost of such food was a key concern amongst several of the participants. The following statements sum up some feelings of many of the women:

- “Previously we were just eating whatever was available but because of the knowledge we have acquired in terms of a nutritious diet, we now eat food from different food groups to ensure we have a more diversified diet to meet our needs in terms of HIV.”
- “I am trying to diversify my diet and observe the six food groups, to sustain a healthy life according to what we have learned, for example in the morning I eat porridge with groundnut, and in the afternoon I change so that I get food from all the required food groups. These changes have led to an improvement in my health.”
- “I am trying to eat well and prepare food properly because I need vitamins in my diet. It is sometimes difficult due to lack of money. I have a better diet now because I am incorporating the six food groups into my diet”

Only a few women said that they had decreased diversity of the diet since they were producing less or no longer had the strength to cultivate different crops. These women expressed a desire to change to a more nutritious diverse diet to improve their health but did not have the money to do so. It appears that eating healthy and having a diverse diet was an important priority for the women, and significant efforts were made to purchase nutritious food even though their production and income had been reduced. Interestingly, several women said that even though

they sometimes had to reduce their meal portions and number of meals they still tried to have a diverse diet.

### **Life story 3: How HIV had a positive impact on Lyndas diet**

Lynda is a 40-year-old married woman with four children. She was diagnosed with HIV in 2010. Since her diagnosis, she has gone from farming only maize to cultivating soya, groundnuts, sweet potatoes and garlic. She says the garlic and sweet potatoes are providing her with nutrients that are good for her health. She is also purchasing eggs because she was told she needed protein. When Lynda prepares food for herself and the family, she is more aware of including the six food groups in her cooking. For example, when she is making porridge, she makes sure to add groundnut powder and during lunch she makes sure to have nsima and eggs instead of just nsima. This is to ensure her body gets the nutrients that it requires.

Since nutritional diversity was such a prominent theme throughout the discussion, the qualitative data was examined to determine if there are any significant difference in consumption of food groups between HIV-affected households and non-HIV affected households (Table 2).

Regardless of HIV status, households eat low amounts of milk products, animal products and fruits and there is high consumption of main staples and vegetables. HIV affected households eat less fruit and dairy products, but consume more oils, vegetables, sugar and condiments. To see if these differences are significant an independent samples t-test<sup>12</sup> was carried out. The p-value is used to determine if the relationship is statistically significant. Cohen's  $d$ <sup>13</sup> (1988) criteria of .2 for small effect, .5 for medium effect and .8 for large effect is used as a measure of effect size (a strong relationship between the variables). Effect size measures the size of the difference between the group means. According to Cohen (1988), "even a small effect size is one in which there is a real effect, but which can only be seen through careful study," whereas a medium or large effect size is "conceived as one large enough to be visible to the naked eye (p.26)". Effect size is important to look at in addition to the p-value as with a large sample size, even the smallest difference between two group means can become statistically significant. So, if the two groups' means don't differ by 0.2 standard deviations or more, the difference is trivial, even if it is statistically significant (Cohen 1988). No statistical differences in consumption of the food

<sup>12</sup> The independent samples t-test is used to determine if there is a statistically significant difference between two groups' mean (Pallant 2011).

<sup>13</sup> The difference in the two groups means divided by the average of their standard deviations (Pallant 2011).



groups between HIV-affected households and non-HIV affected households were found, except in the case of oil ( $p=0.037$ ), although with a weak association. The qualitative interviews also highlight this finding as several of the women spoke of using more cooking oil in their diets since they were diagnosed with HIV.

**Table 2.** Difference in consumption of food groups in HIV affected households - mean count of days in a week when household members consumed a particular food group

	HIV-positive	HIV-negative	p-value	Cohen's <i>d</i>
<b>Main staples</b>	6.7 (0.998)	6.64 (1.16)	0.497	0.02
<b>Pulses</b>	2.16 (1.570)	2.16 (1.79)	0.971	0
<b>Vegetables</b>	5.62 (1.724)	5.52 (1.745)	0.431	0.06
<b>Fruit</b>	1.31 (1.902)	1.41 (2.117)	0.529	-0.04
<b>Meat, fish, eggs</b>	1.96 (1.826)	1.96 (1.703)	0.963	0
<b>Dairy products</b>	0.34 (1.302)	0.41 (1.414)	0.559	-0.05
<b>Sugar</b>	2.78 (2.899)	2.34 (2.854)	0.128	0.15
<b>Oils</b>	3.30 (2.773)	2.98 (2.779)	<b>0.037*</b>	<b>0.11</b>
<b>Condiments</b>	6.68 (1.040)	6.74 (1.003)	0.397	-0.06

Note: Figures are means with standard deviation in parenthesis; \*, \*\*, and \*\*\* denote statistical significance at  $p < 0.05$ ,  $p < 0.01$ , and  $p < 0.001$  levels, respectively.

*Raw data source: Malawi Integrated Household Survey 2016/2017.*

**Changes to food hygiene practices.** Throughout the discussions, hygiene was a recurring theme. The WLHIV were more concerned and aware of hygiene. The motivation behind changes to food hygiene practices was that the women were now more concerned with hygiene after being sensitized to the issue of opportunistic infections and how they are more prone to diseases. Several changes had been made including buying soap, washing hands before preparing and eating food, cleaning plates and utensils, sweeping the house/kitchen more regularly, storing food under cover to protect from flies and distributing the food on different plates instead of everyone in the household eating from the same plate. The following quote illustrates some of the changes the women have made: “At first when we were preparing food, we were not very concerned with hygiene, we were just cooking the food and not covering the food. Now we cover the food so that we don’t contract diseases. We also make sure to have clean plates. This is for

hygiene reasons, so people don't contract diseases, in case someone doesn't wash their hand properly. This is one of the recommended strategies to reduce the contraction of disease”.

## **6.4.Coping strategies**

The previous section presented how HIV has affected food system activities and consumer behavior. The next section presents findings from the interviews and focus group discussions with regards to the strategies that individuals have adopted to cope with the challenges of living with HIV and its impact on the food system. Several different coping mechanisms were reported and here grouped into informal and formal coping strategies. These strategies were able to mitigate some of the effects of HIV on food system activities and outcomes, while others worsened some of the effects. It is worth noting that even though the participants were specifically asked about how they cope with the changes they have experienced following HIV diagnosis, it cannot be assumed that all the below mentioned strategies are solely an outcome of HIV. Some coping strategies may also have been used prior to being found HIV-positive to deal with other issues related to living in poverty but may be increasingly used in light of HIV.

### **6.4.1. Informal coping strategies**

The informal coping strategies used to cope with the effects of HIV on the food system are categorized around the following themes: food and agricultural related coping strategies and non-food related coping strategies.

#### **6.4.1.1.Food and agricultural related coping strategies**

There were 15 food and agricultural related coping strategies identified, which I have grouped into coping strategies with likely positive effects and coping strategies with likely negative effects for food security and health (table 3). Several of these strategies have already been discussed in the sections above, and therefore only a brief overview is given. The findings show that in situations where HIV has resulted in low production and low income, women often employ short-term changes in food consumption, such as changes in meal frequency and portion size. However, this is not the case for all household, as many have done the opposite. Several women choose to adopt coping strategies that are motivated by a desire to improve their diet and health to “stay strong”, most commonly being increasing nutritional diversity of the diet and increasing the number of meals eaten per day.

**Table 3:** Food and agricultural related coping strategies

Positive	Negative
<ul style="list-style-type: none"> <li>▪ Increase crop diversity at farm</li> <li>▪ Increase the number of meals per day</li> <li>▪ Increased participation in extension services</li> <li>▪ Increase nutritional diversity when cooking</li> <li>▪ Work slower when at the farm</li> <li>▪ Take food with ART to reduce side-effects and feelings of hunger</li> <li>▪ Purchasing nutritious food</li> </ul>	<ul style="list-style-type: none"> <li>▪ Reduce land area under cultivation</li> <li>▪ Decrease crop diversity at farm</li> <li>▪ Reduce the number of meals per day</li> <li>▪ Reduce the portion size of meals</li> <li>▪ Sell stored food when in need of money</li> <li>▪ Work harder</li> <li>▪ Reduce working time on farm</li> </ul>

#### 6.4.1.2. Non-food related coping strategies

The women described a wide range of non-food related coping strategies in response to HIV, and these strategies were grouped into two categories: emotional coping strategies and problem-solving strategies. These are shown in table 4 with examples of responses and likely outcomes.

**Table 4:** Non-food related coping strategies

Coping strategy	Examples of responses	Outcomes
<b>Emotional</b>		
<b>Openness about and acceptance of the illness</b>	<ul style="list-style-type: none"> <li>▪ “I was told to be open to everyone about my status, if I feel like I am hiding anything, it will affect my well-being.”</li> <li>▪ “I have accepted that I am living with HIV and I live happily, I don’t have any negatives in my life.”</li> </ul>	<ul style="list-style-type: none"> <li>▪ Improved quality of life</li> <li>▪ Access to support services</li> </ul>
<b>Praying to God</b>	<ul style="list-style-type: none"> <li>▪ “God will give me a better future”</li> </ul>	<ul style="list-style-type: none"> <li>▪ Improved quality of life</li> <li>▪ Hope for the future</li> </ul>
<b>Problem-solving</b>		
<b>Employ laborers to work on farm</b>	<ul style="list-style-type: none"> <li>▪ “My household is affected by the reduction in working hours, so when I have money, I employ some laborers to go to the field.”</li> </ul>	<ul style="list-style-type: none"> <li>▪ Maintain same level of production</li> <li>▪ Likely positive impact on food availability</li> </ul>

<b>Off-farm income generating activities</b>	<ul style="list-style-type: none"> <li>▪ “Sometimes I go to the forest to collect firewood to sell to get an income and sometimes I go to fetch water for people.”</li> <li>▪ “When I am strong, I have a tendency to go to various fields to buy onion, tomatoes, and other vegetable to sell in Mzimba.”</li> <li>▪ “I sell fish, tomatoes, rice – it is very effective because I do not have to beg for money, and I am able to deal with my issues on my own.”</li> <li>▪ “I have a small-scale business – sometimes I sell tomatoes and fish. I buy fish from fishermen and tomatoes from local farmers.”</li> </ul>	<ul style="list-style-type: none"> <li>▪ Generate more income to buy nutritious food and household necessities, e.g. soap and clothes.</li> <li>▪ Likely positive impact on food utilization</li> <li>▪ Increased dignity and well-being by not having to beg or rely on others for help</li> <li>▪ Mitigate impact of reduction in area under cultivation and declining yields on income and food security</li> </ul>
<b>Selling households items</b>	<ul style="list-style-type: none"> <li>▪ “When I want to have money, I sometimes sell the food that I have stored”</li> <li>▪ “Since falling ill I have sold some assets – e.g. bedding and some pots. Selling the assets is not a good idea. I have lost many things and as a result I have nothing in my house.”</li> <li>▪ “Since I fell ill, I have sold some goats to cover some of the expenses I have.”</li> </ul>	<ul style="list-style-type: none"> <li>▪ Short-term food Negative effects on food availability and overall quality of life</li> </ul>
<b>Working on other people land – e.g. tillage, weeding</b>	<ul style="list-style-type: none"> <li>▪ “When I have no food, sometimes I do labor farming just to have some money to have more food.”</li> </ul>	<ul style="list-style-type: none"> <li>▪ Income generation</li> <li>▪ Could have a negative effect for health at it require a lot of strength to work on the farm</li> </ul>
<b>Support from relatives in the form of money, on farm, domestic activities, food items, agricultural inputs</b>	<ul style="list-style-type: none"> <li>▪ “I once received support in the form of maize flower from a relative.”</li> </ul>	<ul style="list-style-type: none"> <li>▪ Likely positive impacts on food security</li> </ul>
<b>More care for personal hygiene</b>	<ul style="list-style-type: none"> <li>▪ “I keep my body clean all the time so that I am not exposed to other disease.”</li> <li>▪ “Since we were diagnosed, we have been taught about personal hygiene, simply to keep the bacteria away. I normally sweep around the premises for it to be clean, so that the bacterium does find room to grow, because I know that I can suffer badly from any diseases, so I take care to keep it clean around me.”</li> </ul>	<ul style="list-style-type: none"> <li>▪ Positive effects for food utilization</li> </ul>

**Listen to the advice given by healthcare workers**

- “I follow all the advice that the doctors are telling me, and I have never meet some of the problems which other people who are positive are facing”
- Increased quality of life and likely positive impacts for food security.

**Emotional coping strategies.** Some participants reported that being open and truthful about being HIV-positive was a way to cope with the disease. Some women decided to be open about their status in order to receive formal support. For example, key informants explained that those who are not open about their status do not dare to go to the health clinic to get ART or for counseling. A second emotional coping strategy involved the use of prayer. The women depended on God as a way to build hope in response to the illness. Religion is an important component of Malawian life and cultural identity.

**Problem-solving coping strategies.** One of the most common problem-solving coping strategies was an attempt to diversify income. Women often engage in off-farm income generating activities to deal with the impacts of HIV on their incomes. Some of the activities mentioned include starting their own business, for example, selling samosas, dried fish, donuts and other snacks. Other women did ad-hoc jobs when in need of money, for example, collecting firewood to sell and fetching water for other households. Other women did work on other farms to generate income.

Interestingly, the selling of assets was not as common as expected amongst the women and no one mentioned selling land as a way to deal with lower income. Those women that did not engage in off-farm income generating activities expressed that they had a desire to do so but did not have the capital to start. Another common strategy was to take more care of their personal hygiene by bathing more and washing their clothes more often than in the past. However, the women said that due to poverty levels, it was often difficult to find the money for soap. Moreover, if possible, women may hire additional labor to compensate for lost production, but most households do not have the resources to do this. Listening to the advice from healthcare workers and doctors on how to look after the body when HIV-positive is another strategy that many of the women use. Moreover, seeking support from family was common. Unfortunately, a

few of the women expressed that they felt their family did not support them because the family considered PLHIV to “already be dead.”

#### **6.4.2. Formal support**

This section presents the various institutions which influence and help to improve coping for WLHIV. Sources of external support reported by participants of the interviews and focus group discussions include services from the agricultural sector, health sectors and from NGOs, including SCT, FISP, community-based organizations (CBOs) (also called self-help groups, support groups), village savings banks, EAS, food aid and distribution of non-durable goods from NGOs and counseling and training from the health center. NGOs that have been or are working in the community include World Vision, NAPHAM, Red Cross, National Aid Committee, Plan International Malawi. The majority of available support was at the community level. Women often received a combination of support from the different sources, however, a small number of women reported that they had never received any support from external sources. The CBO chairperson believed the lack of support for some women was because WLHIV are not working as “hard” as other members of the community: “because we are telling the women not to work as much, because they are suffering, and so when there is support in the villages they are targeting those that are vibrant and working hard.” This issue was also mentioned by one of the women.

The most frequent source of support discussed by the respondents was EAS, which was run by a local NGO with funding from international donors. Less common sources of EAS were provided by the GoM. The NGO followed a lead farmer extension approach and would provide teaching on conservation agriculture, nutrition and homebased gardening. Although very infrequently, the participant would sometimes receive agricultural inputs such as fertilizer, livestock (e.g. goats and pigs) and cassava cuttings. The majority of the women were accessing extension services to some extent. However, EAS were not provided to the women as frequently as one would perhaps expect considering all the women were follower farmers and meetings were meant to be held regularly. The women expressed that they were usually not “called” to attend meetings.

The main motivation for participating in extension services was a wish to learn more, and also some of the women mentioned that they felt that if they participated, they might receive some material support. Some felt the teachings were helpful. Some women expressed that participation in EAS led to increased yields, as the women were taught how to increase production, and therefore not participating in these activities had the opposite effect. For example, one woman expressed that the teachings were “helpful enough to help them in their life, e.g. now know how to make compost manure, they are also not dependent on buying fertilizer, which they have no money to buy, but through the teaching from FYF, they are able to make their own fertilizer. Another said the following: “they try to teach us how to live a better life, how to plant things, how to and increase produce. I feel the support is effective because it helps me at the household.” However, participating in EAS does not necessarily translate to increased production as many women were not able to implement the technologies due to lack of inputs such as manure, summarized well in the following excerpt from a focus group in Mzimba:

Participant 1: “I have learnt something to do with conservation agriculture, especially manure, however, I am failing to implement this because I don’t have animals or cattle”

Participant 2: “I agree with my friend, people are selling manure in the community, but I don’t have the money to buy, and I lack manure as I don’t have livestock.”

Participant 3: “What we have learned is effective, because we are seeing from our friends that they have more produce, but just because we lack manure we have not benefitted, but our friends who have manure are benefitting because they have more produce.”

Unfortunately, many women felt there was lack of transparency and unfairness in the distribution of support. These women felt the lead farmer was not targeting them and would favor his or her friends. For example, several women gave an example of a tractor which was meant to be used by all the follower farmers, but the lead farmer “kept it for his friends”. Other quotes highlight the lack of transparency:

- “We feel like someone is stepping on us and that the support is not fairly distributed. For example, two women went to the same training on conservation agriculture, and one person came home with a bike and the other person did not get a bike.”
- “It is not fairly distributed and there is no transparency. I hear sometimes that cassava cuttings have been distributed and that some teachings have happened. I don’t know how these people have been picked. There is no transparency in how teachings and support in distributed.”

Another common source of formal support was through CBOs. The CBOs would provide education on self-care and nutrition, advice and motivation on medication adherence, and sometimes food-aid. The women expressed that they found the support groups to offer a supportive, encouraging and educational environment, which allowed them to share their experiences and learn from others, leading to improved self-care behaviors. Through support groups, the women were able to reduce the stress that they were feeling: “I feel the support groups are effective, I know things that I didn’t before, and I have reduced stress as a result.” One woman even said that without the support groups, “we think about committing suicide.”

Most of the women that were not part of a CBO were interested in becoming members, and those who were members wished that the CBOs would meet more regularly, motivated by a desire to learn more about self-care. Unfortunately, a common concern was that the support groups were no longer meeting: “At first the CBO activities were being funded, they could provide us with 5 liters of cooking oil and flour porridge, now they are not being funded so the meetings are not happening.” One CBO leader in Mzimba expressed that lack of funding was a major issue that affected their ability to hold regular meetings. Moreover, the women again expressed what they felt was lack of transparency and favoritism in the targeting of beneficiaries: “the managers taking care of the CBO, they normally give the relief to people with old age or orphans. They feel like they are being side-lined from the CBO because they are HIV-positive.”

Support from NGOs (e.g. Red Cross and NAPHAM) would also happen occasionally. However, during the time of field work there were no NGOs operating in the area (to my knowledge), other than the one providing EAS. It appears that NGOs are present, on a sporadic basis, based on funding. The effect of the NGOs support was varied, some felt it was helpful: “the Red Cross



gave us (the household) a bag of soya blend and blankets. The support had a positive impact, even though it is little, there was at least some relief.” However, again, there were feelings of being side-lined and discriminated against due to their status.

The counseling category refers to reaching out to or accepting counseling from health workers and doctors to acquire self-care and nutrition knowledge. This happened either at the health clinic or through visits from community healthcare workers, such as the HSAs. Counseling at the clinic occurred once every month or once every three months when the women went to the health clinic to collect the ART. The occurrence was dependent on the area you lived in. The visits from community health workers happened on a more sporadic basis. The work of the HSAs is summed up nicely with the following quote: “For the WLHIV we are teaching them about the six food groups, trying to make some follow-ups to ensure that these women are actually taking the drugs that they are receiving here at the clinic and encourage them to follow sanitation, e.g. how to care of the food and personal hygiene.” The HSAs felt that the work they were doing is effective, that the majority of the women are listening and trying to implement the teachings. However, as already mentioned eating from all the six food groups proved difficult for a large majority of the women due to lack of money. The HSAs also mentioned that in some areas the HSAs were not very “vibrant,” and the women are therefore not receiving any visits, stating that “some HSAs do not do their job properly, and their work may, therefore, vary in performance.” The HSAs also explained that WLHIV receive supplementary feeding from the health clinic if they have a low weight and low CD4 cell count<sup>14</sup>. In Nkhata Bay several women in the focus groups expressed that they wished they would get the supplementary feeding before their weight dropped below a certain threshold to prevent severe undernutrition. The key informants also expressed that it was very difficult to reach all the women due to lack of transport which forced them to walk or bike large distances in one day:

“The major challenge for us is transportation in order to provide frequent visits for them to be able to visit the women. If you frequently visit the women, that is when you can see a change. The GoM decided to cut the transportation costs, and instead give us a bicycle,

<sup>14</sup> The immune cells that the HIV virus destroys

which is not working properly. So normally they walk to visit the women, but it is difficult for us to walk 5km to meet one person and another 5km to reach the next.”

Nevertheless, the availability of counseling services has shown to have a positive impact in the research area. Interviewees stated that counseling helped them feel better and made them understand their illness better. The women expressed that “what I have been taught has been implemented and it is keeping me strong,” and “the counseling I have received has been effective, it is why I am alive today.” Also, considering the changes many women have made to their diet and hygiene practices, it appears that the counseling services are effective. This was the only category of external support in which the women did not mention issues of unfair distribution. Participants expressed that they had a desire learn more about the disease and how to take better care of themselves and wanted the counselling to occur more regularly.

Very few of the participants had received coupons through FISP or SCT through government SSNs. Again, the women felt that accessing these coping mechanisms was biased, and there was an aspect of “corruption” involved. The key informants also agreed that these forms of support were not distributed fairly stating that “benefits are going to those that are not suffering”, however, this was a general issue for the whole community and not just for WLHIV. Fortunately, the women that had received these services agreed that it had increased food availability and lessened their financial burden.

#### **6.4.3. Discrimination in access to support**

The qualitative analysis revealed that women felt discriminated against in terms of access to formal support services. However, contrary to the women’s experiences, when tested quantitatively, using a chi-squared test<sup>15</sup>, the findings show that HIV-affected households receive more of all forms of support compared to non-affected households, except for free food where they receive less and free maize where it is about the same (Table 5). Cramer’s V<sup>16</sup> is used to measure the strength of the association between the two variables. Cohen’s (1988) criteria of .10 for small effect, .30 for medium effect and .50 for large effect is used to determine the effect size of the association. However, this does not mean that the support is unfairly distributed in the

<sup>15</sup> The chi-squared test is applied to contingency tables and allows us to establish how confident we are that there is a relationship between the two categorical variables in the population as a whole (Pallant 2011)

<sup>16</sup> Cramer’s V is a value between 0 and 1.

community, but it suggests that this is not associated with HIV status. In fact, it appears to be the opposite. The results suggest that HIV-affected households are more likely to receive FISP coupons ( $p=0.012$ ), however, the association is weak ( $V=0.048$ ). As seen in Table 1, more HIV-positive women use fertilizer, which could be related to their higher access to FISP coupons (60% vs. 50%). The test also revealed a significant relationship between HIV status and being a beneficiary of any of the SSNs included in the study ( $p=0.002$ ), with a strong association ( $V=0.59$ ). A more specific breakdown looking at each SSNs shows that HIV status has a significant relationship with participating in MASAF ( $p=0.003$ ) and receiving free maize ( $p=0.033$ ) and free food ( $p=0.011$ ). No significant relationship was found between HIV status and access to extension services ( $p=0.343$ ). However, the results show a significant relationship between HIV status and the number of inputs individuals received advice on ( $p=0.001$ ), with medium size effect (Table 6). A result which suggests that WLHIV receive more advice, compared to their non-affected peers. A finding which is supported by the qualitative research where several of the women said they actively seek out EAS to learn more now that they are HIV-positive.

**Table 5.** Access to social security, extension services and FISP in HIV/AIDS affected and non-affected households

	HIV-positive	HIV-negative	p-value of $\chi^2$	Cramer's V
<b>Access to extension services</b>	86.2	83.3	0.294	0.019
<b>Farm Input Subsidy Program</b>	30.7	22.4	<b>0.009*</b>	<b>0.048</b>
<b>Social Security Program</b>	52.9	41.1	<b>.002**</b>	<b>0.59</b>
MASAF	14.8	8.2	<b>0.001***</b>	<b>0.058</b>
Free maize	29.9	29.4	<b>0.027**</b>	<b>0.041</b>
Free food (excl. maize)	23.3	31.7	<b>0.008**</b>	<b>0.048</b>
Food/Cash-for-Work	2.6	1.6	0.252	0.021
SCT (GoM)	5.3	5.2	0.962	0.001
SCT (other sources)	4.2	2.2	0.075	0.033

Note: figures are percentages; \*, \*\*, and \*\*\* denote statistical significance at  $p < 0.05$ ,  $p < 0.01$ , and  $p < 0.001$  levels, respectively.

*Raw data source: Malawi Integrated Household Survey 2016/2017*

**Table 6.** Number of coupons and number of agricultural inputs that household received advice on.

	<b>HIV-positive</b>	<b>HIV-negative</b>	<b>p-value</b>	<b>Cohen's <i>d</i></b>
<b>How many inputs did you receive agricultural advice on?</b>	2.46 (2.60)	1.78 (1.837)	<b>0.001***</b>	<b>0.30</b>
<b>How many coupons did you receive through FISP?</b>	0.82 (1.41)	0.55 (1.16)	<b>0.011**</b>	<b>0.20</b>

Note: figures are means with standard deviation in parenthesis; \*, \*\*, and \*\*\* denote statistical significance at  $p < 0.05$ ,  $p < 0.01$ , and  $p < 0.001$  levels, respectively.

*Raw data source: Malawi Integrated Household Survey 2016/2017*

## **6.5. Impact of HIV on food systems outcomes**

### **6.5.1. Impact of HIV on income and expenditures**

This sub-section starts with a look at how HIV has affected income and household expenditures. A large portion of the respondents reported changes to household expenditure following HIV diagnosis and many also reported a loss of income following HIV diagnosis. These changes occurred through two main routes: loss in income related to a reduction in production and increased expenditure in healthcare and food-related costs. The majority of the respondents felt that after the detection of HIV, their households' monthly expenditures on food had increased. This increase was primarily related to the purchase of more diverse and nutritious foods, such as sobo (orange squash), stock, margarine, meat, fish, sugar, cooking oil, vegetables, as recommended by healthcare workers, as illustrated by the following quotes:

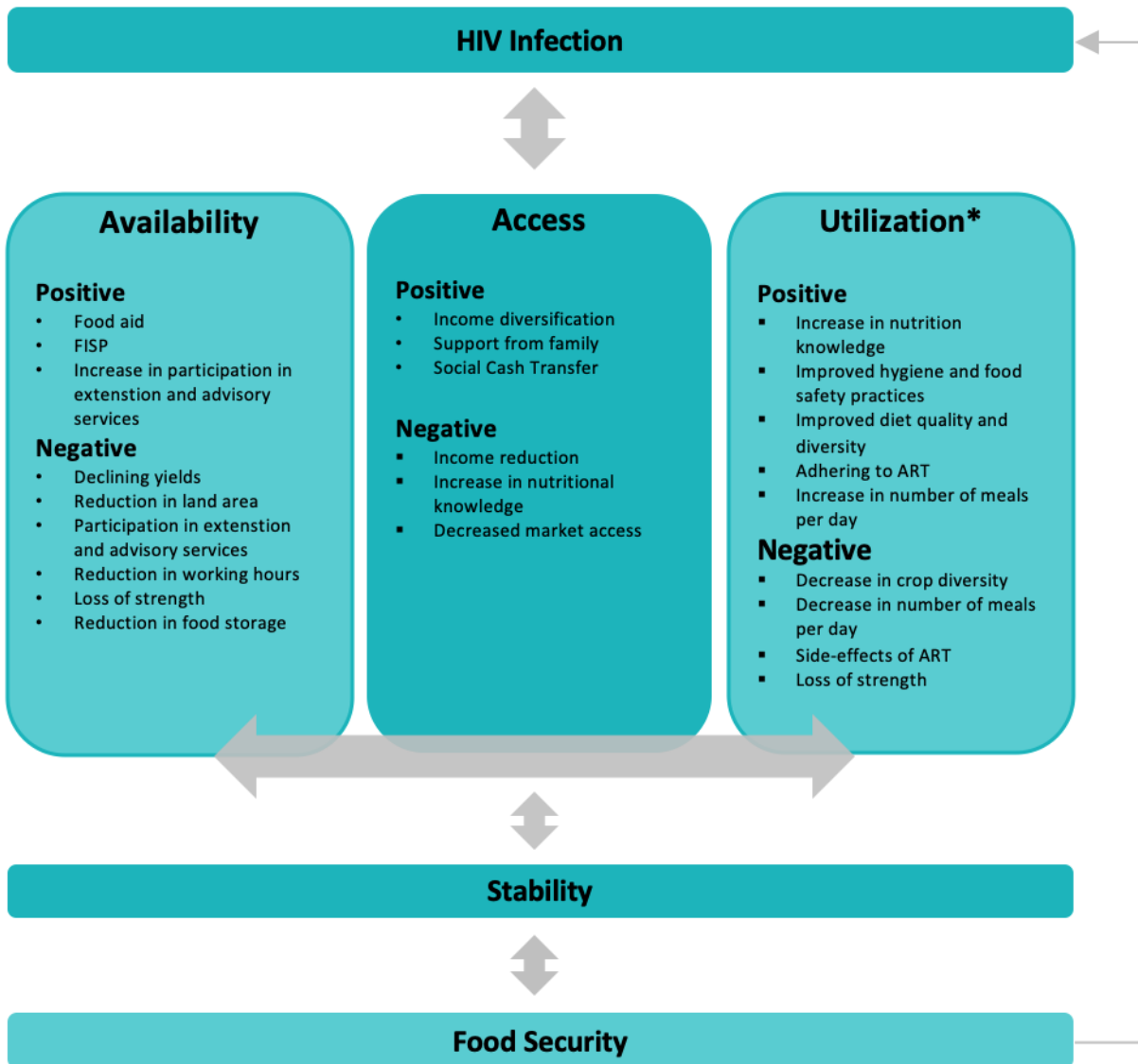
- "I spend more money on tomatoes, onions, cooking oil – simply to be healthier."
- "I spend more money on food because I am now eating breakfast and more money for vegetables to observe the six food groups."
- "Since I am encouraged to eat the six food groups, I spend more money on nutritious food compared to when we would just eat without caring about the nutritious value."

In addition, because of the reduction in yields several women reported that they had to buy food at the market as they were no longer able to produce it themselves, as one woman stated: "since I am not farming like before sometimes we have to spend money on food at the market."

Moreover, even though healthcare is free in Malawi, the diagnosis of HIV has led to increased expenses for many of the women due to transportation costs. This was particularly evident for some of the women in Nkhata Bay who often lived far away from the health clinic, which required them to walk through steep terrain, and they would therefore need to hire a motorbike into town. The women's ability to cope with these changes varied, with some finding it difficult to meet the increased expenses, which would in turn lead to the women having to sacrifice purchasing other necessities such as soap and clothes or to sell food to pay for transportation.

### **6.5.2. Impact of HIV on food security**

The effects of HIV on food security, through its impacts on the food system, has been mentioned throughout this section. Presented here is a summary of the farmer's experience regarding the effects of HIV on food security, categorized according to the four pillars of food security (fig. 7). Both the impacts of the coping strategies that are adopted and the impact on HIV on food system activities are presented in terms of their effect on food security. Since women are primarily responsible for feeding and food provision the impacts are likely to be felt at the individual and at the household level. The findings are mixed in terms of impact on food security, with some women experiencing only positive effects on food security and some only negative, and some a combination of both. Since availability, access and utilization are negatively or positively affected by HIV, these factors affect the stability dimension of food security. The women were not directly asked about food security with regards to the four pillars, except for availability. Rather, the themes and categories were assembled throughout the discussions. It is worth noting that in response to the questions "has the availability of food been reduced because of your HIV diagnosis," many women said that other factors had a more significant effect on food availability than HIV such as losing their husbands or lack of fertilizer.



**Figure 7:** The effect of HIV on the four pillar of food security.

*Source: Author*

Food availability appears to be the least affected pillar of food security as declining yields mean that households often still have enough food for their own production, but they did not have extra surplus to sell, which affected food access instead. Loss of income due to declines in yields, and subsequently reduced access to food was commonly reported amongst the respondents. For most households, food makes up a significant portion of the budget, so even minor changes in income can have large consequences for their ability to access food, especially the ability to access a diverse diet. So, our findings show that both economic and physical access to food has been affected. In addition, market access was affected their declining yields or lack of strength, or

both. For most participants, a lack of money to buy nutritious food was an issue, which for many of the WLHIV was compounded by decreased incomes. Food utilization appears to be the dimension of food security that is most affected by HIV. Several behavioral changes are likely to have a positive impact on food utilization, such as improved food hygiene and safety practices, improved nutritional quality of the diet, adhering to ART and increasing the number of meals per day. Although decreases in crop diversity, side-effect of ART and loss of strength are likely to have the opposite effect.

From the interviewees’ perspective, the findings show that several dimensions of food security are affected by HIV. The quantitative analysis, however, shows some disparities to the reported experiences of the interviewed WLHIV. HIV-affected households have a higher mean FCS (39.08 vs. 38.81) (note: a high score is desirable), but a slightly lower mean number of meals per day (2.25 vs. 2.29) (Table 7). The rCSI was higher in HIV-affected households (12.51 vs. 10.20), meaning that they engage more frequently in negative coping behaviors compared to HIV/AIDS negative households. To test the hypothesis that HIV/AIDS status is associated with statistically different mean food security in the population as a whole, an independent samples t-tests was performed.

**Table 7.** Food security status in HIV-affected and non-affected households, measured by FCS, rCSI and number of meals per day

	<b>HIV-positive</b>	<b>HIV-negative</b>	<b>p-value</b>	<b>Cohen’s <i>d</i></b>
Food Consumption Score	39.08 (13.54)	38.9 (14.80)	0.810	0.01
Reduced Coping Strategies Index <sup>a</sup>	12.51 (11.41)	10.21 (9.83)	<b>0.014**</b>	0.22
Number of meals per day	2.25 (0.57)	2.29(0.53)	<b>0.040*</b>	0.07

Note: <sup>a</sup> data missing for 348 of 2952 respondents; figures are means with standard deviation in parenthesis; \*, \*\*, and \*\*\* denote statistical significance at  $p < 0.05$ ,  $p < 0.01$ , and  $p < 0.001$  levels, respectively.

*Raw data source: Malawi Integrated Household Survey 2016/2017*

The findings show some conflicting results depending on the food security indicator. HIV-affected households have a higher food consumption score; however, this is not statically significant ( $p=0.810$ ). HIV/AIDS negative households have a statistically significant lower mean number of meals per day ( $p=0.040$ ), however with no effect size, and a statically significant

higher food insecurity as measured by rCSI ( $p=0.014$ ), with small effect. A breakdown of the rCSI variable is provided in table 8. Relying on less preferred and/or less expensive food was the most common coping strategy. HIV-affected households are more likely than other households to limit portion size at mealtimes, reduce the number of meals eaten per day, restrict consumption by an adult for a child and borrow food, or rely on help from a friend or relative. The effect size is generally too small suggesting that the difference is trivial according to Cohen (1988), except in the number of meals per day, which indicating a strong relationship between the two variables.

**Table 8.** Food security in HIV-affected and non-affected households, measured using the reduced coping strategies index

In the past seven days, how many days has your HH had to...	HIV-positive	HIV-negative	p-value	Cohen's <i>d</i>
... rely on less preferred and/or less expensive food	2.94 (2.34)	2.74 (2.41)	0.208	0.08
... limit portion size at mealtimes	2.33 (2.41)	1.89 (2.28)	<b>0.020*</b>	0.18
... reduce the number of meals eaten in a day	2.64 (2.66)	1.91 (2.36)	<b>0.001***</b>	0.29
... restrict consumption by adult in order for small children to eat	0.91 (1.74)	0.63 (1.42)	<b>0.049*</b>	0.18
... borrow food, or rely on help from a friend of relative	0.94 (1.52)	0.89 (1.54)	<b>0.050*</b>	0.03
Reduced coping strategies Index	12.51 (11.41)	10.21 (9.83)	<b>0.014**</b>	0.22

Note: data missing for 348 of 2952 respondents; figures are means with standard deviation in parenthesis; \*, \*\*, and \*\*\* denote statistical significance at  $p < 0.05$ ,  $p < 0.01$ , and  $p < 0.001$  levels, respectively.

*Raw data source: Malawi Integrated Household Survey 2016/2017*

These results suggest that HIV status does have a small effect on food security level, as measured by rCSI (although small effect size). However, based on other indicators of food security, food security is does not differ in HIV-affected households compared to non-affected households, a finding which is surprising based on existing literature.

The t-test, however, only provides evidence of a significant relationship and it is important to note that causality cannot be assumed. In addition, it is important to note that the significant relationship established by the t-test could be the result of one or more confounding variables,



defined as a variable that is related to each of the two variables being studied, resulting in the appearance of a relationship between the two variables when in fact it is not real (Bryman 2016). To further explore the relationship between HIV status and food security, ordinary least squares regression analysis was used. The regression tells us how much of the variance in the dependent variable, in this case, food security, can be explained by the explanatory variables, including HIV status (Pallant 2011). Table 9 shows the result of the estimation explaining different indicators of food security. The coefficients provide information on the strength and the direction of the relationship, and it indicates how many units the dependent variables will change when the explanatory variables change one unit. The coefficient is a measure of the effect size. A positive coefficient indicates that the variables move in the same direction, so when the explanatory variables increases or decreases, the dependent variables will do the same. Statistically significant explanatory factors allow for conclusions to be drawn about how changes in these variables are associated with change in the dependent variable (Pallant 2011).

HIV status is included as a dummy variable that takes a value of one if the female household head is HIV-positive. The estimated coefficient for rCSI is positive and significant (0.048,  $p=0.036$ ), indicating that households with a female head that is HIV-positive have a higher rCSI score, meaning that HIV-positive household use negative food coping strategies more frequently. For FCS and number of meals eaten per day the coefficients are small and not significant, indicating that HIV status does not affect FCS and the number of meals eaten at the household level. Although it could be that HIV itself does not cause increased food insecurity, but could lead to lower education and fewer assets and these factors cause less food security.

Years of education and age of the household head are statically significant in explaining these three indicators of food security. Household heads with more education are more food secure, as are households with younger heads. Larger household size is associated with increased rCSI. Asset and livestock ownership and the use of inorganic fertilizer are statistically significant in explaining food security as measured by FCS, rCSI and number of meals eaten per day. The asset index has the highest coefficients, for all three indicators, suggesting that this variable makes the most unique contribution to explaining the dependent variable, when all other explanatory variables are controlled for. Access to agricultural markets and distance to the

nearest road is significant in explaining rCSI and number of meals eaten per day, but not FCS. This finding indicates the importance of market access in food security. Marital status, land and garden size does not seem to affect food security.

The models in table 10 also include a R<sup>2</sup> and adjusted R<sup>2</sup> value. R<sup>2</sup> is a measure of “the proportion of the variance for a dependent variable that can be explained by the explanatory variables in a regression model” (Pallant 2011, p. 161). The adjusted R<sup>2</sup> statistic corrects this value to provide a better estimate, taking into account if you have overfitted the model by including too many explanatory variables. The R<sup>2</sup> values are relatively low, which is not unlikely to happen when studying complex real-world phenomena such as food security. This means that several other factors influence food security in female headed smallholder households. However, the objective here is to determine the role of HIV as a predictor of food security and not to fully explain all the factors, so a further study on all the variables is beyond the scope of this paper.

**Table 9.** Results of estimation of HIV as a determinant of food security in female headed agricultural households

	FCS β (SE)	rCSI β (SE)	Nr of meals β (SE)
<b>HIV status</b> (positive=1)	.021	<b>0.048*</b>	0.001
<b>Education</b>	<b>.175***</b>	<b>-0.056*</b>	<b>.129***</b>
<b>Household size</b>	-.031	<b>.116***</b>	<b>-.049*</b>
<b>Age</b>	<b>-.064***</b>	<b>.084**</b>	<b>-.110***</b>
<b>Marital status</b> (control = married)	0.019	.008	<b>-.063*</b>
Separated/divorced	-.017	-.004	-.011
Widow	.013	.001	.011
Never married			
<b>Asset index</b>	<b>.363***</b>	<b>-.241***</b>	<b>.315***</b>
<b>Livestock ownership</b> (yes=1)	<b>.078***</b>	<b>-.077***</b>	<b>.056**</b>
<b>HH distance to nearest</b>			
Road	-0.034	<b>.077***</b>	<b>-.115***</b>
ADMARC outlet	.024	-.031	<b>.048*</b>
Agricultural market	-.005	<b>-.052*</b>	<b>.063**</b>
<b>Use of fertilizer</b>			
Organic	.005	-.028	.010
Inorganic (yes=1)	<b>.105***</b>	<b>-0.85***</b>	<b>.071***</b>

<b>Land Size (acres)</b>	.014	-.006	0.026
<b>Garden size (acres)</b>	-.016	.008	-.018
<b>Observations</b>	2952	2604	2952
<b>R<sub>2</sub></b>	0.265	0.121	0.211
<b>Adjusted R<sub>2</sub></b>	0.260	0.113	0.204

Note: \*, \*\*, and \*\*\* denote statistical significance at  $p < 0.05$ ,  $p < 0.01$ , and  $p < 0.001$  levels, respectively; (=1) represents dummy variable and coefficients represent change of dummy variable from 0 to 1.

*Source of raw data: Malawi Integrated Household Survey (2016/2017).*

## **6.6. How should policies and programs be implemented and what should be implemented?**

In this section, I present the suggestions from the respondents on how to best implement the support coming into the community and what the WLHIV feel would be more beneficial to improve their quality of life. When discussing what could be improved or what help they wanted the women, often laughed and seemed surprised by the question. Many said that they had never been asked this question before, and especially not by anyone of “my color.” They also expressed that they were very grateful that I asked this question and that they felt very listened to.

### **6.7.1. Suggestions for how to implement programs and policies**

The women and key informants had a few suggestions on how to best implement the support coming into the community, which revolves around the following themes: transparency and accountability, direct support to women, health and agriculture sector working together and home-based care.

#### **(1) The health sector and agricultural sector should work together**

- “People from agriculture should provide training on HIV/AIDS, should not only rely on the health sector to provide training on HIV/AIDSs.”
- “The health sector should reach these people through the agricultural sector, we feel like we can get the right information through the agricultural sector rather than from the health sector, we are not reached in the right manner. In most cases, the support does not reach them when it comes through the health sector, but the support would reach them through the agricultural sector, as they are more present in the community.”

## **(2) Support directly to women**

- “I would prefer for the support to go directly to her. I feel like there is a chain from the donor to the beneficiaries, and along that chain some of the support is lost. There are too many stakeholders involved.”

## **(3) Home-based care**

- “We would like if the local health center could provide some medication to the home-based care people to tackle the issue of distances.”
- “The agricultural sector and health sector should join hands with home-based care which are based in a lot of villages, for them to improve the knowledge of PLHIV.”

## **(4) Transparency and accountability**

- “For the support to be effective and to address the challenge there has to be truth and accountability of the support. For example, here we were trained and given goats, and when the goats reproduce, we were told we should give the goat to another person. Out of the fifteen who have received goats, only six people did that. FYF and other extension workers are not following up to make sure that it is actually happening.”
- “We want FYF and extension workers to hold more supervision to the lead farmers to see if the program that is being implemented is being followed up. Also, the local leaders who are responsible for selecting beneficiaries are not being truthful, they don’t target correctly. There is too much focus on one person or one household (e.g. several people benefitting in one household).”
- “Those that are given authority to handle support, misuse their power, so the real beneficiaries are not getting what they are supposed to get. They find that sometimes support meant for HIV-positive people is found with people who are negative.”

### **6.7.2. Help wanted**

Each interviewee was asked to make suggestions for support that they wanted to receive which would aid them in the challenges they were facing as a result of HIV. The question allows one to identify how the women themselves feel they can best be helped, in order to address this in

programs and policy making. Figure 8 shows an overview of the most common things the respondents felt would help improve their quality of life, alongside some quotes to illustrate typical examples of how such help would benefit the women. There is large diversity in terms of what the women felt would best help them— some emphasized the importance of teachings and more trainings, some wanted capital to start a business to become more self-reliant, while others saw hand-outs in terms of livestock, fertilizer and money as the only solution. A finding that highlights the need of continued communication with the women in order to provide support that will be of most benefit to them. Fertilizer, capital to start a business and teaching were the most common forms of support that the women wanted.



**Figure 8:** Overview of support women living with HIV feel would improve their quality of life.

*Source: Author*

## **7. Discussion**

Using qualitative interviews and statistical analysis, this thesis shows the pathways through which HIV disrupts and drives changes to the food system for WLHIV in rural Malawi. This study highlights the diverse range of circumstances that arise when a small-scale female farmer is diagnosed with HIV, which in turn shape food security and health outcomes. HIV and its impacts can be felt throughout the system and change the way it looks. The following chapter will discuss some of the key findings in light of existing theory. First, I provide a summary of the key findings, followed by a discussion to understand why these effects occur and how some farmers have managed to make positive changes while others have not.

### **7.1. Summary of findings**

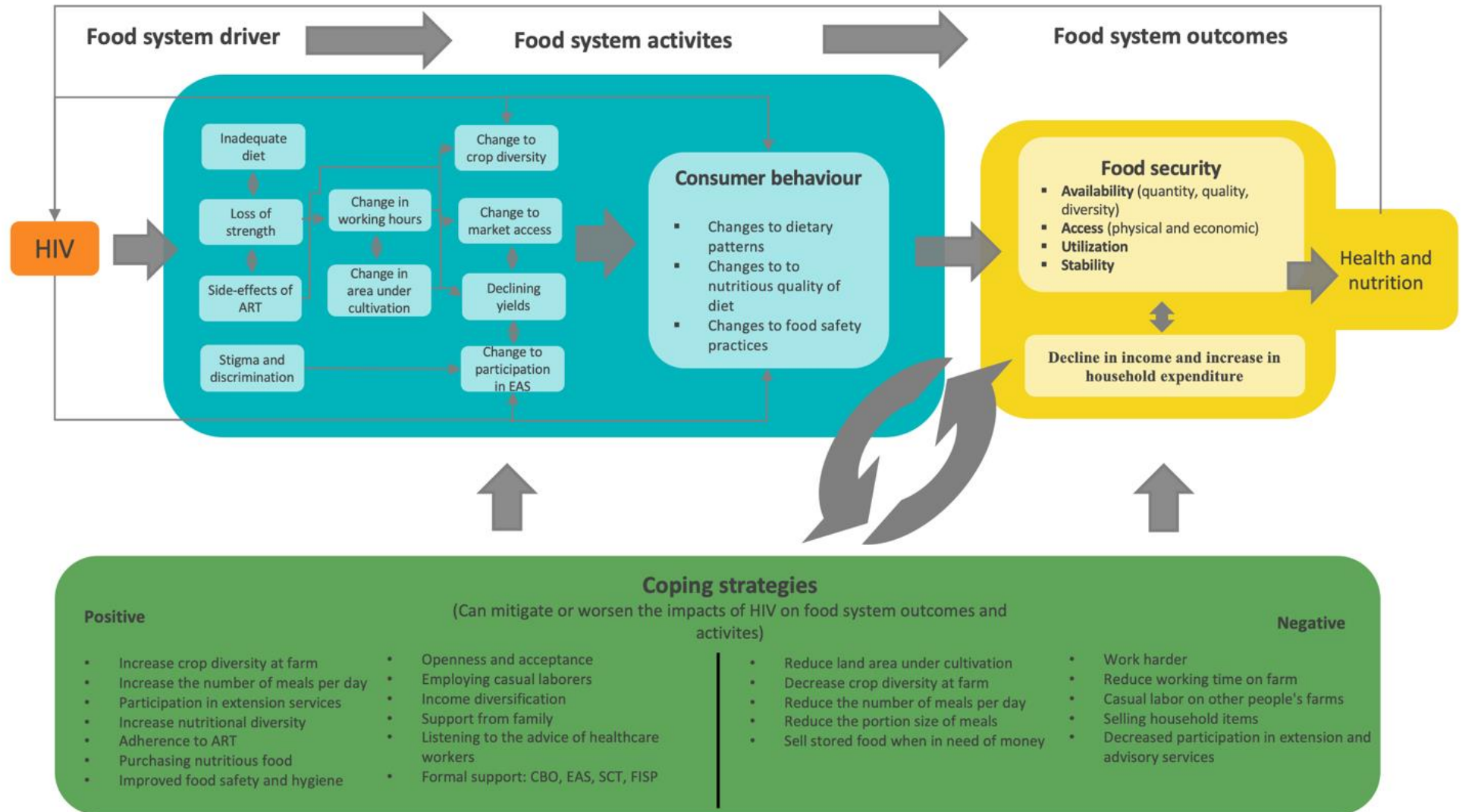
The key findings are summarized in figure 9 organized according to the food systems framework outlined earlier in this thesis. The figure illustrates the pathways and relationships regarding the impacts of HIV on the food system as a whole. What the framework shows is that HIV can impact one aspect of the food system, which not only affects the next stage of the food system, but the system as a whole. However, it is worth noting that the framework, as is the case with most frameworks, is a somewhat simplified version of reality. As argued by Frega et al. (2010, p. S293) “any model is inevitably an imperfect attempt to describe a highly complex reality.” However, the framework provides value as it highlights key causal pathways “at the price of simplifying reality somewhat” (Frega et al. 2010, p. S293). The framework shows a somewhat linear relationship, of which the reality is more complex, and several other factors drive changes to the food system for WLHIV. Nevertheless, the framework provides an understanding of the complex causal pathways through which HIV affects the food system for WLHIV in rural Malawi.

The findings reported here show, consistent with findings from other studies, that women experience several challenges related to HIV: loss of strength, increased psychological challenges, inadequate diet, stigma and discrimination and side-effects of ART. Women also report increased feelings of distress and commonly report feeling worried about their health and their children’s health, particularly regarding access to enough nutritious food.. However, I want

to stress that for some women, HIV did not cause any dramatic changes, and other factors related to living in poverty were bigger concerns compared to HIV. While HIV is a socioeconomic challenge, it is important to remember that other equally challenging issues exist in rural Malawi, affecting livelihoods and food security. The loss of a husband and lack of fertilizer were the most significant issues mentioned throughout the discussions that affected the farmers ability to produce enough food. HIV needs to be seen in light of these challenges in order to ensure that the correct policies and programs are implemented.

A key objective of this thesis was to determine the effects of HIV on the food system for WLHIV in rural Malawi. Consistent with other studies, the most common impact of HIV on the food supply chain relates to a reduction in working hours, changes in land area under cultivation and declining yields. Declining yields manifested itself in less food available to the household or less surplus to sell and subsequently less income. Some women were able to cope with these changes by diversifying income or hiring casual laborers. Other were forced to change their dietary patterns (e.g. fewer meals, smaller portions, less diversity), with likely negative impacts on food security.





**Figure 9:** The impacts of HIV on a traditional food system for small-scale female farmers in rural Malawi.

Source: Author

A much-discussed theme that emerged from the finding is that of working hours, suggesting it is an important area for WLHIV. A reduction in working hours can be seen as both positive and negative in terms of health outcomes. It can be positive as it allows the body to rest, but negative in the sense that it often leads to a decline in production with negative effects for food access. Consistent with many other studies, the results show that women are often not able to work as much and as hard as before they were diagnosed with HIV (e.g. Gill 2010; Asenso-Okyere et al. 2011; Thomas et al. 2019). However, what also becomes clear here is that equally important in terms of working hours is that a reduction does not only relate to a lack of strength or the illness in itself, but a desire for WLHIV not to exhaust the body. Even when adhering to ART, women are still not able to work like before they were diagnosed, suggesting that ART is not enough to ensure that WLHIV regain their full capacity to work. The issue here relating to working hours is that WLHIV are told to not work as hard as before on the farm, but access to social security is very limited to ensure that the lack of production which often results from decreased participation in agriculture has any negative effects on food security and health. Instead, the women are required to purchase more food from the markets with minimal resources, leaving these women and their households in a difficult financial situation.

The findings reported here show that HIV leads to several changes in terms of dietary diversity. Previous studies often report a reduction in crop diversity following HIV diagnosis, the findings here show a similar trend. However, some women also decided to increase the diversity of crops or purchase different types of food to increase the nutritious quality of their diet. Eating a nutritious, safe and healthy diet was a key theme throughout the discussion, highlighting its value for WLHIV. Previous research has shown that dietary diversity is lower in PLHIV (e.g. Gill 2010; Ncube et al. 2016) however, the results from the statistical analysis show very little difference in food consumption groups in HIV-affected households compared to non-affected households. Many WLHIV also changed their food hygiene practices ensuring they did not contract any disease. Women are of course not a homogenous group, and it is therefore not surprising that there is a difference in experiences with HIV however, it is interesting to note that costless strategies that have the potential to improve health, such as covering food to protect it from flies to stop the spread of potential diseases, is adopted by some and not by others. Possible explanatory factors for the adoption of positive health-related behaviors will be discussed below.

In line with existing literature, women adopt a range of different behavioral and cognitive coping strategies that are consistent with findings from other studies. However, coping strategies that have been frequently reported elsewhere, such as transactional sex, withdrawing children from school and selling of land were not reported here (Chop et al. 2017). This suggests that women are better able to cope with HIV than what was expected based on existing literature. Again, this suggests a positive development in the lives of WLHIV. Although there are many unfavorable coping strategies used that could lead to long-term deterioration of livelihoods, as seen in figure 9 the findings show that more positive coping strategies are used compared to negative. Formal support was limited in the communities. EAS, community-based support groups and counselling services were frequently available to the women. However, community-based support groups face issues related to funding. An issue which is commonly reported in the literature (Riehm et al. 2013).

Although there is a large diversity in experiences, I argue based on the findings reported here, that there are two key pathways through which HIV affects the food system for small-scale farmers in rural Malawi:

- (1) The deterioration of livelihoods.** As mentioned at the beginning of the thesis: the introduction of ART has been argued to transform HIV from a death sentence to a manageable chronic illness, which enables PLHIV to live a healthy and productive life (WHO 2019). However, as this research has shown not all women are able to manage living with HIV. As widely reported elsewhere, the findings of this study show that for some WLHIV, income and food reserves are reduced as a result of declines in agricultural production (e.g. ILO 2000; Backman & Booysen 2003; Fox et al. 2004; Donovan & Bailey 2006; Kaler et al. 2010; Gill 2010; Asenso-Okyere et al. 2011). The main reason for this is due to reduced working time on the farm and limited social security available to counteract the effects of working less combined with unfavorable coping strategies. When comparing the results to those of older studies, it must be pointed out that, though HIV can lead to a deterioration of livelihoods, the situation seems slightly less dark, suggesting a positive trend in terms of improved health and well-being for WLHIV. However, it is important not to forget that some WLHIV are still

experiencing the same sort of impacts of HIV on the food system as they were several decades ago. ART came with the promise of new hope, a similar life-expectancy to that of non-affected individuals and a promise of a better life, but the fact that WLHIV are still struggling with the same issues as before the introduction of ART, despite adherence to the medication, suggests that the treatment alone is not working in resource-constrained settings, as several researcher before me have suggested (Rodas-Moya et al. 2015; Nyantakyi-Frimpong et al. 2016).

- (2) The diagnosis of HIV appeared to be a **positive “turning point”** in the lives of some WLHIV in some ways, which can lead to positive behavioral change by directly impacting primary agricultural activities such as changing cropping patterns or by affecting consumer behavior. The findings show that some WLHIV started taking part in positive health-related behavior such as eating more diverse food, improved food safety and personal hygiene practices and taking part in support groups. This has previously been reported in high-income countries, such as the USA, but limited research has been done in low-income countries (e.g. Segal-Isaacson et al. 2006). A few studies from SSA have identified this trend in a very small number of individuals. In a cross-country study, including Malawi, researchers found that HIV had led to positive changes in diet (Makoae et al. 2008). Komwa, Jacobsen and Parker (2010) show that people with HI infection reported eating more nutritious and diverse food, particularly higher levels of fruit and vegetables compared to other HIV-negative participants.

## **7.2. Impact of HIV on food security**

The findings in terms of food security are somewhat mixed. The qualitative interviews show that WLHIV experience several impacts of HIV on food security, either positively or negatively. However, the quantitative analysis reveals that food security does not differ between HIV-positive women compared to HIV-negative, despite WLHIV generally having fewer assets and lower levels of education, which are considered predictors of food insecurity (Benzekri et al. 2015; Masa, Chowa & Nyirenda 201). This finding is surprising based on existing literature, which generally reports higher levels of food insecurity in PLHIV. However, this does not mean that there are not high levels of food insecurity among WLHIV it just does not differ as much between HIV-positive and HIV-negative women, as expected. As mentioned previously 64% of

Malawians report having inadequate food security (NSO 2017). The findings reported here somewhat contradict the New Variant Hypothesis, which appears to have developed into a somewhat “universal understanding” regarding the impact of HIV in agrarian communities (de waal & Whiteside 2003; Arrehag, de waal & Whiteside 2006). The New Variant Hypothesis explained simply argues that HIV diminishes the households coping capacity and ability to purchase and produce food at the household level. Although this is still the situation for some WLHIV.

There could, of course, be methodological reasons for the difference in the results found regarding food security however, I would argue, based on the findings, that there are other plausible reasons which could explain these results, as explained below:

**Women often prioritize food and nutrition over other assets.** A possible explanation could be that WLHIV are more mindful of eating nutritious and diverse food. In the interviews, the women said that purchasing nutritious food takes precedence over other HH necessities, which could explain the fact that food security does not differ despite having fewer assets. Women, in general, have been found to prioritize household food and nutrition higher compared to men, in low-income settings (FAO 2011). Evidence suggests that when resources are scarce, women generally prioritize the nutrition of the households over other personal and household assets (Kweyu Lutomia et al. 2019), which could explain the lower level of asset ownership in HIV-affected households compared to non-affected households even though food security levels are the same. Research has demonstrated how female-headed households can provide an important buffer in times of food consumption shortfalls, thus maintaining food security (Kweyu Lutomia et al. 2019).

**Exposure to nutrition education.** WLHIV have received nutrition counselling which is generally considered an important contributor to food security (Bakusuba, Kikafunda & Whitehead 2010; Hudayani & Sartika 2016). The study participants appear to be highly knowledgeable of nutrition and HIV. They are actively trying to seek out new knowledge and often expressed a desire for more counselling. It is often assumed that health-related knowledge is low amongst PLHIV in SSA (Mengie, Worku & Nana 2018). However, the findings here show

that WLHIV have considerable knowledge regarding HIV, how to take good care of oneself, the importance of nutrition, food safety and personal hygiene. It is not unlikely to assume, that WLHIV, in general, have greater access to nutritional counselling than their negative peers, and thus as already mentioned prioritize their food security over other assets. Similar to other studies, this study shows that knowledge influences dietary practices and decisions regarding food safety (e.g. covering food to protect from flies to prevent disease) (Mengie, Worku & Nana 2018). However, knowledge in itself is not always enough owing to the socioeconomic, cultural and structural factors that affect dietary behavior, which I will make clear throughout this discussion. Consistent with other studies, I find here that the translation of knowledge into practice is difficult due to financial barriers that constrain access to high-quality food (Komwa, Jacobsen and Parker 2010). For example, in Uganda, although 90% of WLHIV report being trained on nutrition and believed it was important, only 40% were able to consume six food groups, as financial realities made it difficult to eat a diverse range of food (Bukusuba, Kikafunda & Whitehead 2007).

**ART adherence.** ART adherence is consistently higher in low-income countries, compared to high-income countries (Watt et al. 2012). However, adherence is negatively affected by food security and by negative side-effects (Watt et al. 2012; Young et al. 2014). In contrast to previous studies conducted in areas where food insecurity levels are high, I find here that WLHIV strictly adhere to ART regardless of having little or no food or experiencing negative side-effects. This begs the question about how these patients have been able to overcome these barriers. Treatment adherence is a complex issue, and there are several reasons why individuals decide to adhere to medication or not (Young et al. 2014). Similar to other studies, for example from Uganda, adherence to ART was motivated by a belief that ART was responsible for keeping them healthy and by a desire to stay alive to look after the well-being of family (Crane et al. 2006). Another plausible reason for the high adherence to ART found in the study sample could be related to stable access to counselling and regular contact with the health center, combined with a motivation to improve their lives in a difficult situation. Studies have shown that achieving optimal benefits from ART requires continuous access to adherence education (Bukunya et al. 2019). Another factor could be related to the fact that the respondents experienced improvements in health after starting ART, which supported their confidence in the

medication and motivates them to adhere. Linked to this is that women may be motivated by a desire to stay healthy for their families (Ware et al. 2009).

Furthermore, lack of trust in health providers is considered to be a factor influencing non-adherence (Watt et al. 2009; Young et al. 2014). Patients do not just receive and follow advice passively but are *active* decision-makers, and so, therefore, trust in healthcare providers is essential (Munro et al. 2007). The women in the study sample frequently mentioned that they listened to the advice and education they received, suggesting they have trust in healthcare providers. Trust in healthcare providers was found to be a facilitator of adherence in PLHIV in Tanzania (Watt et al. 2012). ART adherence is linked to improved health outcomes and improved food security (e.g. weight gain) (Ware et al. 2009), so the fact that WLHIV appear to adhere to ART strictly could be an explanatory factor in the relatively similar levels of food security seen in HIV-affected and non-affected households. Another factor related to ART is that the time on ART and the time since diagnosis could be a factor which influences why some women experience food security to be affected, and others are able to make changes that are likely to lead to improved food security. Research has shown that the impacts of HIV on rural households are most severe in the early stages following infection and stabilizes during the asymptomatic phase and is dependent on the households' access to resources (Gill 2010).

**Food security is measured at the household level.** The statistical analysis includes household-level data on food security. Kaler et al. (2010, p. 511) argue that since many of the HIV/AIDS impact studies use the household as a “homogenous unit with uniform needs and interests”, as is also done here, they overlook important disparities within the households, for example in terms of differing gender roles. Household-level analysis often ignores the fact that although the household as a whole has satisfactory access to food, this does not necessarily mean that the food security needs of each household member is met (Kaler et al. 2010). Intrahousehold food distribution is difficult to track, and the varying needs and vulnerabilities of household members are often ignored, such as the increased nutritional needs of WLHIV. Frequently, while a household may be food secure overall, the unequal distribution among its members, coupled with a poor understanding of individual needs (e.g. increased calories for PLHIV), may lead to food insecurity for the more vulnerable household members (Bloem & Saadeh 2010; Gilbert, Benson

& Ecker 2019). It would, therefore, be of value to collect data on other indicators of food security, such as individual dietary diversity, specifically the Women's Dietary Diversity Score, to account for any issues regarding intrahousehold food allocation.

**Increased psychological stress.** Some of the women reported increased stress and worry following their diagnosis with HIV. Mental distress has been associated with increased food security (Tsai et al. 2013; Masa, Chowa & Nyirenda 2017). Therefore, differences in experiences with added stress could explain the difference seen in experience with food security in the interview sample. The strong association between HIV infection and depression is well established, and food insecurity further increases feelings of depression and anxiety (Tsai et al. 2013; Masa, Chowa & Nyirenda 2017; Meffert et al. 2019). Higher viral loads, lower adherence to ART and reduced engagement in care is associated with depression in PLHIV (Nakimuli-Mpungu et al. 2020) and could thus explain why some women experience more hardship with HIV compared to others.

### **7.3. Explaining differences in behavioral changes and coping abilities**

Throughout the results section I have illustrated how HIV has led to behavioral changes in terms of crop diversity, purchasing more nutritious food, changes to food safety (e.g. covering food to protect from flies) and improved personal hygiene. Furthermore, in line with these changes what has become clear is that the ability to cope with HIV as a farmer living in rural Malawi, is highly diverse. This finding provides a clear example that experiences with HIV are not homogeneous between individuals, households and across communities, regions or countries in SSA, which appears to be the conclusion that has often been suggested in the literature. The diversity of experiences with HIV highlights the need to account for these differences among WLHIV in programming and policies. The diversity in experiences also bring into questions: why is there such a large difference in coping ability and why do some adopt positive health-related behaviors and other do not? Below I will discuss some plausible reasons, based on the findings:

#### **7.3.1. Economic coping capacity**

There are a number of factors that mediate the stress of living with HIV related to economic coping capacity. According to Moser (1998, p.3) “the more assets people have, the less vulnerable they are, and the greater the erosion of people's assets, the greater their vulnerability.”



Therefore, differences in asset ownership could explain increased coping capacity in some WLHIV. In addition, women who have another source of income can purchase more food, particularly nutritious food, or hire agricultural workers to maintain the same level of production while spending more time to rest the body or other less strength consuming income-generating activities. Second, SSNs, such as SCT and fertilizer subsidies, can mitigate the possible negative effects on food security. However, formal SSN are limited in rural Malawi.

I would argue, however, that differences in assets does not completely explain differences in coping ability, especially in a setting where the majority of the population are living in poverty, with low levels of education. As mentioned, coping and health-related behavior change is a complex issue and cannot be attributed to a single factor. Social and behavioral theories related to health argue that “choices are influenced by personal preferences, habits, nutrition information, availability, cost, and placement, among other things” (Glanz & Bishop 2010, p. 401). Moreover, changes in behavior involve changes in actions over time. Some women may not be ready to make changes, while others may are ready to implement changes in their diet and activity levels (Glanz & Bishop 2010). This concept it outlined in the transtheoretical model of behavior change (Glanz & Bishop 2010).

### **7.3.2. Self-efficacy**

Self-efficacy is a key factor in social cognitive theory and is arguably fundamental to the process of behavior change. Self-efficacy refers to that having the confidence in one’s abilities can provide the necessary motivation to follow through with behavioral change (Bandura 2004). Self-efficacy affects all aspects of human behavior. An individuals’ own belief in their power to affect a situation, can strongly influence the person ability to face challenges successfully, but also the choices a person is likely to make. The effect of self-efficacy is said to be particularly apparent, and compelling, regarding behaviors which affect health (Luszczynska & Schwarzer 2005). Self-efficacy influences whether a person adopts and maintains healthy behaviors. High levels of self-efficacy means that individuals are more confident in oneself and are, therefore, more likely to engage in healthy behaviors (Luszczynska & Schwarzer 2005). Poverty (income poverty, poor health and low levels of education) and experiences of stigma have been linked to lower self-efficacy (Tsai, Bangsberg & Weiser 2013; Callander & Schofield 2016). Relating this to the study at hand it can be argued that women experience differing levels of self-efficacy,

which either facilitate or inhibit the adoption of health promoting behaviors and effects a woman's ability to cope with HIV.

### **7.3.3. Increased social capital from CBOs and counselling**

The existence of counselling services and CBOs was mentioned by the majority of women as a powerful coping resource, consistent with findings from other countries in SSA (Paudel & Baral 2015). CBOs have the potential to improve social capital. Social capital, in combination with human capital enhancement, have been associated with positive food security outcomes in Uganda (Sseguya, Mazur & Flora 2017). Increased social capital has been argued to influence behaviors of the group by promoting a quicker spread of information or increase the “likelihood that healthy norms of behavior are adopted by exerting social control over deviant health-related behaviors” (Hsieh 2008, p.165). The issue of increased social capacity could explain differences in coping by WLHIV. Social capital theories suggest that individuals embedded in social networks can access and benefits from group resources (Hsieh 2008). In addition, social capital can affect health behavior as people who are a member of a group or a community that is rich in support, trust and information, has the resources that can help to reach health goals, and inversely, lack of social capital can impair health (Lin 2005). For example, PLHIV may receive information or moral support through social groups which enables them to adopt healthy behavior related to nutrition and food safety (Eriksson 2011). Individuals with limited economic capital can use social capital as a “buffer” against the impacts of poverty on health (Uphoff et al. 2013). In a general context, the buffering hypothesis argues that in certain contexts social capital will be able to protect (“buffer”) individuals from the harmful effects of stressful situations (Cohen & Wills 1985). Research from several countries in SSA shows that social support is a key determinant in ART adherence, as the support emphasized the benefits of treatment and continually reinforced the importance of taking medication as prescribed (Ware et al. 2009). It is not unlikely to assume that community support system can have the same effects on adoption of dietary behaviors and behaviors such as covering food to protect it from flies or using more soap.

The possible benefits of community support groups are arguably more important in resource-limited settings where formal SSNs are limited such as FISP and SCTs and thus ‘community safety nets’ become more important (Ware et al. 2009). In resource-constrained settings where

extreme poverty is prevalent, social and community support structures can play a major role in enabling individual and families to sustain livelihood during times of economic shocks or downturns (Wagner et al. 2009). However, to do so, investments in expanding access to CBOs and community support systems are required. Funding from NGOs and donors should be integrated into existing community support structures, rather than implementing new programs that often phase-out after the project ends, which is commonly reported as a concern regarding the work of NGOs (Swidler & Watkins 2009).

#### **7.3.4. General positive trends in development**

Social cognitive theory argues that positive behavior change may be due to the reduction or elimination of barriers (Manro et al. 2007). The fact that women are adopting more positive behavioral changes in this study, compared to the literature could be a result of an overall positive developmental trend and improved human welfare in Malawi.

#### **7.3.5. Social and cultural norms influence food choices**

Studies have shown that cultural beliefs and cultural preferences for food are strong determinants of eating behaviors (Rodas-Moya et al. 2015). A challenge of attaining diverse diets in Malawi is the strong preference for maize nsima, a dish made mostly of maize flour (Ragasa et al. 2018). These cultural elements could explain why some women choose to change their diets while others to not. The cultural perspective is helpful to understand the numerous factors that affect eating habits (HLPE 2017).

#### **7.5. High access to extension and advisory services, but is it useful?**

Another key finding from this thesis relates to EAS, which is considered an important aspect of agricultural development, and thus important in this context (Christoplos 2010). WLHIV generally report high access to EAS and no difference in access was found between HIV-positive and HIV-negative women, despite reports of women feeling discriminated against. However, it is important to distinguish between access and usefulness. Having access to EAS does not necessarily mean that it is useful. Similar to findings reported in other studies, the results show that implementing the teachings were difficult due to lack of inputs (e.g. manure) (Ragaza & Mazunda 2018). Teaching women technologies that they are not able to implement is not only a waste of limited financial resources, but also a waste of valuable time and strength that is

required to participate (e.g. walking to village centre/demonstration sites). What could be of value in regard to WLHIV is teaching labor-saving technologies (Mandumbu & Mariga 2017). Labor-saving technologies will require less time spent in the field and more time to rest the body or to spend on other income-generating activities that require less strength. Mandumbu and Mariga (2017) argue that technologies such as conservation agriculture, mycorrhizal inoculation technology, intensified cropping, and biochar-based soil amendments have the potential to increase the resilience of WLHIV. Agroecological practices, such as cereal legume intercropping and stubble mulching, have also been found to improve food, dietary and income needs of PLHIV (Nyantakyi et al. 2016). However, studies have also shown that conservation agriculture interventions have increased the workload for women which could have negative consequences for food security when considering the women's role as the primary caretaker responsible for feeding at the household (Johnston et al. 2018). Therefore, agricultural interventions targeted towards WLHIV need to consider the specific time constraints of women and strength constraints related to being HIV-positive in order to implement successful agricultural interventions.

#### **7.6. Enacted stigma or internalized stigma?**

HIV is arguably one of the most stigmatized conditions there is (Turan et al. 2018). Discrimination in terms of access to support systems was a recurrent theme across the interviews, reflecting the importance of the issue in the lives of the women. However, the statistical analysis suggests that discrimination is not related to their HIV status. It appears, in fact, to be the opposite: HIV-positive individuals are more likely to receive SSNs, suggesting that the targeting is effective. Although, as mentioned, this does not mean that there is unfair distribution of support, a finding which is commonly reported in the literature (Chirwa et al. 2015; Duchoslav & Kenamu 2018), it does, however, suggest that it is not related to being HIV-positive. The fact that women relate this to HIV could be related to internalized stigma. High rates of internalized stigma has been reported in WLHIV and is significantly associated with food insecurity (Brouard 2006; Tsai et al. 2012). Internalized stigma refers to feelings and behaviors that stem from an individual's own negative perception about themselves based on their HIV status (Holzemer et al. 2007). The fear of experiencing discrimination can influence

the way in which PLHIV view themselves and how they cope with living with HIV (Brouard 2006).

Internal stigma may discourage people from disclosing their status or cause them to avoid seeking healthcare if they feel shame and guilt or fear of rejection (Brouard 2006). Frega et al. (2010) argue that food insecurity is not only worsened by physical factors such as HIV-related illness leading to job loss and asset depletion, but also by social factors such as HIV-related stigma leading to reduced ability to draw on social networks for assistance. Stigma is a damaging social phenomenon and can have negative effects on health outcomes for PLHIV, including non-adherence to ART, lower healthcare visit attendance, isolation and increased levels of depression, and overall lower quality of life (Tsai et al. 2013; Paudel & Baral 2015; Turan et al. 2018). Another plausible reason related to why the women in the interviews report experiencing discrimination could be that in a situation of poverty it is not unlikely to assume that women may exaggerate their situation as they believe this may lead to more support. An extreme example of this is that there have been cases in which the potential for financial incentive has had a perverse effect on increasing HIV risk behavior (Ostermann et al. 2015).

## **8. Conclusion**

This study has demonstrated the diverse range of circumstances, across the food system that occur when small-scale female farmers in rural Malawi are diagnosed with HIV. The impacts of HIV are felt at several points throughout the system, including primary agricultural production, market access and consumer behaviors. HIV, through its impact of the food system, can lead to the deterioration of livelihoods or in some cases, act as a positive driver of change resulting in improved diets and food hygiene practices. Women also frequently report that being diagnosed with HIV led to no significant changes to their current situation and that there are other factors related to living in poverty that contribute to hardship more so than HIV.

What is perhaps most surprising, is that HIV appears to contribute less to hardship than what was expected based on existing theory. The data suggest that the effective distribution of ART combined with effective nutrition counselling and community social safety nets, and in some cases also access to formal social security relieves some of the negative effects of living with HIV that have previously been reported in the literature. As Malawi continues to invest in

universal health coverage, it is not unlikely to assume that this support will continue and perhaps be scaled up. Translating knowledge into healthy dietary practices was often found to be difficult due to high levels of poverty. However, women frequently report prioritizing eating healthy over purchasing other assets. Community social support appears to be especially important, contributing to improved social capital and acts as an arena for women to receive advice and support from peers. The statistical analysis shows that there are no strong and significant differences between HIV-positive and HIV-negative women with regards to food security, although high levels of food insecurity are found in both groups. Despite what the women themselves feel, the statistical data shows that WLHIV are more likely to receive formal social security and EAS, compared to HIV-negative women, suggesting that targeting is effective and not discriminatory based on a positive HIV status.

It appears that the general trend for WLHIV in rural Malawi has improved in recent years, suggesting that the large investments made into the HIV epidemic that have occurred, both internationally and nationally, in the past two decades has had a positive impact in the lives of HIV-positive populations in Malawi. The fact that women seem to adopt more positive coping strategies compared to negative strategies also supports this conclusion. However, despite what appears to be a positive trend, this is not the case for all women, especially when considering the fact that some women are still struggling with the same issues that WLHIV faced over two decades ago. More interventions are needed to address these issues. WLHIV felt that different types of livelihood interventions, such as learning more technical skills related to agriculture, learning about income-generating activities and access to financial services like village savings banks or credit schemes to start a small-scale business, would improve their quality of life as it would make them less dependent on support from other sources.

I have throughout this thesis aimed to highlight the diversity of experiences with HIV for women in rural Malawi. It is often far too easy, even unintentionally, to categorize people into groups with the same problem that requires the same solution. Perhaps generalizations can be useful and sometimes necessary to make policy, but by doing so, we ignore the unique background, personality, opinions, strengths and vulnerabilities of each individual woman.

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## **Appendix A – Interview guides**

### **Interview guide for interviews**

#### *Food value chain*

1. What do you perceive to be the major challenges of having an illness such as HIV when working as a farmer?
2. Have you observed any changes since you were diagnosed in terms of crop choices, cropping patterns, areas under cultivation, agricultural activities you participate in and different technologies?
3. What is the approximate length of a working day? Have these hours changed since you became ill?
4. Have you changed the way you store, prepare or distribute food since you became ill?
5. Has your ability to access markets or sell produce at markets been affected by your illness?
6. How do you feel your illness has influenced or not influenced your ability to generate an income and produce enough food through working in the agricultural sector?

#### *Food security*

7. Has your illness affected the amount of food you have available to the household?
  - If yes, ask to elaborate why and the possible impacts of this.
8. Have you changed any consumption patterns since you became HIV-positive?

#### *Assets*

9. Since you became ill, what increased expenditures does the household incur?

#### *Coping mechanisms*

10. What strategies have you developed to deal with illness?
11. Do you rely on any external support systems to cope? (e.g. government, NGO etc.)
12. Do you feel positive about your future?
13. How do you feel external support can be optimized to better suit your needs?
14. Anything else?

**Focus group discussion topics**

- Six food groups
- Hygiene
- Side-effects of ART
- Support services – CBOs and EAS
- Distribution of support



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