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Culture, Play and Health: A Folk Media Approach to HIV and AIDS Research in Rural Malawi

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Abstract

Background: HIV and AIDS remains a significant health, social and economic problem in Malawi. Despite improved availability of free HIV related services, multiple behavioural change interventions and high levels of awareness, HIV and AIDS remains the leading cause of death in Malawi. Like other health issues, the response to HIV and AIDS has been significantly affected by colonialism and imperialism where impositions of western naming, understandings, ways of thinking, conceptualizations of disease and treatment practices were made on indigenous populations. Strong arguments have been made to say that HIV and AIDS interventions in Malawi and SSA have often failed because they have largely been conceptualized in western countries and have ignored the realities of the local populations. Attempts to alleviate impositions of interventions and efforts to try to understand communities have been made through calls for dialogical approaches. However, the methods used to dialogue are often imposed on communities which makes it difficult to engage in a truly dialogical, meaningful and transformative manner.

Aims: In this study I explore how to work with communities within the paradigms of their own cultures. I investigate how two rural communities in Malawi understand and make sense of HIV and AIDS and the ways in which folk media as a cultural resource and paradigm can facilitate this research.

Methods: The approach I took is grounded in decolonial thought and indigenous research methods but also in a critical appraisal of these which led me to conceptualise my work in the terms of folk media. Through folk media workshops in two communities, I worked with community members to elicit and explore understandings of HIV and AIDS using forms of expression of their own choosing. These workshops were video recorded, and participants and I also kept audio diaries/fieldnotes of reflections on the process. These data were analysed collectively with participants and, then, post-fieldwork, using a thematic analysis method.

Findings: The research elicited accounts of how HIV and AIDS was initially received by the two communities at the outset of the pandemic. These accounts reveal how these communities first sought to interpret the ‘new’ condition using their existing paradigms, notably conditions which produced the same symptoms. Over time and with the accumulation of experience, the communities came to accept that HIV and AIDS was indeed something novel and not a condition that they had encountered before. However, participants also revealed a range of ways in which biomedical narratives of HIV and AIDS are contested and in tension with their everyday lives. Participants also explored how they approached treatment for HIV and AIDS at length, enabling the construction of a model of treatment-seeking practices, which elaborates the multiple and syncretic approaches that the two communities take. Finally, the thesis reflects on the power of the folk media methodology used in this research to elicit narratives which often remain hidden from community outsiders. In doing so, a methodological model for folk media research is proposed and its limitations considered.

Conclusions: The folk media approach that I have developed and deployed in two Malawian communities enabled the generation of rich, contemporary, accounts of how participants make sense of HIV and AIDS. The accounts shared as part of the research included cultural knowledges that are often hidden from ‘outsiders’, demonstrating the potential of the method to enable better understandings of these communities and their needs. However, the method alone has limitations and needs to be followed by dialogical action to address contestations and tensions which have health-damaging consequences. This dialogical action might be grounded in the methods developed in this project, to avoid further imposition-based public health intervention in the two communities.

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Author’s Declaration

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Printed name: Sharifa Abdulla

Signature:

Definitions/Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
CD4	Cluster of Differentiation 4 (essential white blood cells)
GVH	Group Village Head
HIV	Human Immunodeficiency Virus
NGO	Non-Governmental Organisation
SGVH	Senior Group Village Heads
SSA	Sub-Saharan Africa
TA	Traditional Authority
TFD	Theatre for Development
UN	United Nations
UNAIDS	The Joint United Nations Programme on HIV and AIDS
UNESCO	United Nations Educational, Scientific and Cultural Organization
VH	Village Head
WHO	World Health Organization

1. Introduction

This thesis reports on a study that explored how two rural communities in Malawi understand and make sense of HIV and AIDS using folk media as a method for knowledge generation. Folk media have been described by Ansu-Kyeremeh as:

> any form of endogenous communication system which, by virtue of its origin from and integration into a specific culture, serves as a channel for messages in a way and manner that requires the utilization of the values, symbols, institutions and ethos of the host culture through its unique qualities and attributes. (Ansu-Kyeremeh 1998:3).

Sub-Saharan Africa (SSA), a region of 48 nations including Malawi, is the region most affected by HIV and AIDS and is home to over 70% of the total number of people living with HIV across the globe (UNAIDS 2017). Two out of three of the estimated 6000 new infections that occur in the world every day are in Sub-Saharan Africa (UNAIDS 2017). Malawi accounts for 4% of the total number of people living with HIV in the region (UNAIDS 2017).

This brief introductory chapter sets the scene for my study. First, I briefly describe the HIV and AIDS situation in Malawi considering the impact it has had on the country and its population and provide a brief overview of the current epidemiology of HIV and AIDS. Second, I describe government and health system responses, highlighting that HIV and AIDS interventions in Malawi and SSA have usually failed because they have been conceptualized in Western countries and ignored the realities of the local populations. I then briefly describe the aims of this study and why a folk media approach might offer an opportunity to engage meaningfully with the realities of rural Malawians. Before moving on to a review of the relevant literature, I articulate my positionality in this research and finally I describe the chapter layout of the thesis.

1.1 The HIV and AIDS Situation in Malawi

Lwanda (2002) suggests that the HIV and AIDS story began in Malawi in 1985 when its first case of AIDS was officially diagnosed. The epidemic hit the country hard and has since become one of the major causes of mortality affecting all sections of society. In 2002, almost one in five adults were living with HIV (Government of Malawi 2002) and more than 70% of beds in hospitals were occupied by AIDS patients (Mwale 2002). At that time, without accessible treatment, the epidemic decimated the population and had unprecedented impacts across all sectors of society. It became the leading cause of death in the country responsible for approximately 86 000 deaths annually (WHO 2005).

At individual and household levels families experienced great suffering as they struggled with illness and death of household members. In addition, a vicious cycle in the relationship between HIV and AIDS and poverty emerged (Arrehag, De Vylder and Durevall et al 2006). The levels of poverty for most families worsened due to the illness and loss of income generation. Large numbers of children were orphaned, and elderly people left destitute through the loss of family sources of support (Mwale 2002). In trying to cope with illness, death and social obligations, some poor families had to send household members, including children, to work as casual labourers (Bollinger, Stover and Palamuleni 2000; Arrehag, De Vylder and Durevall et al 2006). Others had to sell their only piece of land to raise money to survive but in doing so, became landless, which meant they could not farm to produce food for themselves. This, in turn, put them at further risk of contracting HIV because payment for 'sexual favours' was one of the few means families had to raise cash.

At national level, the country struggled with the impact of HIV and AIDS in all sectors including health, education and agriculture. There were tremendous losses of skilled workforce members in all sectors that led to low productivity. In education, loss of teachers meant that classes became much larger, and the quality of education lowered (Mwale 2002). On the other hand, loss of parents and guardians for children meant low pupil enrolment in schools and increased school dropouts (Arrehag, De Vylder and Durevall et al 2006; Mwale 2002). All of which made HIV and AIDS a serious national public health and socio-economic crisis for the Malawian people (Mwale 2002).

Currently Malawi's HIV prevalence is at 6.3% overall and 10.6% among adults (U.S. Department of State 2019). Although a small country with an approximate population of 17 500 000 (National Statistical Ofiice 2019), in 2019, there were 1 100 000 people living with HIV with 33,000 new infections and an incidence of

1.94 per 1000 of all population and 3.7 for the 15 to 49 age groups (UNAIDS 2019). In the same year, there were 13 000 deaths due to AIDS with 460 000 children orphaned by the disease (UNAIDS 2019).

In recent years antiretroviral treatments (ARTs) for HIV have been shown to be highly effective in managing HIV so that with good access and good adherence to ART, people with HIV can live long and healthy lives (WHO 2015). Malawi has increased availability of HIV related services with local health centres providing free, integrated HIV services including prevention, testing, treatment and care across the country (UNAIDS 2017; Ministry of Health 2017). Prevention strategies include provision of free condoms (predominantly male with some female condoms); testing strategies include free, Voluntary Counselling and Testing (VCT); and treatment strategies include universal, free access to treatment for all with ART initiated as soon as diagnosis is made (a treatment strategy called ‘Test and Treat’).

These services mean that Malawi has made good progress in achieving the World Health Organization’s (WHO’s) so-called “90-90-90 targets by 2020” for HIV (UNESCO 2017; Ministry of Health 2017; Ministry of Health 2016). These targets refer to the ‘HIV cascade’ of needing to achieve high levels of testing, high levels of treatment and high levels of viral suppression so that by 2020, 90% of people living with HIV should have been diagnosed, 90% of those diagnosed would be on antiretroviral treatment and that 90% of those receiving treatment would have their viral load suppressed. The UNAIDS Country Reports 2019 (UNAIDS 2019) showed that Malawi had achieved these targets, with 90% of people living with HIV currently knowing their status, of which 88% are on HIV treatment of which, 92% are virally suppressed.

However, after 35 years of HIV and AIDS in Malawi, controlling the virus remains a constant struggle. There are still 10% of people living with HIV who do not know their HIV status and with an estimated 33 000 new infections still occurring in a year (UNAIDS 2019) the numbers are likely to rise. Although 88% of those who know their HIV status are on HIV treatment, only 79% of all those who actually have HIV are on treatment, meaning 21% of people with HIV are not being treated. Similarly, although the HIV virus is suppressed in 92% of those on treatment only 72% of all people living with HIV have their viral load suppressed which means that 28% of people with HIV do not have their viral load suppressed (UNAIDS 2019) and could be highly infectious. Perhaps Malawians are missing something.

A Malawian proverb suggests that *umanena chatsitsa dzaye kuti njobvu ithyoke nyanga* (you ought to explain what caused the fruit to fall and break the elephant's tusk). The interpretation of this proverb is two-fold. Firstly, it means that one must find and explain the main/underlying causes responsible for a phenomenon rather than focusing on secondary ones (Kayange 2014). Secondly, it challenges existing explanations as being insufficient to explain the existing phenomenon and demands a deeper and more critical examination and explanation. In this case, it is important to look back to early encounters with the epidemic to understand the main underlying causes of high HIV burden and how they played out to affect the current HIV and AIDS situation.

1.2 Malawi's Response to HIV and AIDS and Its entanglement with Colonial Debris

The response to HIV and AIDS and to health in general in Malawi, as in the wider region, has been deeply affected by colonialism and imperialism which imposed western, biomedical naming, understandings, conceptualizations of disease and practices of medicine on indigenous populations (Dionne 2018; Kagaayi and Serwada 2016; Lwanda 2002). In recent times, neo-colonial tendencies can be observed from world-wide bodies which set the approaches to treatment and responses to pandemics such as HIV and AIDS for African countries. Impositions of colonial knowledge and epistemology on incompatible indigenous understandings during the colonial era laid the foundations for future engagements with HIV and AIDS.

In Malawi, HIV and AIDS appeared just 20 years after the country's independence from British colonial government. Malawi was colonized by the British following Dr David Livingstone's arrival in the country in 1859 which was later followed by other missionaries from the Anglican church in 1861 and the establishment of the Free Church of Scotland in 1875, and later the founding of the African Lakes company in 1878. With the increasing numbers of British settlers, Malawi was declared a British protectorate in 1891(Lwanda 2002). Lwanda (2002) explains that arable land was taken away from the control of the Malawian chiefs along with economic power which in turn ripped apart many legitimizing social constructs and upset local law and order of the people. When Chiefs tried to resist, they encountered persuasion and/or force from the colonial government. Many of the local people were forced to work at tenants on their own lands often under the form of what Lwanda (2002) calls the exploitative *thangata* (Indentured Labor System), while others worked as domestic servants for the British settlers. The local cultures of the people were suppressed, and Western, Christian values were forced on the indigenous populations.

Malawi gained independence in 1964, when Dr Hastings Kamuzu Banda, who was educated in the West and spent most of his life prior to his return to Malawi in 1958 in America and the United Kingdom, took over the Malawian Government (Alexander 1995). Lwanda (2002) argues that Dr Hastings Kamuzu Banda's style of leadership mimicked that of the previous colonial masters, in which his one-party state maintained the capitalist, extractive, economic apparatus imposed by the British, with new Malawian political leaders and elites taking the place of the colonial masters. This included further land being taken from the rural population and reinforced their colonial-era strategy of undermining cultural practices and values, forcing them away from the gaze of the powerful. Banda's style of leadership is also reflected in his adoption of approaches to HIV and AIDS that were riddled with undigested and uncontextualized Western HIV and AIDS prevention strategies that were simply imposed and ignored the realities of rural Malawians.

In her book *Doomed Interventions: The Failure of Global Responses to AIDS in Africa*, Dionne (2018) explains that HIV and AIDS in Malawi and Africa more generally has often been approached with interventions that are imagined and designed in the Global North. Although with good intentions, these interventions do not work in the way they were intended because they ignore the realities of the contexts in which they are applied (Dionne 2018). Many interventions and methods of inquiry fail because they work from a Western-inspired paradigm which is alien to the communities and the people for whom the initiatives are intended (Abdulla 2020; Dionne 2018; Kovach 2009; Chinyowa 2009).

Attempts to alleviate impositions of interventions and efforts to try to understand communities have been made through calls for more participatory approaches which result in interventions that are more culturally appropriate. These approaches include dialogical approaches which include the popularization of Arts Based Approaches across the SSA region. However, as I and others have argued, even with dialogical and Arts Based Approaches, the methods and art forms used to dialogue are often imposed on communities which makes it difficult to meaningfully engage in a truly transformative manner (Abdulla 2016; Chinyowa 2009; Beck 2006).

Further calls have since been made to ground development principles and efforts in peoples' own experiences, using their own cultural resources (Chisiza 2017; Abdulla 2016; Abdulla 2013; Chinyowa 2009; Chinyowa 2005; Darder, Baltodano and Torres 2003; Escobar 1995; UNESCO 1995; Mda 1993). Given that HIV and AIDS is not only a development issue but is also a public health and social issue, the need for culturally relevant approaches to both understanding and intervening in HIV and AIDS in local communities cannot be overemphasized. In more recent times, methodologies to decolonize research processes have emerged and the use of indigenous methodologies as a decolonizing approach has been encouraged (Smith 2012; Kovach 2009; Chilisa 2011).

Thus far we have seen that Malawi has been hit hard by HIV and AIDS with a vicious circle in the epidemic's relationship to poverty. Although treatment can now lead to a long and healthy life, and services have been transformed, there is still a significant burden of HIV and AIDS and a risk that unless the response evolves, progress will slow or reverse. Interventions are not always appropriate and suited to the rural Malawian way of life and ways of thinking and acting that are external to the communities have been imposed on them. These impositions are likely to be one of the reasons that HIV and AIDS interventions fail. It was these concerns that drove my research. I wanted to explore whether we can learn to work with communities within their own epistemologies and to explore whether some of the solutions to the HIV and AIDS burden can come from within, or in dialogue, with these communities.

1.3 Aims, Research Questions and Rationale for the Research

In this study I aimed to explore how two rural communities in Malawi understand and make sense of HIV and AIDS using folk media as a method for knowledge generation. My research addressed the following research questions:

1. How do rural communities in Malawi understand and make sense of HIV and AIDS?

2. In what ways can folk media facilitate research about HIV and AIDS in rural Malawi?

Since over 80% of the Malawian population is rural (Worldometer 2020; WHO 2015) I felt that an important first step was to learn how rural communities understand and make sense of HIV and AIDS. Scholars have suggested that intervention programs and services that are grounded in local realities and which engage with the cultures and meaning systems of communities are more likely to be successful (Chisiza 2017; Abdulla 2016; Abdulla 2013; Chinyowa 2009; Chinyowa 2005; Darder, Baltodano and Torres 2003; Escobar 1995; UNESCO 1995; Mda 1993). Drawing from this suggestion, this study takes up folk media as a potential method for HIV and AIDS research within rural communities.

Folk media forms such as songs and dances, dramatic enactments, folk tales, drumming along with their community specific nuances have a very deep historical and functional embeddedness in Malawian communities (Kamlongera, Nambote and Timpunza-Mvula 1992; Kerr 1979; Chinyowa 2007, 2005). They have functioned as educative, deliberative and constructive spaces and have also been crucial as spaces of resistance to oppression (Kerr 1979; Lwanda 2002). Because of the familiarity and embeddedness of folk media in Malawian cultures I thought their use in my research would provide an opportunity to move away from imposed Western ways of researching and engaging with rural communities and allow me to position the whole inquiry within the cultural paradigms of the communities I was working with.

1.4 Positionality

Positionality has been described as a reflexive statement of a researcher's acknowledgement of their position in relation to the social and political context of the study (Qin 2016; Brydon-Miller and Coghlan 2014). As Brydon-Miller and Coghlan (2014) argue, it is important for researchers to be conscious of themselves as "intentional agents" who research and write about other people's experiences. Since the professional and personal experiences of the researcher shape the inquiry, it is important for the researcher to be transparent about these experiences (Qin 2016; Brydon-Miller and Coghlan 2014). In this particular case, the HIV and AIDS epidemic in Malawi and the subsequent responses are deeply interwoven in the Malawian people's biographies, and my biography as a researcher and "intentional agent" is one of many. In the sections that follow, I describe some pivotal experiences that have influenced my approach to this research.

I am a Malawian woman, mother, wife, scholar and Theatre for Development (TFD) practitioner holding a lecturer position with the University of Malawi, Chancellor College, in the Department of Fine and Performing Arts. I hold a BA in Arts Humanities from the University of Malawi and an MA in Dramatic Arts from the University of the Witwatersrand, South Africa. Before embarking on my PhD research, my work focused on the design and development of Participatory Arts based methodologies that integrate communities as vital agents of change. I have been designing, developing and leading the implementation of participatory health related programs in Malawi including co-founding the Art and Global Health Center Africa (www.aghcafrica.org) for the past 12 years.

1.4.1 My experience working with communities

Through facilitating participatory theatre work in rural communities to explore contextual barriers to accessing HIV related services, as well as mobilizing communities to create community action plans to address them, I have encountered many narratives of HIV and AIDS. I learnt that in some cases, people live in very short proximity to HIV and AIDS related services, but for some reason do not access them. I also found that despite having accurate biomedical information, narratives of fear, stigma and discrimination still lingered in most of the communities. For instance, in 2016, I was leading the implementation of an interactive film project titled *MaKe Art Stop AIDS* in Chingale area, Zomba district Southern Malawi. The community welcomed our team with their own songs and dances, as well as dramatic performances. A community drama group performed first, followed by a support group of people living with HIV. In both cases, messages of despair and pleas to avoid HIV and AIDS because it is was a merciless killer were communicated multiple times. While the support group was established as a space of support for people living with HIV, their performances expressed hopelessness. These performance forms provided insight into the fears of the people, making them a potential source of knowledge about peoples' understandings and experiences with HIV and AIDS.

1.4.2 My personal experience with loved ones

Apart from my work, I also have very personal experiences of HIV and AIDS. In 2003, at a time that Antiretroviral Therapy (ART) was not widely available in Malawi, I lost my cousin (we grew up in the same household) after a very long battle with AIDS. In 2018, when ART was widely available, I lost my father to HIV-related illness, and in the same year, I lost my younger sister to the same illness. I watched them fight for their lives, but slowly get weaker and weaker until they could fight no more. The death of my cousin in 2003 started my journey in working with people affected by HIV and AIDS. Although painful, I could come to terms with his death as there was no universally available treatment in Malawi at the time. But, at the time of my father's and my sister's death, ART was universally available. My sister's death could have been prevented. Even though my sister understood the consequences, she did not take her ART medications which resulted in a lot of suffering and ultimately her death. As can be seen, I am one of the many Malawians who have experienced loss due to HIV and AIDS and an example of what the epidemiological numbers represent on the ground.

Thus, my interest in exploring the narratives of HIV and AIDS from the perspective of rural communities comes from my engagement with rural communities, as well as my personal need to understand how other people have experienced HIV and AIDS and how they make sense of those experiences. This is important because how people understand, experience and make sense of phenomena creates narratives and myths that can become powerful in influencing behavior irrespective of their truth or falsity. I thought it important, then, to reflect on my personal experience with narratives and myths.

1.4.3 The reality of myth in my life

I grew up knowing that children do not eat eggs, that if you urinate on the road or footpath, your mother's breasts would fall off (even if you urinate in the bush and your urine happens to flow onto the path) and that you should never use a pestle on the ground because if you do, you are grinding your grandmother's back and therefore could cause her to be unwell or even die. However, the consequences of these rules were not without redemption, there was another set of rules that enabled you to undo what you had done. But even then, you still had to face the consequences of a tortured little mind wondering whether the neutralization had worked or not, constantly checking in on your mother or grandmother to make sure they were alright. I cannot begin to explain the gravity of the reality of these narratives to me as a child growing up in rural Malawi. They were as real as day and night and as simple as 1,2,3. This ensured that the rules were self-enforced.

As I grew older, I realised that these narratives were not true, they were myths. I also realised that regardless of their truth or falseness, we believed them and that was all that mattered. The narratives served a very important function in keeping social order and hygiene and generally contributed to safeguarding the general wellbeing of everyone. For instance, the rule about children not eating eggs was meant to protect the eggs from being stolen by children, eaten and finished before any chicks had hatched. The second rule helped to keep the footpaths clean and hygienic because most people walked barefoot. Not only did these rules enforce an active care for the whole community, they also gave us (children) a chance at practicing responsibility and learning that our actions can have consequences on not only us, but others close to us.

Although the examples I have given have been easier to discard as an adult, there are some narratives that still linger in my mind so that even though I know that they have no logical basis, they still affect my responses. For instance, it is said that the number of doves one sees can predict the experience soon to follow. If you saw one dove, it meant sorrow was coming, two doves meant gladness, three for receiving a visitor and four for receiving a letter and so on and so forth. Each time I see one dove, I get troubled wondering what would go wrong and bring me sorrow. I often take extra care in my interactions of the day. This points to the power of narratives regardless of whether they are scientifically true or not and why it is important to acknowledge and engage with these narratives, whatever they may be as they make up a big part of who we are and our responses to phenomena.

1.4.4 Living with my plural self and family

I come from a mixed background. My paternal grandfather was Indian, and my grandmother was mixed (Indian and Black). My father was what we call "coloured" while my mother was black. My grandmother and my mother lived in a village in Chikwawa, a rural district in Malawi. As a small child, I lived with my grandmother (Muslim) and sometimes with my mother (Christian-Pentecostal) in the village. However, I was mostly raised by my father's sister (aunt) who was married to a man (Christian-Catholic) born from a white British man and a coloured woman. In this family, I was considered closer to black than I was to coloured. I was the darkest with the kinkiest of hairs. My aunt did her best to make me appear less black by growing my hair and making sure I spoke what she considered good English. On the other hand, when I lived with my mother, I was not considered black. As I lived most of my life with my aunt and her family, I constantly felt I did not belong. The same happened when I lived with my mother. I had difficulty reconciling these multiple parts of my identity. So, when I lived with my aunt in the city, I worked to become more like a non-black person to fit in with my family and community. This community identified more with what would be considered western-like ways of life. And when I lived with my mother, I worked to fit in as a black person and with a Malawian rural cultural life. As I grew older, both my aunt and my father forbade me from dating black boys and often said that any other race would be acceptable, except black. Although in their presence I agreed to avoid conflict, this created a rebelliousness in me so much that I dated only black boys and was bent on never marrying any other race but black. When I moved out into my own space, I realised I could just be me and was able to embark on a journey of renegotiating and reconciling who I was. My journey continues but since then, acknowledging that multiple parts of me can co-exist and complement each other without sacrificing one for the other, has helped my life become more meaningful. As can be seen I have embodied the struggle and tension between Western culture and Malawian rural culture. My story also suggests that imposition can often trigger resistance and a rebellious attitude towards whatever is being imposed. The experiences described above have contributed to my strong belief that respectful and dialogical encounters with rural communities is the most effective approach to engagement.

In summary, my positioning in this research is as a Malawian who has lived in rural Malawi and like many rural Malawians has been closely affected by HIV and AIDS. On the other hand, I do not currently live in rural Malawi, let alone in the communities of this research. I am not of the particular ethnic groups that are of these communities and most importantly, like most scholars in Malawi, I have been educated in a Western system of education and this research is part of my study with an institution in the Global North. Thus, I acknowledge my own position as a possible “insider who is also an outsider”. As I have described in my earlier work, even in the absence of explicit Western influence, the realities of people living within the same country can vary in some cases tremendously, creating a dynamic of “internal externals or insiders that are outsiders” (Abdulla 2020:18).

1.5 Chapter Layout

As I have earlier pointed out, Malawi’s response to HIV and AIDS has been entangled with the debris of colonialism. This entanglement has been suggested as the reason why, despite significant efforts by government and other stakeholders, the HIV and AIDS burden has been slow to ease. In Chapter 2, I explore literature about the historical context of this entanglement and trace its effects to the present. I begin by considering aspects of colonialism and how their encounters with indigenous Malawian cultures created tensions that directly affected HIV and AIDS in Malawi. I situate my study within the broader context of the literature that addresses efforts to mitigate these tensions.

In Chapter 3, I describe the folk media methodological approach to this study. In unpacking the folk media approach, I describe my conceptual framework, provide a background to folk media use in Malawi, outline folk media forms used in the study, and, describe the relationship between folk media and the Chewa epistemological context. I explain how alongside the folk media approach I drew on participant observation, a conventional anthropological method. After establishing the methodological approach, I go on to describe the practical application of the folk media methods. Here I start by briefly describing the Malawi traditional leadership structure. Then, I outline how I identified the communities, negotiated the research with community leaders (chiefs) and my support in the field. I then go on to describe the research process, methods of analysis and ethical considerations.

Chapter 4 is the first of two chapters that present the findings of this study and considers narratives of HIV and AIDS in the communities in which I worked. To answer the first research question, I provide an account of how members of the two communities participating name and make sense of HIV and AIDS. I present the perspectives and understandings of a range of community members and chiefs as they continue to grapple with the many sides of the HIV and AIDS epidemic. I approach these topics through an analysis of narratives that emerged during folk media workshops (songs, dances, dramatic enactment, storytelling), verbal journal entries, community performances and post-performance interviews.

Chapter 5, which considers community perceptions and perspectives on HIV and AIDS treatment, continues to present analysis that answers the first research question. In this chapter, I use two Malawian proverbs as a framework to understand how the communities who participated in the research make sense of HIV and AIDS treatment and healthcare. Through the proverbs, I explore the nature of general treatment seeking practices within the two communities and their relationship to HIV and AIDS. I also discuss the perceived challenges and experiences of the participants with the current HIV and AIDS treatments and structures.

In Chapter 6, I attempt to answer the second research question, which seeks to explore the ways in which folk media can facilitate research of community understandings of HIV and AIDS in rural Malawi. Borrowing from *pamtondo* a Malawian cultural performance and workspace, through the recreation of what I call “the *pamtondo* effect”, I argue that playfulness within indigenous cultural performances can be a useful frame for research when working with rural communities in Malawi, and potentially other performative cultures in Africa. I begin by exploring the concept of *pamtondo* and describing what I am calling “the *pamtondo* effect”. I then go on to explore how play (fulness) created the *pamtondo* effect and enabled a collaborative generation of knowledge about narratives of HIV and AIDS with two rural communities in Malawi.

In Chapter 7, I provide summaries and discussions of my findings on how rural communities understand and make sense of HIV and AIDS. I also summarise how folk media worked as a research method to explore HIV and AIDS narratives of the rural communities. I then go on to discuss the significance and implications of these findings on HIV and AIDS and public health in general and finally reflect on the strengths and weaknesses of my methods.

2 Literature Review

As described in chapter 1, the history of HIV and AIDS in Africa and in Malawi has been entangled with colonial debris (Lwanda 2005,2002; Kagaayi and Serwadda 2016). In this chapter I review literature that explores the historical context of this entanglement and trace its effects to the present.

2.1 Aspects of Colonialism that Impacted HIV and AIDS

Many scholars have articulated that the underlying aim of colonialism was to control indigenous people’s wealth: what they produced, how they produced it and how it was distributed, through military conquests and dictatorship in political arenas (Ngugi wa Thiong’o 1986; Fanon 1961; Smith 2012; Lwanda 2005, 2002; Biermann 2011; Achebe 1994). However, Ngugi wa Thiong’o (1986) asserts that the most significant area of domination was that of the mental space of the colonized peoples. He argues that without controlling people’s minds, other forms of control such as economic, political and cultural domination could never be complete. So, in Ngugi wa Thiong’o’s assessment, through education systems and the imposition of culture, literature and language the colonizers brainwashed and reshaped indigenous people’s perception of themselves and their relationship to the world (Ngugi wa Thiong’o 1986 1992; Lwanda 2005; Smith 2012). Both Ngugi wa Thiong’o (1986,1992) and Smith (2012,1999) have classified the actions of colonialism as “theft”. Ngugi wa Thiong’o (1986,1992) goes on to explain that those who were exploited and oppressed have since come together and have continued their defiance to liberate themselves. However, the main obstacle to the struggle has been what he calls the “cultural bomb”. He asserts that:

> The biggest weapon wielded and actually daily unleashed by imperialism against the collective defiance is the cultural bomb. The effect of a cultural bomb is to annihilate a people’s belief in their names, in their languages, in their environment, in their heritage of struggle, in their unity, in their capacities and ultimately in themselves. It makes them see their past as one wasteland of non-achievement and it makes them want

> to distance themselves from that wasteland. It makes them want to identify with that which is furthest removed from themselves; for instance, with other people's languages rather than their own (Ngugi wa Thiong'o 1986: 3).

Ngugi wa Thiong'o and others have pointed out that language played a crucial role in the success of imperialism and colonialism because language is critical to a people's definition of themselves (Ngugi wa Thiong'o 1986; Kovack 2009; Coetzee 1998). Coetzee also emphasizes the intersection of language and identity when he asserts that "languages embody distinctive ways of experiencing the world and so play a crucial role in defining the experiences of a community as their particular experiences" (Coetzee 1998: 278). Ngugi wa Thiong'o (1986, 1992) holds this view so strongly that his book "Decolonizing the Mind" focuses on the role of language in creating colonial ideology. He draws examples from his home country's (Kenya) experiences as well as his own experiences as a Kenyan. He demonstrates how the imposition of the English language in the education system reshaped how young Kenyans understood themselves and their connections to their communities. Both the imposition of a colonial language and its impact on young people was not peculiar to Kenya, the same can be said for many African countries (Ngugi wa Thiong'o 1986; Lwanda 2002).

The critical role of language in destabilizing the identity of the colonized is also emphasized by considering how the African continent was demarcated, defined and classified based on European languages, i.e English speaking Africa, French speaking Africa and Portuguese speaking Africa. The power of this definition is so normalized and internalized that even African scholars like me (Abdulla 2020), Zarilli, McConachie and Williams et al (2006), have used these classifications without a second thought, in the process reaffirming these imposed identities.

Africans' identity and the right to self-determination was stolen right at the beginning of colonialism when, as described by Ngugi wa Thiongo (1986, 1992), European capitalist powers in 1884 gathered around conference tables in Berlin to divide the entire continent of Africa with its peoples and multiple cultures into colonies. It is in Berlin that the peoples of Africa were divided into European languages (Ngugi wa Thiong'o 1986). However, Ngugi wa Thiong'o

(1986, 1992) makes a critical observation of the continuation of colonial tendencies even after the supposed end of colonialism when he asserts that Africa’s more recent transition into “neo colonies” based on the same lines of division was decided yet again around tables in London, Paris, Brussels and Lisbon.

As indicated by Ngugi wa Thiong’o (1992) and other scholars, the power of colonialism and imperialism continues to linger upon the African continent. In his concept of Epistemologies of the South, De Sousa Santos (2016) clearly explains that colonialism did not end with the end of historical colonialism, which came with foreign occupation, tutelage and prohibition of state formation, instead colonialism is being reenacted in other ways of marginalization and dominance (De Sousa Santos, 2016). The dominance and imposition of colonial culture and ideologies on the peoples of Africa are very salient in the understandings of the body and health. The colonization process included forcing the African people to see the body in biomedical terms while demonizing and assaulting indigenous and cultural frameworks (Lwanda 2002; Kagaayi and Serwadda 2016). As described by Cambrosio and Keating,

> Recent dictionary entries define biomedicine as a branch of medicine that is combined with research in biology or, in other words, as the application of the natural sciences, especially the biological and physiological sciences, to clinical medicine. While, indeed, in present-day discourse the term ‘biomedicine’ (and its adjectival form ‘biomedical’) generally refers to modern, scientific Western medicine. (2001:1222)

As illustrated above, biomedicine has general reference to western medicine which means it is an alien language and culture that was imposed on African people.

In the current post-colonial era, critiques have been made about the tendencies of many practitioners of health promotion and developers of interventions to impose biomedical classifications and understandings on communities (in Africa) without critical reflection and understanding of the communities they are working with (Dionne 2018; Vaughan 1991; Airhihenbuwa 1994; Hann 2009). This suggests the imposition of the language of health on local communities.

Crawford (1993) has spoken against such impositions and has argued that communities have their own understandings and conceptualizations and are faced with their own priorities and concerns surrounding health. The cultural and biomedical imposition, marginalization and dominance that characterized colonialism continues to impact health responses in post-colonial Africa as illustrated by the HIV and AIDS phenomena.

2.2 HIV and AIDS in Africa

When HIV and AIDS emerged in Africa in the early 1980's it became tangled in political, socio-economic and cultural tensions (Kagaayi and Serwadda 2016; Lwanda 2002; Hours 1986; Chavunduka 1973; Lucas et al 1994; Mhiri et al 1992; Waite 1987). Kagaayi and Serwadda (2016), in their article *The History of HIV and AIDS in Africa*, argue that part of the problem was that early researchers from Western countries were bent on proving that HIV had originated from Africa at a time when HIV and AIDS was already laden with stigma and discrimination in Western countries. It was a problem, first, because many African Governments that depended on tourism, including Malawi, felt that the publication of high prevalence rates of HIV jeopardized their economies and because of this they either deliberately ignored the epidemic or denied it all together (Lwanda 2002; Kagaayi and Serwadda 2016). Second, as Kagaayi and Serwadda (2016) noted, standard indicators for diagnosis of HIV (testing for the presence of HIV in blood) was a problem because African countries did not have the same capacity and/or equipment for testing as their Western counterparts. Third, it was also felt that the epidemic in Africa was highly overstated by Western scholars (Kagaayi and Serwadda 2016; Lwanda 2002).

Kagaayi and Serwadda (2016) suggest that the tensions led to the unfolding of the HIV and AIDS epidemic in Africa in three stages. First, the epidemic was deliberately ignored or denied by African Governments. Second, the ignoring and denial led to high morbidity and mortality which forced African Governments to respond when the epidemic had already reached devastating proportions. Third, African Governments then intensified efforts that increased demand and uptake of services to control the epidemic which were further helped by the introduction of antiviral treatment. Although I refer to other countries within Sub Saharan Africa, my focus in this literature review is on Malawi.

2.3 A Brief History of Healthcare in Malawi before HIV and AIDS

As seen from the early imposition of biomedical frameworks on the colonized Africans, tensions between Western epistemologies of medicine and African indigenous understandings of illness, treatment and care pre-exist HIV and AIDS (Lwanda 2002; Moto 2004; Kagaayi and Serwadda 2016).

Lwanda (2002) argues that in pre-colonial Malawi, traditional medicine and related practices, which included preventive, diagnostic and treatment practices based on then current understanding of illnesses and their causation, were crucial in supporting social cohesion. For example, further spread of the infectious diseases smallpox and leprosy was prevented by distancing and isolation of affected individuals and the burning of huts previously occupied by people who had died. Illnesses were treated by practitioners who used herbs, leaves, bark, roots and fauna to effect treatments and cures for various illnesses.

Scholars argue that the concepts of *tsempho* and *mdulo* were used to encourage fidelity and help the prevention of sexually transmitted diseases. Taboos about sex were seen as playing a crucial role in encouraging fidelity and supporting good sexual health among Malawian communities (Lwanda 2002; Rangeley 2000; Drake 1976; Sovran 2013). Transgressing sexual taboos by engaging in promiscuity, infidelity or unacceptable sexual behaviors was believed to cause *Tsempho* or *mdulo* (Lwanda 2002; Morris 1985; Drake 1976; Rangeley 2000; Mvula 2003; Muula 2004; Sovran 2013). The terms *tsempho* and *mdulo* are often used by different ethnic groups in Malawi to refer to the same concept of transgressing sexual taboos. Lwanda (2002) explains that *tsempho* (bypassing) denotes bypassing of rules that govern sexual practice and results from violations of restrictions of sexual practice, promiscuity and extra marital sex. Similarly, *mdulo* (cutting) also suggests the cutting short of someone’s life by transgressing a sexual taboo (Lwanda 2002). Chakanza (2005) further explains that *tsempho* and *mdulo* have physical manifestations such as *kaliwondewonde* (extreme loss of weight, making the person look pale and thin, with thinning of hair texture and/or loss of hair) and *kanyera* (acute diarrhea). Symptoms from *tsempho* or *mdulo* can also include swelling of body parts, chest pain and vomiting of blood.

As Chakanza (2005) argues, matters of illness, healing and health, as understood from the Malawian cultural perspective, includes not only individual level causation but also seeing the individual in harmony with society. Thus, the existence of *tsempho* and *mdulo* in Malawian communities suggests acknowledgement of the role of individual behavioral practices in affecting public health. Indigenous healthcare systems acknowledged multiple interactions between biological, spiritual and cultural dimensions in illness, treatment and care.

2.4 Provision of Health Care Services by Government

The development of the Ministry of Health (MoH) in Malawi can be traced back to the beginning of colonial rule (Baker 1986; Lwanda 2002). Colonial Malawi was initially named British Central Africa (1891-1907), renamed Nyasaland (1907-1964) and finally, named Malawi at independence in 1964 (Baker 1986). Thus, until independence, the country was named by colonialists based on their own constructions of who or what they thought the country and its indigenous population was at the time. The Nyasaland population grew from around 750,000 in 1891 to around 4.5 million in 1974 (Baker 1986) most of which was rural (Lwanda 2002). Up until the 1920's colonial health care services were designed for government officials and were not accessible to the Malawian population. As Baker explains:

> Until the early 1920s the medical service was designed primarily to care for government officials…Government hospitals and medical staff were located where government officials were stationed and not where the bulk of the population lived. (Baker 1986: 301)

Although missionary medical services were present, they had very little impact on the Nyasaland population till after around 1910 (Lwanda 2002; Gelfand 1957). In 1922, there were only 3 hospitals and about 44 dispensaries in the country (Baker 1986) and the population continued to rely on traditional/indigenous medicine. Three main reasons for continued reliance on tradition/indigenous medicine can be discerned. Firstly, as Baker (1986) explained, both missionary and colonial Government doctors were preoccupied with providing health services to the missionaries and settlers. Secondly, Lwanda (2002) argues that because the colonial health services focused on curative medicine and dealt little in prevention, it was not attractive to the indigenous population who, as exemplified by the smallpox and leprosy preventive strategies, were used to preventive and holistic practices. Thirdly, most Malawians lived in the rural areas which were hard to reach and to a large extent closed to direct missionary influence at the time (Baker 1986; Lwanda 2002).

By the end of colonial Government, Malawi's traditional/indigenous medical system, and its core beliefs, were still standing strong (Feierman 1985; Lwanda 2002). The system and associated beliefs and practices had not been disrupted by colonial and/or Christian attacks because they were rooted in rural Malawi and "placed out of colonial gaze" (Lwanda 2002: 90). Beliefs and practices were less visible because they were hidden away for safe-keeping, which was mistaken for the dying out of traditional/indigenous practices under the extensive inhibiting nature of the colonial Government (Lwanda 2002).

Malawi gained independence in 1964 under Dr Hastings Kamuzu Banda's Government. According to Alexander (1995), Hastings was a name Banda adopted from a Scottish missionary, John Hastings, after he was baptized into the Church of Scotland. Kamuzu Banda left Malawi when he was 12 years old to Zimbabwe then South Africa (Alexander 1995). Around 1924, he left Africa and studied in the USA before moving to the UK where he studied medicine and lived till 1958 when he returned to Malawi to join the fight for independence (Alexander 1995; Lwanda 2002).

After independence, although political leaders recognized local chiefs as the custodians and keepers of the "land" (Kishindo 2004), African elites were less concerned about returning to indigenous beliefs and focused more on economic and political power (Lwanda 2002; Shepperson & Price 1958; Rotberg 1965). Lwanda (2002) and Rotberg (1965) suggest that the oppressive nature of Government persisted into the post-independence era through the African leaders. As Lwanda (2002) has argued, the elite used class just as the whites used race before them to impose, dominate and oppress their fellow Malawians.

This was also reflected in the way the Malawi Government handled HIV and AIDS during the early stages of the epidemic.

2.5 The Arrival of HIV and AIDS in Malawi

The first hospital cases of HIV and AIDs in Malawi were described in 1985 (Lwanda 2002; Mwale 2002; National AIDS Commission 2003; National AIDS Commission 2015;), eventually becoming a major cause of mortality, affecting all sections of society (Lwanda 2002; Mwale 2002). According to Lwanda (2002), urban and rural communities noticed the acceleration of deaths in their communities usually following a “slimming disease”. The same reference to “slimming disease” or “slim disease” has been noted in Uganda, Zimbabwe, Zambia, South Africa and elsewhere in Africa (Lucas et al 1994; Mhiri 1992; Lwanda 2002). The name was associated to the manifestation of the symptom of wasting away during the later stages of AIDS (Lwanda 2002; Chakanza 2005).

2.5.1 Government’s early Response to HIV and AIDS

According to Mwale (2002), Malawi's response to the HIV and AIDS epidemic began in 1986 with the implementation of a Short-Term Plan (1986–1988) which emphasised blood safety and Information Education and Communication. A Medium-Term Plan (1989 to 1993), also emphasised blood safety, Information Education and Communication but added management of Sexually Transmitted Infections (STIs). By 1994, although the Government still did not accept the gravity of the epidemic, approximately 20 - 30% of those admitted to hospitals had AIDS related illnesses (Lwanda 1995). A second Medium Term Plan was needed and implemented from 1994–1998 and this time included the need for a ‘multisectoral HIV and AIDS response’ although it is not clear what this was or whether it was implemented. Lwanda (2002) points out that the Short and both Medium Term plans had almost exclusively focused on biomedical aspects of managing treatment and prevention but due to inadequate hospital services, most of the population was left dependent on the traditional/indigenous health care system.

Following a review of the second Medium Term Plan, Malawi developed the National HIV and AIDS Strategic Framework for the period 2000–2004 in order to upscale and accelerate the national HIV/AIDS response. Mwale (2002) argues that this framework was developed through a participatory process and designed to ensure that gender concerns of the epidemic were included in all interventions; greater involvement of people living with HIV/AIDS; intensify responses for and with the youth; and integrate care and prevention as the only meaningful way to effectively respond to the HIV/AIDS epidemic. However, it is clear from language used by the designers of the foregoing interventions that the framework was still based on biomedical understandings of HIV and AIDS. Despite its best intentions the intervention was not integrated with the traditional/indigenous health care systems that most Malawians relied on. Another policy document, "Vision 2020; The National Long-Term Development Perspective for Malawi" (2000) claimed that "Links between traditional and Western medical practitioners must be explored to reduce suspicion and increase collaboration between them" (National Economic Council 2000: 50). However, when Lwanda reviewed its implementation in 2002, this had still not yet been enacted and thus, a large part of the traditional/indigenous health care system was left behind in Malawi's response to HIV and AIDS.

Lwanda (2002) and Msiska (1981) explain that issues related to spirits, witchcraft and taboos played a major role in the conception of illness amongst the rural Malawians and that the *sing'anga* commonly translated as witchdoctor - credited with powers of spirit consultation, healing and divination - was an important figure in indigenous medical practice.

However, the Witchcraft Act established by the colonial Government in 1911 denies the existence of witchcraft and makes those claiming to practice it as going against the law (Witchcraft ACT). This means that the dominant indigenous cultural framework for understanding and approaching illness, that has existed since the pre-colonial era, has been outlawed for a very long time but continues to be practiced and sustained by most Malawians out of both the colonial and subsequent legal gaze thus creating an on-going tension. This tension between the colonial law and the reality of Malawians remained unchallenged until around 2006 when various sectors began to question the grounding of the Witchcraft Act and called for its review. An issue paper for the Witchcraft Act review Program by the Malawi Law Commission (2009) states that the call for the review hinges on the fact that the act ignores the reality of most Malawians for whom access to *sing'anga* is an important part of health and health care.

In November 2020, a National Consultative Workshop on the Review of the Witchcraft Act was held in Lilongwe, capital city of Malawi. Kasanda (2020) of the Times Group online news outlet reporting on the workshop events states that Wezzie Kayira of the Malawi Law Commission continued to argue that the Witchcraft Act should recognize the belief of witchcraft in order to align legislation pertaining to witchcraft with the social-cultural values and beliefs of the Malawian society. As can be seen, while the 109 years old legal status that denies the existence of witchcraft is being contested by legal authorities in the country, the *sing'anga* remains a powerful institution of healing and health care among many Malawians.

2.5.2 Communication about HIV and AIDS in rural Malawi

A key tension in HIV and AIDS in Malawi has always been how biomedical discourse is translated into cultural idioms that do or do not make sense to the Malawians (Lwanda 2002; Moto 2004; Muula 2008). Trying to communicate to rural communities what HIV and AIDS are was a problem that began with the early Government's response to HIV and AIDS. Lwanda (2002) reports that when Malawian communities noticed that there were accelerated deaths associated with slimming disease, they knew that there was something amongst them that was responsible for the deaths. They had also already identified its sexually transmitted nature which was suggested by the local name *magawagawa* (that which is shared/distributed to many generously) which by then, most Malawians used to refer to the epidemic (Lwanda 2002; Moto 2004). Through observation and experience, communities linked its causation and increased risk to *chiwerewere* (promiscuity/infidelity) in such a way that *magawagawa* and *chiwerewere* were commonly used together (Lwanda 2002).

Although, as Lwanda (2002) shows, one of the initial responses to HIV and AIDS was to choose a local name which best described the disease in a way that fitted the local Malawian culture, the Government imposed the name "EDZI" which Lwanda (2002:128) describes as an "Onomatopoeic Chewaizing of AIDS". The naming and handling of the epidemic by the Government led to some calling it *matenda a boma* (disease of the Government/Government's disease) (Lwanda 2002; Moto 2004) suggesting that the imposition of the name EDZI alienated the disease from the experiences of the local Malawians. Apart from having a similar sound to the original AIDS, the name had no proper signification of what AIDS is/was, (in either language), or any relationship to local people's experiences. Lwanda (2002; 2005:118), explains that by translating AIDS as they did, health care workers and Government lost an opportunity to communicate to rural communities the already known sexually transmitted aspects of HIV and AIDS. From the imposed naming, the HIV virus became known as "*kachirombo ka Edzi*" (Lwanda 2002:128), which could be translated as the "little/tiny AIDS beast".

Calling the HIV virus "*kachirombo ka EDZI*" was problematic in multiple ways. Lwanda (2002; 200) has argued that the inference to the singular *kachirombo* contributed to the belief by both patients and traditional medicine practitioners that AIDS could be cured by simply removing the little/tiny beast. Another potential problem was that the term *chirombo* is associated with illnesses believed to be caused by spirits (Msiska 1981; Chilivumbo 1972; Soko 1985). *Chirombo* is also a word that the Chewa (majority ethnic group in Malawi) use to refer to *gule wa mkulu* (big dance), which is said to be associated to the world of animals and ancestral spirits (Kerr 1995; Kamlongera 2002). And so, as Lwanda has asserted, because of the concept of *kachirombo* and its association to spirits, the "spirit possession model" was inducted into the HIV and AIDS discourse by many Malawians (Lwanda 2002: 128?).

As can be seen with the naming of AIDS and the HIV virus, the difficulty of communicating and imposing the biomedical discourse of HIV and AIDS to a people who had their own experiences within a cultural frame that had its own constructions caused epistemological tensions that have had a lasting impact on the epidemic's response. Although indigenous medicine played a major role in health care service provision, Lwanda (2002;2005) notes that there was an absence of dialogue between Western medicine and traditional medicine. In his view, the HIV and AIDS response used "undigested and uncontextualized Western HIV and AIDS prevention strategies" which ignored local peoples' experiences and realities (Lwanda 2002:127). In short, Malawi's early Government and public health response to HIV and AIDS took a top-down approach manifest in its imposition of Western conceptualizations of HIV and AIDS that were poorly translated and largely incompatible with local knowledge systems and peoples' experiences.

2.6 Towards dialogical approaches

Many scholars in health, education and development criticized such impositions and have argued for more dialogic approaches (Freire 1971; Escobar 1995; Chinyowa 2005; Abdulla 2016; Abdulla 2013; Chinyowa 2009; Chinyowa 2005; Chisiza 2017; Darder, Baltodano and Torres 2003; Escobar 1995; UNESCO 1995; Mda 1993; Barz and Cohen 2011; Mefalopulos and Kamlongera 2004, 1992; Kerr). Chinyowa (2005) has argued that the making or unmaking of health initiatives needs to begin by examining the ways in which local people construct their realities in relation to the issues. Not only is the understanding of local realities important, but the nature of interactions with that reality needs to be a dialogical one (Freire 1971, 2005).

Among other things, Freire's work outlines the theory of dialogical action. He is considered by many to be the most influential scholar in the development of critical pedagogical practice and thought (Darder, Baltodano and Torres 2003) and his work raised crucial questions of how relationships of power, culture and oppression play out in education. Freire's book *Pedagogy of the Oppressed* (1971) marked a turn towards radical inclusive approaches to education in schools and communities (Darder, Baltodano and Torres 2003). In Freire's (2005) thought, dialogue denotes an epistemological relationship that positions itself as a requisite of both learning and knowing. Freire explains dialogical action as the opposite of anti-dialogical action which he describes as an instrument of oppression characterised by conquest, manipulation and cultural invasion (Freire 2005).

On the other hand, Freire (2005) emphasizes dialogical action as an instrument of liberation characterised by cooperation, organization and cultural synthesis. In his view, dialogue happens when people meet as subjects of their realities to reflect together on what they know and do not know in order to act critically to transform reality in a continuous process of creation and recreation (Freire 1971, 2005; Shor and Freire 1987). In other words, what needs to be known is presented and people/parties come together for mutual inquiry. Thus, dialogue involves respect and the acknowledgement of ‘others’ right to effect change in their own life. It does not involve one party deciding for or acting on another’s behalf.

More recently, the ‘cultural dimension to development’ as described by UNESCO acknowledges “the need to have regard for cultural identities, to have the population participate in their own development projects and to grant them the right of access to culture” (UNESCO 1995: 89). This means that development strategies, plans and projects including health, and specifically HIV and AIDS, must take cultural specificity into account. One of the ways in which practitioners have responded to calls for culturally inclusive and dialogical approaches in SSA has been through the increased use of Arts Based Approaches (Chisiza 2017; Abdulla 2020, 2016; Bunn, Kalinga and Mtema et al 2020) to which I now turn.

2.7 Arts Based Approaches in Health Promotion and Research

Arts Based Approaches have been used extensively in SSA for health promotion (Chinyowa 2009; Chisiza 2017; Abdulla 2016, 2013) and more sparingly for health research (Allen 2012; Kossak 2012). In this section, I first explore Arts Based Approaches for health promotion before moving on to Arts Based Research.

Bunn, Kalinga and Mtema et al (2020) conducted a scoping review of Arts Based Approaches to promoting health in SSA, to which I contributed. We reviewed 11 databases across biomedicine, social sciences, arts and humanities. Of the 119 studies identified, 52 studies came from South Africa and 7 from Malawi. We found a wide range of art forms had been used in health promotion, including theatre, music, song, dance, visual art, film, photography, photovoice, craft, circus, comedy, puppetry and folk media. Theatre-based work was most prominent at 43.7%, followed by music and song with 22.6%. HIV and AIDS was the most targeted health condition accounting for 84.9% of the papers identified, although Ebola and Malaria also received some attention. Individual studies conducted by Barz and Cohen (2011), Kamlongera (2005) and Bourgault

(2003) have shown that Arts Based Approaches have facilitated collaborative encounters in working with communities to promote various aspects of health.

A handful of studies have considered the effect of using Arts-Based Approaches and suggest that they have the potential to improve positive behavioural changes in relation to health (Harvey, Stuart and Swan 2000; Middlekoop, Myer and Smit 2006). For example, a study in South Africa found that collaborative theatre performances drawing on the local storytelling tradition of the Xhosa people was associated with increased self-referrals to accessing HIV and AIDS Voluntary Counselling and Testing (Middlekoop, Mayer and Smit 2006).

The literature shows that a significant proportion of arts-based practitioners identified their practice within particular theatre practices like participatory theatre (Parent, Ehrlich and Baxter et al 2017), forum theatre (Francis 2010), Image theatre (Chinyowa 2009), Community theatre (Johannson 2010) and Theatre for Development (Abdulla 2020; Mbuyazi 2004; Dalrymple 2006; Chinyowa 2007; Boneh 2013). These theatre practices typically fall under the umbrella of Applied Theatre or more specifically Theatre for Development (TFD).

2.7.1 Applied Theatre and Theatre for Development

Mostly known for his text *Theatre of the Oppressed* (1979), Augusto Boal experimented with Freire's ideas of dialogical action in theatre practice and triggered a series of applied theatre/theatre for activism projects across the globe including what came to be known as Theatre for Development (TFD) in Africa. I start with describing Applied Theatre before unpacking TFD.

Prentki and Preston (2009) in the introduction of the *Applied Theatre Reader* suggest that Applied Theatre is an umbrella term that describes theatrical practices and creative processes that go beyond the scope of conventional theatre practice to reach unconventional settings. As a number of authors have suggested, the practice of Applied Theatre is motivated by a belief that it has the potential to make a difference in the way in which people interact with each other and with the world at large, at least for the participants and audience who engage with it (Abdulla 2016, 2013; Boal 2005; Chinyowa 2009; Mda 1993;

Prentki and Preston 2009; Taylor 2003). The Applied Theatre process allows specificity and ‘enables the participants to (re) discover their innate capacities for play, for imagining, for creating, for relating to others by exploring the self in the other and the other in the self’ (Prentki and Preston 2009: 252). It allows participants to draw experiences from the real world into the make-believe world in order to understand reality better and reflect upon it (O’Neill 1995). Mda (1993) and Mlama (1991) suggest that Applied Theatre can be more effective than conventional social behaviour change programmes because it uses interpersonal modes of communication that have more impact than some mediated forms of electronic and print media used in those programmes.

Theatre for Development (TFD) is a particular approach within the broader field of Applied Theatre. It is a group of practices that share many attributes of other applied theatre practices but is distinguished by an emphasis on development (Chinyowa 2009; Chisiza 2017; Epskamp 2006; Kamlongera 2002; Kerr 1995; Okagbu 1998; Zarrilli, McConachie and Williams 2006). The propagators of Theatre for Development in Africa, Kidd and Bryam (Botswana), Ngugi wa Thiong’o (Kenya), Abah (Nigeria), Mlama (Tanzania), Kamlongera and Kerr (Malawi), based within African universities sought to use theatre as a strategy for dialogue and empowerment that helped marginalised people to critically engage with their issues and problems and explore solutions to deal with them (Abbah 1996; Kerr 1995; Kamlongera 1989; Kidd and Bryam 1982; Wa Thiong’o and Wa Mirii 1982).

According to Zarrilli, McConachie and Williams et al (2006) in their book *Theatre Histories, An Introduction*, the basic early practice of TFD involved theatre practitioners researching a community problem, creating a play and presenting it to the community, followed by a discussion with the community about solutions to the problem and community action planning. The authors note that this is the model of practice that was adopted across English-speaking (sic) African countries around the 1980s, including Malawi.

However, this model of TFD has since come under a lot of criticism from many theatre and community leaders for its exclusion of community participants in delivering the plays and its insensitivity to social and cultural contexts (Chisiza 2017; Epskamp 2006; Okagbu 1998; Zarrilli et al 2006;). More recent renditions of TFD have responded to the criticism and shifted towards the inclusion of the cultural experiences and expressions of local people engaging with it (Abdulla 2020, 2016; Chinyowa 2009; Zarrilli, McConachie and Williams 2006). The inclusion of local channels of communication, participation from the community in both the process of creating the theatre, as well as the product and sharing it with others, is now of key importance in TFD (Abdulla 2020; Chinyowa 2009; Kamlongera 2005). This has positioned TFD as a popular method for tackling development-related problems such as HIV and AIDS or health in general.

Apart from health promotion and interventions, the arts have also been used for health research purposes. Arts Based Research has been described as the use of art forms in generating, interpreting or disseminating findings (Leavy 2017; Cole and Knowles 2001; Knowles and Cole 2008). Researchers such as Baumann (1999) have positioned the arts as an alternative method of knowledge generation that have been said to tap into human experiences that words fall short of representing. It has been argued that Arts Based Approaches can enhance engagement with participants and make research accessible to non-academic audiences (Levin et al 2007). Horne (2011) explains how working with HIV positive Xhosa women using a form of storytelling through body mapping helped the women to see their bodies and share histories that had often not been told and Moletsane and Mitchell’s (2007) use of photovoice has helped to elicit experiences of participants with HIV and AIDS that would otherwise be undescribed.

2.7.2 Critiques of Arts Based Approaches

Scholars have highlighted significant issues of power and imposition as major critiques to the practice of Arts Based Approaches for health promotion as well as research. For instance, in the mid 1980’s, funding changes drove a shift from TFD practice by African universities to NGO driven use of theatre-based practices for ‘messaging’ (Chisiza 2017; Kerr 2009; Mlama 2002). Since then, Chisiza (2017) argues, TFD has lost its truly participatory and dialogical power. Funders (usually originating in rich Western countries) have often dictated the priorities for arts-based projects to NGOs who in turn impose these priorities on the communities/participants they work with through top down and message loaded theatre interventions (Chisiza 2017). Odhiambo (2006:195) notes that arts practitioners have often assumed the position of a teacher and have placed the community in the position of the student who is considered an “empty vessel to be filled with knowledge by the teacher”, reflecting Freire’s (1971) anti-dialogical method and the colonial attitude to interventions on local Malawians.

Apart from the impositions and power dynamics affecting theatre-based practices described above, other forms of Art have also been affected. Beck (2006), in his study on comic-based approaches to HIV and AIDS prevention in South Africa, demonstrates that international agencies have imposed content and narratives that are simplistic and do not resonate with the subtlety and realism of local comic forms.

Another critique highlighted by scholars has concerned the imposition of art forms on communities and/or workshop participants (Chinyowa 2009, 2015; Abdulla 2016; Beck 2006; Kamlongera 2005). Chinyowa (2009:4) argues that ‘more often than not, communities are led into participating in workshops using ‘folk’ songs, dances, poems and stories that have already been planned for them’. This imposition of art forms on participants and communities is problematic as my earlier work demonstrates that the choice of art forms (puppetry, theatre, images, games, comics, songs, dances, drawings) that are used when engaging with participants in Arts-Based initiatives is a strong influence on the quality of the contribution, validity, and impact of the engagement (Abdulla 2020, 2016). Often these art forms are chosen by the practitioners (health promoters or researchers) without paying careful attention to the specificity of how the participants or communities understand and conceptualize these forms (Abdulla 2020, 2016; Chinyowa 2005). For instance, it has been shown that when songs and dances are taken out of their context in one rural community and applied to another without careful appropriation, they can alienate the communities and therefore be treated as a spectacle rather than an opportunity to participate in meaningful dialogue that is transformative (Abdulla 2020, 2016).

Finally, although claiming to facilitate participation, Arts Based Approaches have also been implicated in the exclusion of local communities in decisions pertaining to initiatives and processes that affect them (Chinyowa 2015; Kerr 2009; Abdulla 2020). This is highlighted in the critique of TFD practice described above. In addition, Chinyowa (2015) argues that researchers, facilitators and artists often silence participants instead of empowering them when they fail to put participants at the centre of the intervention or initiative. He argues that participation as practiced is a “repressive myth”. Nelson and Wright (1995) have argued that the shift of paradigms towards people centred approaches that value participation of the marginalized as primary stakeholders has been largely instrumental. Chambers (1997) describes instrumental participation in comparison to transformational participation. He argues that the tendency by practitioners to bring communities to participate in “Our” projects is instrumental participation, while transformational participation occurs when “we” participate in “their” (communities) projects (Chambers 1997:30). Although I do not support the way Chambers polarises participation into “we” and “they”, what he points to is an important tendency for a staged form of participation which undermines dialogue, collaboration and reciprocity.

Examples drawn from comics and storytelling (Beck 2006), Puppetry (Kamlongera 2005), theatre/drama, song and dance (Kamlongera 2005; Abdulla 2020,2016; Chinyowa 2009) illustrate that often, when participants are not at the centre of the initiative, narratives are created that do not resonate with the subtle realities of the communities’ lives (Beck 2006; Kamlongera 2005; Abdulla 2020). Although these critiques may also affect other forms of conventional research, they are particularly problematic in Arts Based Approaches because these approaches exist and depend on their potential to be more collaborative and less imposing.

2.8 Decolonizing Research Through Indigenous Research Methodologies

Smith (2012) has argued that the problems of exclusion, representation, imposition and domination in research lies with the concept of research itself and how it was conducted on indigenous peoples in the colonial past. Malsbary (2008) has explained that researchers came into indigenous territories and colonized lands as explorers and photographers and left with pictures, artifacts and even people that were then exhibited in huge European fairs as primitive and curious objects for the shock and delight of audiences in the name of research. Through these activities, not only did they steal cultural artifacts, but went on to dismiss the established systems of order and knowledge that existed among the indigenous peoples (Malsbary 2008). Biermann (2011:390) explains that historically, the relationship between academia and colonialism has been of interdependence that “resulted in the establishment and development of bodies of knowledge to describe, regulate and order the indigenous Other based on European frames of reference” (Biermann 2011:390). Similarly, Kovach (2009) problematizes the use of Western methodologies when doing research with indigenous people, which he argues has persisted for a long time.

Linda Tuhiwai Smith’s book, *Decolonizing Methodologies*, first published in 1999, highlights the problem of colonizing research. The first part of the book grapples with the historical development and impact of Western epistemologies, assumptions, values and research practices on indigenous peoples. It documents the institutionalization of research in the Western Colonies (territories colonized by rich Western nations). Although Smith (2012) acknowledges that the term “indigenous” may be problematic because it boxes various groups of people into a universal whole, she explains that it is for this reason that indigenous is followed by the plural “peoples” and not the singular “people”. She explains that the (s) on peoples acknowledges the diversity and experiences of various groups of people that fall within the indigenous. She further explains that “indigenous” is an important term because it suggests that the struggles of the marginalized peoples are part of other bigger struggles across the globe (Smith 2012). Smith (2012) has argued that the term acts as a reminder that while local experiences between one group of indigenous peoples may differ from another, they are connected. Their connection is grounded on the historical experiences of being dominated, exploited and oppressed economically, politically and culturally by imperialism and colonialism (Smith 2012).

Smith’s (2012) book moves on to critique the conduct of research in more recent post-colonial times arguing that colonial tendencies persist. Smith (2012:1) bluntly asserts that “the word research is probably one of the dirtiest words in the indigenous world’s vocabulary”. It evokes memories of experiences of violence, theft, extraction, disrespect and oppression among indigenous peoples (Smith 2012).

Smith explains that:

> It appalls us that the West can desire, extract and claim ownership of our ways of knowing, our imagery, the things we create and produce and then simultaneously reject the people who created and developed those ideas and seek to deny them further opportunities to be creators of their own culture and own nations (Smith 2012: 1).

In Smith's (2012) view, research has contributed greatly to the regulation and realization of imperialist and colonialist agendas and has been one of the ways through which imperialism and colonialism has been guarded and sustained (Smith 2012). Practices of research that invalidate indigenous forms of cultural knowledge and deny indigenous people their right to self-determination still dominate (Smith 2012: 1; Kovack 2009; Chilisa 2012; De Sousa Santos 2016). These practices have placed the West as the determinants of what counts as knowledge and what doesn't, as well as what priorities and agendas need to be explored among indigenous peoples (Smith 2012; Chilisa 2012; Biermann 2011; De Sousa Santos 2016). Smith (2012: 1), writes that through a

> collective memory of imperialism that has been perpetuated through the ways in which knowledge about indigenous peoples was collected, classified and then represented in various ways back to the West, and then, through the eyes of the West, back to those who have been colonized (Smith 2012:1).

Recognizing the role of research in propagating and sustaining cultural imposition, discrimination and inequality, scholars have called for a decolonization of research processes (Smith 2012; Kovack 2009; Wilson 2004; De Sousa Santos 2016; Biermann 2011; Chilisa 2011).

In answering the call for decolonizing research, Smith (2012), Kovach (2009) and Chilisa (2011) have suggested the development and use of indigenous methodologies. In simple terms, Indigenous Research Methodologies (IRMs) are methodologies based on indigenous realities engaged with and understood through local indigenous frames of reference (Chilisa 2011; Smith 2012; Kavoch 2009). Smith (2012) uses the case of the Maori, Kovach (2009) uses the Cree and Chilisa (2011) uses a case of the Tswana to suggest how research might be conducted in a decolonizing way by using indigenous methodologies. They highlight four broad points that need to be considered when doing research with indigenous peoples.

To begin with, indigenous methodologies must draw from indigenous frameworks (Smith 2012; Chilisa 2011; Kavoch 2009). This means that on a broader level, if conducting research in Africa, the methodology needs to draw on African frameworks that are compatible with that community. Given the diverse nature of African cultures (Kaphagawani 1998), this might mean going down to the specific indigenous group or community. Kovach (2009) exemplifies this using a "Tribal Based Approach" when she used Cree knowledge as a guiding epistemological framework in her work.

Secondly, researchers need to work with the underlying assumption that research that involves a group of indigenous peoples ought to also benefit those people (Chilisa 2011; Smith 2012; Kovach 2009).

Thirdly, there is need for research to be collaborative (Chilis 2011; Smith 2012). This collaboration can be at different levels, amongst researchers (Western/Indigenous; Indigenous/Indigenous) as well as between researchers and the communities they are working with. In general, Parkinson (2006:3) sees collaboration as 'a mutually beneficial, well-defined relationship entered into by two or more parties to achieve common goals. She goes on to say that a collaborative relationship includes 'a jointly developed structure and shared responsibility'. The concept of collaboration in research is not new. But has often been read as eliciting interest and participation of indigenous peoples. As seen earlier in this chapter, many of the processes that identify themselves as collaborative and participatory (including Arts Based Approaches) have been riddled with impositions either of method or of points of reference and have often been instrumental (Chinyowa 2005; Chambers 1997). However, as Smith (2012) explained, collaboration means that as well as seeking to maximize interest and participation, researchers must let go of their control of research and share it with the indigenous peoples they are working with (Smith 2012). This means that indigenous peoples must define the research, or at least actively contribute to defining it.

Fourthly, decolonizing indigenous research must pay attention to cultural ground rules and address them seriously. Smith (2012) acknowledges that barriers of distinction, expectations and myths that accompany constructions of difference cannot be erased, but researchers can acknowledge them explicitly and work to create spaces for dialogue that recognize the uncomfortableness of power, representation and reality (Smith 2012).

However, like other emerging paradigms, Indigenous Research Methodologies (IRMs) have faced criticisms. One important criticism highlights the problem of creating a binary between IRMs and other approaches to research (Kovach 2009) creating a clear divide between the Western and the Indigenous that overemphasizes differences that are attributed to something stable that doesn't exist (Gone 2019). Another critique has been that given that most indigenous cultures have interacted with Western cultures (Kerr 1981; Kamlongera 1986; Gone 2019), determining what counts as IRMs and to what extent these can be indigenous becomes a laborious task (Gone 2019). In light of the above challenges, scholars like Gone (2019) and Chilisa (2011) have suggested that IRMs might benefit from a mixed form of methodologies although the outline of how this mixing of indigenous and conventional research methodologies might be done is not clearly articulated.

2.9 Contribution and Positioning of this Study

While I draw heavily on Indigenous Research Methodologies, I acknowledge Gone's (2019) concern of the difficulty in defining indigeneity in the context of the globalized exchange of cultural forms and ideas. Therefore, I situate this study in folk media in dialogue with Indigenous Research Methodologies and other conventional research methods. Folk media has been described as the means through which common people communicate their ideas, values and beliefs (Ansu Kyeremeh 1998; Van der Stichele 2000). In positioning my folk media approach in dialogue with both indigenous and conventional research methodologies, I attempt to explore how a mixed methods approach suggested by Gone (2019) might be practiced.

Although folk media is a widely available cultural resource in SSA, it has not been explicitly present in the literature as a research method in SSA. My study experiments with the use of folk media as a research method to exploring how communities understand and make sense of HIV and AIDS in rural Malawi. It is an attempt towards working collaboratively with communities using their own cultural resources for research. By working with the communities and their folk media, I hope to balance power dynamics between me as a researcher and the community participants during research. I also hope to move away from imposition of method and content that have been found to be major critiques of Arts Based Methods in health and development research (Abdulla 2019, 2016; Chisiza 2017; Chinyowa 2009; Beck 2006). I describe in detail the approach I took in the next chapter.

3 Methodology

In this chapter I describe the methodology used to explore how rural communities in Malawi understand and make sense of HIV and AIDS. The first section focuses on the folk media methodological approach I developed. I describe the conceptual framework, the background to folk media use in Malawi, folk media and the Chewa epistemological context and finally how I drew on participant observation as a conventional method used alongside folk media. In the second section, I describe how I applied the folk media method, briefly describing the Malawi traditional leadership structure before outlining the key components of the approach including partnership developments, methods, and ethical considerations.

3.1 Towards a Folk Media Methodological Approach

The concepts of *Decolonizing the Mind* (Ngugi wa Thiong'o 1986, 1992), *Decolonizing Methodologies* (Smith 2012, 1999) and *Indigenous Research Methodologies* Chilisa (2011) have been central to the choices I made in developing a folk media methodology. Chilisa (2011:13) describes decolonization as "a process of centring the concerns and worldviews of the colonized Other so that they understand themselves through their own assumptions and perspectives".

3.1.1 Conceptual Framework

As a reminder, folk media are the ways in which a group of people or a community express themselves, communicate their ideas, values and beliefs (Van der Stichelle 2000). Ansu-Kyeremeh (1998:3) describes this as "the utilization of the values, symbols, institutions and ethos of the host culture through its unique qualities and attributes". These may include beating drums, songs, dances, village criers, folk tales, proverbs, riddles and ceremonies such as initiations, funerals and weddings (Abdulla 2016).

My use of folk media is directly connected to and informed by a commitment to Indigenous Research Methodologies (IRMs) but it is also specific to the community I am working with at any given time. Situating my study in folk media means that I do not have to grapple with the difficult classification of whether the folk media forms/methods used are indeed indigenous or have been appropriated and/or integrated by the community into their cultural frameworks. As Gone (2019) has pointed out, in his critique of discourses surrounding IRMs, the extent to which indigenous forms currently exist in their ‘pure’ forms given their intensive interaction with colonialism may be difficult to determine. Kerr (1981:148) further notes that:

> The impact of colonialism and rapid urbanization created an urgent need for new cultural forms through which the uneducated (referring to formal education) and semi-educated populace could meditate and interpret the rapid economic and social transformation it was experiencing.

Kerr refers to the forms amalgamating from the encounter between indigenous culture and Western culture as “syncretic forms”. These syncretic forms emerged from the prolonged observation of colonial practices by the indigenous population (Kamlongera 1986; Strumpf 1999). Examples of syncretic performance forms in Malawi include the *malipenga* dance commonly found in Northern region and the *beni* dance in the Southern region. Variations not-withstanding, both *malipenga* and *beni* have been described as dances that mimic the military-like marching traditions of colonial marching bands (Strumpf 1999). Though syncretic, both dances are classified as traditional cultural dances in Malawi and other parts of SSA (Kamlongera 1986; Strumpf 1999).

Similarly, there are Malawian riddles that have been constructed and reconstructed as overall reactions to the Western settlers and their culture (Chimombo 1988). These cultural responses do not only capture part of the indigenous people’s historical experiences but also, as Chimombo (1988:299) argues, demonstrate “a society’s own changing and expanding consciousness as it attempts to come to terms with the new realities”.

Given that the Malawian people’s experiences and cultural forms cannot be completely separated from colonial encounters and the ongoing globalization process, the task of establishing indigeneity becomes a cumbersome one. Folk media offers an opportunity to engage with communities without imposing on them the methods of engagement and at the same time allows alignment with indigenous inquiry practices by undoing colonial research approaches.

Through working collaboratively with the communities, using their own folk media forms and drawing on local epistemology, I attempt to encourage ways of researching in decolonized terms that acknowledge and validate histories and narratives other than what De Sousa Santos (2016) calls the “universal” history and narrative of the West. In this vein, I attempt to see research as being reimagined to reflect a more balanced power relationship between me (researcher) and the communities I was working with as well as external and internal knowledge systems. As Smith (2012) asserts, the research space is an active one that can also be a space of resistance and contestation. This means that research can be reframed and considered as a new opportunity to build decolonized relationships that are based on respect of other ways of knowing, and of one another.

3.1.2 Background of Folk Media use in Malawi

As described in chapter 1, folk media have served as reflections on social happenings, critiques of behaviour, creations of social commentaries, social reconstructions and served as means of education in many African communities from the pre-colonial period (Kamlongera 2005). Kamlongera, Nambote and Timpunza-Mvula (1992) explain that before the influence of colonialism and Christianity, Malawian indigenous performances were inseparable from ritual and tradition. Although weaker in contemporary times, the assertion still holds true especially for rural communities in Malawi, which are the focus of this study. Kamlongera, Nambote and Timpunza-Mvula (1992) also argue that function and art in indigenous performance forms merge and feed into each other. As Kerr (1987) exemplifies, *gule wa mkulu*, a dominant masquerade performance amongst the Chewa people, was one of the dances used in retaliating against colonialism and the exercise of its oppressive powers. Ritualistic performances, indigenous songs and dances (*magule*), storytelling, dramatizations, among others were commonly used as educative modes and spaces of social deliberation and reconstruction (Kamlongera, Nambote and Timpunza-Mvula 1992; Kerr 1987; Chinyowa 2009, 2005).

During the colonial era, African performances were often adopted and appropriated by colonial governments for “moral education” whilst in the post-colonial period cultural performances have been used as media for development purposes (Kamlongera 2005). For example, in 1981 Christopher Kamlongera was commissioned by the Malawian Government’s Ministry of Health to lead the Chancellor College Travelling Theatre to create and perform improvised vernacular plays on adult literacy, health and agriculture in Mbalachanda, in the Northern region of Malawi (Kamlongera 1989; Kerr 1987, 1995).

The adoption of folk media in development discourse is founded on the premise that using what is familiar to the people and communicating in ways that are acceptable by the community, improves community participation, agency and ownership of initiatives, which in turn increases impact and sustainability (Abdulla 2016; Mefalopulos and Kamlongera 2004). But many criticisms of the use of folk media are similar to those of other Arts-Based Approaches to health promotion, development and research which I describe in Chapter 2, and many well-intended initiatives have been undermined by similar contradictions. For example, many uses of folk media are stripped of their original ethic, value and meaning. They are taken from their host culture and applied to a different context which can alienate target communities and reduce their meaningful participation in projects and initiatives (Abdulla 2020, 2016). Describing an interview with Kamlongera, Chinyowa (2005) gives the example of an external team using puppetry to encourage food security among the Chewa people. But to the Chewa people the puppets mimicked their *gule wa mkulu* masks which the Chewa peoples’ culture associates with the world of animals and spirits. Chinyowa (2005:222) explains that “the development effort became a contradiction in terms because it attempted to explain rational behaviour through irrational means”.

In an earlier paper I note that traditional songs and dances can be equally problematic if not carefully negotiated with communities in accordance with their specific applications (Abdulla 2016). This is because even when the songs and dances are similar, the specific ethics, meaning, practice, function and nuances can vary greatly from community to community, even when communities appear to have a degree of homogeneity (Abdulla 2020, 2016).

Chinyowa (2005:12) highlights that most proponents of folk media have viewed it as simply a ‘tool’ or ‘instrument’ for development related communication (often imposing content) rather than a structuring element for intervention or research. In this study, I use folk media as a fundamental structuring element for my research as it not only constructs the methods of inquiry, but also frames the basis for my understanding of the outcomes.

3.1.3 Folk media and the Chewa Epistemological Context

Drawing on the principles of indigenous methodologies as a decolonizing approach, I give great importance to the epistemologies of the local communities in Malawi. Malawi has ten major ethnic groups whose cultural traits are common enough for the various groups to identify as Malawian, but which are nevertheless distinct. The Chewa ethnic group is the largest in Malawi and Chewa epistemology contributed important cultural context not only to my conceptualization and application of the folk media methods but also to understanding the ways in which the two communities who participated in this research understand and make sense of HIV and AIDS. Thus, in this section I briefly explore what constitutes the Chewa epistemology.

According to Kaphagawani (1998:240), “knowledge presupposes truth”. Therefore, to say that you know something is the case is to say that the thing is true. To the question of what constitutes truth in African epistemology, Kaphagawani (1998:240) responds by saying that “to have an answer to this is to mistakenly presume that all African cultures conceive truth in the same way”. Thus, Kaphagawani focuses on the Chewa conception of truth, which is manifest in Chichewa, the national language of Malawi. In the Chichewa language, the immediate word that bears an equivalence to truth is *zoona* which is literally translated as “the seen”, derived from the verb *kuona* (to see), which has *kuonedwa* as its passive (Kaphagawani 1998). Strictly speaking, “the seen” or “the visible” ought to be translated as *zoonedwa* or its variants, but passive words are not used in the Chichewa language when making claims of truth (Kaphagawani 1998). What is used instead is *Zoona* which Kaphagawani (1998) describes as a truncated form of *zoonedwa* which he further asserts can be argued to be yet another truncated form of *zoziona*. The word *Zoziona* means things that have been seen or things that have been visualized. Therefore, in the

Chewa epistemology truth is equal to experience. That is to say that what is true is that which is experienced (Kaphagawani 1998). This suggests that the Chewa notion/concept of truth is experiential, and their valued knowledge tends to be empirical.

While experiential knowledge is of great value to the Chewa, as illustrated by the literal meaning of *Zoona*, the general connotations of the word go beyond its literal meaning to include that which is perceived (Kaphagawani 1998). Kaphagawani (1998) notes issues of witchcraft, sorcery and hypothetical engagements/discussions often used in juridical matters as some of the truths that require a more cognitive engagement than a visual experience.

A translated extract from an interview with Group Village Head (GVH) Miyowe in Dedza, one of the two communities I worked with, summarises Kaphagawani's exposition of the Chewa epistemology:

> To the question that you asked about how we come to know,
>
> There are things we know by seeing…Smelling…
>
> touching/contact even though we have not seen…
>
> listening/hearing (chronicles) from our parents (elders/forefathers) …
>
> listening/hearing from those who have encountered/experienced things
>
> (Interview with Group Village Head Miyowe, Dedza)

As can be seen in the extract above, multiple senses in addition to the visual contribute to knowing. One can therefore argue that cognitive engagement, and the feelings associated with it, count as experience. As explained by GVH Miyowe, this experience need not be from the immediate people still living but might be experiences with phenomena that have been handed down from one generation to the other. All in all, seeing and/or perceiving is a fundamental principle of the Chewa notion of truth.

The importance of experience in the Chewa conception of knowledge is visible through other intangible cultural heritages such as proverbs. The Chichewa term for proverbs is *miyambi* (plural) or *mwambi* (singular). *Miyambi* have been described as stores of indigenous knowledge that has been gained and accumulated over time (Chakanza 2000; Kaphagawani 1998; Banda and Banda 2016). They express a people's traditional values and reflect their ways of thinking and seeing the world (Chakanza 2000). They offer guidance and wisdom that touches on various conditions of life and all groups of people within a community (Chakanza 2000). Because *miyambi* reflect a people's way of thinking and of seeing the world, they provide important frameworks for understanding the ways and experiences of Malawian communities. As such, I used *miyambi* in this study to guide my practice of methods and inform my understanding of the findings.

As can be seen above, *miyambi* communicate messages that have meanings indicative of the Chewa people's conception of knowledge (Kaphagawani 1998; Banda and Banda 2016). For instance, the *mwambi* "*akulu akulu ndi m'dambo mozimila moto*" which translates literally as "elders are the rivers where fire is extinguished", has been used by Kaphagawani (1998:241) to illustrate this point. He explains the *mwambi* as meaning "elders are living encyclopaedias to which reference can be made to troublesome questions (they have most if not all solutions) to any kind of problem". The elders are considered in this way because they have lived longer, through conditions such as war, famine, peace, epidemics and so on. Thus, they have had more experience having learnt from their own mistakes and successes and those of others through observation. Because of their assumed learning and experience, the elders are respected and are considered authorities of knowledge from which people were willing to shape their ways of seeing and doing (Kaphagawani 1998). Their cumulative experiences call for maximum respect and authority. However, Kaphagawani (1998) makes a distinction between knowledge and wisdom to say that not all who have knowledge have wisdom because wisdom is a product of knowledge while knowledge is accumulated experience. In Chichewa it is possible to say someone has knowledge but deny them wisdom because wisdom requires reflection and judgement.

Although the elders are considered highly in the Chewa epistemology, serving as living reservoirs of knowledge, experience is highly valued regardless of who shares it. Another common *mwambi* when unpacked allows for knowledge from younger peoples' experiences. The *mwambi* "*kuona fisi si kubadwa kale koma kuyenda usiku*" which can be translated as "seeing a hyena is not determined by being born a long time ago but by moving/walking at night" suggests that being old is not enough to "see a hyena". Younger people can gain experience by being in the right place at the right time, that is, younger people can contribute to knowledge if and when they have encountered a phenomenon. Before I wrote about this *mwambi*, and what it reveals, I verified my interpretation with GVH Miyowe who supported my interpretation.

3.1.4 Drawing on Participant Observation

In my research methods, I interweave the use of folk media with selected Western qualitative research practices to form a culturally "specific" methodology. As earlier stated, the aim of this study is to learn how two rural communities understand and make sense of HIV and AIDS using their own folk media. The *mwambi, 'Ali dele nkulinga utayenda naye'* (You can only say he/she is like this or like that after you have moved/walked with him/her) suggests that to know another requires walking or being with them. This led to my decision that when conducting research, I should spend time with communities and live as they live. In doing this, I drew not only on decolonizing indigenous methodological frameworks but also on a conventional social science research method, participant observation which I found compatible with my folk media methodology and indigenous methodologies in general.

Participant observation enables researchers to learn about a people or phenomena in their natural setting by actively participating in the activities as they observe them (Musante & DeWalt 2002). Participant observation cannot be described adequately without reference to ethnography. Traditional ethnography is based on the belief that in order to know other human beings the ethnographic researcher must share in the experiences and daily realities of the participants (Madden 2017; Malinowski 1999; Geertz 1973; Conquergood 1985). In his book, *Being Ethnographic: A guide to the Theory and Practice of Ethnography*, Raymond Madden (2017) argues that the ethnographer needs to place themselves in the same social space as the participants. Ethnographers use a mixture of methods - both qualitative and quantitative - to construct accounts of communities and their practices that reflexively represent, often through ethnographic storytelling, the experiences and viewpoints of community members.

Participant observation, as one of the methods of ethnography, is aimed at interpretation of the significance of happenings in the cultural lives of people and not just description (Geertz 1973; Hoey 2014). Decolonising and indigenous methodological approaches that ground my methods insist that this cultural interpretation be made using the cultural and philosophical frames of reference of the people with whom the research is taking place. Drawing on the participants’ choices of their own folk media forms, together, we adapted, tested and re-adapted them for use as research methods in the study. Traditional ethnographic techniques such as establishing rapport, keeping a journal, and transcribing text, just to mention a few, have stood the test of time and have been particularly useful in this study. As described earlier, I used participant observation to get to know the community and become familiar with the folk media forms that each of the communities had and their specific nuances. This helped me to more ably participate and facilitate knowledge generation using the communities’ own folk media forms as will be illustrated later in this chapter. Throughout the study, I wrote reflexive field notes every evening which supported my familiarization with the context.

3.2 Research Sites

Before describing the research sites, and then the specific approaches to using folk media, I need to briefly describe the traditional leadership structure in Malawi.

Malawi is divided into three regions: Northern, Central and Southern region, covering 28 districts. Each district consists of traditional leadership structures in the form of chieftaincies. According to Eggen (2011) modern chieftaincy in Malawi is a key aspect of state power which fuses everyday state governance with traditional/cultural authority. The chieftaincy system has strong cultural autonomy and is strongest in rural communities so that people in rural communities are simultaneously citizens of the state and a chieftaincy system (Eggen 2011).

A typical structure of traditional leadership hierarchy consists of Traditional Authorities (T/As) which oversee Senior Group Village Heads (SGVH) who in turn oversee Group Village Heads (GVHs) who in turn oversee Village Heads (VHs). Typically, a GVH oversees a minimum of 5 VHs and can have as many as 40 or more. The traditional leadership structure contributes significantly to the identity of a Malawian and their description of where they call home. This is reflected in state processes, for example, when applying for official documents such as a passport, we need to state a home village (typically the name of the Village Head) and Traditional Authority. In some cases, the government authorities even require a letter of confirmation from your Village Head, as they did when I was getting my passport and a birth certificate for my son.

I worked within the traditional leadership structure to identify and select communities in which to work. There were four steps, and at each step I was supported by different stakeholders. Table 1 summarises the process which I describe in more detail in subsequent sub-sections.

Step	Level of selection	Stakeholder
1	Selecting Regions	Myself
2	Selecting District and Health Centres	Program officer of Art and Global Heath Centre Africa and Myself
3	Selecting Traditional Authority (T/A) and Group Village Head (GVH)	Health Surveillance Assistants (HSAs)
4	Selecting Participating Villages and Participants	Group Village Heads (GVH) and their Village Heads (VHs)

Table 1 – summary of steps to identify and select communities.

First, I needed to decide which regions to work in. I wanted to capture diverse experiences, but a number of other factors also influenced the decision. I had time and resources to work with only two communities, and I needed the communities to be physically accessible to my base in Zomba, Southern region. Most importantly, I needed to be able to communicate effectively and fluently in the language of local communities. I speak Chichewa fluently and as this is the language mostly spoken, with variations in accent, in Central and Southern Regions of Malawi, these were the regions I chose.

Second, I needed to identify districts within the regions, from the 13 districts in Southern region and nine in Central region. To do this I drew on prior knowledge and in particular, previous work with Art and Global Health Centre Africa (2020), a non-profit organization based in Zomba. Health Centres are based in each district in each region and Art and Global Health Centre Africa has worked with health care workers in several local Health Centres across the country including some of those in Southern and Central regions. I asked Rodger Kumalire Phiri, program officer at Art and Global Health Centre Africa, to recommend districts with Health Centres that have characteristics shared by most rural areas in Malawi that would also be accessible during the rainy season (fieldwork took place in January and February). After lengthy deliberations, we selected Dedza in the Central region and Thyolo in the Southern region -- about 340 kilometres apart. Within these, we settled for Kaphuka Health Centre in Dedza and Mikolongwe Health Centre in Thyolo districts as most suitable. Kaphuka Health Centre has a catchment area population of 30855 and serves 11 GVHs from 3 Traditional Authorities. Mikolongwe Health Centre has a catchment area population of 32769 and serves seven GVHs from two Traditional Authorities.

Previous relationships that Rodger had with Kaphuka and Mikolongwe Health Centre Officers in Charge enabled him to introduce me to them and for me to seek their advice on which communities to work with. During face to face meetings, I introduced myself, the aims of my research and explained how I had identified their specific Health Centre. With their permission, I then met Senior Health Surveillance Assistants (SHSAs) in each Health Centre, who are most knowledgeable about communities because they are responsible for direct engagement with communities and serve as a bridge between the Health Centre and communities. The senior HSA (in charge of overseeing HSAs at the local health centres) in consultation with their HSA's suggested the Group Village Heads (GVHs) in each site as likely to be interested and arranged for a meeting with them.

The third step was engagement with the GVHs and in doing this I was guided by a *mwambi* which says "*ukapita kwa eni, chakwanu leka*" (literal translation might be, if you go to another's home, leave behind what is from yours, and has similar meaning to the English phrase 'when in Rome do as the Romans do'). I sought a mentor like relationships with the GVHs in each district, meeting regularly to discuss the progress and next steps. For instance, GVH Miyowe was very involved in all aspects of the research, I met with him every 3 days to brief him on progress of the workshops and sought his advice on any challenges I was encountering or anticipating. We met periodically throughout the fieldwork, suggesting his high investment in the research and the extent to which he and his community had welcomed us. This level of commitment to the research was established from the outset by my initial encounter with the GVH where he contributed to how the research unfolded in the field.

During the initial meetings with GVHs, I introduced myself (name, tribe, home village, district, my family, where I lived and what I was doing), I introduced the study, and negotiated answers to such questions as, whether to conduct the study at GVH level or VH level, where to base the study, how to select the participants and distribution of which participants come from which villages, whether or not to live with the community, how best to do this, and who else needed to be included in the study to achieve the best results.

Finally, I needed to select villages and participants and in this I was guided by the GVHs. In Dedza, GVH Miyowe oversees 17 villages, each with a chief (Village Head). GVH Miyowe thought it would be best to organise the research at GVH level so that he could keep an overview of activities and that the research would capture experiences of a wider group. We agreed that GVHs would identify around 20 participants who were 18 and above. With 20, I felt I would manage to facilitate the process and give attention to all the participants and I also had sufficient funds to provide lunch to this group. GVH Miyowe also thought that each village should be represented in the workshops and to aim for a gender balance. He and his VHs selected the participants for the study and also agreed that I should stay with community members and selected a home for my research assistant and I to stay in for the duration of the research.

GVH Miyowe also suggested that the study needed to include the chiefs (GVH plus VHs) as participants at some point. He explained, "*It is important to include a chat with the chiefs because your research is looking to understand our perspectives on HIV and AIDS in the context of our culture, using our culture, and chiefs are the custodians of culture, they determine whether a* *culture lives or dies and will be able to give you a picture of the general perspectives of their people as well. That way you can compare your notes*" (GVH Miyowe, extract from my field notes in Dedza). Although the chief's session was not part of my original design, I included it in the study because the custodian of the people and their culture (the GVH) said it was important and we co-facilitated the session.

In Thyolo, GVH Chidothe's area comprised of 5 big villages. Initially, when I went to visit GVH Chidothe, he was not there, his duties had demanded he attend a funeral. Although I waited, I was not able to see him and left a message with his wife. Because Thyolo was a distance away and the community challenging to reach (up a muddy, rough, hill which was slippery during the rainy season) we made our arrangements by phone, acceptable to GVH Chidothe because he knew I had followed culturally acceptable protocol and made an effort to see him personally. During this phone call, GVH Chidothe also suggested conducting the research at the GVH level, that participants from all of his 5 villages should participate and that there should be a gender balance. He also agreed it would be good to include village chiefs in the study and also co-facilitated that session with me.

Practical arrangements were not so straightforward as in Dedza, possibly because I had not been able to discuss in person with GVH Chidothe so he was not able to see my commitment to the study. When we arrived, accommodation had not been arranged and five of the participants who came on the first day were quite elderly and didn't quite understand why they were there. Luckily, the GVH's sister, also a VH, offered to have us in her home with her six children and were able to renegotiate participation with the older members, GVH and VHs and their VHs sent replacements. On-going mentoring was quite easy in Thyolo also because I was living in a village chief's house (VH), and I was able to consult with her almost daily. When I needed further guidance then I met with the GVH Chidothe.

Site	GVH	T/A	Participants	Sex	Age Range	Level of Education	Estimated no of people engaged through all 3 phases
Dedza	Miyowe	Chauma	18	9F 9M	30-54	0-form 2	800
2 Thyolo	Chidothe	Chimaliro	18	9F 9M	27-63	0-form 4	110

Table 2 - Participant details

Table 2 provides an overview of the participants. In addition, 1 GVH and 16 village heads (Chiefs) in site 1 and 1 GVH and 5 village heads from site 2 were engaged in the exploratory sessions with the chiefs.

When all the arrangements had been made and it was time to move into the community to begin the research, I recruited one of my former students Misheck Chiwanda, a graduate from Chancellor College to help me. Being male allowed a gender balance for facilitation and Misheck's support was useful when participants had to work in different groups. He also helped me with capturing data when audio or video recording and since there was no electricity in the villages in Dedza, Misheck also often helped me to get the data capturing equipment charged at a primary school about 3-5 kms away.

3.3 Outline of Phases of Research and Methods

Once in the communities I conducted the research over 15 days in three phases. Table 3 summarises the activities in each phase which I describe in more detail in subsequent sections.

Research Phases	Aims	Methods
Phase 1	Sensitization to the community and environment identification of folk media forms in everyday interactions	Participant Observation and fieldnotes
Phase 2	Folk media workshops and creating a community-wide performance.	Folk Media Forms and verbal journals (captured through audio and video recordings) and field notes
Phase 3	Data gathering through community-wide Performance event including performance and audience discussions	Community Folk Media Performances and fieldnotes

Table 3 - Summary of the research process

3.3.1 Phase 1: Sensitization to the community and *environment.*

As earlier stated, *ali dele nkulinga utayenda naye* (You can only say he/she is like this or like that after you have moved/walked with him/her). Drawing on this *mwambi*, and following the principles of participant observation, Misheck and I lived with the community throughout the duration of the fieldwork. We lived with one of the families in the village, shared meals and evenings of singing after the evening meal. This was the only meal of the day in Dedza as we did fieldwork in ‘the hunger season’ (see section on ethics for details of meal arrangements). In Thyolo, people had a bit more to eat, perhaps because the community is close to a big trading centre where members of the communities often trade.

When we arrived, the GVH settled us in with our host family and introduced us to some of the participants who would be joining us in phase 2 of the research. During the first three days which we allocated to phase 1, we worked towards integrating ourselves into the community’s daily lives, helping with routines around the home, visiting neighbours and chatting with other members of the community, building relationships, and generally getting to know the community, their ways and their folk media forms, which we both observed and asked about in informal interviews. From phase 1, we learnt some folk media forms of the communities such as *masewero* (plays/dramatic enactments), *magule* (traditional songs and dances), *nyimbo* (songs), *kuyerekezera* (role play), *nthano* (folktales), *ndagi* (short riddles), *masewera* (games), and *miyambo* (etiquette and initiation activities). During this process we also focused on learning when, who and how the community used these forms. At the end of the day, Misheck and I met to share what we had learnt during the day and I wrote detailed notes and sometimes audio recorded our discussion.

Having had a basic understanding of some of the community's specific folk media forms in each setting, I had further consultation with the GVH in each community as regards how I might approach the participants in phase 2 to explore what forms might be useful in exploring what knowledge. This conversation gave me a starting point. The rest of the workshops were developed together with the participants.

3.3.2 Phase 2: Folk media workshops and creating a final performance.

The learning from phase one helped me to facilitate the folk media workshops and relate with the participants more easily as I was more familiar with the communities' ways. The participants chose the folk media forms for engagement and together we negotiated what we would do in each session and what the areas for exploration would be. We used *mlozo* (map/ping), *nyimbo* (choir like songs), *magule* (indigenous songs and dances), *nthano* (folk tales), *ndagi/zilape* and *ntchezero* (riddles), *bwalo la mafumu* (forum/arena of chiefs) and *masewero* (plays/dramatic/theatrical enactments). Alongside participants' reflections, these folk media were methods of data generation that prompted and mediated diverse understandings and articulations of participants' experiences of HIV and AIDS and health in general.

To capture the participants' individual private reflections during the workshop process, participants kept verbal audio journals which we called "*kaundula*" (register/record). The verbal journals were more accessible to participants than written journals because many of them did not go far with formal education and found it difficult to write. Part of the discussion on journaling involved exploring together with the participants how we could maintain privacy and anonymity in the *kaundula*. First, drawing on folktales we agreed to use animal names. Since by this time, we had established that the community was rich with *nthano* (folktales) that are often set in the jungle and that use animals as characters that speak and often embody human traits and experiences, we decided together that each of the participants would be a jungle animal. Each participant chose the animal they would be privately, so much that unless the participant made an open declaration of the animal's name, the rest of the participants could not know who which animal was.

In Thyolo, participants also wanted to be jungle animals. After negotiations, however, they settled on the world of plants and agreed amongst themselves to be edible plants only. So, whenever it was *kaundula* time, the participants took on the name of the animal or plant and introduced themselves by that animal or plant. For instance, they would say "*Dzina langa ndi Mvuvu* (My name is Hippopotamus)" in Dedza or *Ndine Kabitchi* (I am cabbage)" in Thyolo before they went on to voice their thoughts. The participants made verbal journal entries at the end of every other day's sessions. In Dedza, two recorders were used, one in the empty room where we conducted the workshops and another in a private spot outside the room providing space for each participant to make their entries privately. In Thyolo, the workshop room was big and so, the recorders were placed at opposite ends of the room.

Table 4 summarizes the folk media workshops which I go on to unpack in more detail in the sections that follow.

3.3.2.1 Day 1: Familiarization with the participants, building rapport and establishing norms

As is the community's tradition, each day started with a prayer which the participants took turns in offering. In these communities it is believed that when a prayer is offered, it invites God to be present during the activity which facilitates success. Through the prayer the participants also often voiced their thoughts on the process of engagement, how they felt about it and what they were hoping for in the session.

Days	Objectives	Methods
1	- Familiarization with the participants, building rapport and establishing workshop norms	Nyimbo/Magule (Songs and dances), Ndagi/ ntchezero (riddles), Nthano (folk tales)
2 and 3	- Getting to know the community from the participants' perspective'	Mlozo (Map-ping), Chipako (game), Kuyerekezera (miming), Sewero (dramatic enactments), Nyimbo ndi magule (Songs and Dances), Reflections
4, 5 and 6	- Exploring how the participants and their communities understand and make sense of HIV and AIDS	Nyimbo (Songs) Magule (dances), masewero (dramatic enactments), Bwalo la mfumu (arena/forum of chiefs) Ndakatulo (Poem), Reflections
7,8 and 9	- Creating a community-wide performance	Group discussions and presentations, Nthano, sewero, magule, Nyimbo

Table 4 - Summary of folk media workshop process (Phase 2)

The first day was dedicated to getting to know each other, building a good working relationship, and setting the pace for the rest of the workshops. Although the participants, Misheck and I had already been introduced by the GVH and had interacted during the consent seeking process (see ethical considerations section), it was important that we got to know each other in the context of the workshop space. Therefore, we used our first sessions not only to introduce ourselves to each other, but also to encourage ownership of the process and foreground our engagement through folk media.

To do this, I asked the participants in each community if they had folk media forms that they used in their community to get to know one another. They conferred and, in both communities, agreed to use songs and dances. After the introductions, we continued to sing and dance together as the participants continued to lead the session with one song after the other. Among the songs that emerged were children's songs, moonlight songs and dances (songs, dances and games that children, and/or older children play and sing at night under the moonlight) and *magule* (indigenous songs and dances). After the songs, participants in Dedza spontaneously started riddles and folktales. While it was similar in Thyolo, we had a little break after the songs before moving on to riddles and folktales. We spent most of the first day just singing, dancing and playing together. It was important that these initial sessions be led by the participants as this encouraged their ownership of the process. Songs and dances continued to become part of our daily routine for starting our workshop sessions for the day. Towards the end of the day, we reflected on some of the games we played to help us in co-establishing workshop norms of engagement with each other in the workshop space.

3.3.2.2 Day 2 and 3: Getting to know the community from the participants' perspectives

On the second day of the workshops the focus was on getting to know the community from the participants' perspectives and to create a platform for the participants to gradually begin sharing about aspects of their lives and their community. *Mlozo* (Mapping), *masewera* (games) and *masewero* (dramatic enactments) were used. I will explore the folk forms as they were used.

Mlozo (Mapping)

In order to learn from the participants how to explore the physical spaces that were important to the community, I began the exploration session by asking how I could get to the local health centre. The participants' responses in each community started our conversation about mapping as they took turns giving me directions and mentioning major structures and spaces in the process. In Dedza, in the participants' attempts to help me not to get lost, some of them drew the directions on the ground. A participant referred to it as *mlozo* (literally translated as that which points to, also known as *mapu*). Together we adapted this process to explore the geography of the community using flip charts and markers. After agreeing on mapping their community as a group, I explained that it was important to include all landmarks, places and spaces that were important to the everyday lives of their community. The participants used symbols to represent places/spaces. Figure 1 and 2 are pictures of participants mapping their community together. The process can also be viewed in Video 1.

Figure 1 - Participants during mapping process in Dedza

Figure 2 - Participants during mapping process in Thyolo

After the *Mlozo* (map) was complete, I asked the participants to guide me through the map and explain the spaces and why they were important to their lives. They started from the top of the map, as though they were giving me a tour of their community, all the way to the bottom of the map, taking turns to tell the story of the spaces and their relationship to the community.

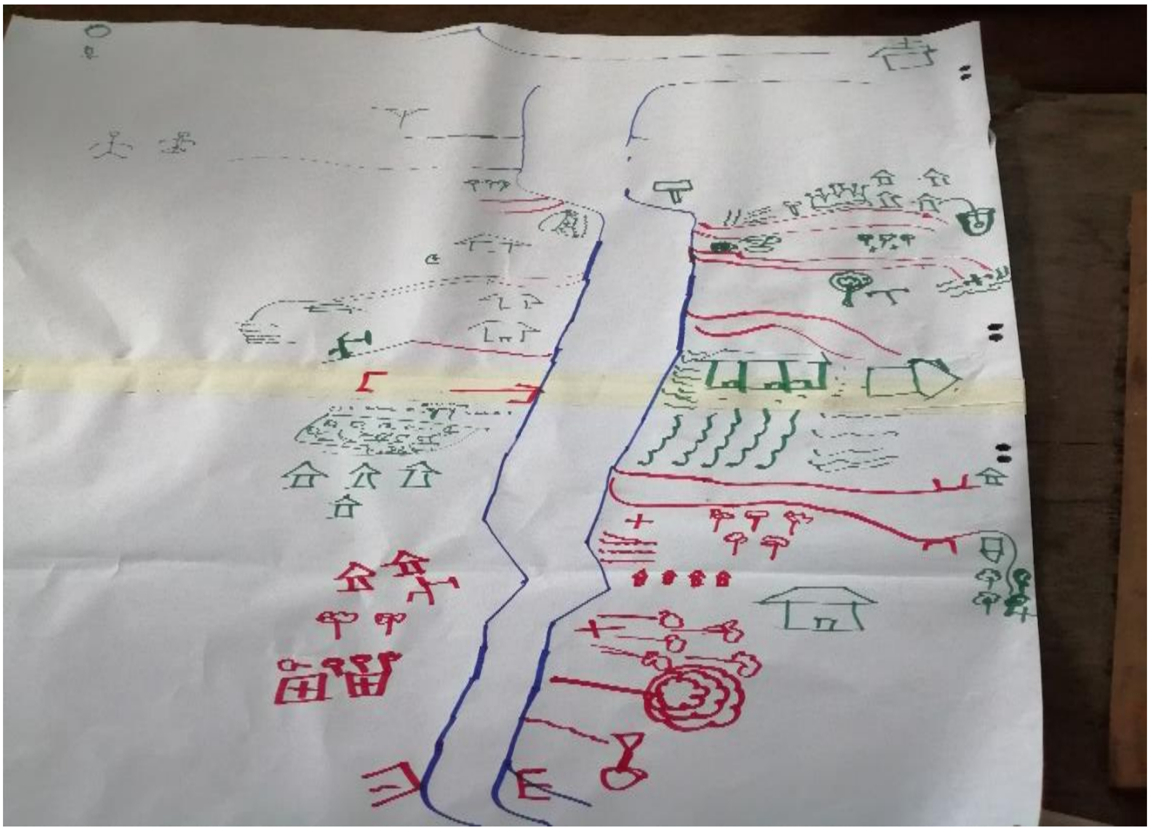

Figure 3 - Map by participants in Dedza

Through the map, we explored physical spaces (health centre, *sing'anga*, market, school, churches, mosque, boreholes, graveyards, hills, trees, farming lands etc) and available services within the community and how they relate to each other. Diseases and illnesses (including HIV and AIDS) that affect the community, when and where they seek treatment for which illnesses also emerged as the various spaces were explored. The mapping process on this day ended with the participants, Misheck and I identifying and summarising the key areas/themes of the community's lives that had emerged. These key areas/themes provided us with the topics for exploration in the sessions that followed. Guided by their relationship to the overall topic of HIV and AIDS, we explored the themes one by one through whichever forms of folk media that the participants chose. The process can also be viewed in Video 2.

Masewera (Games)

After the mapping session we went on to explore important events that had happened and that had affected the community to date in the past five years. Together we identified and adapted a popular children's game called "*chipako*" (similar to "tag" or "you're it" in the English language) as a method for the exploration. Games have been described as activities aimed at achieving a specific task that are framed in a marked-out place and time within specified rules (Chinyowa 2007). They allow the players to enjoy the freedom to play having transformed their attitudes, purposes and behaviours to suit the tasks involved in the game (Chinyowa 2007). They offer opportunities for participation, engagement, freedom, fun and the responsibility of playing within specified/agreed rules. An example of the use of games can be viewed in Video 3.

Together we negotiated how we would use the *chipako* game, setting the rules together. Keeping the original structure, and rules of the game, we reshaped the narrative of what was happening in the game. We set it up as a village tasked to present the major events that affected their village in the past five years. The players became the villagers and the person who was 'it' became the authority who was responsible for appointing a speaker, who would present the events on behalf of the village. As this was considered a big responsibility, the villagers tried to avoid it by running away. However, when the player was tagged, they had to present an event, when it happened and details of the event, then tag someone else. The game worked well in identifying important events in the community in a playful way. The participants led the process with a song supporting the game. Although with slight variations, the *chipako* game was used in both Dedza and Thyolo to explore major historical events.

Aided by the farming lands that were identified on the map, we also explored the community's seasonal calendar (when they do what at which months of the year). However, while participants in Dedza chose to draw a table to share their seasonal calendar, participants in Thyolo decided to use miming while verbalising (a sort of dramatization) to share their seasonal calendar. The day ended with a recap of the day's workshop and an agreement to think and prepare for the following day's sessions. The participants were to share their community's life cycle (important stages from birth, growth, marriage, death etc) using whatever folk forms they used to teach their children about life. The participants having a choice of what folk forms to use for exploration was important in sustaining their ownership of the process and giving them confidence to express themselves in the best way they knew how.

Masewero (Dramatic enactments)

By day 3, it was evident that the participants understood that they were co-owners of the research process and that they had the freedom to choose what folk media forms to use for any given exploration. For instance, day 3 started with exploring the community life cycle as agreed on the previous day. Participants in Dedza had said they would use *nthano* (folk tales) to show how the life cycle unfolds in their community. But when it was time to share, the participants spontaneously came up with a whole group *sewero* (dramatic enactment). The term *sewero* is used as the Chichewa equivalent of a play, whilst *masewero* as the equivalent of plays. But the word generally translates to that which is played with a sense of make-believe/pretend play. The *sewero* is usually a dramatic enactment. According to O'Neill (1995), drama allows participants to draw experiences from the real world and take them into the make-believe world in order to understand reality better (O'Neill 1995). It opens new and alternative ways of knowing and understanding that enable a deep sense of empathy (Dimm 2002). Turner (2003) suggests that drama can provide an opportunity for societies to look at themselves (like a mirror) and examine themselves.

The *sewero* that the participants presented explained and showed their understanding of when and how life begins, stages of life, all through to death and after death. The *sewero* was played by everyone in the group changing the people that played the same characters as the story progressed. Issues of illness, treatment, health, education, ritual also emerged through this enactment including the beliefs that accompany these notions.

In Thyolo, participants decided to divide into two groups, some chose to use *nyimbo* (songs) while others used *sewero* to explore the life cycle of their community members. Each group discussed, created their performances and presented to the whole. During this time, everyone got a chance to interact with each group's presentation and because the participants were working in groups and not presenting at the same time, it provided some distancing that allowed for more diverse and critical engagement with each group's presentation. With both the Dedza and Thyolo participants, the process was accompanied by clarifications and reflections which I facilitated at strategic points to help with detailed exploration as well as to assist my understanding and interpretation of what I was seeing.

3.3.2.3 Day 4 and 5: Exploring how the participants and their communities understand and make sense of HIV and AIDS

Through reflecting together on the process thus far, we found that HIV and AIDS was a theme that needed further exploration. Then we went on to focus on exploring understandings of HIV and AIDS. It was important to first learn the folk media forms about HIV and AIDS that already existed in the community prior to my research as they would provide a basic understanding of the communities response to HIV and AIDS, and what they thought of it. It would also allow the participants, Misheck and I to identify areas of the community's interest for further exploration. To do this, I asked the participants to think about all the folk media forms that the community already had about HIV and AIDS prior to this study. The participants came up with, *nyimbo* (songs) *magule* (indigenous/traditional songs and dances), *ndakatulo* (poems) and *masewero* (dramatic enactments). The participants then divided into groups based on the folk media forms they wanted to work with. As I have already unpacked *masewero* (dramatic enactments) when exploring days two and three, I shall focus on unpacking *nyimbo ndi magule* (songs and dances) and how these were used.

Nyimbo ndi Magule (Songs and Dances)

Songs and dances were very helpful to our learning about how the communities positioned HIV and AIDS. According to Nthala (2009), music/songs and dances do not only reflect cultural patterns and structures of a given group, but also provide a space for generating meaning. People within the community use songs and dances to express attitudes and feelings towards certain phenomena that they encounter (Nthala 2009). Thus, careful observance and review of communities' songs and dances can enable one to describe, interpret, understand and identify with the cultural group and its social arrangements.

Each group of participants performed their folk media forms to the rest of the group which made additions and/or clarifications where necessary. Then together we reflected on the forms and unpacked the stories that the songs were telling, who was speaking, who they were speaking to, what they were saying and what the mood/atmosphere/emotion in the forms were and why. Reflections at the end of each set of performances allowed participants to share what was being communicated through the forms, the background stories and events that led to the creation of the forms and other details of the forms that helped me to better understand the experiences of the community that were stored/captured in the folk forms they presented.

Building on what emerged, such as descriptions of AIDS, its origins, its impact on the community, people's feelings towards it, issues of prevention and relationships between people, I asked participants to create their own new pieces expressing their own perspectives of what HIV and AIDS was.

Although I brought to the table the overall topic of HIV and AIDS, I wanted the participants to determine the details of what we explored and how we explored it. Given the sensitivity of HIV and AIDS and that it also touches people on a personal level, it was important for the folk media form to provide a distancing that helped to lessen inhibitions and enable critical and reflexive exploration. To do this in Dedza, we had to use a folk media form that would allow for open exploration and so, we agreed with the participants to use a *sewero,* to make-believe that they were all researchers who were asked by the District Commissioner (DC) of the area to conduct research in the community to understand how the community members made sense of HIV and AIDS. This type of *sewero* is often described in literature as role play, a type of dramatic enactment that allows participants to “take on roles of other people and act out the others’ feelings, thoughts and behaviour” (Chesler and Fox 1966: 9). By taking on other people’s roles, and by pretending to think, feel and act like them, participants act out their true feelings without the risk of judgement or what Chesler and Fox (1966) call “sanctions and reprisals”.

In Dedza, in preparation for the *sewero*, the participants divided into two groups to discuss and write down their findings. Then they were invited to present their findings at the DCs office. The *sewero* scene opened with a convening of a meeting to report and discuss the findings of both groups’ research. I introduced myself as the DCs assistant and welcomed the participants as researchers to the meeting. I explained that the DC was away and had asked me to convene the meeting on his behalf. I facilitated the meeting in role as the DC’s assistant. This enabled me to ask questions, seek clarification and further explorations without breaking the *sewero*. The particular framing of this role play is often used in a dramatic form called process drama. Process drama is a type of improvisational drama that is concerned about process rather than product (El-Nasir 2008). It is a dramatic engagement that “provides a framework for the exploration of ideas and feelings” (Bowell and Heap 2005: 60). This is done through the creation of what O’Neill (1995) calls a “dramatic elsewhere”. In creating and maintaining these worlds, participants construct and explore roles, ideas and situations. The drama helps in discovering and articulating ideas, feelings and attitudes, and shaping these private understandings into public form (O’Neill 1995). Through this *sewero*, the participants were able to share their perceptions and experiences of HIV and AIDS freely without fear of judgement. And so, we generated data about their understandings of what HIV and AIDS is, where it came from, who is responsible for its presence, prevention, treatment, care and other issues related to it.

In Thyolo, participants chose to create a *sewero* that told a story about a family's experience with HIV and AIDS. After presentation, we reflected on the *sewero* together paying attention to the story it told, the characters in each of the scenes, the relationships between characters, the issues it raised and what informed the *sewero*. This unpacking was necessary because it revealed that the *sewero* was made up of a series of interconnected fragments of moments representing real experiences of the participants. From this *sewero* which appeared to tell one chronological/logical simple story of one family, through unpacking and reflecting on the fragments revealed not only the complex stories and experiences of the participants with HIV and AIDS, but also of various groups of people within the community.

Story Sharing

By this time, our relationships in the workshops were characterised by togetherness, friendship, respect and trust. As such, day 5 was dedicated to sharing personal stories about how HIV and AIDS had affected the participants and/or their community. After establishing that we had stories to tell, we borrowed from the community's cultural story telling tradition where people sit in a circle and tell stories (including folktales). We then agreed to use audio recording only, to enable participants to share their stories without concerns of being identified beyond that space. I started by sharing how HIV and AIDS had affected me through my sister's life living with the virus and the disease. Then one by one the participants shared how they had been affected by HIV and AIDS through family and close friends. Stories of recovery from AIDS-related near-death experiences, struggles with treatment, as well as losing family members and friends to AIDS were shared. I found that sharing my own personal story first, helped to foster the connections between us and showed the participants that I trusted them with my story and that it was alright to share.

3.3.2.4 Day 6: Bwalo la Mafumu (Arena/forum/council of chiefs

On day 6, the participants had a break while Misheck and I engaged with the chiefs (GVH and Village Heads). The aim was to explore the chiefs' perspectives on HIV and AIDS related issues. Given that these were chiefs, special consideration had to be made as to how to engage them in explorations. Upon consultations with the GVHs, it was agreed that since it is a once off session, it would be best to conduct it as a *bwalo la mafumu* (arena/forum/council of chiefs) session. *Bwalo la mafumu,* as referred to by GVH Miyowe, is a community structure in which chiefs meet to discuss important issues in their community. This was adapted for the workshop session, and considering that I was not a chief, we agreed that we would co-facilitate the session, with the GVH taking a leading role as he does in real life when chiefs gather to discuss village matters. In Thyolo, GVH Chidothe, also agreed that a *bwalo la mafumu* session would be best and that we co-facilitate the session.

3.3.2.5 Days 7, 8 and 9: Creating a performance for engagement with the wider community

On day 7, we resumed the workshop process with the participants. Having generated data on the participants perspectives on HIV and AIDS and health in general, we recapped what had emerged in a participatory analysis process. Workshop participants divided into two groups and were asked to: recap and summarise what we had explored in the workshop sessions; identify what was important to them and their communities from the explorations; prioritize the key ideas, issues and insights that were most important to them; and, make meaning from what they had identified as key issues and tell stories from it. From this process, the participants identified what they called "*mitu ikulu ikulu*" (big heads/headlines) which is an equivalent to major themes or topics from which they developed stories that happen in their communities in relation to those themes. These stories were used to create performances for the wider community for Phase 3 of the research.

In creating the performance from the stories, we developed fragments of moments that represented the experiences of community members in relation to the story, weaved them together to make a *sewero* and finally prepared to present it to the wider community. Drawing from how the stories in *nthano* (folk tales) are structured, we were able to develop a cohesive storyline for the play. We also explored how *nthano* engages audiences to participate and contribute to delivery and applied it to the delivery of our *sewero* to the rest of the community. Our creation of a *sewero* drawing from *nthano* highlights the flexibility of folk media forms and opportunities for creators to weave together aspects of multiple forms to create new forms of folk media. As we developed the play, our objective was to raise issues that the participants found critical to explore and facilitate their fellow community members in responding and sharing their own stories and experiences. Through the process of creating the performance, details of participants' experiences with HIV and AIDS were further explored. The participants' priorities on matters that needed further discussion and input became more visible.

3.3.3 Phase 3: The performance for the wider community

The community wide performance created in phase 2 was performed by the workshop participants to an audience of other community members in phase 3. Participants engaged the audience in a way that facilitated expression of their opinions, views and perspectives on the issues raised. Thus, the performance itself generated data and with permission, I video recorded the performance and also conducted informal interviews with audience members, to understand their responses. The performance events were popular and attended by one GVH, 11 VHs and approximately 800 community members in Dedza and 1 GVH, 4 VHs and approximately 110 community members in Thyolo.

When we arrived at the village arena, we engaged in pre-performance rapport with members of the community who had come to watch the performances. Led by the participants, we sang and danced. Audience members began to join in and lead some of the dancing, while some male members started to beat drums. As per protocol, when the people had gathered, the chief spoke and opened the event in both communities. He then handed the space over to the performing team. The performers began with fun songs and dances as *kalambula bwalo* (literally translates to clearing the arena, often done immediately before performances). Then the participants went on to act out the *sewero* they had created which they used to engage their fellow community members. For instance, the character in the *sewero* in Dedza defaulted from HIV treatment and in Thyolo threw away condoms. As if part of the *sewero*, the characters in the scene asked the audience whether this happened in their community. The performers moved back and forth between the action in the *sewero* and the thoughts and experiences of the audience members. They worked with those experiences, to support interactions and motivations of the characters and then offered them back to the audience. By doing this, the characters shared their stories and experiences with the audience and the audience shared their experiences with the characters facilitated by the participants who acted out the characters. Both the creation of the *sewero* and the delivery of the performance reflect how an integration of aspects of both local storytelling and our dialogical research approach in the workshops came to influence the *sewero* performances by the participants in the final phase of the project. This illustrates that folk media are responsive, dynamic and alive. While this process helped to generate knowledge about the wider community's experiences with HIV, it also helped in triangulation. An example of audience contribution can be viewed in Video 4.

During the event, the community in Dedza shared their own performances. The chiefs performed a *njedza* dance, the women performed *chinana* and there were *gule wa mkulu* performances as well. Some of these performances also had HIV and AIDS topics in them. Thus, these too added to data.

3.4 Analysis

I approached analysis in two ways. Firstly, as part of the folk media workshop process with the participants and secondly, on my own, in the months following the fieldwork. In the first instance, as I described above, after exploring the narratives of HIV and AIDS with the participants, Misheck and I engaged them in a participatory form of analysis which helped identify what the participants called "*mitu ikulu ikulu*" (big heads/headlines) for phase 3 but also helped us all to reflect on our experiences and findings. The process was an important step for me in considering the main findings.

By the end of fieldwork, I had 26 hrs of video recording, 10.5 hours audio recording, 7 hrs participant verbal journal entries and my field notes. While I engaged in my own analysis in the months following the field work, I integrated the themes the participants constructed and prioritized in my coding and theme development process. My analysis of the data was informed by Braun and Clarke's (2006) thematic analysis. According to Braun and Clarke "thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data" (2006:79). It is a reflexive process that minimally organizes and describes data in detail and can go on to help interpret various aspects of the research topic (Braun and Clarke 2006). Adapting Braun and Clarke's (2006) six phases of thematic analysis, I took a stepwise approach to my data analysis.

Firstly, the authors suggest familiarizing oneself with the data and identifying items of interest (Braun and Clarke 2006). I began familiarisation by facilitating the generation of the data in the field, watching and listening to the audio and video recordings and pictures every evening, as I renamed them by day and session, saved and transferred them from the phone to my hard drive on a day-to-day basis. I also noted items of interest and my reflections on them in fieldnotes as I reviewed the material. After the field work, while maintaining a file with the data organised by day and session, I created another file where I organised the data by site, day and type of data. I then listened to the audio data and watched the video recorded data again after the field work in each site was complete to refamiliarize myself with the entire data one site at a time. As I did this, I took additional, typed notes, to describe the content, annotated with ideas based on initial interpretation.

The second step, according to Braun and Clarke, is to generate codes, which Braun and Clarke (2006) describe as pithy labels that capture what is interesting about the data. This time, I went through the data again, and from it developed phrases that captured ideas that were talking about similar aspects. During this process, I cross checked my phrases with the ideas, insights and themes that the participants had extracted during the participatory analysis and added and adjusted accordingly. I then used these phrases as codes in a coding frame. To apply the coding frame, I created a large table, with code phrases in one column and in the next, data excerpts from all data sources that referred to that phrase or the meaning of that phrase (see Appendix 1). In this way, all the data that referred to a specific code was logged. For example, if the code phrase was, 'origins of HIV and AIDS', all data from all data sets that talks about origins of HIV was logged in to that row in its respective column depending on data set (whether it was a video, audio, journal, group process review). So, DA-d2 vid 3 (22:20-30:00) means it was in data from the Dedza site, on day 2 and video recording number 3 between 22 minutes 20 seconds and 30 minutes into the video. I then re watched and listened again to the coded items and transcribed what the participant said at each captured data set. This process is illustrated in Appendix 1.

Braun and Clarke’s (2006), phases three, four and five are generating themes, reviewing potential themes and defining and naming the themes and I combined these into one stage, 3. I developed themes based on the data in each coding phrase. I listened and watched the data again to see if I had missed anything, added, removed and moved themes and codes around accordingly.

Braun and Clarke’s sixth and last phase involves producing the report/thesis and my final, fourth, step did this. This consists of arrangement of themes with analytic commentary and data extracts as supporting evidence. When I was confident of the main findings, I wrote the narrative of the data down. I wanted to confirm my analysis with the research participants’, but I was not able to do it with all participants, because by this time I was in the UK. Instead, I held about 11 phone calls with GVHs, discussing with them my preliminary findings and how I had presented them and then my firmer understandings by presenting them verbally and asking for their feedback. This was an on-going process.

3.5 A note on languages

Throughout the research process, Misheck and I conducted our interactions in Chichewa. At times we ‘code-switched’ to include English words or phrases, as this is normal practice across Malawian communities. During the analysis phase I used a mixture of Chichewa and English. When summarising data, I tended to use English. When transcribing directly from video or audio sources, I used the original Chichewa as spoken by the participants. Data presented in this thesis in English are my own translations of participants’ words and where possible were guided by the principle of trying to preserve the meanings of the Chichewa words and phrases, rather than using English-oriented categories and idioms. For example, the category *achipatala* was translated as ‘hospital people’ rather than ‘healthcare workers’.

3.6 Ethical Considerations

3.6.1 At institutional level/Glasgow

This study (application number 400180029) has been reviewed and cleared by the College of Social Sciences Research Ethics Committee, University of Glasgow. I took care to implement the study in accordance to the processes described in the ethics application and approved by the ethics committee.

3.6.2 At community level

In giving examples of some important colonizing practices by researchers on indigenous people Smith (2012) highlights the breaking of cultural protocol, negating of cultural values and ignoring of key people and authorities. Therefore, Indigenous Research Methodologies' as decolonizing approaches emphasize cultural protocols and values as a vital part of a methodology which must be given serious attention (Smith 2012). These cultural practices and values govern and shape the social lives of people and influence their psychosocial and behavioral expressions particularly within rural communities (Appiah 2020). In the sub-sections that follow I describe how I entered the community, how I sought informed consent, how I managed incentives for the participants and navigated cultural sensitivity, all of which Appiah (2020) describes as important ethical matters.

3.6.2.1 Community Entry

Considering that chiefs are the custodians of culture and the gatekeepers of the rural communities (Eggen 2011; Appiah 2020), I sought guidance for community entry and permission seeking protocols from the Group Village Heads in each site and followed each community's protocols accordingly.

In Dedza, even when the GVH had already given his permission for us to work within the community, he also had to present us (Misheck and I) to the Traditional Authority (T/A). There we presented ourselves again and our research aims. When going to the T/A, we took a monetary gift equivalent of a rooster, as by my cultural knowledge one does not appear before such an elder and authority empty handed. Another gift equivalent of a chicken was given to the GVH after I had confirmed with him that this was indeed the cultural practice in this community. Both the T/A and the GVH expressed amazement and approval of our attention to cultural detail. The GVH even said that I behaved as though we were initiated in the community as community members. In Thyolo, the GVH advised that it was enough to seek permission for working with the community from him and did not need to go to the T/A so, that was what we did.

3.6.2.2 Informed Consent

Informed consent was sought for all three phases of the research process. For phase one of the research (participant observation), in addition to following the community cultural protocol for general permission seeking, I read the participant information sheets (see Appendix 2) with the GVHs and got their verbal consent to conduct the research in their areas with their people (see Appendix 3).

In phase two (folk media workshops) Mishek and I, read out and recorded the participant information sheets (see Appendix 4) and consent forms (see Appendix 5). This was to make the information accessible to the participants in a concrete way as they did not go far with formal education and could not read properly. We played these to the participants, welcomed questions and played them again and provided clarifications and further explanations where necessary. Each participant then gave their verbal consent to participate in the study and consented for their photographs, audio and video recordings to be captured and used in this study (see Appendix 6). I asked for their confirmation again midway through the process.

In Phase three, the GVHs made an announcement during the community wide performances at the start of the activities and explained that we would be taking pictures and video recording the event and that those who did not wish to be video recorded were free to leave the event and that staying entailed consent.

3.6.2.3 Navigating incentives and cultural sensitivity

When working with the participants and the communities in general, every decision related to our engagement with the participants was carefully negotiated with the GVHs and the participants depending on who the decisions affected. When a matter I was not sure of arose, I consulted with the GVHs and they advised how to navigate whatever issues there were. Everything in the workshops was negotiated with the participants. We negotiated rules of engagement, meal arrangements and whatever was agreed, we did together. For instance, because it was hunger season and most of the people in the village were having one meal a day, participants did not want to eat lunch in the workshops when their families at home were going hungry. So, together, we agreed to divide each day's small lunch allowance (1.25 GBP) so that each participant takes home (1GBP) at the end of the day and the remaining money was used to buy whatever snack we could find on that day. This was a very small amount, but it was all that I could afford as a PhD student, and this too was communicated to the participants. So, if there was a bun for each of the participants for that day, we all ate buns. In terms of dressing, both Misheck and I dressed in the same way that the participants dressed and did our best to observe the same rules that the participants observed.

Everything was negotiated and done collaboratively with the participants. This includes workshop schedules. In Dedza, we had participants with Christian, Muslim and Cultural Practice (Gule wa Mkulu) affiliations. Given that the workshops were nine to ten days long and that the Christian and Muslim faiths prayed across three days (Friday, Saturday and Sunday) we had to negotiate how to go about the workshops on these days. An agreement was reached to say that we work through all the days and that we would have a short service of prayer together led by the participants. All in all, I think we were able to conduct ourselves and our research as ethically as we could through collaborative engagement and paying careful attention to observance of cultural norms. The GVHs (Dedza) constant reference to us as "*Ometa*" (one who is shaved which means one who is initiated into the culture), both in private and in his opening speech during the community wide performances suggests a positive perception of our engagement with the community during our research.

It is evident from the description of my method that through interweaving folk media, a cultural paradigm of the two communities participating in this research with participant observation, a Western qualitative research practice, a culturally responsive and specific research methodology emerged. Strong collaboration with the GVHs and participants allowed for shared ownership of the research process and provided an ethical space for the generation of deep knowledge about understandings of HIV and AIDS. This culturally responsive methodology moves away from imposition of methods and strongly reflects the principles of decolonizing indigenous research methodologies (Smith 2012; Chilisa 2011).

4 Understanding and Making Sense of HIV and AIDS

Chuluke chuluke ngwa njuchi umanena iyo ya kuluma

Many is the nature of bees, but you speak of the one that stung you.

(Malawian *mwambi/*proverb)

The *mwambi* above acknowledges the nature of bees as being many/multiple whilst highlighting the tendency of a person to identify and speak about the particular bee that stung them. I use this *mwambi to* illustrate that there are many narratives and experiences of HIV and AIDS, but people and communities tend to name and speak of those that affect them or are most relevant to them. As I wrote in section 2.6, Freire's dialogical theory of human sociality suggests that to be human is to be able to name the world in which one lives (2005). The fundamental essence of this *mwambi* is consistent with Freire's concept of a person's right to name their world.

In this chapter, I draw on both the *mwambi* and Freire's concept of a person's right to name their world to answer my first research question, which seeks to explore how two rural communities understand and make sense of HIV and AIDS. To do this I present an analysis of the perspectives and experiences and narratives of HIV and AIDs that emerged from the workshops with community members using folk media, participant verbal journals, community performances and post-performance interviews.

I divide the chapter into three major sections. In the first section, I re-trace the discursive lineages of HIV and AIDS as understood by the two communities, before, in the second section, going on to explore participants' current understandings and explanations of HIV and AIDS. Finally, I explore contestations of participants' current understanding of HIV and AIDS with some biomedical explanations and the tensions that emerge when biomedical knowledges are positioned within the everyday context of the community members' lives.

4.1 Discursive Lineages of HIV and AIDS

Before HIV and AIDS received its contemporary names and understandings, it was interpreted by both Dedza and Thyolo communities within established cultural frameworks. Specifically, community members positioned HIV and AIDS as an established illness, *kaliwondewonde* and *kanyera wa mkulu* respectively, both of which are illness associated with *tsempho*, which, as I described in section 2.3, is caused by a transgression of sexual taboos.

In Dedza, the Group Village Head (GVH) shared an account that demonstrates this understanding during the *bwalo la mafumu* (council of the chiefs) session:

> So at the beginning of this AIDS disease around the 1980s, the people who were affected by this disease appeared thin with very fine hair, the body's colour would change to pale and our elders and parents would say that 'what they are saying that there is AIDS is not true, It's a white peoples thing, this is *tsempho*' (GVH Miyowe during *bwalo la mafumu* session on day 6 in Dedza).

This was echoed during the role play exercise in Dedza:

> Here when a person is sick in that way (showing those symptoms), we say it is *kaliwondewonde*… in other words *adamusempha* (has been affected by *tsempho*) (Participant during role play on day 4 in Dedza)

In Thyolo, a presentation of a drawing during exploration of the participants' understandings of HIV and AIDS on day 4 of the folk media workshops suggests a similar understanding. I present below an extract of part of the presentation:

> In the early days of the AIDS disease, people did not recognise it as AIDS. In those days when a person starts to have very fine hair like this, losing weight, warming themselves on the fire every now and then, sleeping in the sun, it was said that they were suffering from *kanyera wa mkulu*. (Participant during presentation of a drawing on day 4 in Thyolo).

As evidenced by the extracts above, the symptoms that HIV and AIDS brought were interpreted by both communities as *kaliwondewonde* and *kanyera wa mkulu* respectively. Chakanza (2005) translates *kaliwondewonde* as “extreme loss of weight” characterized by a pale appearance and thinning of hair texture and/or loss of hair and *kanyera* as “acute diarrhea” which is followed by similar symptoms. Both *kaliwondewonde* and *kanyera wa mkulu* have also been referred to by Malawian scholars as “wasting or slim disease” (Muula 2008: 854; Moto 2004:1; Lwanda 2002). The symptoms of *kaliwondewonde* and *kanyera wa mkulu* described by participants in the extracts above as well as by scholars are consistent with descriptions of early manifestations of HIV and AIDS (Chakanza 2005; Muula 2008; Moto 2004; Lwanda 2002).

Because HIV and AIDS mimicked the symptoms of two conditions that already existed in the communities, it initially led to the denial, dismissal or rejection of biomedical explanations of the disease as illustrated by “*what they are saying that there is AIDS is not true…*” in the first extract. The attribution of HIV and AIDS to a “*white people’s thing*” highlights the community elder’s efforts to alienate the biomedical explanations of the disease from the understandings of the community. It further suggests a defensive response against what looked like imposed explanations of the symptoms that people in the community were experiencing and/or witnessing and had done so for a very long time. In light of the Chewa epistemology where elders are considered authorities of knowledge from which members of a community are willing to shape their ways of seeing and doing (Kaphagawani 1998), the rejection of HIV and AIDS by the “elders”, as illustrated in the first extract, suggests that the communities adopted this rejection and continued to live as though there was no HIV and AIDS.

Analysis of data from Dedza suggests that gradually the word AIDS began to be used as an alternative new way to describe *kaliwondewonde*. Below I present a transcribed extract of part of a *sewero* (role play) performed as part of the exploration of HIV and AIDS in which participants played the role of researchers (see section 3, days 4 and 5). The scene of the *sewero* opens with a meeting convened to report and discuss the findings of their research. Below is an extract of part of the participants’ report:

> In the peoples' understanding, this disease (AIDS) is *kaliwondewonde*, a person can eat but the body is still unhealthy but since now there is the word AIDS they just use AIDS, but here in our community, when the person is sick in that manner, we call it *kaliwondewonde,* it means *adamusempha* (has been affected by *tsempho*). (Participant during role play on day 4 in Dedza)

The extract above suggests that the terms AIDS and *kaliwondewonde* began to be understood and used synonymously to refer to a set of symptoms caused by *tsempho*.

Similar understandings were illustrated in Thyolo through a drawing (see Figure 4). During the folk media workshop on day 4, participants were asked to share their understanding of HIV and AIDS using folk media forms of their choice. In response, one of the groups created a drawing which I present below:

Figure 4 - Drawing demonstrating similarities of symptoms between HIV/AIDS and *kanyera wa mkulu*

The participants used the image to demonstrate that the symptoms of HIV and AIDS were understood as the same as *kanyera wa mkulu*. The image shows two men: one big and plump-looking, representing a healthy body; and the other tiny, very skinny with rib bones showing, representing a sickly body. The appearance of the sickly-bodied man including the spiky lines on his head that represent thin hair /hair loss correspond to the symptoms that were understood to be of both HIV and AIDS and *kanyera wa mkulu* as well as *kaliwondewonde*.

However, with time and experience community members in both Dedza and Thyolo began to realise that despite having identical symptoms HIV and AIDS was a different illness from *kaliwondewonde* and *kanyera wa mkulu*. An extract from the *bwalo la mafumu* session in Dedza illustrates this point:

> So, when this disease (AIDS) came, people thought it was this (*kaliwondewonde*). Slowly we began to see that it was not *kaliwondewonde* but AIDS which is transmitted through sex according to them (GVH Miyowe during *bwalo la mafumu* session on day 6 in Dedza).

Although both HIV and AIDS and *kaliwondewonde* had sexually related causation aligning to a description by Lwanda (2002), the nature of this causation began to be understood differently. While *kaliwondewonde* was understood as being caused by *tsempho*, the transgression, often by another person and not the patient (suggesting spiritual/supernatural connection), HIV and AIDS was said to be transmitted through sex, the biological act itself involving the patient. This distinction highlighted the active role of the person infected with HIV in sexual practice and led to the common association of HIV with failure to abstain from sex, acts of promiscuity, infidelity and adultery which were subject to moral, religious and cultural judgement. Scholars have often linked these associations to stigma and discrimination of people who test positive for HIV in Malawi and other parts of Sub-Saharan Africa (Sovran 2013).

In Thyolo, participants reported that the realisation that HIV and AIDS and *kanyera wa mkulu* were different came after experience of failed indigenous treatment efforts for symptoms that were attributed to *kanyera wa mkulu*. An extract from the participants' presentation of the drawing I presented earlier demonstrates this:

> We see that when we drink medication for *kanyera wa mkulu* we do not get better, but when we take the medication from the hospital, we get better and become restored with strength. Now we see that *kanyera*

> *wankulu* is now AIDS and there is no treatment that works for *kanyera wamkulu* at the *sing' anga* anymore, because it's not *kanyera wa mkulu* anymore, its AIDS, so medication from the hospital is what helps (Participant during presentation of a drawing on day 4 in Thyolo).

Drawing on the extracts from both Dedza and Thyolo, we can see that HIV and AIDS did not appear to the communities as something new; but rather a shifting experience of something familiar. Their knowledge, familiarity and experiences with the symptoms of HIV and AIDS as manifested in *kaliwondewonde* and *kanyera wa mkulu* made it difficult for them to perceive it as anything other than what they already knew. As demonstrated by the discussion thus far and consistent with Chewa epistemologies (Kaphagawani 1998; Interview with GVH Miyowe in Dedza 2019), it took time, continued interaction with the disease, lived experience and failed local treatment efforts for the communities to begin to consider the biomedical explanations of the symptoms they were experiencing and accept them as HIV and AIDS and not *kaliwondewonde* or *kanyera wa mkulu*.

At the time of my research, it was evident that both communities had extensively encountered biomedical explanations of the disease. As seen in the discussion above, many community members, but by no means all, have come to understand that some of the signs and symptoms that they encountered in the early years of the epidemic, were indeed AIDS.

More evidence for this point comes from the existence of *Nyimbo and magule* (songs and dances) about HIV and AIDS prior to my fieldwork. Song 1, presented below, accompanies a women's dance called *chinana* (see Figure 5), which participants in the folk media workshops and women from the wider community performed in Dedza during the community performance event (phase 3 of the study):

Song 1 EDZI / *AIDS*

Edzi edzi edzi /*AIDS AIDS AIDS*

Wakwanira edzi /*AIDS has saturated*

Wakwanira edzi dziko lonse /*AIDS has saturated the whole country*

Figure 5 - Chinana dance during community performance event in Dedza

The song is performed as a call and response with rigorous fast paced steps that follow the rhythm of the drums. The fast-paced movements are contrasted with voices that have a sad tone that sounds almost like a cry. The song acknowledges that HIV and AIDS is within the community and the use of the word "*wakwanira*" emphasises the extent to which the disease has affected the community suggesting an understanding of HIV and AIDS as an epidemic, consistent with how biomedical experts describe the disease. Footage of women dancing *chinana* during phase 3 of the research in Dedza can be seen in Video 5.

Having accepted that HIV and AIDS was present and was different from *kaliwondewonde* and *kanyera wa mkulu* the communities began to experience it as a new disease with new understandings and perceptions. In most of the pre-existing songs and dances participants shared during the workshops, HIV and AIDS is presented as a dangerous disease, causing untold suffering, the deaths of many community members and socio-economic devastation. The songs carry strong warnings to the community about AIDS, descriptions of the experiences with the disease and people's feeling towards it.

Song 2 from Dedza highlights the perceived danger of HIV and AIDS and its impact on the family:

> **Song 2 EDZI EDZI / *AIDS AIDS***
>
> Edzi Edzi / *AIDS AIDS*
>
> Edzi nthenda yoopsya / *AIDS is a dangerous disease*
>
> Yatenga amayi, yatenga abambo yasiya ana nalira / *It has taken mother, it has taken father and has left children mourning*
>
> Edzi nthenda yoopsya / *AIDS is a dangerous disease*

The song presents HIV and AIDS as dangerous, relentless and merciless so much that it has robbed both parents from children and left them mourning and in despair. It points to the devastating impact of the disease on the family and community and how it has disrupted people's lives and left children as orphans to fend for themselves. UNAIDS (2019) reports that there are about half a million children in Malawi orphaned due to HIV and AIDS and Song 2 is a cry of people from rural communities who have experienced in full force what these figures suggest. The mood of the song is sombre and is sung in a choir-like way with the different voices further highlighting the collectiveness of the cry. A performance of Song 2 in Dedza can be viewed in Video 6.

Song 3 from Thyolo further suggests AIDS as a leading cause of death in the community:

Song 3 Watitha iwe Edzi / ***You have finished us AIDS***

Edzi ikutsogolera anthu / *AIDS is leading people*

Pa ulendo opita ku manda / *on a journey to the grave*

Komwe akapita sabwerera / *where when they go, they do not return*

Watitha iwe Edzi / *you have finished us AIDS*

Watitha iwe EDZI / *you have finished us AIDS (chorus)*

Tilowere kuti / *where do we run to*

Watitha iwe EDZI / *You have finished us AIDS*

The song uses metaphor to visualise the close relationship between people and AIDS. A female voice starts the song with "*AIDS is leading people*" and a tenor leads the response by calling out, "*on a journey*…" to which the rest of the group responds. The song then moves from describing what AIDS is doing to the community to addressing AIDS directly as seen in "*you have finished us AIDS*" which is sang first by one voice with the rest of the voices joining in, one at a time each time the line is repeated, creating a unified response. The joining in of the voices suggest an affirmation of the line by various groups of people in the community. The song characterises AIDS as a leader who is leading people on a journey to the grave. However, unlike normal journeys, when those who embark on this journey reach the destination, there is no coming back. The act of dying has been likened to a journey in the song, something that is progressive, which might also point to an understanding of the nature of HIV and AIDS and its progression from contracting it to dying from it. On the other hand, the grave is portrayed as a physical immovable destination that the song uses to represent death and its permanency. This song points to a desperate attempt by the communities to understand AIDS from a familiar point of view. Song 3 as performed in Thyolo can be viewed in Video 7.

Both songs suggest that AIDS has caused a lot of death amongst the community, taking valuable members of the community. Desperation and helplessness in the face of AIDS seems to be present in the song as seen by the first line after the chorus which says "*where do we run to*" which suggests that there is a feeling that AIDS is out to get them. Now I go on to explore the participants' current understandings of HIV and AIDS.

4.2 Current Understandings and Explanations of HIV and AIDS

I have shown that although HIV and AIDS was originally interpreted within existing terms of reference, as *kaliwondewonde* and *kanyera wa mkulu,* with time and experience it began to be seen as different. The *bwalo la mafumu* session, together with folk media created and performed by the participants during the exploration of what HIV and AIDS is in phase 2 of the research, suggest that some at least have current understandings of the disease that are consistent with biomedical explanations and knowledge. To demonstrate this, I present an extract from one of the Village Head's (VH's) explanations of AIDS during the *bwalo la mafumu* session in Dedza:

> The hospital people tell us that AIDS is an anarchy of diseases. This anarchy of diseases comes because the defences in a person's body have declined (*chatsika*). (VH during bwalo la mafumu session on day 6 in Dedza)

The VH's explanation in the extract above illustrates a detailed understanding of the immune response to HIV infection, highlighting the source from which the chief has adopted this biomedical understanding.

In Thyolo, there was a similar understanding. In my fieldnotes I described in detail a *sewero* which the participants titled "*chipwirikiti cha matenda*" (anarchy of diseases). An extract from the fieldnotes demonstrates that the biomedical knowledge received from the "hospital people" *(achipatala)* about the description of AIDS has been accepted and engrained in participants' understandings:

> There was a family with one teenage daughter. The daughter often came home with money to give to her parent which she got from sexual relationships. One day she came home complaining of not feeling well, to which the family didn't think much of. She then became very ill, that she lay down weak, shivering complaining of a headache, pain in the stomach, back and legs. The parents upon seeing the condition of their daughter, deliberated and concluded that people who were jealous of the food they ate and the money their daughter brought had bewitched their daughter. And so, they took the girl to a *sing'anga*. However, as time passed, the treatment did not work, the girl got worse. Then, the parents sought counsel from other older relatives. Together, they concluded that it was *tsempho*. When treatment for *tsempho* did not work, a friend advised them to go to the hospital, where the girl was found to be HIV positive. (Extract from my field notes on day 4 in Thyolo)

The title of the *sewero* and its performance suggests an understanding that AIDS is an anarchy of diseases caused by the HIV virus. During the *sewero*, the girl's performance of symptoms of illness suggest that she is suffering from multiple and concurrent diseases highlighting an understanding of the chaos of a body without an effective immune system. Both this extract, and the one from the *bwalo la mafumu* session in Dedza, demonstrate an understanding of HIV and AIDS that is consistent with biomedical explanations of the disease.

Participants' reflections on folk media performances and their verbal journal entries demonstrate that most members from both communities understand that the HIV virus is transmitted through contact with infected blood through sharing of sharp objects such as razors or needles, through blood transfusions or through exposed wounds. Unprotected sex with multiple partners is also seen as a culprit, and many of the songs already existing in the two communities make it clear that sex is seen as the primary method of HIV transmission, so abstinence is seen as the most encouraged method of prevention. The lyrics of Song 4 from Thyolo and parts of Song 5 from Dedza illustrate the emphasis on sexual transmission of HIV and AIDS:

Song 4 Udzisunge / *Preserve yourself*

M'bale wanga ganizira moyo wako dziko la pansi / *My friend, think of your life in this world*

Udzisunge, udziletse, udyere nawo mmmm / *Preserve yourself, abstain, live long mmmm*

Kachirombo ka EDZI sikadziwika / *The virus that causes AIDS is unidentifiable*

Pena iwe uli nako, pena ulibe / *Maybe you have it, maybe you don't*

Katemera wa Edzi ndikudziletsa / *The immunization for AIDS is abstinence*

Udzisunge, udziletse, udyere nawo mmmm / *Preserve yourself, abstain, and live long mmmm*

(Songs and dances presented as existing in the community in Thyolo on day 4)

Song 5 Siyani za chiwerewere / *Stop promiscuity*

Siyani za chiwerewere / *Stop promiscuity*

Suyo EDZI / *There goes AIDS*

Wasakaza miyoyo ya wanthu / *Has destroyed people's lives*

Kamba kosadzisunga / *Because they were not abstaining*

(Songs and dances presented in Dedza as existing in the community)

Both songs suggest that contracting HIV is associated with a person's failure to abstain from sex and acts of promiscuity which as I described earlier is often linked to stigma and discrimination of people living with HIV and AIDS (Sovran 2013; Sindarreh, Ebrahimi and Nasirian 2020). Both songs were performed as a choir accompanied by gentle dance steps. While the lyrics and tone of song 4 communicated a sense of concern and a plea from one friend to another, as demonstrated by the first line which says, "*My friend, think of your life in this world*", the performance of the lyrics and tone of song 5 suggested an instruction or command from someone who considers themselves an authority to other people, as highlighted by "*Stop promiscuity*" which had an accompanying sense of judgement and blame.

Some of the songs and dances already existing in the communities express an understanding of the nature of sexual transmission of HIV more explicitly. Song 6 presented by participants in Thyolo demonstrates this:

> **Song 6 Aka aka aka / *This this this***
>
> aka aka aka kadzanditengera matenda aka / *This this this little thing is going to contract the disease for me*
>
> Aka aka aka kadzanditengera matenda / *This this this little thing is going to contract the disease for me*
>
> Kodi ndi n'dule-dula / *What shall I do then, chop it off? Chop it off!*
>
> Kodi ndi mmate-mata / *What shall I do then, seal it up? Seal it!*
>
> Aka aka aka kadzanditengera matenda/ *This little thingy over here shall contract the disease for me*
>
> (Participants' presentation during folk media workshops on day 4 in Thyolo)

During song 6, the male and female performers physically pointed at their penises or vaginas respectively as they danced, accusing them of almost certainly contracting the virus for them in the future (See Figure 6). The line, "*what shall I do then, chop it off?*" and "*what shall I do then, seal it up?*" when sung in Chichewa has an underlying tone of both acceptance and mockery of sexual transmission and almost carries a connotation of fatalism. The song suggests desperation to find a course of action that might prevent the penis or vagina from contracting the disease, implying that without the two there would be no sex, therefore no risk of HIV infection. Given that chopping off the penis and sealing up the vagina to prevent HIV is impractical, the song gives the underlying sentiment that as long as one has a vagina or penis, contracting the disease is a fate they cannot escape. It positions sex as inevitable and consequently HIV contraction as unavoidable while sex organs remain. Song 6 as performed in Thyolo can be viewed in Video 8.

Figure 6 - Participants dancing Aka aka aka / *This this this*

Although there is an overwhelming acceptance within the two communities that HIV is transmitted through sex, there is also a strong, powerful, though minority, discourse that sex does not transmit HIV. Below, I present two extracts that illustrate this point from the *bwalo la mafumu* session in Dedza:

> …I cannot deny that AIDS is indeed among us, this I accept, but that it is sex that transmits it? mmm no!... The way I remember the coming of AIDS and how we were hearing it, at the beginning it was difficult to believe that it comes from having sex. But still, even now, in my mind/thoughts without considering what I hear, when I look at the life of sex and the way it is today (suggesting it has gotten out of hand), I still don’t understand. You mean to tell me that the people who get HIV/AIDS get it through sex?

> Aah aah no, if that was the case, people could have all perished. There must be some other way that the disease comes…maybe through witchcraft…the belief that this AIDS comes through sex, is insufficient in me… (GVH during bwalo la mafumu session in on day 6 in Dedza)

> So, they say AIDS is transmitted through blood and through sex, mmmm no! if you talk of needles, razors yes! But not sex. Is blood released when having sex?...AIDS is there yes, but we know blood, blood is red. And during sex you do not give blood, so how does sex transmit AIDS (HIV)? (VH in the *bwalo la mafumu* session on day 6 in Dedza)

The extracts demonstrate that although the chiefs are aware of the explanation of the sexual transmission of HIV and AIDS, they do not accept it because it does not align with their prior knowledge and experiences with sex. This misalignment of knowledges suggests that the participants draw their knowledge of HIV and AIDS from multiple sources. GVH Miyowe summarised the contents of the *bwalo la mafumu* session to the audience participating in the community-wide performance in Phase 3 of the research and this can be viewed in Video 9.

Below I bring together some extracts that further highlight participants' awareness of the sources of their knowledge about HIV and AIDS and the value they place on them:

> …So this name [AIDS] we see that is alien because it came with *achipatala* (the hospital people). The hospital people explained to us that AIDS comes through different ways, but here as per our culture we used to say it was *tsempho*. (Verbal Journal entry on day 5 Dedza)

> They tell us that one way of preventing HIV is through condoms but if we investigate further, condoms are not helping us. (Verbal Journal entry on day 5 in Thyolo)

The extracts above highlight a "*they say, we think/feel/believe/experience*" dichotomy of knowledge sources through which participants have engaged with HIV and AIDS. The "*they say*" suggests knowledge that they acquire through what Borkman (1976) describes as discursive reasoning, observation and reflection on information provided by others, and the "*we think/feel/believe/experience*" suggests knowing based on their experiences and culture. The weight attached to each set of knowledge and whether or not that knowledge is prioritised is dependent on its source. As is consistent with the Chewa epistemologies (Kaphagawani 1998), the extracts suggest that the knowledge accumulated through experience is highly favored in these communities consistent with Borkman (1976) who argues that experiential knowledge carries a high degree of conviction, authority and validity in the lives of people.

In the two extracts above, the participants acknowledge and accept that HIV and AIDS are indeed in their community which as we have discussed earlier in this chapter has been confirmed by their experiences. This acceptance suggests that the biomedical information (from external sources) that explains the existence of HIV and AIDS in the community and the participants' experiences have been reconciled. This reconciliation strongly suggests that the participants and members of the community are likely to apply this knowledge in their health seeking behaviours pertaining to HIV and AIDS in favour of recommended public health practices. On the other hand, the biomedical explanation about sexual transmission is being contested, which suggests that the participants and community members are unlikely to adhere to recommended sex related HIV prevention strategies (Refer chapter 5 for detailed discussion on how participants navigate the different knowledge systems and their corresponding healthcare systems). This strongly suggests that although most of the biomedical explanations about HIV and AIDS, as explained by what the participants call "*achipatala*" (hospital people) have been reconciled with the participants' experiential and cultural knowledges, this reconciliation is partial as there is a strong undercurrent of contestation of some of the biomedical explanations, in particular relating to prevention and cause, which I now go on to unpack.

4.3 Contestations and Tensions in HIV and AIDS knowledges

Folk media from both communities brought out a range of accounts that reveal some biomedical knowledges of HIV and AIDS that are contested by members of the two communities and highlight tensions in the application of some of the biomedical knowledges in the everyday lives of the community members. I begin by unpacking some contestations before moving on to explore some of the tensions.

4.3.1 Contested Biomedical Explanations

In both Dedza and Thyolo there was a strong resistance to the biomedical indication of condoms for HIV prevention. The Malawi National Condom Strategy 2015-2020 states that condoms are an important biomedical intervention and the cornerstone for preventing HIV transmission. Condoms, when used properly and consistently, are about 90 % effective in preventing HIV transmission in heterosexual encounters (Heart and Chen 2004). However, in this study, data from folk media workshops, participants' verbal journals, play performances and community performance events all point to widespread beliefs that rather than prevent HIV transmission condoms were, instead, responsible for it. Below are two songs composed by participants in both Dedza and Thyolo for the community wide performance (days 7, 8 and 9, phase 2, chapter 3) that demonstrate this point:

Song 7 Iwe condom / *Hey you condom*

Iwe condom ngotani x2 / *Hey you condom what are you like*

Wabweretsa matenda / *You have brought disease (AIDS)*

Wabweretsa mavuto / *you have brought problems/trouble*

Iwe condom aye condom ndadabwa x2 /*oh condom, condom I am appalled at you/your behaviour*

(Song accompanying a scene in the creation of the community wide performance in Dedza)

Song 8 Abale ndiuzeni / *Please tell me*

Abale ndiuzeni / *Please tell me*

Ntchito ya condom nchiyani / *What is the use of the condom*

Chifukwa sindidziwa / *Because I do not know*

Ndingapulikiretu /*lest I suffer from ignorance*

Ndimamva chisoni / *I feel sorry*

Kuona bambo wa bwinobwino / *to see a good strong man (gentleman)*

Akuvala condom / *wearing a condom*

Mmalo moti akakhale ndi moyo / *with the intention of saving/having his life.*

Ine toto! Ine toto! Ine toto za condom / Not me! Not me! Not me! The condom is not for me

Ine toto! Ine toto! Ndikakhale ndi moyo / Not me! Not me! I want to save/have my life

(Song accompanying a scene in the creation of the community wide performance in Thyolo)

Song 7 characterises the condom as a person and goes on to reprimand it for bringing trouble/problems. The last line says, *"condo I am appalled at you/your behaviour"* which shows disgust that the condom pretends to be for prevention when in essence it is the one responsible for transmitting the disease.

Song 8 simply says, "*can someone tell me the use of the condom*?". The question is rhetorical and emphasizes the condom's uselessness or failure to do what it is said to do. The first part of the song is sung with a sense of sarcasm which is highlighted by the line, "*lest I suffer from ignorance*". The song highlights a contestation of condom use, a rejection of the condom as a preventive measure suggesting it is responsible for transmitting HIV evident in the last two lines which say" *Not me! Not me! Not me! The condom is not for me: Not me! Not me! I want to save/have my life*". The song represents conflicting views and dilemmas when grappling with the use of condoms amongst different members of the community. Many of the participants also expressed similar concerns in their verbal journals. Below is a transcribed and translated example of one of the many verbal journal entries:

> They give us the condoms to protect from diseases (HIV) but in the condoms there are substances that cause us the disease, there are oils that make us to transmit the disease (HIV/AIDS) (Verbal Journal entry on day 5 in Thyolo)

These sentiments were not only expressed by the participants in the workshops and private verbal journal but were also verified by the wider community. During the final performance where the participants in the folk media workshops performed and used the performance to engage the wider community in dialogue, an audience member in Dedza shared his experience below:

> I was saying that the condoms they give us to protect ourselves have oils, we don't know what that oil means, and when we take that same condom and put it in the sun in a bottle, there are tiny worms in them, so those tiny worms, is that not spreading the disease? (clapping and cheering and ululating by audience)...So, wherever this disease was found, far away in the land of whites, and they just give to us here, we don't even know the need/use of these things and yet we just receive…(Community audience member during community-wide performance on day 9 in Dedza).

The two extracts suggest that there is a feeling of mistrust in the community, and that there are suspicions about the real purpose of the condom and the motives/intentions of the people who promote them to the community, implicitly suggesting the presence of conspiracy narratives in the community which I go on to unpack more explicitly.

There is a strong belief in both communities that HIV and AIDS is a conspiracy perpetrated by rich Western countries and the Malawian Government to reduce the Malawian population. Data strongly suggests that the condom is at the centre of these conspiracy narratives as will be evident in the following example. As part of the reports during the *sewero* in Dedza which was set in the DC's office and in which participants took the role of researchers, the participants explained that people in the community think the virus was created to reduce the population, mainly through condom use as the extract below demonstrates:

> P1: The people said that HIV and AIDS came in order to reduce the population because they say that in order to protect yourself from the disease, you should wear a condom…
>
> F: So, who wants to reduce the population according to your research.?
>
> 4 Participants at once: Outside countries.
>
> P2: Today the world has changed. How come the entire world is failing to find medication for this disease. So, people think that this failure to find medication is deliberate with the intention of reducing the population, because it is impossible that this whole world should fail to find a cure. They are making things that wage war on other countries, things that have no driver/pilot to blow up other countries. So why are they failing to find medication to eradicate this AIDS disease? It means they deliberately made this disease so that our population can decrease. (Participants during a *sewero* on day 4 in Dedza)

In Thyolo, during the community wide performance creation when the participants were analysing and prioritizing the top 4 themes, they justified the prioritization of the condom as an issue for discussion as below:

> The condoms used to appear as though they were for protection but based on our own research and experience with the condom, there are oils inside the condom…so, we ask ourselves if indeed it is true that the condom protects. (Participant during theme prioritization on day 6 in Thyolo)

The above sentiments indicating distrust and suspicion were also reflected in verbal journal entries of many of the participants as evidenced from the entry from Thyolo below:

> They tell us that one way of preventing HIV is through condoms but if we investigate further, condoms are not helping us, why am I saying they are not helping? Because the *achipatala* (the hospital people) are giving us things that are spreading diseases like AIDS, in the condoms, there are little worms. (Verbal Journal entry on day 5 in Thyolo)

The extracts above suggest that participants from both communities see the condom as contributing to the persistence of HIV and AIDS in their communities. This apparent irreconciliation of biomedical indications of condoms for HIV prevention and the participants' understandings/perceptions of condoms as HIV transmission tools suggests the likelihood of individuals practicing unprotected sex and thus threatens public health objectives. Therefore, there is need for urgent intervention that engages these communities in meaningful dialogical processes to facilitate reconciliation of these understandings.

From the long extract it is clear that the explanation that there is currently no cure for HIV and AIDS has not been accepted, instead the participants argue that the lack of cure is deliberate. The extract clearly shows that participants cannot reconcile scientific technological advancements and the failure of science to cure HIV and AIDS, raising questions in their minds which are answered by conspiracy narratives.

In Thyolo, some members of the community drew on their experiences of the Government's actions to explain their understandings of HIV and AIDS as a conspiracy. Below is a short metaphorical story that a GVH shared during the *bwalo la mafumu* session as he explained his beliefs of conspiracy:

> Imagine you are in your house, you are there, mother and father and you have given birth to many children. And so, the father tells you that iiih *koma* (signifying a complaint), you children are too many in this house and then what follows, the children start to get sick and start dying. Will one child not think that the words that the father was saying were bad? And yet today, the government stood on an anthill (platform) to say iiih *koma*, we are too many in this country. And yet God created us so that we fill the earth and live in it and then they go and say, you people are way too many, what should we do to reduce the population? Yet the people are

> already living. There, there is a question mark. And now people are complaining of death, sudden and unexplainable, so who should we say is killing the people?
>
> VH's in Chorus: Our parent!
>
> (Extract from *bwalo la mafumu* session on day 7 in Thyolo)

In the extract above, the GVH uses *chifanifani* (short metaphorical story) to point to a government conspiracy to reduce the population through the HIV and AIDS epidemic. The standing on an anthill in the Malawian cultural context signifies making a public announcement. Thus, the extract suggests that the public announcement about overpopulation by the Government coincided with the coming of the HIV and AIDS epidemic in Malawi which is consistent with Lwanda's (2002) assessment that condom use was promoted at the same time as both family planning and HIV prevention programs neither of which were embedded in existing understandings and cultural practices of the Malawian people and led to suspicion of all three programmes.

Fassin (2011) argues that conspiracy narratives about HIV and AIDS are as old as the epidemic itself. He explains that in the early stages of the HIV and AIDS pandemic, Americans and Europeans saw Haitians and Congolese people to be originally responsible for the spread of the virus on their continents whilst Caribbeans and African people held the "whites" responsible. A study by Kaler (2004) in Malawi also highlights conspiracy narratives about HIV and AIDS. The existence and persistence of conspiracy theories have important implications for the fight against HIV and AIDS. Studies in South Africa have found that conspiracy theories have been associated with failure to use condoms (Grebe and Nattrass 2012) as well as, failure to test for HIV (Bogart et al 2008; Tun et al 2012).

Consistent with the findings in this research, Fassin (2011) notes that despite the passage of time and contrary to some predictions, the increasing authority of science over other knowledges has not been successful in dispelling these conspiracy theories which suggests that countering conspiracy theories might not be about asserting the authority of scientific knowledge over other knowledges but an attempt at reconciling scientific knowledge to other experiential and cultural knowledges of communities.

Findings from both Dedza and Thyolo suggest that the imposing nature of early communications about HIV and AIDS by the Government and public health professionals may have contributed to the contestation of biomedical knowledges and their irreconciliation with multiple knowledges and experiences of communities. Below I present an extract from the *bwalo la mafumu* session in Dedza which demonstrates this point:

> First time I heard about it (HIV/AIDS) was at a political gathering of the Malawi Congress Party (the first political party to rule after independence led by Dr Hastings Kamuzu Banda), there was only one party then. We had gone to Biwi (name of a place) for the gathering and the area chairman said, "Ladies and gentlemen, I want to let you know that there is now a disease that has come, a disease called AIDS, this disease they say has no cure and it comes through sex so we should beware!!!" (GVH during the bwalo la mafumu session in Dedza)

In Thyolo, the GVH also shared his experience during the *bwalo la mafumu* session below:

> I believe it was in 1985 when this word (AIDS) came out for the first time. But this word (AIDS) seems to have come out like a *mkango* (lion) coming out from the *ngolowela* (fully grown maize gardens that almost look like a forest of maize stalks and can cover up a fully-grown man). When a lion suddenly comes out from the *ngolowela* and surprises you as you are on the road (walking), know that if you were close to a stump at that time, that that stump is going to injure you when you are running away. This means that when this word came out that AIDS has arrived in this country and that this AIDS is a dangerous disease, and because people only highlighted the dangerousness of the word, many of us went into places that shouldn't be entered. Now we regret because if we look closely at the way the word came out that aaah there's AIDS, we wonder to say how did this AIDS come, which road/direction did it come from? (GVH during bwalo la mafumu session on day 7 in Thyolo)

In the last extract, the GVH makes use of a metaphoric form of storytelling which in Chichewa can be termed *chifanifani,* to explain his experience of the communication (by public health officials and the Government) to the rural communities about the coming of HIV and AIDS. He uses the symbol of the *mkango* (lion) to express the invocation of fear and panic that the communication caused. The *mkango* (lion) in many significant narratives has been used as a symbol of unchallenged power and domination that invokes fear and almost gives the person meeting the *mkango* a sense of helplessness (can't fight and can't escape).

The way the GVHs from both Dedza and Thyolo in the extracts above recount their first encounters with HIV and AIDS communication is consistent with Lwanda's (2002) analysis of the early communication of the epidemic to rural communities by public health officials and Government. As discussed in section 2.4, Lwanda (2002) argues that public health communication to rural communities about HIV and AIDS was characterised by imposition, non-dialogue and dismissal of existing cultural knowledges, which in my analysis resulted in lost opportunities to engage in dialogical processes that may have helped with the reconciliation of knowledges and thereby reduce contestation. Having explored some of the contested knowledges, I now move on to explore some knowledges that have come into tension with the cultural practices and everyday life in the community.

4.3.2 Tensions Emerging Between Knowledges and Everyday Life

Findings from both Dedza and Thyolo suggest that although some biomedical knowledges of HIV and AIDS may have been accepted by members of the community, they can sometimes come into conflict with cultural practices and everyday life situations that community members consider necessary. The findings highlight that HIV and AIDS in these communities are considered as one problem among a range of problems that members of the community must negotiate daily. This range of problems creates tensions between HIV prevention and other needs.

This tension can be exemplified by the persistence of cultural practices such as *fisi,* which the communities themselves consider as increasing the risk of HIV and AIDS. *Fisi* literally means hyena. But in the Dedza and other communities in Malawi it refers to a group of customary sexual practices. This description of *fisi* was also reflected in the Government of Malawi's National HIV/AIDS policy of (National AIDS Commission 2003) where it highlighted several cultural practices said to contribute to transmission of HIV and AIDS.

> Some customary practices increase the risk of HIV infection. Among these are polygamy, extramarital sexual relations, marital rape, first aid to snakebite victims, ear piercing and tattooing (*mphini*), and traditional practices such as widow- and widower- inheritance (*chokolo*), death cleansing (*kupita kufa*), forced sex for young girls coming of age (*fisi*), newborn cleansing (*kutenga mwana*), circumcision (*jando* or *mdulidwe*), ablution of dead bodies, consensual adultery for childless couples (f*isi*), wife and husband exchange (*chimwanamaye*) and temporary husband replacement (*mbulo*). (Government of Malawi 2003, p. 21).

During reflections on song 5, which in part contains the line, "*siyani mwambo wa ufisi (Stop the fisi tradition),* the participants explained the continued practice of one of the *fisi* traditions. Below I present a long extract that demonstrates the strong empathy round the practice of *fisi* in order to have a child:

> P1: It's like how I will explain now. Say I got married and we are just staying without having children, so the *fisi* comes by agreement, meaning he agreed with my husband for him (*fisi*) to help him(husband), then he will be coming into the house so that it appears like my husband is fertile (capable of having children)
>
> P2: The objective is for them to receive a gift (baby) in the house
>
> F: Does the husband know?
>
> Participants in chorus: Yeeees!!!

P3: He is the one who goes and gets his friend (the person/fisi). It means he is failing in the house, so he gives an able person (*ochangamuka*)

F: Why?

Participants in a chorus: For the gift/ the baby/wanting a child

P4: It's because he is having sex with his wife but is unable to give her a child, so he looks for someone who can give her the child. So, because this one (husband) is failing to have a child, this one (*fisi*) accepts in order to conceal his dog-ness (*ugalu*)

F: If a person is not able to have children he enters into dog-ness?

Participants in chorus: Yes!

P4: people mock him saying "this one is a dog, since he has been in the house, he hasn't done anything"

P1: The woman is also laughed at by friends saying, "so you are going to meet with your brother?" (referring to her husband).

P6: When the *fisi* is going into the house, he takes a little white stick and stands it like this (against the frame, she was using her shoe to demonstrate). So, when he puts it like this, that one (husband) knows that my friend (*fisi*) is here so let me sit here in the kitchen (the kitchens are outside the house/hut but close, sometimes directly opposite sometimes attached). So, the owner of the house stays in the kitchen while the *fisi* enters the house. And when he (husband) peeps and sees that the little stick is still there, he says to himself let me remain here (kitchen), the stick is still there. And when he peeps and sees that the stick has been removed, he knows that the *fisi* is gone and asks his wife to open the door for him. Then he enters his house

P3: Which means this one (husband) just sleeps (does not have sex with his wife)

> P7: That’s how *fisi* works
>
> F: So, this *fisi*, does he do it for free?
>
> Participants in chorus: Yes, but sometimes he has to pay
>
> F: Who makes the payment?
>
> P7: If this one and I agree that he should enter my house for me (as a *fisi*), when the job is done (wife gets pregnant), I should pay him, because he has removed my shame and because it was agreed.
>
> F: So, the child, whose child is it?
>
> P7: When growing up the child is mine, but the owner (*mwini wake*/biological father) is this one. Once the child is born and as he/she grows, he/she is mine, but the one who is biologically responsible for the birth is this one (*fisi*)
>
> F: So, what if this one (*fisi*) wants the child?
>
> P in chorus: No!
>
> P1: He never claims the child
>
> P in chorus: It is kept secret
>
> F: If this one (*fisi*) revealed it, what would happen?
>
> P7: There is (would be) no evidence, but you (husband) would know that it’s true.
>
> (Participants reflections on a song during folk media workshops on day 4 in Dedza)

In this long data extract, it is clear that the man is under pressure to give/provide the woman with what Tavory and Swiddler (2009) call the "sweetness of fertility" and the woman to protect her husband and save herself from ridicule. From the extract, it is evident that participants think that having a child is worth the private shame of using a *fisi*.

When the participants were asked whether or not the people practicing *fisi* were aware of the risk of HIV, their response captured a sense of empathy for the desperation and lack of alternatives on the part of the man who gets a *fisi* and pointed to the high value that is placed on having children in this community against the risk of HIV and AIDS:

> P1F: They know that *fisi* spreads the AIDS disease but because they want to hide themselves so they appear like they are fertile, they still take *fisi* to enter their house with the intention to be called daddy by someone, because they want to be known as father of Junior or father of Martha they still get the *fisi* to come into the house for a baby.
>
> P2M: To conceal idiocy, I should not appear as someone who is infertile, but this one should fix it for me so that I appear as if I am fertile, even though I am infertile (Participant's reflections on a song during folk media workshops on day 4 in Dedza).

The discussion of *fisi* above suggests that participants and members of the community empathize with the practice because they feel there is no other option which shows that they are not aware of alternative treatments/responses to infertility and highlights the need for both the provision and communication about the availability and accessibility of these services that can help couples to have children.

In Thyolo, findings demonstrate that the risk of contracting HIV sometimes comes into conflict with economic needs for survival. During reflections on the *sewero* that one of the groups had presented as a medium of voicing out their views on HIV and AIDS, we discussed the issues that emerged from the enactment. As an extension to the discussion of risk, a male participant shared the following:

> P1: Here in our village in Thyolo, we grow cabbage, tomatoes and other things, but when our tomatoes are ripe, women here do basket businesses. They find us in the gardens and ask about prices, and considering all the time and energy and care I put into my crop, when I tell them the price, they say, mmmmmm come on, while they are doing this (demonstrating opening of legs), and the *chitenje* (traditional cloth women wear as a wrapper) is moving up (meaning revealing the thighs) and as you know, a man is gullible to these things and he starts stammering and because she is showing you things that are supposed to be hidden, things that are shown only in the bedroom you find yourself giving the basket of vegetables for close to nothing. She has taken it and she is gone! So, you ask her for a sexual relationship and because she sees that you have a garden full of tomatoes, she accepts with the intention of getting the tomatoes. When the tomatoes season comes to an end, she moves on to the next man who has vegetables that are in season. So, it's both men and women who are at risk.
>
> P2: And, that's just the general, but it happened to me personally, in my tomato garden. I must say though that if she had been my age group, I could/may have tried my luck.
>
> P3: It happened to me too.
>
> (Participants' reflection on a *sewero* on day 4 in Thyolo)

The extract above demonstrates that while some men find themselves in sexually tempting positions that put them at risk of contracting HIV during certain seasons, some women put themselves at risk throughout the year for economic reasons. The extract suggests that in these women's assessments of priorities, economic survival ranks higher than HIV prevention.

Researchers have linked the low use of HIV prevention strategies such as condoms in SSA to the persistence of HIV and AIDS in the region (Tavory and Swiddler 2009) and have tried to explain low condom use in terms of beliefs and attitudes (Chimbiri 2007; Kalipeni 1999; Mcphail and Campbell 2001; Obbo 1995), or by understanding sexual behaviour choices in broader contexts of social meanings (Ragnon 2004; Tavory and Swidler 2009). This study suggests that the contestations of biomedical knowledges of condoms for prevention, conspiracy narratives surrounding HIV and AIDS and the condom as a population control mechanism combined with tensions between biomedical knowledges of HIV prevention and the needs of everyday life in these communities contributes to explaining the ongoing HIV and AIDS epidemic.

4.4 Chapter summary

I have explored how participants in the Dedza and Thyolo communities understand and make sense of HIV and AIDS. By unpacking the discursive lineages of HIV and AIDS, I have shown that initially the symptoms were interpreted by both communities within their established cultural frameworks of illness. Because HIV and AIDS mimicked the symptoms of *kaliwondewonde* and *Kanyera wa mkulu,* illnesses said to be caused by transgression of sexual taboos, it led to the denial, dismissal or rejection of biomedical explanations of the disease.

Gradually, the word AIDS began to be used synonymously with *kaliwondewonde*. With more time and experience with the disease, as community members observed transmission patterns and failed treatment efforts from indigenous healers for symptoms that previously could be treated by the healers, HIV and AIDS began to be distinguished from *kaliwondewonde* and *kanyera wa mkulu* at least by some. Consistent with Chewa epistemology, it took time and continued interaction with the disease, for the communities to begin to consider the biomedical explanations of the symptoms and accept them as HIV and AIDS. Following this acceptance, the communities began to experience HIV and AIDS as a new disease which triggered feelings of fear, desperation and a sense of fatalism in most members of the community.

I have also shown that while current understandings of HIV and AIDS are mostly consistent with biomedical explanations, there are some biomedical explanations of the disease that are contested because they do not reconcile with their experiences and cultural knowledge. For example, sexual transmission and condom use for HIV prevention are treated with scepticism and explained by conspiracy theories. Finally, I have shown that although some biomedical knowledges of HIV and AIDS are not contested, they sometimes come into conflict with cultural practices and everyday life situations that community members consider necessary. By exploring these tensions, it is clear that in these communities, HIV and AIDS is one problem among a range of problems and prevention does not always rank as an immediate priority, for example, when weighed against the need for a child or economic survival.

In the next chapter I move on to describe my analysis of participants' understandings and perceptions of treatment for HIV.

5 Understandings and Perspectives on Treatment for HIV

Kali kokha nkanyama, ali awiri ndi anthu
(The one who is alone is an animal, and those who are two are human beings)

Mutu umodzi susenza denga
(A single head does not carry/support/hold up a roof)

Above are two very popular Malawian proverbs (*miyambi*). As children, we used to play a game and sing a song which was simply repeating the first proverb, while clapping and clinging on to each other in pairs and sometimes groups, pointing to those who were still by themselves. Part of the game involved imagining a dangerous animal or monster on the loose that would prey on those who were alone. You were only safe when you were with others. The singing would encourage those who were alone to quickly seek someone to be with as their safety and wellbeing depended on togetherness.

Coming across the *mwambi* in academic literature as an adult has opened my eyes to the meaning of what I effortlessly sang and performed as a child and how this may have shaped my way of working and relating to others. According to Kayange (2014), the proverb *kali kokha nkanyama, ali awiri ndi anthu,* is best interpreted as, “to be human is to collaborate with others” (Kayange 2014: 221). This meaning is also echoed in the second proverb cited above. The proverb, *Mutu umodzi susenza denga* (A single head does/can not carry/support/hold up a roof), suggests on-going effort and teamwork. It draws from the process of building a mud hut that people used in the past. The hut and the grass thatched roof were constructed separately, and the final step was to lift the roof onto the hut, mostly using the head for support and many people’s heads were needed. In more direct terms, the proverb means no-one can solve all problems by themselves, or put another way, that the solution to the problems one encounters cannot come from a single source.

This perspective, that “to be human is to collaborate with others” that the proverbs put forward, is also expressed by Freire (2005:1971) when he argues that if teachers or facilitators are to help others in the process of humanization, they have to do so in partnership with them. Both ideas of partnership emphasize collaboration as a characteristic of being human that is also highlighted by Smith (2012) as an important principle of decolonizing practices when engaging with indigenous peoples. In collaboration, there is need for dialogue, which is conditioned by trust, respect and value of the other (Smith 2012; Freire, 1971).

In this chapter, I use the two Malawian proverbs with which I began the chapter as a framework to understand how the participants and communities who participated in this research understand HIV treatment as the second part of answering my research question which explores how rural communities understand and make sense of HIV and AIDS. Through the proverbs, I explore the nature of general treatment seeking practices and their relationship to HIV and AIDS. Then, I go on discuss the perceived challenges and experiences of participants with the current HIV and AIDS treatments.

5.1 Understandings of Illness and Treatment Seeking Practices

Treatment seeking for HIV in the two communities of this research was understood into the context of general treatment seeking practices. The mapping process carried out during the fieldwork brought out beliefs, perceptions and practices of treatment seeking which were subsequently further explored by the participants through *masewero* (dramatic enactments). The local health centre, which the participants referred to as *chipatala cha chizungu* (the hospital of the whites/Western hospital), and the *sing'anga*'s (traditional healer and diviner who works in consultation with spirits) emerged as the main spaces where treatment for various illnesses was sought.

Figure 4 below shows two participants in Dedza explaining community members' treatment seeking practices during the mapping process in the folk media workshops.

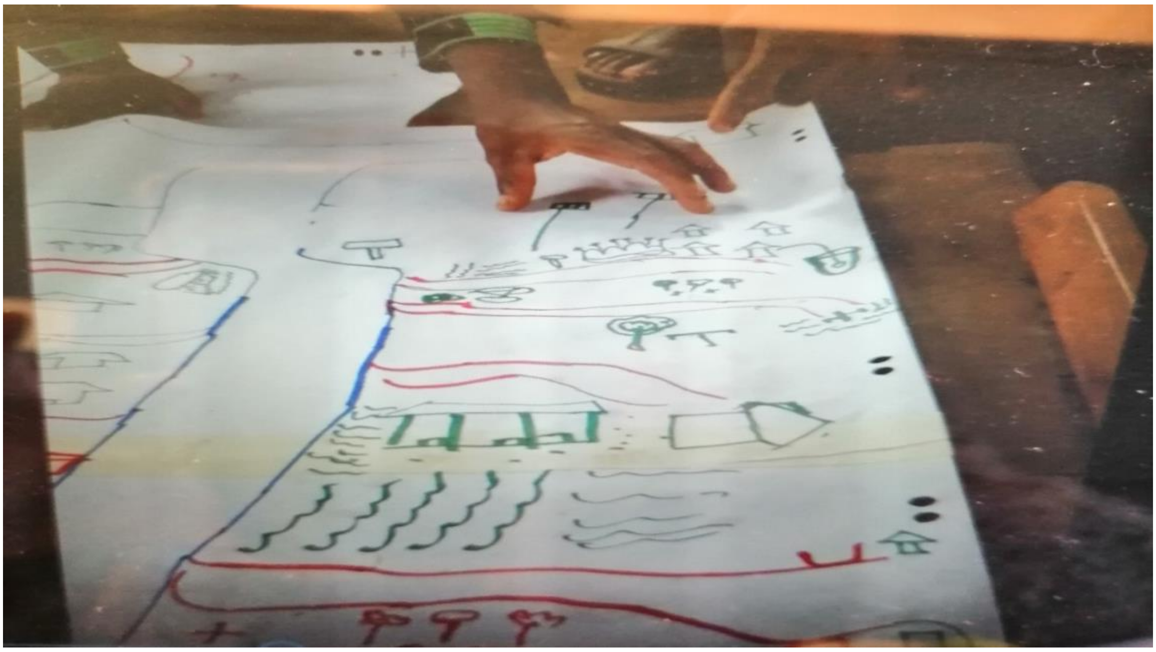

Figure 7 - Mapping process in Dedza

In the picture, the finger on the top right corner is pointing to the *chipatala cha chizungu* and the hand is pointing at the *Sing'anga's.* This moment, captured by the photograph was accompanied by the following explanation by one of the participants:

> When the chipatala cha chizungu fails to cure an illness, we go here (pointing to the flags on the map that were representing the sing'anga). It sometimes happens that you have an illness and you go to the chipatala cha chizungu here (pointing to the local health centre on the map). There they give you medicine, but you are still not feeling well. Then it occurs to you that maybe you have been bewitched, so you come here (pointing to flags on the map representing the sing'anga). There they examine you through their spirits and tell you that you have such and such a disease. Then you ask if it is possible that you can get better. The sing'anga assures you that you can get better as long as you follow the advice/instruction that he gives you. Then he begins to give you treatment, mankhwala a chikuda (black medicine). Then you can differentiate with the medicine you were taking from the chipatala cha chizungu to say you are feeling better because you took mankhwala a chikuda. This means the illness was caused by people…And if this one (sing'anga) fails to treat an illness, you die (Participant during mapping process on day 2 in Dedza).

As evident in the simultaneous indication of *chipatala cha chizungu* and *Sing'anga* on the map by the two participants' hands in the picture above, as well as the accompanying extract, community members use both indigenous and biomedical healthcare systems in managing illness.

Kleinman (1978) argues that there are three arenas in which healthcare manifests: the popular, the folk and what he calls the professional arenas. In Kleinman's (1978) understanding, the popular arena is characterized by family, relatives, friends and other social networks and communities with no expert or professional experience. This is where illness is first identified, assessed, defined, therapeutic options weighed and decided upon and activities of treatment initiated but it does not involve formal consultation with medical practitioners or folk healers (Kleinman 1978). The folk arena is characterized by traditional healers of all kinds including *sing'anga's,* commonly understood by Malawian communities as healers and diviners who practice in consultation with spirits in traditional/indigenous medicine in Malawi. Finally, what he calls the "professional" arena is characterized by biomedical practitioners who practice based on biomedical scientific knowledge, also referred to by participants in my research as *chipatala cha chizungu* (hospital of the whites). Although my findings relate to Kleinman's manifestations of healthcare, the use of the term "professional" by Kleinman to refer to biomedical practice seems to presuppose that there are no professional healers within traditional medicine which does not reflect how members of the two communities understand healthcare as will be evident in the coming sections.

Plurality in treatment seeking is common within Sub-Saharan Africa, where members of the population draw on popular, folk and "professional" health systems for their healthcare needs (Lampiao, Chisaka and Clements 2019; Zuma, Wight and Rochat et al 2018, 2016; Simwaka, Peltzer and Maluwa-Banda 2014). This plurality as practiced in Sub-Saharan Africa is a manifestation of the continent's encounter with Western understandings and practices of medicine through colonialism (Lwanda 2002). Although most research has focussed on folk (also often called traditional/indigenous) and professional (often called western/conventional or biomedical) medicine (Lampiao Chisaka and Clements

2019; Simwaka, Peltzer and Maluwa-Banda 2007; Lwanda 2002), traditional medicine is broader and is described by World Health Organization (WHO) as,

> the sum total of the knowledge, skill, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness (World Health Organization, 2013)

Given the high burden of disease and lack of adequate biomedical healthcare in resource poor countries like Malawi (Lampiao, Chisaka and Clements 2019; Rosenthal, 2017; Simwaka, Peltzer and Maluwa-Banda 2014; Lwanda 2002), the Malawian communities' strong reliance on traditional medicine as providing healthcare that meets both physical and spiritual needs (Lwanda 2002), provides vital healthcare support. Around 80% of Malawians are said to seek treatment from traditional medicine practitioners (Simwaka, Peltzer and Maluwa-Banda 2007).

In Dedza, through a performance-based exploration of the community life-cycle (the stages of life of a community member from birth to death), participants revealed two more conditions that rely completely upon the indigenous health systems: those that require a performance of rituals at a shrine and those that require neutralising of a sexual cultural transgression. I will discuss these in detail when I explore causal domains of illness in the sections that follow. Before I discuss further, it is important to first understand how the participants in these communities understand illness.

5.1.1 Defining illness

Participants in both the Dedza and Thyolo communities understand illness or sickness as a disturbance to how the body functions and the presence of pain that disturbs daily life to the extent that one is unable to go about daily chores and duties. This understanding is illustrated in a conversation on day three in Dedza, as we further explored what emerged through the mapping process:

> Facilitator: So, when we say a person is ill, what do we mean?
>
> P1: It means the person is unable to do any work, they are always sleeping and when they do get up, they can only sit up, that's when we say that the person is ill.
>
> P2: They also feel pain in their body and walking is a problem.
>
> P3: Illness we can say that is the breaking down of the body.
>
> (Extract from mapping process, Dedza)

The above description of illness is consistent with the explanation of illness as a failure of everyday life or a disturbance of equilibrium by Kleinman (1978) and Simwaka, Peltzer and Maluwa-Banda (2014). It is also consistent with descriptions of symptoms being identified as illness when everyday functioning is interrupted, as identified by Global North scholars such as Mildred Blaxter (1990).

5.1.2 Causal domains of Illness and Implications for Health Seeking

Data from folk media workshops in phase 2 of the research in both communities suggests that the decision of which health system to seek healthcare when a person is ill depends on the evaluation of symptoms, consideration of circumstances surrounding the illness and the assessment of what caused the illness. The latter finding on assessment of causes of illness relates to what Simwaka, Peltzer and Maluwa-Banda (2014:156) describe as a "traditional Malawian theory of illness". In their paper, *Indigenous Healing Practices in Malawi*, the authors state that among the Malawian people, illness can be attributed to three major influences, which they call "aetiologic agents", namely, a supreme being (God), ancestors (spirits of the dead) and witches.

Although my findings fit in with these aetiologic agents of illness, there are some variations in the way participants articulated God’s role, as well as elements of cultural causation as I describe below. In the two communities, illnesses were seen as resulting from factors emanating from four domains: natural/biological, supernatural, cultural and spiritual. I describe each in turn.

5.1.2.1 Matenda a Chilengedwe (Natural/biological domain)

Matenda a Chilengedwe were explained as illnesses caused by nature and were associated with seeking treatment at *chipatala cha chizungu*. The participants used the phrase *chipatala cha chizungu* to talk about the local health centre, the district hospital and the mission hospital that they encountered. All these, practice biomedical healthcare which in Kleinman’s (1978) exploration fall under the “professional” arena. Treatment at *chipatala cha chizungu* was sought when a person suffered from illnesses that were considered by the community to be *matenda a chilengedwe* (diseases of nature, by which they meant illnesses caused by natural biological factors and bodily malfunctions). Diseases such as malaria and anaemia were classified as *matenda a chilengedwe*. Simwaka, Peltzer and Maluwa-Banda (2014) suggest that in their study, the same illnesses were seen as caused by a supreme being (God). However, in this research, although participants acknowledged natural causes as being related to God, the relationship was mainly with respect to God being the creator of nature, that is, illnesses that are attributed to natural causes by default fell within God’s jurisdiction rather than caused directly by God. Explanations by some of the participants about seeking treatment at *sing’anga’s* suggests that they believe that God has overarching jurisdiction over everything including both biomedical and indigenous systems of healthcare. This is expressed by a participant as she explained seeking treatment at the *sing’anga* following biomedical practitioners’ failure to diagnose and consequently treat an illness:

> So, at the hospital, they tell you that they cannot find any disease/cause of the illness. So, we leave and go to the flags (representing the sing’anga on the map), and with good fortune and when God places his hand over it, the sing’anga finds the disease/cause of the illness and gives treatment (participant during mapping process in Dedza.)

Based on symptoms and circumstances of the illness the ill person or family members may decide to consult the *chipatala cha chizungu* however, as seen in the extracts above, participants reported that when the *chipatala cha chizungu* failed, they sought treatment at the *sing'angas*. Sometimes the failure was acknowledged explicitly by the *chipatala cha chizungu*. Although participants suggested that no formal referral is made by *chipatala cha chizungu to* indigenous systems, in some cases patients and/or relatives are told indirectly, unofficially by some *chipatala cha chizungu* staff that "*Ponda pondani*" (may be directly translated as step around/step here and there), which means try indigenous spaces for treatment, often carrying a connotation that the person may have been bewitched. On the other hand, participants asserted that the *sing'anga* can make an informal referral to *chipatala cha chizungu,* saying something like, "*my assessment of the child suggests that it is malaria that has rushed to the head (cerebral), go to the hospital*" (Participant during reflections of mapping process in Dedza). This suggests that indigenous health care practitioners sometimes refer patients to the biomedical practitioners. Either way, as is clear that although the participants have embraced the *chipatala cha chizungu*, they also expressed belief that not all illnesses can be treated by it, some can only be diagnosed and treated by the *sing'anga,* indicating that biomedical management is limited to naturally induced phenomenon.

5.1.2.2 Za mwa anthu (Supernatural domain/witchcraft related)

Participants explained that illnesses outside of nature, caused by other people through supernatural means, which they referred to as *za mwa anthu* (of other people) or *Zaufiti* (that of withcraft) or *zolodzedwa* (of bewitchment) can only be treated by a *sing'anga*. The *sing'anga* is a practitioner within traditional medicine which in Kleinman's (1978) framework falls under the folk arena. In both Dedza and Thyola is was apparent that these practitioners fall under subcategories; those who heal and those who harm. Participants in Dedza made this distinction during a brief spontaneous role play enactment that was triggered by the wavy lines on the map seen in figure 4 representing farming land. When explaining why some people may want to harm others, a participant said that dispute over farming of land tended to be at the core of disputes that led to bewitchment. He then decided to enact a scenario as he explained:

> P1: Like these lines here (pointing to symbols of farming fields on the map), these lines, here in our village cause trouble: how dare he cultivate on my land or part of it, I have to think carefully about this, why is he doing this, he shall see, I shall put this little thing (charms) for him.

The participant said the above as he enacted putting charms on a path so that someone that he wanted to harm stepped on them. Another participant next to him got up and enacted being the target and stepped on the charms. Immediately after stepping on the charms, the participant enacted falling ill. Reflections on the enactment revealed that there were two types of *sing'anga* as evidenced below:

> Facilitator: So, where does this little thing (charm) come from?
>
> Chorus: From a sing'anga as well!!!
>
> P2: The sing'angas are in groups, there are others who help people get well/heal, there are others who sell *ufiti* (witchcraft) to others with the intention that when they buy it, they should go and kill others.

The two types of *sing'anga* described in the above extract suggest the multiple roles that traditional /indigenous healers play in the community, which is consistent with studies from elsewhere in Sub Saharan Africa. A study conducted in rural Kwazulu-Natal in South Africa by Zuma and colleagues (2016) on the role of Traditional Health Practitioners found that there were 3 types of practitioners. There were those referred to as *Isangoma* (diviners), *Inyanga* (focuses on traditional herbal and other medical remedies) and *Umthandazi* (faith healers). The two types described by participants in this research would be consistent with the diviner as they both operate based on consultation of spirits and other supernatural forces. Although the participants explained that there were different types of *sing'angas*, they emphasized that the *sing'anga* they were referring to on the map, the one who is in the village is the one who helps with healing people. However, participants clarified that depending on the request of the patient or his family, this *sing'anga* may also perform a "back to sender" ritual, which means whatever harm or charms that were making the patient ill will be sent back to the person who initiated them. This often means that the sender will get sick and often finds it harder to recover because the illness is caused by his own charms. The manifestations of illness caused by charms may include, swelling of limbs, rotting of limbs, stomach problems and other symptoms that may mimic natural illness which are characterised by non-responsiveness to treatment efforts from *chipatala cha chizungu*. This *sing'anga* can also play the role of herbalist, providing treatment for some illnesses perceived by the community as having natural causes.

5.1.2.3 Tsempho (Cultural domain/transgression of cultural sexual practices)

Illnesses caused by sexual transgression may call for a visit to a *sing'anga* but can also be treated by family and relatives who have knowledge of herbs and remedies, in what Kleinman calls the popular sector.

As I have described in section 4.1, illnesses associated with *tsempho* (transgression of sexual taboos) are common in Malawian cultures and include *kaliwondewonde and kanyera wa mkulu*. Part of a *sewero* (dramatic enactment) on the community life cycle in Dedza demonstrates behaviour in relation to a type of *tsempho*. Participants performed a scene of a man asking his wife for sex, and another scene followed in which a friend warned about insisting on having sex with his wife too soon after childbirth as below:

> Main character's friend: If you had insisted on having sex with your wife, you would have been in real big danger. Do you know *Kanyera*?
>
> Main character: Yes! I know, that's why I did not insist. (Participants' dialogue during an enactment on day 3 in Dedza)

The Kanyera that is mentioned above is the same illness that I described in chapter 4 which has symptoms similar to HIV and AIDS but is said to be caused by transgression of sexual taboos. The allusion to cultural sexual transgression in this conversation further highlights the importance of adhering to cultural practices as part of prevention of illness. Upon reflections on the scene above, participants reported that these situations would call for visiting a sing'anga or seeking treatment from family or friends.

5.1.2.4 Mizimu (Spiritual domain/Departed Spirits)

Finally, participants described some illnesses that were said to be caused by *mizimu* (departed spirits). These illnesses according to the participants can only be treated through offering a sacrifice (local beer, rice, nsima, beans or whatever the departed person liked, he/she may even demand a song or dance) around a shrine, which is usually a sizeable tree. In this case, the spirits possess a person, making them seriously ill. At some point the sick person starts to speak in the voice of the departed person demanding whatever sacrifice to be made/giving instruction. Often led by a clan elder (extended family elder/head), when the sacrifice is done, the sick person is cured. In this case, the ceremony becomes the treatment. For this treatment to work, there appears to be a need to follow the instructions that the departed spirit has given carefully. Below is an extract from reflections that emerged during a sewero in Dedza, while exploring the community life cycle:

> You may be surprised when you see a tree with pieces of cloth wrapped around it. We call that *Kachisi* (Shrine). This is a place where we expect that our parents who died (forefathers/mothers) come/gather. So, sometimes children and even adults can become ill and hysterical (*bwebweta)* saying, I am so and so, and I want beans, or this or that. So, they cook the food and bring it to the shrine to offer sacrifice. You also see that sometimes when people are ill, they (people concerned with the illness) ask the spirits of ancestors to heal them. (Participant’s reflection during a sewero on day 3 in Dedza)

Figure 8 - Ancestral shrine in Dedza

The participant’s explanation demonstrated that life does not end after death, in other words, there is life after death as evidenced by the interference of ancestral spirits in the lives of the people.

5.1.2.5 Treatment Seeking Model

The discussion above illustrates that treatment seeking practices in both the Dedza and Thyolo communities is a powerful embodiment of the *mwambi* “*mutu umodzi susenza denga*” (a single head does/cannot carry /support a roof). This is evident in the dependence on plural healthcare systems, with participants and members of their community seeking help from the system that seemed most appropriate depending on the likely causes of illness. This multiplicity of treatment seeking suggests that the human body is understood to exist within multiple domains, the biological (natural), spiritual, supernatural and cultural and this determines where treatment is sought when illness occurs. The diagram below summarises treatment seeking practices in the two communities:

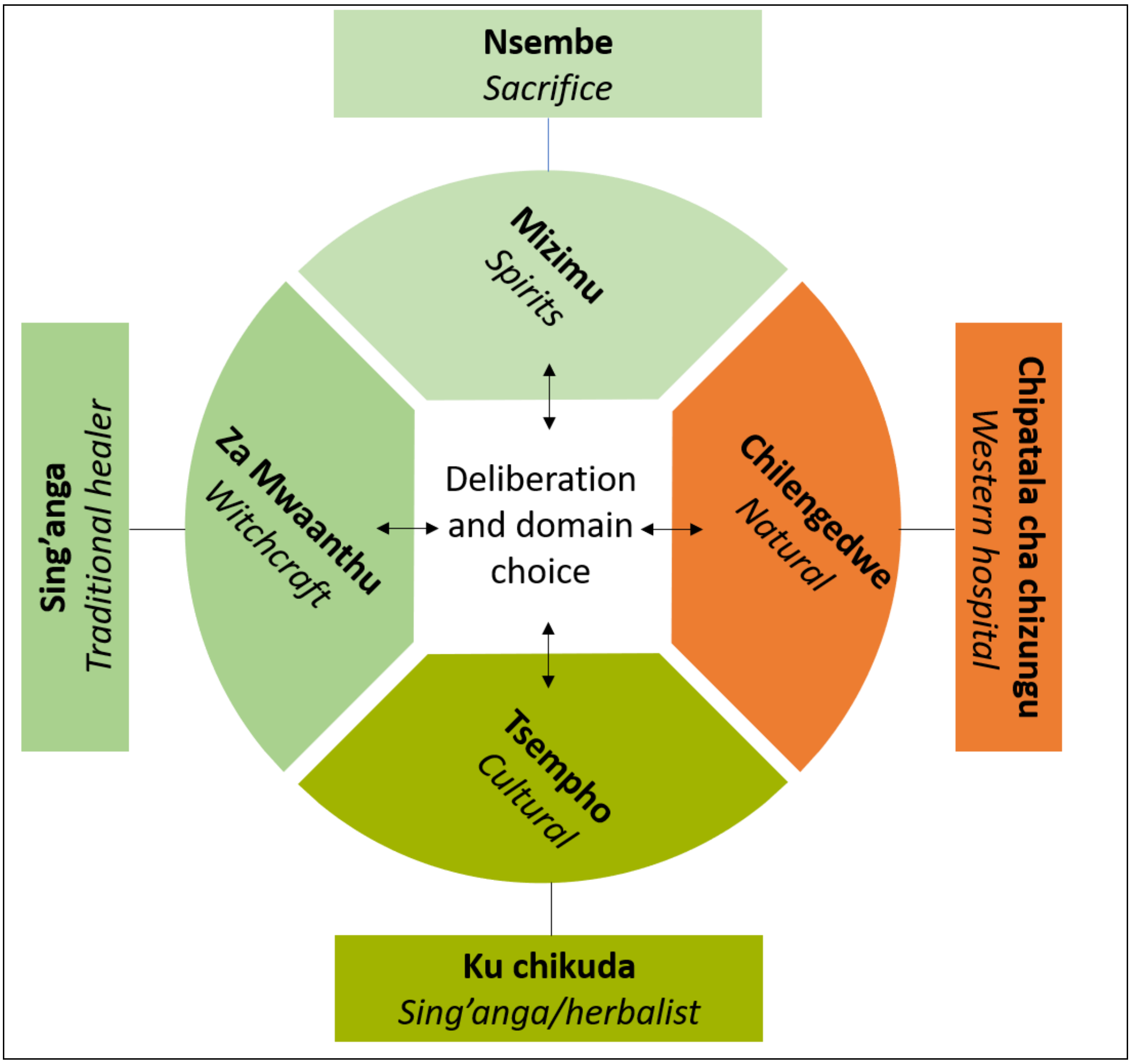

Figure 9 - Treatment seeking model

Figure 9 represents the treatment seeking framework used by the participants and members of their community so that, as we have seen, when symptoms arise, they are assessed and attributed a causal domain and treatment sought from the appropriate healthcare system. Although the *chipatala cha chizungu* is a direct result of Malawi's encounter with colonialism, its integration into the communities' treatment seeking model suggests a reconciliation of fundamental aspects of biomedical understandings of disease, illness, treatments and health in general by these communities with their own indigenous health systems. This reconciliation and integration further highlight what Chimombo (1988:229) describes as a society's own changing and expanding consciousness as it attempts to make sense of new realities. Explorations of *masewero* (dramatic enactments) from both communities show that the people involved in influencing the decision about treatment depend on the severity of the illness. When the illness is less severe, the ill person and their immediate family can make the decisions, but when the illness is severe, extended family members are invited into the deliberation space. As I described in section 3.1.3, in Chewa epistemology, the value placed on the experiences of the elders among the Chewa people is tremendous (Kaphagawani 1998; GVH Miyowe, informal interview), as such, elders play an important role in influencing decisions about treatment seeking. As can be seen, no single person is alone in illness or making decisions of treatment reflecting the *mwambi* "*kali kokha nkanyama, ali awiri ndi anthu*" (the one who is alone is an animal, and those who are two are human beings).

Although figure 9 may suggest a neat relationship between perceived causes of illness and the healthcare system within which members of the community seek treatment, distinctions can be blurry and any attempt to make it neater risks oversimplification. For instance, treatment may be sought from multiple health systems simultaneously rather than sequentially. Deliberation is continuous and domain choice may change. When treatment in one system fails, family members start the process all over again, only this time factoring in experience from their previous treatment seeking attempts. The ways in which the participants described navigating multiple healthcare systems using their knowledges of contrasting constructions of illness and treatment, highlights the sophistication of their social action.

5.2 HIV and AIDS treatment: *Matenda a chilengedwe*? Or *Za mwaanthu*?

As I described in section 4.2, HIV and AIDS is understood by some as being caused by biological factors (*matenda a chilengedwe*), as well as supernatural forces (*za mwaanthu*). In this light, attributing causation of HIV and AIDS to both natural and supernatural domains indicate that members of the community are as likely to seek treatment for HIV and AIDS from the indigenous healthcare systems as they are from the biomedical healthcare system. However, given that the treatment seeking model suggests that treatment for any disease and/or illness in these communities is determined by the perceived domain from which the illness emanates, members of the community are likely to consider *chipatala cha chizungu* as the first point of contact, considering that HIV and AIDS was initially perceived as coming from the "whites" (refer section 4.1) as such, treatment is likely to be successful if sought from *chipatala cha chizungu* (hospital of the whites). Previous research in both Malawi (Hatchet, Kaponda and Chihana et al 2004) and South Africa (Zuma, Wight and Rochat et al 2018) similarly found use of plural health systems to manage HIV and AIDS. For example, Hatchet, Kaponda and Chihana et al (2004) conducted semi-structured interviews about treatment seeking for AIDS and suggested that it was based on progression of symptoms. Firstly, people responded to symptoms with home treatments from family members, followed by seeking treatment from traditional healers if the initial treatment did not work, then finally moving on to biomedical practitioners if symptoms persisted after the first two treatment options (Hatchet, Kaponda and Chihana et al 2004). In Zuma, Wight and Rochat et al's (2018) study in Kwazulu Natal, South Africa people also typically used both biomedical and indigenous health care systems. The authors reported that people often used indigenous systems to meet family expectations as well as to satisfy their own belief that some illnesses were caused by spirits and thus could not be cured by biomedical practitioners. However, just as the findings from the Dedza and Thyolo communities demonstrate, Zuma, Wight and Rochat et al (2018) found that in the context of HIV and AIDS it was difficult for participants to separate some culturally and spiritually caused illnesses from those caused by biological factors.

Participants in this research practiced both concurrent and sequential use of different health systems. This sequential nature of seeking treatment based on different but evolving explanations for the causes of illness could lead to delay in diagnosis of HIV and thus in delayed initiation of ART. Early initiation of anti-retroviral therapy is crucial to suppress viral load and reduce onward transmission (WHO 2015). During the folk media workshops in phase 2, the *masewero* (dramatic enactments) that the participants presented as part of the exploration of what HIV and AIDS was in both communities showed people finding out about their HIV positive status at the *chipatala cha chizungu* when they were critically ill because they had first sought treatment in indigenous health systems before seeking help at the *chipatala cha chizungu*. The performance of the *sewero* the participants titled "*Chipwirikiti cha matenda*" (Anarchy of diseases) in Thyolo, which I described in section 4.2 demonstrates this more clearly. Below I present part of the extract that highlights the common treatment seeking practices when illness occurs:

> And so, they took the girl to a *sing'anga*. However, as time passed, the treatment did not work, the girl got worse. Then, the parents sought counsel from other older relatives. Together, they concluded that it was *tsempho*. When treatment for *tsempho* did not work, a friend advised them to go to the hospital, where the girl was found to be HIV positive...(Extract from my field notes on day 4 in Thyolo)

When reflecting on the scenes of the *sewero* that reflected the description in the extract above, the participants said that most people, but especially men, tend to find out about their HIV status when they are sick and end up at the *chipatala cha chizungu*. This finding is consistent with a study conducted in rural South Africa which also found concurrent and sequential treatment seeking across indigenous and biomedical health systems and that participants had sought help from traditional providers before initiation of ART (Moshabela, Pronyk and Williams et al 2011).

Malawi has a policy on mandatory HIV testing during pregnancy, to protect against mother to child transmission of HIV (Ministry of Health 2016). This policy was reflected in community experience, with a frequent route to identification of HIV status for women in both communities being during pregnancy when they go to the *chipatala cha chizungu* for antenatal clinic. This means that women are more likely to know their HIV status earlier which often leads to earlier initiation of treatment.

5.3 Perceptions and Experiences of HIV Treatment

As stated in the Malawi National Strategic Plan for HIV and AIDS 2015-2020, the successful suppression of HIV depends on adherence to medical regimens which, for most HIV+ people, means that the single daily tablet is taken on schedule (National AIDS Commission 2014). In this section I explore the views and experiences of the Dedza and Thyolo communities with ART. While the participants were appreciative of ART, they also explained that they faced significant challenges to adherence. I will begin by exploring the positive experiences of the communities with the treatment, followed by the challenges that the communities have experienced.

5.3.1 Life saving

Participants in both communities shared positive experiences of ART from their family and friends. They were grateful for ART suggesting that it had saved many lives which would otherwise have been lost. Some participants explained that when patients take the medication as prescribed by the doctors and follow their advice, they recover and live a normal vibrant life. I present two examples that emerged during a story sharing circle on day 5 of the folk media workshops in Dedza. As explained in section 3.3, during the story sharing circle participants shared experiences of HIV and AIDS most of which were stories of close family members. In the first extract the participant told how her aunt recovered from serious sickness. The aunt had been very sick, but after being admitted to hospital and being tested for HIV, she was found HIV positive and after counselling was put on ART:

> From the time she started taking the medication in 2013 to this day (she has been fine), now she is an amazing woman. When we talk about people who have been infected by this disease, she is the chairperson for the entire Dedza (district) hospital, and she is the one taking part in all activities there (Female participant during story sharing on day 5 in Dedza).

The second extract below from another participant also demonstrates recovery of the patient after serious illness:

> I am also one of the people who has been affected by HIV and AIDS. I have my brother, the eldest in my family. In the past years he suffered a lot, to the extent that we, as family lost heart, and did not know what to do. But I did not give up. Together with other relatives, we tried to convince him to go to the hospital but whenever we tried, he insulted us and got very angry almost wanting to beat us if he had the strength. But I still didn’t give up, I went to the health centre and discussed with the health worker there and told him the whole story. The health worker insisted that we do

> our best to get him to the clinic and promised that they would counsel and help him accept the situation…As I speak now, he is well and healthy, he was counselled, tested and given treatment (Male participant during story sharing on day 5 in Dedza).

Like the experiences narrated in the extract above, Burns, Borges and Blasco et al (2019:1113) refer to a recovery from a near death experience by HIV positive patients as the “Lazarus effect” where many HIV patients in Sub-Saharan Africa had a feeling that they had been given a second chance during the early scale up of ART. As part of the scale up, the Malawian government currently provides free HIV testing and diagnostic services, free ART for people with HIV and has made these services available in local health centres which are reachable for most Malawians.

The accessibility of ART and the subsequent narrated positive experiences do not include experience of side-effects consistent with findings reported by Dovel, Phiri and Mphande et al (2020), which drew on data from 12 focus group discussions with health care workers in central Malawi and found that patients who were already very ill at the time of starting ART are more likely to not notice the side effects or bear them more willingly with a hope for improved health.

5.3.2 Mental Health Disturbances

Other participants in Dedza and Thyolo expressed concern about the experiences of their family members, friends and other members of the community with current ART. Participants reported that around 2016, people living with HIV started receiving new medication which has had significant side effects on them.

In Thyolo, participants reported side effects of ART that focused on personality/behavioral changes such as increased aggression and unpredictability which often led to difficulty relating and living with others. Several participants shared this in Thyolo during the story sharing circle. Below are two participants’ observations about people on ART:

> But when a person starts taking the medication, they become confused/disoriented (*kubalalika*) and the person does not speak well (aggressive and insulting), so much that if you took it to heart, you would stop helping them. (Male participant during story sharing on day 5 in Thyolo)

Another participant added in agreement:

> When they are taking the medication, they behave as though they are getting rabies. (Male participant during story sharing on day 5 in Thyolo)

The reported aggressive behaviors displayed by people receiving ART as described in the extracts above make it difficult for them to live peacefully with their loved ones and those who support them. In some cases, this jeopardizes their adherence to treatment as their guardians (people authorized to collect medication from healthcare facilities for them and care for them) can sometimes get offended and upset and threaten to stop collecting the medication from the health facility for them. In response to the stories of others, one of the participants in Thyolo shared her own story:

> Let me bear witness to what is being said that sometimes you can quarrel/ get upset with your relation for whom you collect medication. It’s true, I did this in 2005 I was collecting medication for my relative from the hospital in Thyolo, so one of the days we had a disagreement. She spoke words to me that hurt me deeply and I thought to myself that “we shall see, if you have such strength we will see if you will go to the hospital to collect your medication yourself”…so I was sulking (*ndinanyanyala*) for one week, she cried and summoned our uncle on me and told him that I was refusing to collect medication for her. When he asked me I said yes it was true and told him that she needed to treat me properly because [she was treating me as if] I was her servant, and she was my boss, [and] going from here to Thyolo (district hospital to collect her medication) was not a joke….But I eventually went to collect because she was my mother, yes, this was my own mother(Female participant during story sharing on day 5 in Thyolo).

Although the extract above captures an experience from 2005, the participant was bearing witness to recent experiences raised by the other participants. The ongoing interactions and condition of relationships between the person receiving ART and his guardian (treatment supporter) is structurally crucial to treatment because the rules for dispensing ARVs stipulate that “only the patient and his individual registered guardian is allowed to collect ARVs” (Ministry of Health 2016:52). Apart from logistical importance, family and relatives are an important aspect of HIV and AIDS patients’ support to treatment. Yet, some participants’ experiences with their loved one’s reactions to taking ART tends to threaten these relationships.

Apart from reported aggression and difficulty in living peacefully with others, participants also reported that the medication caused serious mental health issues for some people who were taking them as described by the participants below:

> Sometimes they (medicines) can confuse them (people on ART) to the extent of even going mad and running away from home. People (family and friends) go around looking for them (person taking the medicines) (Male participant during story sharing on day 5 in Thyolo)
>
> I can also comment on that; my sister’s husband was from Phalombe (district neighboring Thyolo). We had no *misala* (madness) problems with him before living (together) in the homestead. But as soon as he started receiving the medication, he started…do you remember? (she was asking the rest of the participants, who responded with a yes, in chorus) (Female participant during story sharing on day 5 in Thyolo)

Some of the above experiences of side effects of ART are consistent with the effects of one of the drugs used in earlier treatment regimens called Efavirenz (Kennedi and Goforth 2011). In their study titled *a systematic review of the psychiatric side-effects of efavirenz*, Kennedi and Goforth (2011) reported finding neuropsychiatric side effects that included vivid dreams, insomnia and mood changes in half of the patients receiving the drug. The authors further assert that the side effects were often mild and transient in nature and emerged quickly, peaking at two weeks into treatment (Kennedi and Goforth 2011).

However, Kennedi and Goforth (2011) also found reports and uncontrolled data that suggested higher rates of more severe side effects.

5.3.3 Physical and practical effects

While participants in Thyolo reported mental and behavioral disturbances affecting people on ART, participants in Dedza reported more physical manifestations and practical challenges of taking ARVs. They explained that some people got swollen limbs while others got dizziness, black outs and fainting due to the medication as evidenced by *"some people say that when they take the medication, they get dizzy and there is darkness in their eyes"* (Participant during the story sharing session in Dedza). Dizziness is one of the side effects acknowledged in the current guidelines for clinical management of HIV and AIDS in Malawi (Ministry of Health 2016) which explains that the side effects are limited to the first four weeks of treatment.

Participants in Dedza reported that side effects of the HIV medication are particularly worse during hunger season as there is not enough to eat. The hunger season is shown by the seasonal calendar the participants made on the 2nd day of the workshops, usually around January to April. Based on their own and others' prior experience, lack of food was said to deter people from taking the medicines for fear of adverse reactions. One participant explains how someone came to her home to ask for something to eat just so that they could take their medication. They said they were told that:

> I have come to you because of hunger. I take medication (ARVs) and now that they have changed the medication for us, the one we are taking now is very strong, it happens that when I take it without eating food, I can reach the extent of falling and fainting…

Another participant also shared his encounter below:

> This same year (2019) while I was at the farm, my child came to tell me that there was a visitor at home. I left my hoe at the farm and hurried back. When I arrived home, I found a man sitting by the *chigafa.* After pleasantries he said "Brother please do not fear me, I am just hungry. I

> take medication, and since the last I took my medication yesterday was also the last time I had something to eat. Right now my heart is racing and I was wondering if perhaps your wife could make me a little porridge so that I can eat and take my medication (Participant during story sharing on day 5 in Dedza).

One participant from Dedza generalised the explanations:

> Many people wish they could take the medication but because of the poverty they have in their home they believe that if I take the medication, I will fall (faint) as I have no food, and so let me just put them here (tuck them away). They say that it's the changing of the medication, and so if I take them today, I don't have food, will I be alright? The medication makes you so weak that you can't even walk (Participant during story sharing on day 5 in Dedza)

From the extracts above we see that hunger and poverty play a vital role in determining whether treatment of HIV is adhered to or not, a fact not acknowledged in Malawi's clinical guidelines (Ministry of Health 2016). In the above extract, we see that in the people's calculations, the effects of taking the medication on an empty stomach and the accompanying risk of not being well enough to find food for one's family during an already difficult time of hunger far outweighs the long-term benefit of adherence. The relationship between HIV and AIDS and poverty has often been discussed in terms of factors contributing to HIV transmission in relation to forcing people to engage in transactional sex (Sovran 2013) and as an effect of severe illness where the patient is a bread winner and is unable to provide for his/her family due to severe illness (Burns, Borges and Blasco et al 2019). However, analysis of the participants reported experiences in Dedza suggests that fear of further immediate poverty and hunger in the home created by the side effects that some people experience with ART is more dominant.

As we have seen, participants' experiences with ART are not consistent with the suggestion that "current ART regimens are easy to take and rarely cause serious side-effects" detailed in the guidelines for clinical management of HIV and AIDS in Malawi (2016:6). Treatment fatigue, as described by Tabatai, Namakhoma and Tweya et al (2014) extended beyond the person with HIV in Dedza to those who support them. This participant explains more explicitly:

> Is it not possible for the research experts to find a vaccine (also meaning injection) that people can receive every two or three months so that a person could at least receive the vaccine (medication) three times a year or so. This could be more manageable because let's say if the person refuses to take the medication, we would take him say to the hospital, they will administer the medication, even if they get angry and aggressive, it would still have been done. There wouldn't be any problems. But with this medication, today I should go to his/her house to hold him/her down (force to take medication) in the afternoon, tomorrow we should go and hold him down again in the afternoon. In the end people reach a point of saying, it's her/his life (giving up) (Male participant during story sharing on day 5 in Dedza).

The extract above suggests collective effort and the responsibility that family and friends of people on ART assume in ensuring adherence and general care. It also highlights how difficult this collective effort can be when the patient is non-compliant and aggressive. The constant daily battle may lead to resignation and withdrawal of active support by the patient's loved ones, as we saw in the example above from 2005. This might be a contributing factor to the situation which Tabatai, Namakhoma and Tweya el at (2014) demonstrated that one in four patients do not remain in care after 2 years. This includes Malawi.

5.4 Problematizing Treatment and Public Health Approaches

In 2015, the World Health Organization recommended that ART be initiated among all adults living with HIV as soon as they receive a diagnosis of HIV regardless of clinical stage or CD4 cell count. This Test and Treat regimen has been widely adopted in Sub-Saharan Africa, forming the basis for changes in policy and management of HIV and AIDS (Dovel, Phiri and Mphande et al 2020). In Malawi, the test and treat regimen was implemented in 2016 as illustrated in the 3rd edition of the country's guidelines for clinical management of HIV and AIDS (Ministry of Health 2016). The document states that early initiation of ART is the most powerful intervention available to prevent high morbidity and mortality and prevent further transmission of HIV. Successful ART leads to viral suppression which greatly reduces the risk of sexual transmission as well as mother to child transmission of HIV (Ministry of Health 2016).

5.4.1 Reactions to the Test and Treat

The relatively new Test and Treat regimen was raised and discussed at length by participants in Thyolo during the folk media workshops although it did not emerge as a topic at all in Dedza. An overwhelming majority of the participants in Thyolo did not follow the reasoning for the Test and Treat system as it did not fit into their general model of health seeking which is about responding to symptoms. During the folk media workshops the participants had chosen to use a *sewero* to explore the community life cycle. The *sewero* opened with a couple's conversation that indicated that the woman was pregnant. It then moved on to show scenes representing the journey of a community member's life from pregnancy, birth to old age. During reflections on the *sewero* and the stages of life it portrayed, illnesses that affect people at every stage and their treatment options emerged which led to the discussion about HIV treatment. Below is an extract of a conversation that developed from one of the participant's reflections on his understanding of ART and the shift to Test and Treat:

> P1: Here's what happens based on my understanding, every healthy person is supposed to have protection in the body or should I say soldiers, 1500. So, if we go back, when the ARVs were first introduced, you could have HIV but if all the 1500 soldiers were still there, you were not given treatment. But when they got down to 500, 1000 less (than what you had) meaning that your body is weak and if any disease came, you would get sick, that's when you would start the ARVs because your defenses have reduced…But today that has also changed, if you test positive they give you medication there and then, why? How does that happen/work?
>
> P2: It is because they reduced the strength of the medication.
>
> P3: They saw that at that time when the defenses were too low, some were failing to take the medications because they were too ill, and maybe

> their guardians were not caring for them well and so, many people were dying. So, they decided that whoever is found positive should start medication there and then to try and save lives…
>
> P1: So, you were explaining that if they give you the medications while you were already sick, you did not take long to die isn't it?
>
> P3: Yes
>
> P1: Right, it was helping in that way, okay, today, they have made it so that if they found me with the virus as I am, am I showing any signs? So, they should give medicines today to take because I have the virus. And, no one knows how I am (HIV status). Do you think as I am (healthy looking) it would be difficult to take ten or twenty people behind me (to infect)?
>
> P2 and 3: Very possible (to infect)
>
> P1: So, do you think this could have been possible/happening in the way it (treatment model) was before?
>
> P2: No
>
> P1: So now do you think the government has helped us or not (by moving to Test and Treat)?
>
> Chorus: Yes! No!
>
> (Participants' reflections on a *sewero* on day 3 in Thyolo)

The first part of the long extract above demonstrates an in-depth understanding by the participants of both the current Test and Treat and the previous treatment model consistent with biomedical explanations as described in the current Guidelines for Clinical Management of HIV and AIDS (Ministry of Health 2016). However, the first participant shows skepticism and questions the reason/logic behind the shift from the previous treatment model to Test and Treat. Despite participant 3's effort to respond to his questioning, he insists that the change to Test and Treat is not a helpful one. In the last part of the extract, participant 1 ends by challenging the rest of the participants to reflect on the extent to which the change to Test and Treat is helpful. Few of the participants thought that the change was indeed helpful while an overwhelming majority of the participants said it was not a good step. As seen by participant 3's response, support for Test and Treat revolved around better health outcomes for the person receiving treatment. On the other hand, the arguments for those who thought government did not help them by changing to test and treat are captured in this participants response:

> P4: They (Government) have not helped us because the people have not yet started showing signs/symptoms. In the past you could see the hair changing texture as if the person had fallen into thobwa (local drink made from millet), and you could tell (that that person is HIV positive). In others you could see the adjustment of the trousers and could tell that there he goes. So, I should go to test, as I am (she is quite heavy-considered an example of healthy by community), who would think that I was receiving medication? No one! So, would I refuse if someone asked me out (for sex)? No! I would not, I would accept so that Mr Cabbage (not real name) and Mr Nandolo (not real name) should follow suit.

As can be seen above, while a few participants based their support for Test and Treat on the affected individual's wellbeing, the majority looked at it from a social/community safety and protection perspective reflecting Chakanza's (2005) argument that the Malawian cultural perspective of illness and health does not only focus on the individual but also on seeing the individual in relation and harmony with society. According to the participants, for the protection and wellbeing of the many, the person who has HIV needs to first have visible symptoms so that other people can see and take better care when having sexual relationships with them. The negative perceptions of Test and Treat have implications for early ART initiation. Dovel, Phiri and Mphande et al 's (2020) study, which examined health care workers perceptions and experiences on how "feeling healthy" influences ART initiation among HIV positive clients, suggests that people living with HIV who "feel healthy" may face additional barriers to ART initiation including, fear of stigma and discrimination, unwanted disclosure, fear of side effects, disruption of their daily lives and limited knowledge on the benefits of early ART initiation (Dovel, Phiri and Mphande et al 2020). The aspect of limited knowledge is consistent with the findings of this study as suggested by the extracts from Thyolo. As suggested by the discussion in this section, there appears to be a gap in dialogical communication between the healthcare providers and the community about the relevance of Test and Treat and how it works. I will unpack this gap in the section below.

5.4.2 The problem of communication

Participants in both Dedza and Thyolo expressed overwhelming concern over lack of proper communication by health care providers with either patients or with the wider community. In Thyolo, problems of communication were raised by participants during reflections on the *sewero,* titled *"anarchy of diseases"* which the participants created on day 4 of the folk media workshops as part of the exploration of what HIV and AIDS was (see extract of description of the story line in section 4.2). Verbal journal entries of the following day reflected strongly the participants disapproval of the lack of communication and impositions of treatment regimens by the health care providers on their patients. One of the participants reflects below:

> The problem is that the government does not consider/think of us. When they create/make medicines, they just come to us and say we have made these new medicines you have to take. There is no chance/opportunity for us to ask what the side effects are…Although we may be reluctant, we have no freedom to ask, it's just imposed on us. (Male Participant during reflections on sewero in Thyolo)

While the participant in the extract above complains about the lack of adequate information on new drugs and their potential side effects, other participants were more emotional about their dissatisfaction as expressed below:

> You doctors are not helping us because you change medicines without telling us, yet we are the ones drinking/taking the medicines. So, when you do not inform us, what does that mean? Are you thinking of us/considering us? What exactly are you up to? Are you intending for us to die or to save our lives? who exactly do you consider us to be? I thought

> when you change the medicines you are supposed to tell/inform the people for whom you are changing the medication for them to know exactly how they work. (Female Participant, Verbal Journal entry day 5, Thyolo)

The lack of communication about changes in medications/treatment regimens created feelings of confusion, distrust and suspicion in some of the participants as reflected in the verbal journal extract below:

> I want to speak about the issues that happen here (in my home area). The hospital people are confusing us a lot with their plans and programs…Suddenly, we just hear that medicines have been changed, particularly with ARVs. You just hear that oh the Panadol (paracetamol), or the parapain (another painkiller) that you used to receive, you will no longer receive, instead you will receive this one (new drug). These things () have been unsure and suspicious because all the while we were receiving parapain (same medicine). And today, why are you changing the medicine without explaining to us, the people who use the medicines, here in the village? Yet you say this medicine (previous one) was not agreeing with the patient. Who did you tell that the medicine was not agreeing with the patient? You! Hospital people!...(Male Participant, Verbal Journal entry day 5, Thyolo).

The long extract above demonstrates the participants’ desire for dialogue and adequate information and continuous/ongoing communication between health care providers and health care seekers. It also suggests a need for accountability of health care providers to the people they serve.

In Dedza, the participants’ discussion of communication focused on the inadequate information given to the community at the start of public health promotion programs, and the dissemination of information to the community by inappropriate people. Through a *sewero* including participants taking the roles of researchers conducting research about peoples understanding of HIV and AIDS in Miyowe village (their own village), issues of conspiracy around HIV and AIDS emerged and reflections went deeper (see section 4.3). Participants discussed other health related issues that contributed to suspicions and lack of confidence in the health care system. The participants shared an example about a public health program: they explained that sometime between October and December 2018, parents were called to the school and informed by the head teacher that girls from ages 10-19 would start receiving iron tablets every Wednesday under the supervision of the teacher. This research was conducted in January and by then, the program had not yet started because parents had refused to allow their children to take the tablets. The participants reported that parents (some of whom were also participants) did not feel they had enough information about the program. Teachers had not answered their questions or addressed their concerns so parents were not satisfied with simply being told that their children would receive the drugs. The participants explained that some parents even demanded that the teachers take the tablets first, before giving them to their children, but the teachers refused. In response the parents demanded that:

> We want the health people to come here and explain because we see that this is a bullet you want to finish our children, how can you say that you want to give our children medicines with unknown origins and you say that our community has been chosen, No! (Participant during reflection on a *sewero* on day 4 in Dedza)

One of the participants gave a first-hand account of what happened during the meeting and said:

> On this day when the school called the parents to tell them about the medicines that add blood, I as the chair of the school committee was there. The issue was that the health people (Health care workers) were not available, Mr Mphaka (Not real name) and his friends [who work in the health system] were busy with other things and were not there. So, the issue is that teachers do not know about medicine, if they were talking about chalk, that would be great. But the issue of medicines that children take at school should be handled by health people. The health people (Health Surveillance Assistants) should first go into the villages to explain to parents about it because that day it was difficult. The questions were coming (from parents) to the teachers, but the teachers know about chalk and not about medicine (so they could not answer), it is the hospital

> people who are responsible, and they were not there at the time. From that time till now, they have not yet come to the villages and so the work has not yet started. (Participant during reflections on a *sewero* on day 4 in Dedza)

As is evident in the extracts above, the community rejected the program and would not allow their children to receive the iron tablets. Their resolve at the time was such that some of them kept their children away from school on the days that they were supposed to receive the tablets. I realised this when on one of the days there were increased number of children peeping through the windows of the workshop space at a time when they should have been at school. When I asked, the participants reminded me (of the earlier discussion), that it was because the children's parents did not want them to receive the tablets and so, had kept them home.

This section has shown that poor or no communication by health care workers of programs can affect willingness of communities to either take medicines or participate in health promotion activities and impede access to health care at biomedical health facilities. A study that conducted 30 in-depth interviews with pregnant women admitted for delivery in 6 health facilities in Malawi found that women who were satisfied with the way health care providers communicated with them had motivation to deliver at a health facility (Madula, Kalembo and Kaminga et al 2018). A much larger study from the 1990's which involved about 4000 patients suggested that interpersonal engagement and communication by health providers was of far greater significance to the experiences of the patients than the actual clinical or technical care (Ruben 2016). The author reports that most patients' frequently remembered experiences were associated with personal engagement and communication (Ruben 2016). It is evident that effective communication is critical to health care delivery and access. As seen in Dedza, the imposing, instructional approach to communication can lead to boycotting of healthcare programs. According to Ruben (2016), communication scholars understand the complexity and nuances of the process of communication. The problem, he argues, arises when the concepts of communication are translated and appropriated into health care practice where the complexities and nuances are often overlooked in favour of simpler information exchange (Reuben 2016). Ruben (2016) argues that the changing health care landscape is more likely to exacerbate the problem than it is to alleviate it. Effective communication has been found to be vital to reducing the uncertainty of patients, improving adherence to treatment and increasing effective utilization of health care facilities (Ruben 2016: Madula, Kalembo and Kaminga et al 2018). Given the multiplicity of treatment seeking practices in both the Dedza and Thyolo communities, the perceived communication gap by biomedical health care providers could force some members of these communities to seek treatment within the indigenous health care systems, even for illnesses that they know need biomedical treatment.

5.5 Chapter Summary

I have explored how communities who participated in this research name and make sense of HIV and AIDS treatment. Here we have seen that treatment seeking for HIV in the two communities is understood in relation to the communities' general treatment seeking frameworks. In these communities, people seek treatment from two major health systems namely biomedical healthcare system represented by the *chipatala cha chizungu* (hospital of the white people) and from the indigenous/folk healthcare system as represented by the *sing'anga* and herbalists.

Once illness is established, the decision of which health system to seek healthcare from when a person is ill depends on the evaluation of symptoms, consideration of circumstances surrounding the illness and the assessment of what caused the illness. We have also seen that in these communities, illnesses are understood as emanating from four causal domains namely: *Matenda a Chilengedwe* emanating from the natural domain and are associated with seeking treatment at *chipatala cha chizungu*; *Za mwa anthu* emanating from the supernatural domain (witchcraft related) can only be treated by a *sing'anga*; *Tsempho* emanating from the cultural domain and caused by transgression of cultural sexual practices are treated by the *sing'anga* as well as herbalists; And, finally, there were illnesses caused by *mizimu* (departed spirits) emanating from the spiritual domain and can only be treated through offering of sacrifices.

It is clear from my findings that HIV and AIDS is understood by some members of the communities as being caused by biological factors (*matenda a chilengedwe*), as well as supernatural forces (*za mwa anthu*). Because of this attribution many members of the community seek treatment for HIV and AIDS from both indigenous healthcare systems and the biomedical healthcare systems concurrently and sequentially. It is also clear that the sequential nature of seeking treatment often leads to delay in diagnosis of HIV and thus in delayed initiation of ART.

Through this chapter, we have also seen that participants have had both positive and negative experiences with HIV and AIDS treatment. While they demonstrated gratitude for the life-saving treatment, the majority of participants expressed concern about negative side effects experienced by their family members, friends and other members of the community with current ART. They reported both mental and physical health disturbances in people on ART manifesting symptoms such as increased aggression, dizziness, black outs and fainting.

In the last parts of the chapter, participants in both Dedza and Thyolo expressed overwhelming concern over lack of proper communication by health care providers with either patients or with the wider community. The lack of communication and impositions of HIV treatment regimens by the health care providers on their patients was detested by the participants. As a result, we see that in Thyolo, an overwhelming majority of the participants did not follow the reasoning for the new Test and Treat system as it did not fit into their general model of health seeking which is about responding to symptoms. In Dedza, the problem of non-dialogical, inadequate information given to the community at the start of public health promotion programs, and the dissemination of information to the community by inappropriate people made the community members to reject and boycott the health initiative. We have seen here that poor communication and/or no communication by health care workers and public health practitioners with the communities they are serving can adversely affect willingness of communities to either take medicines or participate in health promotion activities, thereby impede access to health care at biomedical health facilities.

6 The *Pamtondo* Effect: Exploring Narratives of Health (HIV and AIDS) through Cultural Frames of Play(fulness)

Pamtondo ndi pa macheza
(Pamtondo is a place/space of play(fulness)

Ukafuna bodza upite pa mtondo, ukamva
(If you want gossip, go to pamtondo, you will hear it)

(Extract from a phone conversation with my mother, a Matchona 2020)

Having explored how the two rural communities understand and make sense of HIV and AIDS through chapters 4 and 5, I now focus my attention on the ways in which folk media can facilitate research of HIV and AIDS among communities in rural Malawi. As described in previous chapters, grounding development initiatives (agriculture, education, health etc) in the experiences of communities using their own cultural resources has proven to be effective in achieving greater impact (Chisiza 2017; Abdulla 2016; Abdulla 2013; Chinyowa 2009; Chinyowa 2005; Darder, Baltodano and Torres 2003; Escobar 1995; UNESCO 1995; Mda 1993). Folk media forms such as proverbs, songs, dances, drama and storytelling are a crucial resource in most African cultures including Malawi.

According to Kamlongera, Nambote and Timpunza-Mvula (1992), the Malawian people have expressed themselves through folk media performances since the pre-colonial period. The performance-based nature of Malawian cultures is manifest in all aspects of life and is evident in politics, religion, spiritual and social dimensions of life (Kamlongera, Nambote and Timpunza-Mvula 1992; Chirwa 2001; Kerr 1987; Sembereka 1996; Lwanda 2002, 2003). In Kamlongera, Nambote and Timpunza-Mvula's (1992) explanation, African performances before the influence of colonialism and Christianity were inseparable from ritual and tradition. Although weaker in contemporary times, the assertion still holds true especially for rural communities in Malawi, who are the focus of this study. Kamlongera, Nambote and Timpunza-Mvula (1992) also argue that function and art in indigenous performances merge and feed into each other. As Kerr (1987) exemplifies, *Gule wa Mkulu,* a dominant masquerade performance amongst the Chewa people, was one of the dances used in retaliating against colonialism and the exercise of its oppressive powers. Ritualistic performances, indigenous songs and dances (magule), storytelling, dramatizations, among others were used as educative modes and spaces of social deliberation and reconstruction (Kamlongera, Nambote and Timpunza-Mvula 1992; Kerr 1987; Chinyowa 2009, 2005).

Folk media performances have long been used to create spaces that facilitate reflection on social happenings, constructions and critiques of behaviour, and making of social commentaries. These spaces allow for venting and expression of feelings and emotions by various groups of people within the communities in a safe and culturally acceptable manner (Kamlongera, Nambote and Timpunza-Mvula 1992; Kerr 1987; Lwanda 2003). One such space is *Pamtondo*, which I go on to describe in detail later. For now, *pamtondo* can be best understood as a cultural space of work and play where women pound grain as they sing songs, gossip, laugh, discuss current affairs and voice their joys and grievances.

In this chapter, I attempt to answer the second question of this study; in what ways can folk media facilitate research about HIV and AIDS in rural Malawi. In doing so, I present my exploration in two major sections. In the first section I describe how folk media facilitated a conducive environment for research practice in this study. l unpack the concept of *Pamtondo* and describe what I am calling “the *pamtondo* effect”. I then go on to explore how play(fulness) created the *pamtondo* effect and enabled a collaborative generation of knowledge about narratives of HIV and AIDS with the two rural communities who participated in this study. In the second section, I focus on exploring the modalities of play within folk media that allowed for the generation of data. I describe how the frames of make-believe, living improvisations, spontaneity and collaboration generated data about how the two communities understand, experience and make sense of HIV and AIDS.

In parts of this chapter, I share insights into my heritage as one who was and continues to be moulded by the Malawian culture. I describe relevant experiences, oral histories and stories told to me by my mother and grandmother which were present in general popular discourse within my village and other villages I have worked with across Malawi. Although these oral histories and stories are not written down, they are firmly established in Malawian culture and thus provide important context to this chapter.

6.1 Facilitating a Conducive Environment for Research Practice

6.1.1 Pamtondo

Pamtondo is a Chichewa term that denotes a Malawian cultural space where women pound grain, sing songs, gossip, laugh, discuss current affairs and voice their joys and grievances. A literature search on the topic reveals almost no description of *pamtondo* in formal research or social commentary. Only one author, John Lwanda, goes beyond mention of the term. In his paper *Mother's Songs: male appropriation of women's music in Malawi and Southern Africa (2003),* Lwanda briefly describes *pamtondo*. He says:

> In rural Malawi, where maize mills may be far or unaffordable, women commonly still pounded maize at the mortar (pamtondo). In the process, they sing blues, folk or other songs…

Lwanda's (2003) explores the songs sung at *pamtondo* in relation to popular music, appropriation, and thus the public. As he put it, *pamtondo* has its own beat, phrasing and social modes in which women express sexual and matrimonial issues among each other (2003:116). He explains that *pamtondo* was a place where women expressed gossip, laments, joy and other emotions through song in coded language with and to each other (Lwanda 2003).

Due to the scarcity of published scholarship on *pamtondo*, I turn to my own experience and that of my mother. As a curious little girl (age 8-10) growing up partly in the city (with my aunt) and partly in Kanjedza, a rural village in Chikwawa district, in the southern region of Malawi (with my mother and grandmother), I was fascinated by my village life and wanted to know everything there was to know there. I snooped into forbidden spaces, participated in those spaces which welcomed me, and everything in between. *Pamtondo* was one of the spaces in which the presence of little girls like me was welcomed and perhaps even demanded as part of our training into future womanhood. As the women pounded their maize, they gave us (little girls) some maize to pound as well using our pint- sized mortars.

The term *Pamtondo* originally comes from the *mtondo* tree (Cordyla Africana). The *mtondo* tree was considered the strongest tree locally and readily available, strong enough to make durable mortars (the mortars were also named *mtondo* after the tree). Due to its big size, the *mtondo* tree also provided shade from the hot sun, which made it a suitable and preferred place for women to gather when pounding maize, sorghum or anything that needed extensive pounding. In the Chichewa language '*pa*' is a locative prefix (Kunkeyani 2007). '*Pa*' is often used as the equivalent of the English word "at" or "on". In this case, *pamtondo* refers to at the *mtondo* or at the place/space where the *mtondo* is. *Pamtondo* has since been used to refer to the space where women gather to pound irrespective of whether that is under a *mtondo* tree or not.

In my village, women who needed to pound organized themselves and met under the *mtondo* tree, each with their maize, (sorghum, millet,) *mtondo* (mortar), *munsi* (pestles) and *lichero* (winnowing baskets) to fulfil part of their duties of womanhood (making flour for their families) while they sang, gossiped and laughed. Some who did not need to pound also gathered along to help their friends with pounding and join in the songs and gossip. However, it was not only a space where women shared with each other, or complained to each other, but it was also a space where women would express their grievances with the community as well as address concerns they would not otherwise dare to, mainly through song. The women could break the silence and voice their feelings and would not be punished for it because it was done within the *pamtondo* frame. "*Pamtondo ndi pa macheza* (*Pamtondo* is a place/space of play)" was my mother's response when I asked her (March 2020) what *pamtondo* was (she still lives in the Village). My mother, commonly known in my village as *mache* Sharifa (mother of Sharifa), or a Matchona, shared with me her recollection of an instance that happened with her elder cousin when she was a young woman and a song that her cousin sang at one of the *pamtondo* gatherings in response:

> Achimwene dzikwatilani tsopano mwakula / *Brother, go get married, you are now grown/adult*

Tiyeni tiwaseke, iiih iiih aayeee! / *Let us laugh at him, iiiiih iiiih aayeee!*

My mother explained that she had heard this song at *pamtondo* from *mache Joni* (mother of John) who was her elder cousin. She explained that *mache* Joni's elder brother was an adult who was not married but still lived with his parents. The women of the household tried many things to encourage him to get married and leave, but to no avail. They tried to let him go hungry by eating early before he got home, but he would just come in, open the relish pots and cook *nsima* (very thick porridge made from corn flour, a staple in Malawi) for himself and ate (a grown male entering the kitchen and opening pots was not socially respectful), drink whatever milk the women had kept for the following day, and sat around with nothing much to do. His sister, *mache* Joni, was so tired of his behaviour that at the *pamtondo*, she shared and sang the above song, making sure he heard it. "Why did she not just tell him?" I asked my mother with deliberate naivety, "this was so that she did not speak to him directly, because it might have caused a big quarrel/fight and gotten her into trouble, so she took it to *pamtondo*" she responded. When I asked my mother if her cousin got into trouble for the song, she laughed and said "*aaah ndi pamacheza ka, ndi nyimbo*" (aaah it is a space of play, it's a song).

Typically, the women would start with sharing their issues and stories, then they would go on to compose or edit songs from the issues depending on whether the song was for their own therapeutic purposes, speaking with each other or keeping/storing experiences. When they wanted to communicate only with each other they disguised the songs and used coded language as Lwanda (2003) has described. But if the song was/is intended to speak to anyone in the community (husbands, authorities etc), it was composed using simple language. If there was a song that already expressed the feelings or issues, they sang it and/or edited it accordingly. In *mache* Joni's case, once the song was started and taught to the other women, they helped to sing it. The collective singing distributes the weight and responsibility of the song and its contents among the women. So, although the issue she was raising was of a serious nature, the *macheza* frame shielded by *pamtondo* provided a platform for *mache* Joni to feel safe enough to voice her thoughts and speak to her elder brother, who she could not speak to directly about such a matter (without causing trouble for herself).

6.1.2 The *pamtondo* effect

As explored above, *pamtondo* was a cultural safe space that allowed women (who did not have much voice in a community that was predominantly patriarchal) to express/sing about their views and grievances, say things that they would otherwise not say, while being protected by the frame of *macheza*, (playfulness). It is the safety, freedom and collectiveness intermingled with playfulness that *pamtondo* afforded women when they stepped into the *pamtondo* space that I refer to as, the *pamtondo* effect. In other words, the *pamtondo* effect evokes a silent cultural licence to openness, freedom, collaboration and safety.

According to Chinyowa (2005), folk media in African contexts are transformational performance activities grounded in play, so that play becomes the how of folk media. A crucial characteristic of this play is that it resides in a paradox in which both the real self and the "play self" converge and exist together (Chinyowa 2005). Bateson (1972) posits that play relates to reality in the same way that a map relates to actual territory. "However, rather than having a one-to-one correspondence between play as map and ordinary reality as territory, play would likely create new 'maps' by either transforming old 'maps' or revising them rather than merely reproducing them. Hence play involves the negotiation of both internal and external realities" (Chinyowa 2007: 16-17). The player self is engaged in a two-way existence between the real and play worlds, during which there is a shift in consciousness that involves holding lightly one's own self-consciousness for a time being to assimilate to the consciousness of play, combining the sense of self with the logic of the play world. This requires giving the self over to the 'happening' without losing it completely. The moment or condition of "in-betweenness" is when the world of reality experienced by the self and the world of fiction enacted by the role the self is playing in play, collide and exist together at the same time. It is in the space between the play self and the real self, between the fictional and the real contexts, that endless opportunities for reflection about who and what we are as human beings reside (O'Connor 2003:43 cited in Chinyowa 2007). Chinyowa argues that during play, there exists an inter-play between the actual and the fictional worlds which can lead to participants' increased awareness. Some scholars, in the fields of play and education, have described this space of "in-betweenness" as transitional space (Perry and Rodgers 2011; Ellsworth 2004). It is in the interplay between reality and fiction, in this space of “in-betweenness” that access and exploration of reality through the play world is possible.

Malawian cultural performances and practices are no exception. As explained above, *pamtondo* is a culturally established space of work and *macheza*. *Macheza* is a concept that embodies what Sutton-Smith (1997:148) describes as “playfulness”. It signifies Bateson’s (1972: 179) “this is play”. It can be both serious and not serious at the same time. If a person says this is *macheza*, they are telling you that this is play and evoking a licence to freedom and fun. *Macheza* leans towards subverting, teasing, insulting, criticizing, ridiculing, celebrating or any engagement that people agree to be open about but not take too seriously or take offense (avoiding consequences) often drawing from current and past real events. Various folk media forms such as *nyimbo* (songs), *magule* (dances), *masewero* (dramatic enactments), *magemu* (teasing), chatting or any other forms of communication those engaging in *macheza* might choose are used. So, if someone says “*awa ndi macheza*” it can literally be translated as meaning “This is not serious, it is just having fun” or more directly, “This is play”.

From an ethnographic perspective play has been explained as “human symbolic interaction of a performing kind” (Ben-Amos and Goldstein 1975:3). Play can be characterized by fun/enjoyment, space, rules, imagination, secrecy/disguise and freedom (Chinyowa 2005; Huizinga 1955; Schechner 1993; Izzo 1997; Voss Price 1998; Handelman 1977). According to Handelman (1977), the freedom that play affords provides a route to communicate easily things that would otherwise be difficult. Playfulness has the capacity to disrupt the status quo (Sutton-Smith 1997; Schechner 1993:26); and as Voss Price (1998) asserts, it affords those who are participating in the play frame an opportunity to minimize the consequences for their actions. In simple terms, play enables people to do and/or say things that would otherwise be unacceptable to voice out in their communities.

6.1.3 Why the *pamtondo* effect can aid research

As expressed by scholars such as Lwanda (2002), Mvula (2004), Kerr (1987) and Page (2019), most Malawian cultural practices are loaded with do’s and don’ts of acceptable social conduct which predefine what members of a community can and cannot do or say. This means that Malawian cultures are loaded with what Lwanda (2002, 2003) and Mvula (2004) call taboo topics. Topics related to sex fall under the taboo; framed as a taboo topic by both cultural gate keepers and by political structures. According to Page (2019), the Chewa, who are the biggest ethnic group in Malawi, consider sex as part of creation aimed at reproduction and the continued manifestation of God's power to sustain humanity, making it sacred and as such everything around it needs to be regulated. On the political front, Kerr (1987:121) states that, "the censorship control of entertainments act of 1968 established a censorship board which by 1972 began to impose draconian measures on films, plays, books etc…it suppressed any frank portrayal or discussion of sexual, religious or political matters".

Although censorship is much reduced today, the legacy of the political and cultural distaste of discussion of sex lingers on. Culturally, although the public discussion of topics such as sex were a taboo, there were specific/designated performance structures set up within cultural parameters which provided space for such topics to be discussed and reflected upon.

Having conducted this research based on play using folk media forms, I believe that when used carefully in the context of research, play(fulness) can recreate the *pamtondo* effect to enable both male and female community members to speak more openly to and with each other and myself as well as speak to the people or situations of power that they would otherwise not be able to. I found that the *pamtondo* effect created by play facilitated a space of *macheza* (playfulness) which allowed for the temporal partial suspension of immediate restrictive social reality, creating a temporary reality of its own where rules were broken or renegotiated, taboo topics discussed, and authority/power/roles subverted and challenged.

In both Dedza and Thyolo, participants' reflections from individual verbal journals and group process reviews show that openness, freedom, safety, active participation of everyone, and speaking what was in one's heart without fear characterised the folk media workshops. Below are some participants' reflections from two group process reviews:

> It is helpful using *sewero, nyimbo* because all of us in here who are taking part in this process, everyone is taking part and participating. There's no difference between male (men) and female (women). Everyone is able to express their views and thoughts. (Participant during a group process review on day 3 in Dedza)
>
> We were able to speak out our thoughts so that those in government also know what our concerns and worries are as people who live in the village (Participant during a group process review on day 4 in Dedza).
>
> If we were not using these ways methods (*njira*) it could have been difficult because people who speak are few, some just listen and are afraid (*owopa*). But these methods (*njira*) be it using singing or *masewero*, they are giving joy/pleasure as well to everyone and taking away/removing fear from them so that they take part and participate easily, unlike just talking where they'd need to raise a hand so they can speak, it kind of instils fear in some people (Participant during group process review on day 3 in Thyolo).

The *pamtondo* effect also provided an opportunity for deeper individual and collective reflection on the encounters, experiences and processes that have framed the participants present views, perspectives and behaviours. I will unpack this later in the second section of the chapter when I explore how the *pamtondo* effect helped to generate knowledge through four modalities of play within folk media.

While HIV and AIDS often evokes discourse on structural issues (such as poverty, healthcare provision and corruption), it also touches people on a personal level and necessitates cultural infringements or exploration of "taboo" topics. Thus, I argue that the pamtondo effect provided the participants, Misheck (my RA) and I with unspoken cultural permission and structure to talk about these taboo topics. In the sections that follow, I attempt to explore how we (the participants in this study, Misheck and I) created the *pamtondo* effect and how this enabled us to explore individual and community narratives of HIV and AIDS.

6.2 SPEAC: Reaching for the *Pamtondo* Effect

As described above, the *pamtondo* effect is manifest when the characteristics of playfulness/and fun, freedom, safety, openness and shared ownership of process are guiding the process of engagement in a workshop space with research participants. Drawing from my reflexive analysis of field notes, participant verbal journals and continuous reengagement with the workshop video data from both Thyolo and Dedza, I noted features of my practice that I believe helped to create the *pamtondo* effect. I suggest a practice model that can be summarized as S.P.E.A.C: (**S**pend time on Macheza (play/playfulness), **P**articipate in all activities, **E**stablish a routine of Macheza, **A**ccept being led, **C**onduct yourself as a member of the group). I argue that the folk media workshops I conducted in the two communities, summarised subsequently by the SPEAC model, enabled the *pamtondo* effect to be manifested which in turn facilitated the collaborative generation of rich knowledge. I go on to describe how I enacted each element of the SPEAC model below.

6.2.1 Spend time on Macheza (play/fulness)

A very important step toward creating the *pamtondo* effect was to build a friendly and trusting environment with the participants. In order to do this, Misheck and I needed to spend adequate time with the participants, getting to know each other, playing together and building familiarity. Building rapport has long been established as important in qualitative research, as well as when working with communities during implementation of development initiatives (Mefalopulos and Kamlongera 2004; Boneh and Jaganath 2011; Denzin and Lincoln 2011; Glesne 1989; Watts 2008; Tickle 2017; Abdulla 2016). In an effort toward building rapport, practitioners in development have turned to playfulness, taking various forms such as games, exercises, music, songs and dances just to mention a few. All this is an attempt to create an environment of familiarity and trust which facilitates dialogue and meaningful learning (Freire 2005; Mefalopulos and Kamlongera 2004). Mefalopulos and Kamlongera (2004) have argued for the use of what is familiar to the people in order to encourage familiarity, empowerment and ownership of initiatives. In qualitative research, building rapport has been established as an important aspect of data generation/collection so much that in simple terms, the quality of rapport determines the quality of data (Denzin and Lincoln 2011; Tickle 2017).Guided by a Malawian proverb which says *Mmera mpoyamba,* meaning the harvest is determined by the start, it was important to invest adequate time on building a conducive environment at the start of the workshopping process. This helped to establish playfulness, facilitate familiarity, and encourage the participants to assume ownership and leadership of the process. In both Thyolo and Dedza, Misheck and I spent considerable time early in the workshopping process on establishing *macheza* (playfulness) before we went on to use that same playfulness for knowledge generation.

In Dedza, I began by asking the participants what they did when they met others for the first time. Their response was that they introduced each other. When asked how they did this, the participants responded that they used song. So, the participants led us in the process of introductions through song.

The participants begun by rearranging themselves and each other in a circle to make a mixed gender distribution, while others were mumbling and humming trying to get the tune right. They then begun to sing the song below while clapping:

Tidziwane x2 / *let us know each other*

Tidziwane tidziwane x4 /*Let us know each other Let us know each other*

Ine ndine… / *I am…*

Tidziwane tidziwane x4 / *let us know each other, let us know each other*

As we sang, randomly participants went into the circle one at a time to introduce themselves, whenever the song was at “I am…”. “Stop!! stop first” a participant shouted barely 2 minutes into the song. We stopped the song as some participants noted the chaotic nature in which the song had started. Then the participants began to negotiate how to sing, dance and introduce ourselves in a coordinated manner.

Having introduced ourselves through the song, I explained that we would spend the day getting to know each other, and playing together, doing whatever the people do when they are at leisure/doing *macheza* in their community. During this time of *macheza* in the workshop, a series of childhood games, moonlight songs and dances (usually sung by pre-teen and early teen boys and girls when playing in the moonlight) emerged. We (participants, Misheck and I) played, danced and sang together with much excitement, enthusiasm and enjoyment. Participants took turns in leading the songs, dances and games, all the while, reminding, facilitating and negotiating with each other about the rules of the games, the tempo of the songs and dance steps. This negotiation and collaboration that started with the very first song set the nature of interactions that followed throughout the workshopping process.

In a group process review on day 3, participants expressed the following sentiments:

> P1: We have all taken part (actively participated) because these things we are doing, we had forgotten, we used to do them when we were little (young/children).
>
> Participants in a chorus: "*Zatikumbutsa chikale*" (It has reminded us of the good old days).
>
> P2: It is as though we are going back to the way we were then/used to be" (Participants during group process review on day 3 in Dedza).

The above sentiments suggest a sense of liberation by the participants through the playfulness of engaging in their own childhood games. As Dekoven (2007) has pointed out, ordinary children's games can be used in the service of 'reminding people how to play, how to explore spontaneity and the building of mutually supportive relationships (in Blatner and Wiener 2007:332). In my earlier research (2013) I argued that Dekoven's assertion is particularly true when such games belong to the traditions and culture of the participating individuals, which has further been demonstrated by the sentiments expressed by the participants in Dedza.

Although touching and holding hands between men and women who are not in a love relationship was not usually allowed in this community, the participants were breaking the usual norms of how they lived in their community during the childhood games and moonlight songs and dances. There were no segregation/discriminations based on gender (as is traditionally the case with most dances) age, religion, ethnicity, rank or otherwise among the participants. We all played, sang and danced together just as children did when they played and danced. By playing the children's games, the social adult rules were held lightly, and moonlight play children's rules were evoked.

After about 2 hours of playing, singing and dancing, we agreed to take a break. As we sat down to rest, one of the participants spontaneously yelled, "ndagi!" and the rest of the participants including myself responded, "gize!" with a similar enthusiasm, almost by instinct. This call and response marked the start of another form of *macheza* called "*ndag*i" or "*zilape*" (riddles). We went on with the riddles while we rested, taking turns for approximately 30 minutes. When one person posed a riddle, the rest of us tried to solve it. When an answer came out right, and did not make obvious sense, the rest of the participants demanded an explanation of how that response solves the riddle. This was true even if it was the poser of the riddle who had given the answer following everyone's failure. During this time, the space was filled with excitement, giggles and laughter. The riddles seemed to have added to the spirit of *macheza* and demonstrated that we had achieved familiarity and openness with each other as we had become co-players. The level of familiarity and acceptance we had achieved with each other can be seen when Misheck also posed the riddle as below:

> Misheck: Ndagi!
>
> All: Gize!
>
> Misheck: Njira ya kumanda yokumbika kumbika / *the road to the grave is full of holes (pot holes)*

As we struggled to solve the riddle, one of the middle-aged male participants responded and said:

> P1: pepani abale ndinena/nditchula basi, kunkolokolo / *I am sorry my friends but I just have to say it, the anus/bum hole*
>
> All: broke out in loud laughter

Although this participant did not get the riddle right, the language that the participant used in the extract above suggests that the participants had begun to see us as one group of people (friends) who socialized and played with each other. With each passing day, we became closer and closer. As explained by most of the participants in their verbal individual journals, as well as process group reviews, *macheza* (playfulness) throughout the workshops encouraged familiarity, friendship, trust, openness and freedom. The example below is a reflection by one of the participants during a process review on the last day of the workshops in Dedza:

> Things have worked really well, as we were in here, each of us even though we are of the same area but each of us was coming from their own side (different part of the area). we are people that do not meet up/come together to chat (socialize), but because we came here and started spending time together, we are taking things as though we have always stayed/been together, all the time. We are free and open about everything without thinking/feeling that we haven't lived/ stayed with these people before so we should be embarrassed or that we should hide/conceal some things, which I see as something very precious/of high value (*chinthu cha mtengo wapatali*). (Participant during a group process review on day 10 in Dedza)

While the extract above points to the familiarity, friendship, freedom, openness and safety that was manifest during the workshops, the spontaneous leading of some workshop sessions and the evoking of multiple folk forms of *macheza* by the participants points to a feeling of confidence and ownership of the process.

However, each group of participants is different from the other, thus, the time and effort needed to invest in creating such an open and free environment can vary from one participant group to another. While we had managed to create a cohesive group and playful environment by noon on the first day in Dedza, to reach a similar space in Thyolo took us till a little later into the afternoon. By the start of the workshop on day two, we had pretty much achieved it, as seen by this participant's reflection during a group process review session on day 2:

> When we started yesterday, we had some glitches but today, when I looked around everybody was open and free, they were doing things freely without being self-conscious, unlike yesterday, even when dancing they were a little self-conscious, but today everybody is energetic (Participant during group process review on day 3 in Thyolo).

Another participant added that:

> but that's only because they had fear, they were not sure of what would happen, but now, we have start(ed/ing)/getting/coming to know each other/ to get familiar with each other, even if we had to start a song now, you'd see, that's because everyone's fear has disappeared/gone (Participant during a group process review on day 3 in Thyolo)

The extracts above suggest the need to spend enough time with participants, getting to know each other, playing together and facilitating familiarity. The data also shows that while the process can take less time with some participants like in the case of Dedza, it can also take longer with others like it did in Thyolo. *Nyimbo* (songs) *magule* (dances), *nthano* (folk tales), *ntchezero* (riddles) and gossip were the main forms of *macheza* that emerged in Thyolo. Just like in Dedza, we also achieved a free and open environment where we could talk and chat about sensitive matters in Thyolo.

For instance, like the *ndagi* scenario in Dedza, participants in Thyolo also demonstrated openness in a similar way only that in the latter it involved most of the participants. During the early days, while we waited for lunch to be served, some of us sat under a tree while others stood around as we chatted about random things and snacked on *makata* (fresh beans boiled while still in their pod husk, you unhusk them as you eat). This chatting saw us discussing *mavuzi* and *mabuzi* (pubic hair) and its variations. We debated whether there is or should be a different name and/or pronunciation given to pubic hair depending on levels of maturity of the person who has it. Some suggested that *mabwizi* should refer to more mature pubic hair and *mavuzi* to the less mature. Others argued that it should be the other way around as the sound of *mavuzi* carries more weight. The discussion was provoked by one of the older male participants. This level of openness also demonstrates the level of trust and friendship that we had built together.

The above instances, demonstrate that an important step toward creating the *pamtondo* effect, was to allocate enough time for *macheza* at the beginning of the workshops, as well as during workshop sessions. The time we spent on *macheza* for building rapport was based on continuous assessment of the specific participant groups we were working with at the time.

6.2.2 Participate in all activities within the workshop space

As I described in chapter 2.6, both Freire (1971) and Smith (2012) argue that, if you want to help others in the process of humanization, you must do so in partnership with them. During this workshopping process, Freire's assertion translated to working with the participants in a way that acknowledged their contribution to the process as partners. This meant that no one partner was a designated instruction giver while the other followed the instructions as the giver observed. But rather all give instructions and participate together at given times in the process. Thus, regardless of who was leading an activity during the workshops, it was important that Misheck and I participated in all activities within the workshop space, whether led by participants, or by ourselves. In both Dedza and Thyolo Misheck and I participated in the songs and dances that the participants led, the *ndagi, ntchezero, nthano*, gossip as well as the workshop data generation sessions that participants took a leading role in facilitating. Although we did not contribute to the views that went into the songs, we participated by supporting the singing and dancing. When we could not sing, then we danced along mumbling what we could. Below is part of a reflection by a participant in Dedza during a group process review on the last day of the workshops:

> Right at the very beginning before we started our learning (workshops), you called us here in this very place and explained to us that our workshops will be conducted in this and that way and we all agreed that

> we would take part in these workshops…Everyone has been taking part (participating) and you did not show any grumpiness or that you were unhappy with anything, all the way to yesterday when we went to the gathering at the grounds (for phase 3). There, you showed/did the same, everything that was happening there, you were taking part (participating), be it magule, you were dancing.

As illustrated in the extract above, our (Misheck and I) participation as participants in the data generation process was highlighted by the participants as an important aspect of the workshops. It allowed for the feeling of appreciation and valuing of the participants efforts. It helped to show that activities facilitated and led by the participants were as important as those facilitated by the researchers in the workshop space. This balanced power relationships between us and the participants. It also appeared to reduce spectatorship, as the participants, Misheck and I, led, facilitated and participated in the activities of the workshop together.

6.2.3 Establish a routine of Macheza

Many forms of *macheza* in the Malawian culture often begin with a formula, a phrase, a line, or something that indicates Bateson's (1972: 179) "this is play". In *nthano* (folk tales), there are slight variations in the ways in which this formula/opening phrase is articulated, even within the Chichewa language. While some open with *padangotero*, others use *padangokhala* (Mphande 2017: Chimombo 1988), but the essence remains the same. The storyteller often begins with *padangokhala* or its variation (which aligns roughly with "Once upon a time…"). The storyteller then waits for a response that signals consent and participation of the listeners which is "*tiri tonse*" (we are together/ we are with you). Only then can/does the storyteller continue with the tale. If there is no response or the response is weak, the storyteller often repeats the opening word, *padangokhala*. When there is a response that the storyteller considers good enough, he/she continues with the story telling, but if there isn't, the storyteller can stop the session all together as it may be read as unwillingness to join the story telling experience.

Once the initial invite is made and answered, and the storyteller proceeds to tell the story; it is expected that those engaged in the storytelling experience will actively participate whenever necessary, either through responding to song, dialogue or sometimes even dance. These phrases not only mark the beginning of the storytelling experience as a participatory one, but also sets up the frame of playfulness, almost like a signpost saying, we are now entering a folk tale frame in which case some frames of reality have to/ may be suspended.

Given that the folk media workshops in Dedza and Thyolo were 10-day processes, the environment of *macheza* that we had created together with the participants during the first sessions needed to be sustained. In a similar way to the beginning of participatory story telling (*nthano*), during our research project, we started every day of the workshop by reminding everyone that, we are now entering that same space of *macheza*, that we have made to be safe and free to engage with each other. So, in both Dedza and Thyolo, just as with *pamtondo*, when we came in for the workshops every morning one by one, we would greet each other, gossip about what's going on in the village, and laugh about nothing till we had all gathered. Then, we would open the workshop with a prayer (as per custom there) and then go on to sing and dance whatever songs and dances we wanted, led by the participants. This was done every morning (routinely) at the start of each day's workshop for at least the first 20-30 minutes, almost like an "opening ritual" that performed a similar function to the *padangokhala* in the *nthano*. The entry served a function of reminding everyone that we are now entering our designated space of *macheza*, openness, freedom, safety and generation of knowledge about HIV and AIDS.

6.2.4 Accept to be led

A major factor that helped in our attempts to ensure an inclusive, participatory and productive engagement when working with the two communities was to allow ourselves to be led by the participants/community. Collaborative approaches that aim at empowering communities and facilitate shared ownership of initiatives have identified the agency of communities as crucial for success (UNESCO 1995; Chinyowa 2005; Freire 1971; Darder, Baltodano and Torres 2003; Abdulla 2016, 2020). However, practical applications on the ground have proven to be more challenging (Chisiza 2017; Rosenthal 2016; Abdulla 2016, 2013; Chinyowa 2009). As stated in previous chapters, Chinyowa (2009: 4) has argued that “more often than not, communities are led into participating in workshops using “folk” songs, dances, poems and stories that have already been planned for them”. This is one of the contradictions and criticisms that have arisen in the theatre for development discourse around the use of folk media in aiding participatory approaches to development. Van der Stichele (2000) has also argued that too much emphasis is placed on using folk media as a tool for communication for development at the expense of understanding the context in which these media operate. As explained in my earlier work (Abdulla 2016), the attempt to use folk media without careful understanding of the specific contexts and nuances of specific folk media forms by practitioners has often led to the alienation of participants and communities for whom the initiatives are intended. With this understanding of our limited knowledge in the particular folk media forms of the two communities, it was important for Misheck and I to allow ourselves to be led by the participants, as they were the creators and experts of their own folk media. What did this mean in the context of our research? Facilitating processes that created a conducive environment for participants/communities to lead and guide the process, was crucial to achieving meaningful knowledge generation.

In the case of this study, not only were the participants/community experts in the specific methods (folk media) of knowledge generation, but they were also the owners and keepers of the narratives (of HIV and AIDS) which the study sought to explore. Thus, while I determined the broad topic that needed exploration (HIV and AIDS), it was even more important that the participants take a leading role in guiding me through the knowledge generation process, thus they guided the practice of each activity taken up within the workshopping process. (see research process in section 3.3). In both Thyolo and Dedza, participants led the start of all the workshop sessions with prayer, songs, dances and games, while Misheck and I followed their lead. Participants also led in adapting folk media forms to be used for exploration. For instance, on day 2 after we (participants and researcher) identified *chipako* (see day 2 in 3.3) as a game, the participants explained the different ways in which the game was played in the community. Then participants also led in adapting *chipako* as a method for exploring important events that had affected the community in the past 5 years.

In both communities, while I instigated the workshops by asking the questions that guided the exploration, the method/medium by which the exploration was done was chosen by the participants. For Instance, in Thyolo during the folk media workshop, participants were asked to share their understanding of HIV and AIDS using folk media forms of their choice. In response, they presented dramatic enactments, choir songs, poems and drawings. In Dedza in response to a request to share the life cycle of a typical member of the community, they came up with a form of group story telling theatre (see section 3.3). Facilitation of some data generation sessions was also done by some of the participants (see: bwalo la mafumu in section 3.3). In some instances, the participants led the process through a form of guidance. Asking for guidance, listening to the participants suggestions and deciding things together helped to reinforce collaboration and co-ownership of the knowledge generation process (see section 3.3). As this participant reflects, "*malingana ndi zolinga zathu, zinakwaniritsidwa ndi chipakocho*" (in accordance with our objectives, they were fulfilled through the *chipako*) (Group process review on day 3 in Dedza). The reference to the workshop objectives as "our" points to a shared ownership which Smith (2012) highlights as an important aspect of decolonizing research.

6.2.5 Conduct yourself as a member of the group

In addition to spending enough time on *macheza*, participating in all activities within the workshop space, establishing a routine of macheza and accepting to be led by the participants, creating and sustaining the *pamtondo* effect through play (fulness) required Misheck and I to conduct ourselves as members of the participants' group even outside of data generation activities. When talking about Theatre for Development, Kamlongera (2004) encouraged practitioners to get to know the community they are working in and to share in their daily lives. In order to achieve a more inclusive theatre for development process, he suggested living with the community. According to Kamlongera (2004), living with the community is an essential part of the research component of TFD as it enables shared experiences, shared understanding and shared life. It reduces the gap that exists between practitioners and the community, which in turn challenges social structures that foster oppression through the creation of binary divisions based on economic and cultural supremacy. Kamlongera (2004) argues that binary divisions of ‘haves’ and ‘have nots’ thwart the democratic participation of all people which may hinder empowerment and ultimately inclusion. As Freire (2005) has argued, no dialogue can come out of arrogance or a feeling of being superior to others. I think this applies very strongly to research activities that involve working with communities.

In this study, our (Misheck and I) behaviour and conduct emerged strongly in participants’ reflections in individual verbal journals as well as in audio group process reviews. Below are some of the participants reflections during the group process review on the last day of the workshops in Dedza:

> …Even when we were doing lunch, you were not excluding yourselves to say, ‘we live like this and we eat this and that food’. Everything that was happening here, you were also doing the same, if it was tea, you were also drinking the same tea, or if it was frozy (locally available fizzy drink), you were also drinking frozy like everybody else, which shows that you have followed our way of life here very well. Even our friends out there are admiring how you have lived with us here in our area, especially on behaviour/conduct. (Participant during group process review on day 10 in Dedza).

The above extract suggests that how we conduct ourselves as researchers when engaging with participants is an important aspect of creating a conducive environment for knowledge generation. Being and doing like the participants appears to have helped in balancing power relationships and acknowledging a oneness with the participants. This helped to build and sustain friendship and trust between the participants and us (the researchers) as reflected below during group process reviews by participants in Dedza on day 5 and 10:

> The best part is that there is no segregation/difference between you the visitors and we, the owners (members of this community). We are just as though we are all the same (Participant during group process review on day 5 in Dedza).

> We were doing everything as though we were all children of the same household, yet we had just met, but it was as though we were children of the same family (Participant during group process review on day 10 in Dedza)

So far, we have seen that through the *pamtondo* effect that was recreated through my research practice as described by the SPEAC model, folk media facilitated a conducive environment for research practice. Now, I go on to explore how the modalities of play within folk media operating within this conducive environment for research practice enabled the generation of data.

6.3 Modalities of play within folk media and the generation of data

As discussed in section 3.3, with the support of the *pamtondo* effect, we went on to use folk media forms such as *magule* (dances), *chipako* (children's game), *nyimbo* (songs), *masewero* (dramatic enactments/plays), *ndakatulo* (poems), *ndagi* (riddles) and *mlozo* (mapping) to generate data. Throughout phase 2 of the research process participants were asked to use folk forms of their choice. All the participants felt that the folk media methods used to generate knowledge worked very well. While some emphasised on how the playful methods worked, others made comparisons to other methods. As these participants from Dedza and Thyolo reflect during group process reviews:

> If it was not for this method, much of what has come out here, would not have come out in the slightest (*nkomwe*). Without the methods of play we were following, if we had/were to just discuss saying so what happened here, aaah not much would have come out. But this method (njira) surely aaaah it has revealed/excavated (*ya vumbulutsa*) a lot of things (Participant during group process review on day 10 in Dedza).

> There was *magule* (traditional songs and dances), *ndakatulo* (poems), *masewero* (dramas). These methods are very deep (*zozama kwambiri*). They give opportunity so that everyone can take part and give/share their thoughts/views. (Participant during group process review on day 9 in Thyolo)

As evidenced by the extracts above, the *pamtondo* effect created a conducive environment of friendship, freedom, openness and safety that gave licence to participants to use folk media forms for the exploration of their own narratives of HIV and AIDS. Drawing examples from the workshops we conducted in Dedza and Thyolo, I go on to explore how these frames emerged and worked.

6.3.1 Make-believe/*Sewero*

Make-believe is a frame of play that is also known as pretend play or an “as if” mode of play (Fein 1981). The essence of make-believe is captured in the Chichewa concept of *sewero. Sewero* can generally be translated to “that which is played” and would normally cover forms such as drama, theatre, dramatic enactments, role play and any other forms of pretend play. *Sewero* (plural form is *Masewero*), involves an agreement by those involved to suspend social reality and enter/create a pretend or imagined world. When talking about drama in education (process drama), O’Neill (1995: XVI) calls this imagined world a “dramatic elsewhere”. This pretend world allows the players to become anyone or anything they want to be, break the rules of space and time and establish new rules that govern the imagined world. Edminston (2008;9) states that “in pretend play, people pretend together to move and talk and interact as if they are whatever people or creatures they want to be, in any time or space, engaged in any imagined activity”. This make-believe expresses itself through physical embodiments of *masewero* (drama/play, theatre, role play and enactments) whether prolonged or episodic. It can also manifest through oral narrations such as *nthano* (folk tales), *zifanifani* (metaphors/parables) and *ntchezero* (riddle stories). In this section, I focus on physical embodiments of make-believe. However, I shall discuss some oral forms of make-believe when I discuss spontaneity later in this chapter.

During my research, various types of *masewero* (dramatic enactments such as role play, group storytelling) required the physical embodiment of make-believe. For instance, as I explained earlier in section 3.3, during the folk media workshops, we engaged in role play. The participants had taken the role of researchers from the District Commissioner’s (DC) office who had gone to Miyowe village (which is their own village) to conduct research with people of Miyowe village to find out what their thoughts were about HIV and AIDS. The scene was set at the DC's office and opened with a convening of a meeting to report and discuss the findings of their research. I facilitated the meeting and sharing in role as the DC's assistant with the explanation that the DC himself was away.

During this role play, the participants and I created a make-believe scenario whereby the participants became researchers (an expert position) and I moved out of my researcher role to become an assistant of the DC. The ordinary everyday space that we were meeting in, with no doors, windows and had a mud floor was suspended and transformed through our imagination and agreement into the DC's office. This agreement to pretend together is manifested in this participant's view during a group process review on day 4:

> I am very happy with what happened today because we were conducting research in Miyowe area and I am very happy because we were doing it together with the people of that area (participant during a group process review on day 4 in Dedza).

The participant's view suggests that at the time of make-believe, she held her social identity (of being a mother, wife, farmer who could hardly read) lightly to embrace the expert identity of a researcher, allowing her to exist both as her real herself and the play self at the same time, which temporarily freed her from the confines of her immediate social reality.

As participants shared their views on HIV and AIDS, they did so in the make-believe role of researchers who were compelled by their profession to speak about the narratives of HIV and AIDS in the community but not as their own views but the views of others (their research participants). By taking the role of the researcher, the participants were able to express their understandings and experiences through their play selves and free themselves from being fully responsible for what they shared during this make-believe frame. In other words, the make-believe frame offered the participants a safer space to be able to express views they may have not been able to express as themselves. The participant below explains during a group process review on day 4 in Dedza:

> The people of the village had no space to offload/express (*kutulila nkhawa zawo*) the concerns/worries that they had/have and experience in their area. They couldn't find a way, but today they found an opportunity to express what was in their hearts and what they wished they could speak out about, and they did (Participant during a group process review on day 4 in Dedza).

The extract above attests to the observation that play (through make-belief) liberates the players to do and say things that they would not otherwise express for fear of consequences (Chinyowa 2005; Handelman 1977; Voss Price 1998) making it a valuable asset for research. Through their researcher roles, participants shared how they made sense of HIV and AIDS, what they thought it was, what they had come to understand it was and also shared thoughts around HIV and AIDS as conspiracy by govt and other outside countries to reduce the Malawian population. Participants expressed their suspicions and distrust in the motives behind the existence and promotion of condoms and contested some of the information they received from health care workers and public health promoters. Although expressed through their make-believe roles, what the participants reported and expressed in role as researchers was also rearticulated in their individual verbal journal entries of that day emphasizing the realness of the thoughts, perceptions, perspectives and experiences they shared during these roles and evidencing that they used their play self to express their real self.

Make-believe was also manifest in the framing of the verbal journals (see section 3.3 phase 2 of the research). As described in section 3.3, the first day of the workshops, we discussed keeping verbal journals which we called "*kaundula*" (register/record) of participants' thoughts and reflections. Participants took on the names of plants and animals, through which they expressed themselves. This participant's reflection on day 5 during a group process review in Dedza demonstrates the importance of the *kaundula*:

> I am very thankful for the part where we were going aside privately to speak what was deep in our hearts, anonymously one could speak out all

> their thoughts (Participant during group process review on day 5 in Dedza).

The freedom and safety that this aspect of *kaundula* provided for the participants during the research process is evident in the above extract. Make-believe, through pretending together to be jungle animals or edible plants whose names the participants adopted during *kaundula*, provided them with a sense of anonymity, safety in a playful way and consequently, allowed participants to express their inner thoughts, feelings and experiences with less inhibition.

Having discussed make-believe, I now move on to living improvisations. Although the frame of mak-believe is also manifest in the examples I give, I focus on living improvisations and how these enabled generation of data.

6.3.2 Living improvisations

Improvisation has been described by Drewal (1991) as the moment-to-moment movement/actions based on learned embodied skill to attain a type or style of performance. In play frame, improvisation is almost inseparable from spontaneity which is described by Blatner and Blatner (1997) as a type of improvised action that manifests within the paradox of play. Improvisation almost always calls for what Chinyowa (2005) calls “reflection-in-action” while exploring and presenting narratives/happenings. Okpewho (1977:53) describes it as “the drama of the moment” which comes into existence through creating the story that is being performed. Although improvisation and spontaneity are almost inseparable in practice, I have decided to explore them separately so that I can give each enough attention considering their role in my research. I start with improvisations before exploring spontaneity.

What I am calling living improvisations, are improvisations that are being created by the people, from the lived realities/experiences of the people who are creating and performing them and/or their communities. In other words, when the participants are performing themselves through improvised pieces, they are engaging in living improvisations.

In both communities, facilitating the research workshops required approaching folk media both as reservoirs of the communities' understandings and experiences about HIV and AIDS and, as a mode of reflecting and exploring the participants current understandings and experiences. While the former required participants to recall and share folk media forms on HIV that already existed prior to this research, the latter required participants to reflect and deliberate on their experiences and re-construct and share them through improvised creations of *nyimbo* (songs), *magule* (dances) and *masewero* (dramatic enactments). My focus in this section is on the latter. Drawing examples from Thyolo, I shall explain how some folk media worked to generate knowledge through living improvisations.

My first example draws from a *sewero* which the participants in Thyolo titled "*tiuzeni zoona*" (tell us the truth). On day 5, the participants identified major themes that emerged through various forms of folk media during the workshops and re-engaged with them at length. On day 6, participants were asked to prioritize the themes and then create folk media performances from the prioritized themes. We agreed that the participants would use the performance pieces to perform to and elicit the wider community's views and experiences around the issues we had identified in the workshops. Participants chose to use two forms of folk media, which were *nyimbo* (songs) and *sewero*. We then divided into two groups to create the performances. Below is my description of the performance that the *sewero* group presented:

> The scene opens with a man sweeping, as a patient looking seriously ill and their guardian arrive at the local health centre (clinic). The patient lies down on the floor while the guardian goes to greet the man who at that point, we find out is the caretaker. As the guardian asks for the doctor, the caretaker tells her that he is not yet in. He then leaves to go and get the doctor. Next, we see the caretaker at the doctor's house telling him that there is a patient waiting for him at the clinic. The doctor responds by asking sarcastically, whether the person was unconscious to which the caretaker's response was no. He then tells the caretaker to tell them that he was coming (insinuating if the patient isn't unconscious, then they can wait, the illness isn't serious enough). As more patients

> come in, the caretaker makes 3 trips to call the doctor. When the doctor finally shows up, he enters the room where the patients are and starts making announcements. First, he said that drugs have changed, but gave no further explanation. Then in the middle of all this, his phone rings, he answers it loudly and walks out chatting with a friend (paying no attention to the seriously ill patient). The other patients and guardians protest, but he pays them no attention. When he comes back, he announces to say, “all those who receive ARVs will go through that door and the rest through the other”. When patients and guardians complain of his behaviour, he responds rudely. (Extract from my field notes on day 6 in Dedza)

After the participants who worked on the *sewero* presented to the entire group, I asked the rest of the participants to reflect and comment on the *sewero,* so that we could unpack and explore the *sewero* together. Below are the first and second comments that kick started the reflections:

> This *sewero* is good, in it we have seen the doctor not being helpful and not caring/minding about the people, but doing his own thing because he says the money (spent on fees to educate him) was paid by his mother and father (not the patients, so they can’t tell him what to do).This is also what happens at the clinic, what is happening here is what happens when patients come..(Participant during reflections on sewero on day 6 in Thyolo)

> I would say, the *sewero* I saw showed very real issues that my relations or even myself have experienced. It would remind me of what I would have experienced at the hospital/clinic at that time (Participant during reflections sewero on day 6 in Thyolo)

These initial comments not only demonstrate the relevance of the situations and experiences that the participants were performing in their own lives and encounters at the clinic, but also offer guidance as to the questions that need to guide reflections on *ma sewero* as a method of getting to know peoples’ understandings and experiences. These reflections helped to make explicit the connections between the "play" and the lived experiences of the community. Based on the extracts above, these questions include; what is the *sewero* talking about (issues raised)? who are the players and what is their relationship? how is each issue raised in the *sewero* related to the experiences of people in the community?

To the first question participants identified the following issues/themes during the reflections:

- Change of medications without giving explanations
- Reception of patients at the clinic
- Clinic opening time vs medical personnel start time
- And clinic staff publicly making announcements that expose people who receive ART at the clinic. (Participants' reflections on day 6 in Thyolo)

The above were problematized in the *sewero*, so we went on to discuss how these issues were related to the real life of the participants. The responses demonstrated that what was improvised and portrayed in the *sewero* was in fact a representation of an amalgamation of participants' and their community's lived experiences. They were improvising their own shared/collective lived realities and performing themselves. The issues that were raised in the *sewero* were also present in the individual verbal journal entries, with participants focussing on detailing their individual feelings around the experiences which either happened to them, their relatives or they bore witness to.

Drawing from the story line of the *sewero*, the participants reflections on it, and the individual verbal journal entries, we see that as I described in section 3.3, the *sewero* contained representations of a series of fragments of experiences that were weaved together and reconstructed to make a cohesive "dramatic elsewhere" (*sewero*) so that when any piece or moment of the *sewero* was cut and unpacked, it revealed embodiments/representations/summaries (files if you will) of what the participants emphasised were real experiences they encountered at the clinic.

Using the fragments as points of entry, I facilitated reflections through asking the participants questions that helped to bring out more details on the experiences that were represented by each fragment. And so, entire narratives of experiences that informed the fragments emerged. Participants recalled experiences of themselves, relatives, friends and other members of their communities in expanding each fragment. For instance, the fragment about changing medications without explaining why the medications were being changed, opened up sharing of experiences with problems of adherence to treatment, people's experiences with ART, and consequently, the participants general perspectives on HIV treatment (see chapter 5).

In order to facilitate these reflections, it was necessary to watch the performances in particular ways. We paid keen attention to the characters, settings, relationships and interactions between characters (including conversation), their movements, gestures, emotions, actions and reactions or responses to happenings within the *sewero*. Picking up on these, helped to guide reflections and expansion of fragments into more detailed narratives of participants experiences that also gave a clearer picture of context and causal relationships.

Another example that demonstrates the use of reflections to unfold/expand/unpack fragments of participants' experiences from a presented *sewero*, is given below. In one of the sewero in Thyolo, a man received condoms from the clinic and threw them away on his way home. We identified throwing away the condoms as one of the fragments. We then went on and explored why he had thrown the condoms away, why the participants had chosen to include this action in their performance, (response was that because it happened in the community), how it manifested/played out in the community? what are the activities or events that happen before the decision to throw away/ not use condoms, and what happens as a consequence? In this case, the *sewero* that the participants presented (play world) was the entry point for further exploration of the participants real experiences.

In summary, the process of creating these living improvised pieces starts with the participants reflecting on their experiences and that of their community, deconstructing the experiences into fragments and deliberating on them, followed by selecting fragments of experiences and weaving or reconstructing them into a cohesive storyline that tells yet a different version of combined reality, and then communicating through living improvised pieces. Paying attention to details of movements, activities, gestures, emotions, relationships and settings, we focused reflections to unpack the fragments and elicit detailed narratives and experiences that are represented by them. Having explored living improvisation and how these enabled the generation of knowledge, I go on to unpack spontaneity.

6.3.3 Spontaneity

Spontaneity involves thinking and acting freely in expressing oneself (Chinyowa 2005; Van Erven 1992; Fromm 1960). It can be from the position of an instigation and/or as a response to one. As articulated earlier, Blatner and Blatner (1997) describes spontaneity as a type of improvised action that is manifest within play, thereby placing the two in a symbiotic type of relationship. It has been argued that spontaneity is an important aspect on the road to freedom and liberation as it allows for the expression of the self with less inhibition (Van Erven 1992; Fromm 1960). Chinyowa (2005) has gone further to assert that spontaneity can work towards replacing the culture of silence with one of freedom and liberation. The examples I present below, reaffirm Chinyowa's assertion. In this study, spontaneity played a crucial role in guiding the knowledge generation process. I will draw on two examples from the folk media workshops to help illustrate this point.

To begin with, the folk media knowledge generation workshops, were a collaborative effort between us: the researchers and the participants. In exploring narratives of HIV and AIDS, I approached the participants with a pre-defined area of focus, which was HIV and AIDS. From this focus, I asked the participants to share any folk media forms that touch on HIV and AIDS that already exist in the community prior to the study. From what the participants shared, using a similar process of reflection that I described in the above section on improvisation, we identified areas that needed to be further explored. That is to say that questions about HIV and AIDS were developed from what the participants had presented. This meant that we had to work spontaneously with what the participants gave/offered to develop the explorations that followed.

This gave the participants, the freedom to determine what knowledge needed to be generated.

The next example of spontaneity was manifest when participants selected folk media forms of their choice to explore various aspects of HIV and AIDS. Because the workshop environment encouraged spontaneous ways of engagement, participants felt free to call upon various cultural forms of expressions to aid communication of their views, thoughts and feelings. Participants in both communities spontaneously used oral narrations such as, *zifanifani* (metaphors/parables) and *ntchezero* and parody/satire in order to put their points across.

For instance, as earlier described in section 4.3 in the sub-section on contested biomedical explanations, during the *bwalo la mafumu* session, one of the village heads in Thyolo used a *chifanifani* (metaphor) as below:

> Imagine you are in your house, you are there, mother and father and you have given birth to many children. And so, the father tells you that iiih *koma* (signifying a complaint), you children are too many in this house and then what follows, the children start to get sick and start dying. Will one child not think that the words that the father was saying were bad? (GVH during *bwalo la mafumu* session on day 7 in Thyolo).

Here, the chief invites us (group of chiefs, myself and my facilitator assistant) to join him in seeing the image that was in his mind. In this image, he offers us the role of mothers, fathers or even children. He tells the story as much as he performs it, using the change of tone and depth of his voice as he plays the father. As we followed the teller into the imaginary world, we implicitly agreed to suspend the reality of that moment (where neither of us had 10 children or 9 other siblings) to enter a fictional moment where we were a member of that make-believe household. I will use my own experience of participating in this make-believe world to explore what the story facilitated.

As one of the people in the room listening to the story, I found myself entering this fictitious family as the mother of the 10 children. As the chief took us through the story to the end, I found myself blaming the husband for the death of the children. By the time he had finished the story, he had taken me (us) on a journey that helped me (us) appreciate his process of thought and the premises that had led him to believe what he was putting across. That is to say, the GVH's view that the death of so many people caused by HIV and AIDS was a plot by the Government to reduce the Malawian population (see chapter 4.3).

The teller upon finishing his narration of the fictitious story connected it to his lived experience and explored the relationships between characters of the fictional world and the real characters they represented (see section 4.3 in the sub-section on contested biomedical explanations). The storyteller transferred the fictional characters and events projecting them onto the real world. The father in the fictional story was said to be the government, the mother was the country/Malawi and finally the children was the population of Malawi. But before the story, the teller/chief had to first recall and reflect on his feelings and experiences of the events of the real world to create the fictional world then import it back to the real world (creating a cycle). This gave him and us the freedom to express our views on the characters and events of the fictional world without any fear. This is evidenced by the fact that when the fictional story ended, the teller asked "*tingati akupha ana ndi ndani*" (who can we say was responsible for the death of the children)? and we all unanimously responded to say, "the father!"….but when the story was imported and projected back to the real world, we did not have to say a word because our response was necessitated by the projection of our fictional response. The story ended at, so who can we say is responsible for the death of the people (through HIV and AIDS). Through this story, I was able to gain insight into the participants' views, and the processes of thought that led him to hold the views that he had.

In the story of the *mkango* (lion) (refer section 4.3), the participant (chief) spontaneously makes use of a metaphoric form of storytelling which in Chichewa can be termed *chifanifani,* to explain his experience of the coming of HIV and AIDS. He used the symbol of the *mkango* (lion) to express the invocation of fear. The *mkango* (lion) in many significant narratives has been used as a symbol of unchallenged power that invokes fear and almost gives the person meeting the *mkango* a sense of helplessness (can't fight and can't escape). The storyteller invited/s the story telling participants to accompany him into a fictional world where AIDS was *mkango* (a lion) coming out of the *ngolowela* (fully grown maize gardens that almost look like a forest of maize stalks and can cover up a fully-grown man). Then someone just shouts, "*mkango*!" without any more information as to the direction from which the *mkango* was coming from, at what speed etc. The participant allowed us into his thoughts to imagine the nature of carelessness in which HIV and AIDS was introduced to the community, the feelings the scenario evoked and consequently, the panic that ensued at the time. Using the story, he tries to evoke in us the fear and panic that he and others had experienced when AIDS was announced in the manner that it was in the early days (see section 4.3). As for me, listening to him and the way he used the symbols of *ngolowera* and *mkango*, I could very much understand him and almost relate to his feelings. The time of *ngolowela* is already a time where members of the community are cautioned not to walk alone or after dark. The addition of *mkango* coming out of the *ngolowela* heightens the fear and panic. Therefore, by expressing himself through the story, the participant was able to communicate his emotions and experiences of the coming of HIV and AIDS by invoking a version of similar feelings in the people listening to the story. This gave the listener's insight into some of his experience. When engaging in this type of make-believe one simply needed to momentarily agree to suspend reality (Chinyowa 2005) of AIDS being a disease and accept it as a *mkango*. Then see it coming out of the *ngolowela*.

In both uses of the stories, we see that the participant was at liberty to express his views and experiences about HIV and AIDS using forms that he thought he would best express them. This was possible through spontaneity and improvisation.

Spontaneity, improvisation, make-believe and collaboration worked together to generate knowledge with the wider community. On the last day of the workshops, the participants put up a performance for their wider community. The participants used their performances, to trigger dialogue with the audience about issues that emerged in the workshops, which they thought were important.

When we arrived at the village arena, we engaged in pre performance rapport with members of the community who had come to watch the performances. Led by the participants, we sang and danced. Those members of the community who had come began to join in and lead some of the dancing, while some male members started to beat drums. As per protocol, when the people had gathered, the chief spoke and opened the event. He then handed the space over to the performing team. The performers began with fun songs and dances as *kalambula bwalo* (literally translates to clearing the arena, often done immediately before performances). The *kalambula bwalo* signaled Bateson's "this is play" (1972: 179). The ululating, clapping, cheering and even singing along, during the *kalambula bwalo*, acted as consent by the audience to participate in this playfulness. When the *sewero* started, everyone knew that it was make-believe but as it was being performed, the story that the make-believe *sewero* told matched the experiences of real people in the community, including the participants who were performing them.

During the performance, make-believe and participants' reality were contained within the same performance, at the same time, demonstrating the paradox of play (Chinyowa 2005). In this example, the performance and "imagined world" is interrupted or interwoven with direct personal responses from the lived experiences of the audience members. In the *sewero* in Dedza, the character defaulted from HIV treatment and in Thyolo threw away condoms. As if part of the *sewero*, the characters in the scene asked the audience whether this happened in their community. The performers moved back and forth between make-believe and reality, in and out of the *sewero*, taking real experiences into the play frame, working with those experiences, to support interactions and motivations of the characters and then offering them back to the audience. By doing this, the characters shared their stories and experiences with the audience and the audience shared their experiences with the characters facilitated by the participants who acted out the characters. While this helped to generate knowledge about people's experiences, it also seems to have provided a space for reaffirming that neither the participants, the characters in the *sewero* nor the members of the community in the audience were alone in the experiences reflected in the performance. By opening up the play to the audience, the participants offered a space for community members to share their thoughts, views and experiences (see example in section 4.3). As can be seen in the above exploration, make-believe, living improvisations and spontaneity come together to make sharing of experiences of the community possible. In the following section, I shall explore collaboration, yet another frame that was also present above.

6.3.4 Collaboration

According to Parkinson (2006:3), collaboration is ‘a mutually beneficial, well-defined relationship entered into by two or more parties to achieve common goals’. She goes on to say that a collaborative relationship includes ‘a jointly developed structure and shared responsibility’. Freire (1971) argues for collaboration when he advocates for a partnership between those who seek to facilitate others and those who are to be facilitated. A collaborative relationship allows for a distribution of power and acknowledges each partner’s abilities. Based on Freire (1971) and Parkinson’s (2006) description, we have seen collaboration at play throughout the knowledge generation process in this study (see methods). Although collaboration has already featured in most of the explorations in this chapter (including through creating the *pamtondo* effect, during make-believe, living improvisations as well as within spontaneity), my focus in this section is on the collaboration between/among the participants in creating the folk media forms that they presented in the workshops.

Chinyowa (2005) asserts that in the African context, “during song, dance, drumming and even storytelling, performers usually negotiate with each other within a competitive frame”. I add that this negotiation can also take place outside a competitive frame, but within a collaborative frame, especially when the performers are in the same group. Below I share a reflection of a participant during a group review process on day 3.

> As for me, on my part, I think that the methods (*njira*) that we are using are good, like ma *sewero* and songs. To me, they are helping me. Why do I say this? I was never able to compose a song (s). but today I was able to. While others were composing, others like myself were adding in salt (important ingredient for seasoning-food without salt is often considered tasteless. And when a person says the argument had no salt, it means it had no substance). For me, I feel this is opening me up, through these songs and the masewero (dramas), they are making me to be immersed in

> it, and also to do something tangible… (Participant during group process review on day 3 in Thyolo).

The participant's reflection above suggests that the process of creating the songs and *masewero* (dramatic enactments) during the workshops was collaborative. He describes how the participants worked together, bringing diverse skills together to create the songs and dramas which they used to share their perspectives and experiences in the workshops. As already discussed earlier, part of the creation process also involves reflecting on their experiences, which they then use to create the performances. After participants share their stories, thoughts or concerns, they deliberate and then create the songs and/or dramatic enactments. The performances comprise of various people's perspectives and experiences so much that as they perform, it becomes a cumbersome next to impossible task to know who shared what. This means that, just like *pamtondo*, the responsibility of the song is distributed and shared. Thus, collaboration created safety by providing anonymity through collective ownership of what was created.

The extract above also suggests that, even in performative communities like the one in Thyolo, people may not have all the skills to create all the various forms of folk media. However, through collaborating with other members of their community, the views and experiences of those who do not have all the necessary skill to create the folk media, can be represented. The realization that participants from performative communities may not all be gifted in the same way when it comes to some folk media forms, makes it even more important that the participants chose which forms they use to express themselves.

6.4 Chapter Summary

In this chapter, I have addressed the second question of this study: In what ways can folk media facilitate research about HIV and AIDS in rural Malawi? As can be seen, in the first half of the chapter, I explored how folk media facilitated a conducive environment for the practice of research in this study. Here it is clear that folk media in Malawi has always provided culturally acceptable structures and spaces for communities to talk about sensitive matters and taboo topics.

One such space is *pamtondo* which can be described as a cultural space of work and play where women pound grain as they sing songs, gossip, laugh, discuss current affairs and voice their joys and grievances. We have also seen that *pamtondo* was a safe space that allowed women to express their views and grievances while being protected by the frame of *macheza*, (this is not serious this is just play).

Through exploration in this chapter we have also seen that my practice in this study as manifested through the SPEAC model recreated “the pamtondo effect”, a phrase I use to describe the fundamental characteristics of *pamtondo*. As we have seen, the *pamtondo* effect is manifest when the characteristics of playfulness, freedom, safety, openness and shared ownership of process are guiding the process of engagement in a workshop space with research participants. It is evident that through SPEAC, *macheza*/play(fulness) can recreate the *pamtondo* effect to enable both male and female community members to speak more openly and with less inhibition during the research process. The *pamtondo* effect allowed for the breaking or suspension of immediate restrictive social reality, creating a temporary parallel reality of its own where rules were broken or renegotiated, taboo topics discussed, and authority/power/roles subverted and challenged. In other words, the *pamtondo* effect evoked a silent cultural licence/permission to openness, freedom, collaboration and safety among the participants of this research.

We have also seen that make-believe allows the participants freedom to suspend their immediate social reality and embrace the make-believe role which temporarily frees them from the confines of their immediate social reality and allows them to speak freely about their understandings and experiences with HIV and AIDS. In other words, the make-believe frame offered the participants a safer space where they were able to express themselves in ways they may have not have been able to as themselves.

In describing living improvisations, we have seen that participants were performing themselves and their experiences with HIV and AIDS. We have seen that when the participants presented a *sewero*, the *sewero* contained fragments of experiences that were weaved together and reconstructed to make a cohesive alternative reality (*sewero*) that was make-believe but at the same time real.

Through unpacking these fragments, participants' detailed experiences and narratives were explored. Spontaneity throughout the research process enabled the participants to tap into cultural forms such as *zifanifani* (metaphorical stories) which enabled them to express themselves freely in ways they already know how. The entire research process was guided by spontaneity which allowed for the input of the participants to shape and guide the research. This leads us to collaboration. The collaboration necessitated by the folk media forms provided an opportunity for the views and experiences of every participant to be represented and unpacked. Just as in most of the folk media forms, the stories experiences presented through the folk forms consisted of a collective ownership. Thus, the chapter has explored the ways in which folk media can facilitate research about HIV and AIDS in rural Malawi.

7 Conclusions, Implications and Recommendations

This study explored how two rural communities in Malawi understand and make sense of HIV and AIDS using folk media as a method for knowledge generation. The approach I took drew on decolonizing and indigenous methodologies. I worked closely and collaboratively with members of the two communities using their own folk media forms such as *masewero* (plays/dramatic enactments), *magule* (traditional songs and dances), *nyimbo* (mostly choir like songs), *kuyerekezera* (role play), *nthano* (folk tales), *ndagi* (short riddles) and *masewera* (games) and attempted to answer the questions below:

1. How do rural communities in Malawi understand and make sense of HIV and AIDS?

2. In what ways can folk media facilitate research about HIV and AIDS in rural Malawi?

In this chapter I summarise and discuss my findings in relation to these two questions and go on to discuss their significance and implications for public health in Malawi. Lastly, I suggest what I see as the next steps of engagement from this research process.

7.1 Making Sense of HIV and AIDS in Rural Malawian Communities

There are multiple, overlapping understandings of HIV and AIDS in the Dedza and Thyolo communities that draw from multiple sources of knowledge. In this section, I will explain the multiple ways in which their understandings of HIV and AIDS unfolded.

HIV and AIDS is understood within the context of the communities' pre-existing understandings and practices in relation to illness and disease. Specifically, symptoms are understood in relation to a range of underpinning causes and are connected to routine treatment seeking practices which are seen to be consistent with those causes. In accordance with the Chewa epistemologies, these understandings have been drawn from the collective and accumulative lived experiences of the community (Kaphagawani 1998; Interactive interview with Group Village Head Miyowe of Dedza 2019). For example, in section 4.1 we see that before HIV and AIDS received its contemporary names and understandings the symptoms it brought had been interpreted as consistent with those of *Kaliwondewonde* and *Kanyera wa mkulu,* illnesses familiar to the community and said to be caused by cultural sexual transgression. Because HIV and AIDS symptoms mimicked those of already existing illnesses in these communities, the biomedical explanations of the disease were dismissed and rejected.

The findings also show that at the time of this research both communities had also encountered extensive biomedical explanations of HIV and AIDS. This knowledge was accumulated through interactions with biomedical healthcare staff and through health promotion campaigns usually delivered to these communities through radio broadcasting. Thus, the communities' current understandings of HIV and AIDS also drew on biomedical frames of reference in a process of what Borkman (1976: 446) describes as "discursive reasoning, observation or reflection on information provided by others". However, we see in chapter 4 that initially, even after being told by Government through radio messages and public health awareness campaigns that HIV and AIDS was responsible for the illnesses and deaths they were witnessing, the communities dismissed that it was different from *Kaliwondewonde* and *Kanyera wa mkulu*. Only after the communities' continued interaction with the disease, failed treatment efforts from indigenous healthcare providers, and their lived experiences, did they begin to accept the biomedical explanations for symptoms and illness – that is that HIV and AIDS was indeed among them. The communities' confidence in the biomedical explanations of HIV and AIDS was heightened by their experiences with ART as they witnessed patients recover from near death experiences.

This process, the time it took, strongly suggests that within these communities cultural and experiential ways of knowing were prioritized. The concept of experiential knowledge recognizes knowing that comes from everyday interactions and experiences with phenomena (France 2010; Borkman 1976). As was with both the Dedza and Thyolo communities, experiential knowledge carries a high degree of conviction, authority and validity in the lives of the people (Borkman 1976) and is also reflected in understandings of symptoms, illnesses and treatment seeking within the community which is consistent with Chewa epistemologies.

Through explorations in chapters 4 and 5, it is clear that participants were actively aware of the separation of the nature of what they know about HIV and AIDS. This awareness is evident in the participants' frequent use of "they say…" and "we see/think/feel/experience/believe/say…" articulations in the exploration of HIV and AIDS related topics during engagement with the research process. The framing of these articulations play an important role in indicating how these communities experience and position themselves in relation to knowledge and experience of HIV and AIDS. As earlier stated, language is very crucial to a people as it embodies distinctive ways of defining the experiences of a community as their specific experiences (Coetzee, 1998: 278).

Findings from both communities suggest that when information enters a community from a new or external source, as did biomedical explanations of HIV and AIDS, it undergoes trial where it is examined, deliberated, tested and compared to existing knowledge and experience. The trial consists of two main questions of the new information: how does it fit our existing cultural frameworks? and how does it fit in with our experiences? The answers to these questions then result either in reconciliation, contestation or rejection of explanations. If found to complement, extend, resonate and reconcile with the people's experiences on the ground, then that part of the knowledge is integrated into their experiential knowledge, transforming it into something new which in turn transforms their understandings of illness and consequently influences treatment seeking practices.

As can be seen from chapters 4 and 5, in most cases many of the participants were able to reconcile, to weave together, their cultural, experiential and biomedical understandings of HIV and AIDS in terms of, what it is, how it is diagnosed, risk factors, as well as required treatments. This reconciliation is evident in the communities' integration of biomedical health care (*chipatala cha chizungu*), as a culturally acceptable treatment seeking option for the management of HIV and AIDS and related illnesses. Wyke, Adamson and Dickson et al (2013) argue that culturally acceptable responses are informed by knowledge that is accumulated over time by all actors of the social world. Consistent with Wyke, Adamson and Dickson et al (2013), the extent to which symptoms impose themselves is crucial to the interpretations of illnesses and evaluation of possible responses and interventions in the two communities.

However, if found lacking, the new/external information is contested, not reconciled and remains alienated, parallel knowledge that holds its own separate space and is not fully integrated into the acceptable knowledge systems that influence health seeking practices in the communities. The condoms discussion in section 4.3 demonstrates that there are instances where certain biomedical information is contested by the communities and has not passed the test and so has not been reconciled with cultural knowledge and/or experiences on the ground. Where there is contested and irreconciled information/knowledge, members of the two communities showed scepticism about the validity/truth of the information as well as those giving it. It is also clear that where knowledge was not reconciled/failed to reconcile, it produced defensive responses and counter narratives that led to distrust, suspicions and conspiracy theories. These negative feelings in turn jeopardize positive health seeking practices as can be seen from the participants’ rejection of condoms which have biomedically been shown to help prevent HIV transmission. However, it is evident from this study that in some cases, even when biomedical knowledges have been accepted by members of the community, they can sometimes come into tensions with cultural practices and everyday life situations that community members consider necessary. And, because it is clear from the findings of this study that HIV and AIDS is considered one problem among a range of problems members of the community must negotiate daily, preventing infection doesn’t always rank as a priority when weighed against other problems.

As seen in Chapter 4 and 5, a major factor for failure of knowledge reconciliation is the way in which biomedical information is translated into cultural idioms that do not make sense to the rural communities. As articulated in section 2.5, the imposing and top-down nature of early communication about

HIV and AIDS biomedical information to the rural communities (Lwanda 2002), led to communities having difficulty and delay in accepting it. My findings confirm this and suggest a continuation of this trend to the present as demonstrated by the discussion about the iron supplements schools' program in Dedza and the shift to test and treat HIV treatment model in Thyolo. The findings also suggest that failure to engage and negotiate with situated cultural and experiential understandings at the onset of public health initiatives leads to a series of resistances and delays in integration of crucial knowledge into the communities' operating knowledge systems.

Furthermore, findings discussed in section 5.4 suggest an absence of consultation and ineffective communication with the rural communities about health promotion programs they are expected to participate in, and changes in treatments and treatment approaches that affect them. In cases where the communities are informed, it is done in such a way that they have no opportunity to ask questions or engage with the information they are receiving and the people they are receiving it from, as such, they go home with incomplete and irreconciled information which they do not understand and does not fit in with their realities. This imposing, dominating top-down health care approach is ineffective in facilitating knowledge interaction that allows reconciliation of knowledges to make them transformative. As research has shown, effective communication in healthcare is vital to reducing the uncertainty of patients, improving adherence to treatment and increasing effective utilization of health care facilities (Ruben 2016; Madula, Kalembo and Kaminga 2018). Therefore, in order to be effective in supporting rural communities, healthcare provision and public health promotion campaigns need to start by respecting existing understandings, experiences and sharing new knowledge in a way that enables it to be questioned, examined and evaluated in dialogue with existing knowledges. This dialogical approach will help to lessen the knowledges that are contested and facilitate reconciliation of the knowledges and ultimately their integration.

7.2 How folk media facilitated the exploration of HIV and AIDS narratives

My approach to folk media worked to excavate and reveal the communities' multiple knowledges of HIV and AIDS, including those that are being contested and have not yet been reconciled. As described in sections 1.3 and 3.1, my use of folk media as a method was grounded in decolonizing indigenous methodologies. In using them I aimed to avoid imposing or prioritising "Western" ways of knowing that indigenous peoples and communities have suffered at the hands of colonialism and imperialism and its lingering effects (Smith 2012; Chilisa 2011; Kavoch 2009). The approaches are aimed at centring the concerns and worldviews of the indigenous, so that they can engage with research on their own terms through their own assumptions and perspectives, as such, they draw from indigenous cultural resources and frameworks (Chilisa 2011).

Folk media is a crucial cultural resource in Malawi, and has functioned as a mode for social commentary, critique of behaviour, retaliation against oppression, education, and has also been used as a mode for social examination, deliberation and reconstruction (Kamlongera, Nambote and Timpunza-Mvula 1992; Kerr 1987; Chinyowa 2005). As explored in chapter 3 and 6, the collaboration between participants, Misheck my research assistant and I, used folk media forms chosen by the participants to explore how the two rural communities understand and make sense of HIV and AIDS. Because the approach was collaborative and the methods used were indigenous, Misheck and I were able to enter the world of the two communities on the "We" side of the "They say, and We say/feel/experience/say" articulations. Through the SPEAC model (**S**pend time on Macheza (play/playfulness), **P**articipate in all activities, **E**stablish a routine of Macheza, **A**ccept being led, **C**onduct yourself as a member of the group), we were able to recreate "the pamtondo effect", an environment of friendship, collaboration, freedom, openness and togetherness where both participants and researchers felt safe. I found that the internal indigenous nature of the folk media, operating in "the pamtondo effect" space, evoked a silent cultural licence (permission) to openness which allowed for rich sharing to occur. In this conducive space, operating within the paradox of play in which the real self and the play self, exist together using frames of play such as make-believe, living improvisations, spontaneity and collaboration, folk media worked in the following ways.

Firstly, folk media revealed the participants' multiple understandings and knowledges about HIV and AIDS (cultural, experiential, biomedical). This was facilitated in a respectful and safe way which did not induce a sense of vulnerability in the participants or fears that I was trying to change or attack their understandings and/or practices. Because the participants felt safe, as evidenced in section 6.1, the process did not evoke defensive discourses/mechanisms to safeguard their understandings, knowledges and practices. Cultural understandings, practices and experiences tend to be hidden by Malawian communities when people feel that those understandings, practices and experiences are being/or will be attacked, assaulted, undermined, unappreciated or judged. Lwanda (2002) explains that during the early encounters with colonialism, when the colonial settlers and government began to assault their cultural beliefs and practices, Malawians hid significant crucial parts of their cultural practices/existence by placing them out of the colonial gaze. This disappearance from the gaze was mistaken as the dying out of practices and frames of reference that are very much alive. As can be seen from chapter 6, pointing to different aspects of SPEAC, participants reported feeling safe, comfortable and not feeling the need to hide aspects of their understandings or practices. Therefore, this folk media approach expelled the need for participants to go into what I call "ghosting" (hiding in a way that make them appear non-existent in order to protect or for safe keeping) their closely held knowledges/understandings and practices.

Secondly, the approach encouraged participants to choose which folk media forms to use, enabling a confident excavation of their own understandings, experiences and misgivings drawing on both cultural and biomedical frameworks about HIV and AIDS. After excavation, songs and dramatic enactments that represented the understandings and reflection on the process, enabled the participants to explore and examine what had emerged in further detail. This is illustrated strongly in section 4.3 where participants were able to identify and critique some of their own cultural practices as increasing risk of HIV and AIDS, eg. *Fisi*, and were also able to acknowledge the tensions that are responsible for the continued practice of *fisi*. By critically reflecting and openly sharing their reflections, understandings and experiences confidently through the folk media forms, contested knowledges, gaps in reconciliation between the various multiple knowledges they held were revealed and tensions in the application of some of these knowledges were highlighted. The process also provided opportunities for participants not only to represent their experiences and perspectives, but also to *inquire* into them, to explore and research *with* me.

Thirdly, the folk media approach as facilitated in this research provided a space for the participants to question and challenge biomedical information and the nature of communication of that information or lack thereof, by biomedical health providers, public health professionals and Government. They were able to express their feelings of anger, suspicion and frustration at how HIV related services are changed by Government as implemented by biomedical health care providers without consultations or proper communication with the communities and the people who receive the care.

7.3 Awiri Sayenda Asadapangane: Significance and Implications

Awiri sayenda asadapangane is a *mwambi* (Malawian proverb) which translates to, two people do not travel/journey together without an understanding. The *mwambi* signifies the importance of dialogue that leads to an understanding between two parties that embark on a journey together. In application, public health and biomedical health care practitioners and the communities they serve cannot work together for better health outcomes without an understanding. When biomedical explanations and treatments are imposed or are not proposed in dialogue then reconciliation between existing and new frames of reference cannot happen and knowledge is ignored. This problem is continuing even now. During a phone conversation about my findings with the Group Village Head (GVH) of the Dedza community early 2020, he asked me a question about COVID-19 which I was unable to answer. Here’s what he said:

> I am a little confused. They (government/public health professionals) are telling us that there is this corona disease, and they are saying we need to practice cleanliness and wash our hands often to prevent the disease. But

> I also hear that prince Charles in the UK has the disease, are you trying to tell me that the prince of the UK is filthy and is unable to wash his hands? (GVH Miyowe, during a phone conversation extracted from my field notes in April)

The GVHs question already demonstrates how simplistic, top down, imposing and one-way communication approaches pose challenges in reconciling knowledges. These recurring problems suggest an underlying logic about how biomedical approaches to health are received and negotiated within these communities. It is important to understand this because effective community health care provision requires capacity for having effective dialogue between biomedical public health professionals and communities in ways that allow differences of understandings and opinions to be explored and reconciled where possible, and to reduce harmful discourses and missed opportunities for effective treatment and patronage of HIV related services on the journey towards improved health.

I argue that the folk media-based approach provided a space for the collaborative and collective identification of contested and irreconciled knowledges and that this could then become the entry point or foundation for future engagements, dialogue and negotiation towards transformative action. This transformative action can only be achieved when the multiple knowledge systems and multiple stakeholders involved come together in dialogue and action (Freire 2005).

7.4 Reflections on the methods

As can be seen above, the folk media approach worked very well for purposes of excavating, revealing, and exploring narratives of HIV and AIDS. It also worked well in eliciting both individual and general community understandings and experiences with HIV and AIDS by giving power to the participants to decide what needed to be explored based on their experiences pertaining to HIV and AIDS. This demonstrates that folk media is a strong, replicable, decolonizing and indigenous exploratory method. However, the approach is not without challenges.

Given the openness, safety and freedom of expression provided by this particular application of folk media, it means that various narratives are excavated and shared in an intensive manner, including those that might be unhelpful or harmful to health seeking objectives. I will share my experience as a facilitator in the folk media workshops as an example. As the participants continually expressed their misgivings about condoms, and the worms found in them, and conspiracies around them, I struggled to not be convinced and affected by the participants' stories and explorations. They shared their views and experiences with such passion and conviction that I found myself not only empathizing with them but convinced by the stories. I did not realise the extent to which I had been affected until I got home after the fieldwork. At home, I often mumbled and even expressed to my husband my dislike of condoms. I struggled with this for a while.

My struggle with what I carried from my participation in the folk media workshops suggests that the space had the potential to be a hub for transference. This means that even though the views are already circulating within the community, the conducive environment of the workshop space can provide a platform for further spreading and reinforcing of unhelpful thoughts that could plant a seed of disruption to health seeking attitudes and behaviours. In my case, I felt that countering what I thought were unhelpful and dangerous narratives was my ethical responsibility. However, because this process of research was aimed at understanding the communities' understandings and how they make sense of HIV and AIDS, attempting to counter these understandings and views within this process, irrespective of subtlety would appear as an attack or an undermining of how the participants see and name their world. In addition, I would also be reinforcing imposition and the superiority of my knowledge of biomedicine. It could also presuppose that I think I know better about the realities of the participants, than they do, thereby reinforcing unbalanced power dynamics that we had worked so hard to undo. This might have led the participants to "ghosting" some critical understandings of HIV and AIDS. This experience goes beyond my individual experience as a researcher and raises a wider ethical question of what happens when we set out to understand other people's realities when those realities come into tension with our own realities and we believe that the realities as described by our participants could be harmful? Do we denounce them during the inquiry process, or do we remain silent in the name of research and in so doing implicitly condone the dissemination of knowledge known to us to be harmful?

7.5 After revelations

My reflections on the folk media workshops I developed have led me to believe that it is not enough to facilitate a process of uncovering or revealing understandings and experiences of participants and communities. This revelation process is incomplete if it stops with “knowing”. Thus, I suggest that the revealing process need to be followed by a facilitation of engagement and critical dialogue to collaboratively identify and unpack tensions, contested knowledges as well as knowledge that have not been reconciled. I propose facilitating a space where the multiple knowledges intersect and dialogue with each other; a sharing of knowledge where both can be questioned, challenged and transformed for contextual understanding and application. I propose working within this culturally responsive folk media approach to engage communities in dialogue about how to create the space to unpack contested understandings and knowledges and who should be involved in unpacking these knowledges. Using the SPEAC model, the process might begin with collaboratively identifying contested understandings and knowledges, then as Freire’s (2005) theory of dialogical action asserts, bring these to the table for mutual unpacking and inquiry in order to develop a community-specific approach to addressing them.

However, such an undertaking is a new research project in and of itself. Yet it is necessary and urgent. It is *necessary*, because communities across Malawi, and the wider world, continue to face health inequalities that are at least partly attributable to imposing approaches to public health. It is *urgent*, because new threats to human health are always emerging and collective action is required to defeat them, as we have seen with COVID-19. Yet, collective action requires a degree of shared understanding, as the *mwambi “awiri sayenda asadapangane”* reminds us. Using the folk media approach that I have developed in this thesis, I have found a way to reveal lines of contestation which often remain hidden, but I feel that my next step *has* to be to explore how shared understandings can be negotiated dialogically. For, as I and many others have shown, imposition does not work and leads communities to construct “they/we” dichotomies and to engage in culturally defensive practices.

Sadly, these imposition-based practices remain extremely common in public health initiatives in Malawi. To illustrate this and to help bring my thesis to a close, I want to retell a story about a water, sanitation and hygiene initiative that took place in my home district of Chikwawa. During fieldwork in Chikwawa District in 2016, we found some community members building typical pit latrines found in rural areas, that use grass fencing to provide privacy. We also noticed that there were beautifully constructed toilets made of brick and cement, with iron sheet roofing, which were not being used. When we inquired why these toilets appeared not to be used, some community members told us that these toilets were “NGO toilets” and that they feared that they were not safe, as in their area, the earth is not stable especially during the rainy season when the ground shakes, moves and sometimes cracks. So, they feared that these “NGO toilets” would collapse on them and cause injury. These toilets were the products of an NGO’s initiative, who came and built brick toilets, with the aim of improving hygiene standards in these communities, and yet failure to understand the local community’s experience of permanent structures left them unused, and essentially purposeless.

Having constructed a method for revealing and understanding how rural communities in Malawi make sense of aspects of the world they live in, I want my work to ensure that the metaphorical “toilets” we build are co-owned and not seen as belonging to “others” who do not understand how the local land works. Instead, I want these “toilets” to be used and for communities and their health to benefit from them, not for them to stand as monuments to neo-colonial imposition.

8 Appendices

Appendix 1: Sample from data coding framework

Theme	Data/Potential Themes/Potential sub-themes	Notes
Perspectives of HIV treatment (diagnosis??)	● Many receive ARVs but are causing problems for alot of people ● the new tablets are too big and make it difficult for some to swallow....DA-d9 vid2 57:13 - 58:16 performance audience member 2 woman...Ma RVwo atichepetsereko poti kugwidika zinthu zija zukanika.. The tablets are causing loads of side effects on those who take them including mental illness, ...fainting? ● stigma and discriminations…DA-d4 vid 6 45:00 the issue of ARVs being named as Nyemba..called nyemba because amabwira and they are as big as kidney beans ● DA-d4 vid 6 50:00 - During the hunger season, the effects are more adverse as the meds seem very powerful and need to be taken alongside food..for many food is scarce (especially January to April...my observation) ● Tiresome to take on a daily basis.. ● Aware that the meds do not cure HIV just put it under control	Copied from latest current guidelines for clinical management of Hiv and Aids in Malawi (2016) An electronic copy of this guideline is available on the website (www.hiv.health.gov.mw) of the Dept. for HIV and AIDS of the Ministry of Health **2 Summary of new policies** **Key facts for patients and providers** ● All HIV infected people should start ART as soon

	● Propose that the meds should come in injection form that would be taken once a month, week or something like that ● Unconvinced that an HIV cure is not available..see it as a deliberate attempt to let people die..linked to conspiracy... ● **DA-d6 vid 2** Others are afraid to receive treatment because they fear being exposed..once one is known to have HIV, their market is destroyed..married or not.. ● The ‘kachikwama’ in many cases, people are diagnosed by the community as having HIV when they carry a certain specific size type of bag when going to and from the hospital. Apparently thats where they carry the ARVs..this specifically applies to women as men mostly just put them in a jacket pocket..(I relate this to the cultural dressing where wrappers are used and big clothes with pockets rarely worn) ● Bad Hosp reception and care... **TO-d6 vid 12 00-04:45** During group presentations- the group that was doing play creation/drama They show a scene with an very sick person at the hospital but the doctor is not available when he was called, he took his time and when he did come he started with making general announcements before attending to the sick person and the people complained so he	as possible for their own health and to prevent passing the virus on to others. ● Serious HIV-related diseases can occur even in patients with high CD4 count (>500), without any previous symptoms. Immediate ART greatly reduces this risk. ● Current ART regimens are easy to take and rarely cause serious side-effects. ● ART for all HIV infected people is the most effective prevention

	started looking at the sick person and then his phone rang, he stopped to chat on the phone...he then quickly gave medicines and said medicines have now changed, they will be receiving different medications, the people murmured and when they tried to ask or protest, the doctor said he was the one who had the doctors degree/education and that his parents sent him to school to do medicine so they should not bother him..the scene also shows the doctor announcing to the people who were there to say all those looking to receive ARVs use that door and all others use this door...the scene ends with people complaining **TO-d6 vid 12 05:25** reflections on the scene presented...the rest of the group agreed that there were indeed the issues, happening at the hospital...”what was happening here in the play is indeed what happens at the hospital when the patient comes in”a woman said **TO-d6 vid 13-** during all group scene development from the storyline of the play, we together as a group developed scenes and discussed the play in detail..the themes and issues that the play raises and how best to present them including how to engage the wider community in dialogue to hear their views on the issues raised...the play raised major issues like , condom use and throwing them away, how they are received at the hospital, changing of medication without informing and explaining to the people who receive them .**DA-d9 vid2 54:00** during performance another audience member **TO-d6 vid 5 02:44-03:20** during prioritization presentations one of the points was hospital reception and care..in explaining and discussing what issues are encompassed in this point	method available: Successful ART leads to very low levels of virus in the blood and in body fluids (viral suppression). Viral suppression greatly reduces the risk of sexual or mother-to-child transmission. There was also an issue concerning test and treat.. 3 of the 17 people said it was a good idea... And 14 of them said it was a very bad idea. As both sides were given space to express their views and why.. It appeared that the 3

	and why it is a priority ...complaining that the hospital staff don’t treat them as people..they go there with a sick person and are not attended to properly, they take their time even though the patient is seriously ill ● Test and Treat, Problem or not **TO-d5 audJ2** cabbage says many people are dying because the medication is being given while the person is healthy, before they start getting sick..he thinks this should be changed **TO-d5 audJ2 08:37** Therere...she doesnt think that people should be given ARVs (test and treat) she strongly disapproves..she says the first model was better because now, lots of people will contract the virus because when people start ARV bfore they are sick, they get fatter and there is no way of knowing which puts others at risk **TO-d3 aud 1** during reflections on a play one group presented There was also an issue concerning test and treat.. 3 of the 17 people said it was a good idea... And 14 of them said it was a very bad idea..They argued that it was best to allow the person to first start getting ill then provide the drugs.. Arguing that for the sake of everyone else who might sleep with the person if they never get ill and yet they are HIV positive... It's a big threat to everyone else **TO-d6 vid 5 02:07-02:30** changing of the treatment approach to test and treat is very troubling	were seeing it from the affected individuals perspective while the rest were looking at it from a social perspective [11/02, 14:56] Sherry: Social safety and protection if I may put it that way..More of a utilitarianism kind that Sherry: For the protection of many, when the person atleast gets ill, then people can see and take better care in having sexual relationships with them [11/02, 15:01] Sherry: Apparently the issue of illness and treatment also comes

	TO-d3 aud 1 40:00 discussing illness ignited by a play- the man talks about the system of treatment based on CD4 count....generally one has 1500 soldiers in the body and even if u are positive but still have 1500 they did not give u treatmment but only if they were 500..and now test and treat..why do they do this? Was a question he raised, 2-3 others said its bcz they reduced the strength of the medication...another responded saying its because they realised that for some people with less care, it was too late to start at 500...test and treat is called 90:90 pompo pompo you take once only..another adds there are new ones which you take in the morning...(the community seems to identify the drugs through dosage and size)....the meds are specified for people , the hosp people have told them not to take a variety of the ARVs if they are still intending to	up... If you take medication before you are ill, it triggers illness

Appendix 2: Information Sheet: Phase 1

Project Title: Culture, Play and Health: A Theatre for Engagement Approach to exploring narratives of HIV and AIDS in rural Malawi

Researcher: Sharifa Abdulla

Supervisors: Dr Mia Perry, Prof Sally Wyke

Course: PhD in Education

You are being invited to take part in a research study. A research study is a way of finding out more about something. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What will happen if you take part?

The purpose of this study is to find out more about the narratives of HIV and AIDS from the perspective of the rural community. But before then, I would like to get to know this community better and this is the reason I invite you to this conversation.

If you decide to take part I will ask you a few questions about the way you live as a community, sources of livelihood, the seasonal calendar, and historic events that have shaped life in this community. I would like to find out about the main places and spaces of significance to your everyday life, major stages and transitions of life in this community, your celebrations, dances, songs, games and anything else you would like to share with me about you or your community. You do not have to answer any questions that you don’t want to, or share anything you do not feel like sharing. This engagement will take about 15-30mins of your time and it is okay to talk while you go about your business. I will write notes, take pictures of the activities that unfold and record your answers on a voice recorder and video recorder so that afterwards I can watch and listen carefully to what you said.

You do not have to take part in this study, and if you decide not to, there are no consequences to you or anyone else. If you do, and after you have started to take part, you change your mind, just let me know and I will not use any information you have given me.

Keeping information confidential

I will keep the information from the study in a locked cabinet or in a locked file on my computer. When I write about what I have found out, your name will not be mentioned. If you like you can choose another name for me to use when I am writing about what you said. No-one else will know which name you have chosen.

However, if during our conversation I hear anything which makes me worried that you might be in danger of harm, I might have to tell other people who need to know about this.

The results of this study

When I have gathered all of the information from everyone who is taking part I will write about what I have learned in a thesis, which is a long essay, which I have to complete for the course I am studying on. This will be read and marked by my teachers at university. I will tell you and the other participants who have taken part what I have found out about what you think about HIV and AIDS and everything I have explained above. When the outputs are ready (photo book and/or film), I will bring to show them to you and leave a copy with the group. The local health centre staff will be invited to share the findings and discuss with you, the community how to best serve the community.

I will keep all notes and recordings in a secure place for future reference and/or use for 10 years and then will destroy the original data to ensure it is never used by unauthorised people.

Sharing information

Please note that the information I gather here may be made Available to others from the researchers by personal request if necessary, in this case only anonymised or consented data will be made available.

Images and outputs (such as personal Photos, drawings) from the research process may be used and disseminated publicly. However, consent will be sought and only those images that you have consented will be used publicly. If there is something/image you would not like to be shared, this will not be shared.

Review of the study

This study has been reviewed and agreed by the College of Social Sciences Research Ethics Committee, University of Glasgow

Contact for further Information

If you have any questions about this study, you can ask me, Sharifa Abdulla on cell [redacted] or email [redacted] or Officer in charge[redacted] or local health centre cell [redacted] or my supervisor, Dr Mia Perry, cell [redacted] or email [redacted] or the Ethics officer for the College of Social Sciences [redacted]

Thank you for reading this!

Appendix 3: Consent Form: Phase 1

Project Title: Culture, Play and Health: A Theatre for Engagement Approach to exploring narratives of HIV and AIDS in rural Malawi

Researcher: Sharifa Abdulla

Supervisors: Dr Mia Perry, Prof Sally Wyke

Course: PhD in Education

I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

I consent to engage in conversation about our way of life in this community, cultural norms, performance forms, songs and dances in our community and that the researcher will be taking notes, pictures and audio video recording the activities.

I acknowledge that participants will be referred to by pseudonym in any report or publication arising from the research.

I understand that:

- The material will be treated as confidential and kept in secure storage at all times.

- The material will be retained in secure storage for no longer than 10 years for use in future academic research

- The material may be used in future publications, both print and online.

- I waive my copyright to any data collected as part of this project.

- Other authenticated researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.

- Other authenticated researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.

I agree to take part in this research study ☐

I do not agree to take part in this research study ☐

Name of Participant Signature

Date

Name of Researcher Signature

Date

……………………………………………… End of consent form ………………………………………………

Appendix 4: Information Sheet: Phase 2

Project Title: Culture, Play and Health: A Theatre for Engagement Approach to exploring narratives of HIV and AIDS in rural Malawi

Researcher: Sharifa Abdulla

Supervisors: Dr Mia Perry, Prof Sally Wyke

Course: PhD in Education

You are being invited to take part in a research study. A research study is a way of finding out more about something. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What will happen if you take part?

The purpose of this study is to find out more about the narratives of HIV and AIDS from the perspective of your rural community. This community is one of two communities in Malawi in which this study will be taking place. About 20 people from this community will be participating in this study and you have been chosen to participate because you are an adult member of this community (above 18 years of age) and have lived most of your life in this community, and have not participated actively as a facilitators or agent of change in HIV and AIDS campaigns.

If you decide to take part, you will be asked to work with the group of other participants and engage with theatre based activities (such as songs, dances, drama skits, roleplays and other theatre based activities) to explore what HIV and AIDS mean to this community, and what ideas such as “self,” “illness,” “suffering,” “risk,” “prevention,” “treatment,” “wellness” and “general purpose of life” means to you and your community. Then we will as a group create a performance and host a performance event to which the entire community will be invited. What is included in the performance will be decided by the group and if there is anything that you do not want to be shared in the performance, it will not be shared. You do not have to participate in any activity that you do not feel comfortable participating in, and you do not have to answer any questions that you don't want to. You will not have to share anything you do not feel like sharing. This engagement will take about 4 to 5 hours everyday for a period of 10 days. Lunch and refreshments will be provided during these sessions. Throughout this period, I will write notes, take pictures of the activities that unfold and record your answers on a voice recorder and video recorder so that afterwards I can watch and listen carefully to what you said. I will also ask you to keep a journal (either on paper or by recording your voice) of your thoughts and reflections on the process and your engagement with it.

You do not have to take part in this study, and if you decide not to, there are no consequences on you or anyone else. If you do, and after you have started to take part, you change your mind, just let me know and I will not use any information you have given me.

Keeping information confidential

I will keep the information from the study in a locked cabinet or in a locked file on my computer. When I write about what I have found out, your name will not be mentioned. If you like you can choose another name for me to use when I am writing about what you said. No-one else will know which name you have chosen.

However, if during our conversation I hear anything which makes me worried that you might be in danger of harm, I might have to tell other people who need to know about this.

The results of this study

When I have gathered all of the information from everyone who is taking part I will write about what I have learned in a thesis, which is a long essay, which I have to complete for the course I am studying on. This will be read and marked by my teachers at university. I will tell you and the other participants who have taken part what I have found out about what you think about HIV and AIDS and everything I have explained above. When the outputs are ready (photo book and/or film), I will bring to show them to you and leave a copy with the group. The local health centre staff will be invited to share the findings and discuss with you, the community how to best serve the community.

I will keep all of my notes and recordings in a secure place for future reference and/or use for 10 years and then will destroy the original data to ensure it is never used by unauthorised people.

Sharing information

Please note that the information I gather here may be made Available to others from the researchers by personal request if necessary, in this case only anonymised or consented data will be made available.

Images and outputs (such as personal Photos, drawings) from the research process may be used and disseminated publicly. However, consent will be sought and only those images that you have consented will be used publicly. If there is something/image you would not like to be shared, this will not be shared.

Review of the study

This study has been reviewed and agreed by the College of Social Sciences Research Ethics Committee, University of Glasgow

Contact for further Information

If you have any questions about this study, you can ask me, Sharifa Abdulla on cell [redacted] or email [redacted] or Officer in charge[redacted] or local health centre cell [redacted] or my supervisor, Dr Mia Perry, cell [redacted] or email [redacted] or the Ethics officer for the College of Social Sciences [redacted]

Thank you for reading this!

Appendix 5: Consent Form: Phase 2

Project Title: Culture, Play and Health: A Theatre for Engagement Approach to exploring narratives of HIV and AIDS in rural Malawi

Researcher: Sharifa Abdulla

Supervisors: Dr Mia Perry, Prof Sally Wyke

Course: PhD in Education

I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

I consent to engage with theatre based activities (such as songs, dances, drama skits, roleplays and other theatre based activities) to explore what HIV and AIDS mean to this community, and what ideas such as “self,” “illness,” “suffering,” “risk,” “prevention,” “treatment,” “wellness” and “general purpose of life” means to me and my community. Then we will as a group create a performance and host a performance event to which the entire community will be invited. I also consent that the researcher will be taking notes, pictures and audio video recording the activities.

I acknowledge that participants will be referred to by pseudonym in any report or publication arising from the research.

I understand that:

- The material will be treated as confidential and kept in secure storage at all times.
- The material will be retained in secure storage for no longer than 10 years for use in future academic research

- The material may be used in future publications, both print and online.
- I waive my copyright to any data collected as part of this project.
- Other authenticated researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.
- Other authenticated researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.

I agree to take part in this research study ☐

I do not agree to take part in this research study ☐

Name of Participant Signature

Date

Name of Researcher Signature

Date

…………………………………………… End of consent form ……………………………………………

Appendix 6: Media Consent

Photographs/Audio/video Recordings

I confirm that I consent that

- My Photographs may be used in the production of a thesis, conference paper, academic journal publication or book.
- Images and outputs from the research process may be used for reasons stated above.
- This applies equally to both printed and electronic media

//

Please Tick: Yes No

<u>Participant</u>

Name:

Signed: Date:

<u>Researcher</u>

Name:

Signed: Date:

9 Glossary

Chichewa term	**Author's translation**
Achipatala	Hospital People/Health Care workers
Adamusempha	Was affected by a transgression of sexual taboos
Bwalo la mafumu	Arena/forum/council of chiefs
Bwebweta	Speak hysterically
Chewa	Biggest ethnic group in Malawi
Chifanifani	Metaphorical story
Chigafa	Shed for used for drying tobacco
Chimwanamaye	Wife and husband swapping
Chipatala cha chizungu	Hospital of the whites
Chipwirikiti cha matenda	Anarchy of diseases
Chitenje	Traditional Wrapper
Chokolo	Wife/husband inheritance
Edzi	AIDS
Gule wa mkulu	Big cultural dance
Fisi	Hyena, referring to a group of cultural sexual practices
Jando	Initiation ceremony accompanied by circumcision, common am amongst the Yao tribe.
mdulidwe	Circumcision
Kachisi	Shrine
Kaliwondewonde	Illness characterized by extreme loss of weight
Kanyera wa mkulu	Illness characterized by acute diarrhea
Kaundula	Record
Kubalalika	Scattered
Kuona / Kuonedwa	Seen/being seen
Kupita kufa	Death cleansing
Kusokonekera	Confused
Kutenga mwana	New-born cleasing
Kuyerekezera	Demonstrating/role playing/miming

Macheza	Playful
Magule	Traditional/cultural dances
Mankhwala a chikuda	Medicine from the blacks (african)
Matenda	Diseases
Matenda a Chilengedwe	Diseases of nature
Masewera	Games
Masewero	Plays/theatre/dramatic enactments
Mbulo	Temporary husband replacement
Misala	Madness
Miyambi / Mwambi	Proverbs/proverb
Mizimu	Spirits
Mkango	Lion
Mlozo	Map
Mphini	Little cuts that traditional healers make on the body to get medicine into the blood.
Ndinanyanyala	I got fed up and sulked
Ndagi / Zilape / Ntchezero	Riddles
Ngolowela	Fully grown maize gardens that almost look like a forest of maize stalks and can cover up a fully-grown man
Nsembe	Sacrifice
Nthano	Folk tale
Nyimbo	Song (s)
Pamtondo	A cultural space of work and play where women pound grain as they sing songs, gossip, laugh, discuss current affairs and voice their joys and grievances
Ponda pondani	Step around/go around which means try indigenous spaces for treatment
Sing'anga	Commonly translated as witchdoctor - credited with powers of spirit consultation, healing and divination
Thobwa	Malawian locally brewed drink
Tsempho	Cause of illness by transgressing sexual taboos

Ugalu	The act of being a dog or dog-ness
Wakwanira	Saturated
Za mwaanthu	From other people/ from being bewitched
Zaufiti	Of/from witchcraft
Zolodzedwa	From being bewitched
Zoona / Zoonedwa	The seen/that which has been seen
Zoziona	Things that have been seen of perceived

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