

**INTERROGATION OF DOCUMENTARY FILM AS A TOOL FOR  
ADVOCACY FOR POSITIVE LIVING WITH HIV/AIDS IN SIAYA  
COUNTY, KENYA.**

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**JANUARY, 2022**

## DECLARATION

I declare that this thesis is my original work and has not been submitted for a degree in any other university.

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## **DEDICATION**

I dedicate this thesis to my dear wife Mary Akelo, my son Joseph Were and daughters Janet Adhiambo, Violet Emily Neema and Agnes Spencer. It is also dedicated to the late Violet Wanja Gerald. You provided the inspiration I needed to move on. I do appreciate you.

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## TABLE OF CONTENTS

<b>DECLARATION</b> .....	<b>ii</b>
<b>DEDICATION</b> .....	<b>iii</b>
<b>ACKNOWLEDGEMENT</b> .....	<b>iv</b>
<b>TABLE OF CONTENTS</b> .....	<b>v</b>
<b>LIST OF FIGURES</b> .....	<b>viii</b>
<b>OPERATIONAL DEFINITION OF TERMS</b> .....	<b>x</b>
<b>ABBREVIATIONS</b> .....	<b>xi</b>
<b>ABSTRACT</b> .....	<b>xii</b>
<b>CHAPTER ONE: INTRODUCTION</b> .....	<b>1</b>
1.1 Background.....	1
1.2 Statement of the Problem .....	8
1.3 Objectives of the Study .....	8
1.4 Research Questions .....	9
1.5 Assumptions of the study .....	9
1.6 Significance of the study .....	10
1.7 Scope and limitations .....	10
1.8 REVIEW OF RELATED LITERATURE AND THEORITICAL FRAMEWORK .....	11
1.8.1. Introduction .....	11
1.8.2. Character Portrayal in Documentary Films on HIV/AIDS .....	11
1.8.3. Voice as an Agent for Positive Living Documentary Films on HIV/AIDS .....	13
1.8.4. HIV/AIDS Visual Depiction in Documentary Films .....	18
1.8.5. Synopsis of Documentaries Selected for Study.....	21
1.10.0 Theoretical and Conceptual Framework.....	30
1.10.1 Reception Theory .....	30
1.10.2 Semiotics Theory .....	32
1.10.2 Conceptual Framework .....	33
1.11.0. Methodology.....	35
1.11.1. Introduction .....	35
1.11.2. Research Design .....	35

1.11.3. The Study Location .....	36
1.11.4. Sampling.....	36
1.11.5. Data Collection Methods.....	42
1.11.6. Data Analysis .....	44
1.11.7. Validity and Reliability .....	44
1.11.8. Ethical Considerations.....	44
1.12. Conclusion .....	45
<b>CHAPTER TWO: PORTRAYAL OF CHARACTERS WITH HIV/AIDS IN DOCUMENTARY FILMS .....</b>	<b>46</b>
2.1 Introduction .....	46
2.3. PLWHA Characterised as Poor .....	46
2.3.1 Maria; The epitome of poverty in Fishers of Pain.....	50
2.3.2. Dying of HIV in 2017- Poverty in a family living with HIV/AIDS.....	58
2.3.3 Mary Achieng stands out in the face of HIV/AIDS-Mercy in Action (2014) .....	60
2.4. Characterisation of hopelessness in documentaries.....	61
2.5. PLWHA Characterised as Social Misfits .....	72
2.6. Ignorance and HIV/AIDS devastation.....	75
2.7. Characterization of Children as orphans due to HIV/AIDS .....	77
2.8. Conclusion .....	79
<b>CHAPTER THREE: DOCUMENTARY VOICE AS AN AGENT OF ADVOCACY FOR POSITIVE LIVING IN DOCUMENTARY FILMS ON HIV/AIDS .....</b>	<b>81</b>
3.0. Introduction .....	81
3.1. Voice in documentary title .....	81
3.2. Narration voice as voice of documentaries.....	86
3.2.1 Narration voice as bearer of News of Death .....	86
3.2.2 Narration voice and Immorality .....	90
3.2.3 Narration voice and Ignorance .....	92
3.3. Documentary voice in up sounds of talking heads .....	94
3.4. Documentary voice in visual images.....	102
<b>CHAPTER FOUR: HIV/AIDS VISUAL DEPICTION IN DOCUMENTARY FILMS .....</b>	<b>110</b>
4.1. Introduction .....	110

4.2. Visual images of characters infected with HIV/AIDS in documentaries.....	110
4.3. Visual pictures of dwelling places for people living with HIV/AIDS .....	130
<b>CHAPTER FIVE: SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS .....</b>	<b>134</b>
5.1. Introduction .....	134
5.2. Summary of Findings .....	134
5.2.1 Character Portrayal in HIV/AIDS Documentaries as Vehicles for Positive Living with HIV/AIDS .....	134
5.2.2 Documentary Voice as an Agent of Advocacy for Positive Living with HIV/AIDS .	135
5.2.3 Visual Depiction of HIV/AIDS in Documentary Films .....	136
5.3. Conclusions of the study .....	138
5.4. Recommendations .....	140
<b>REFERENCES .....</b>	<b>143</b>
<b>FILMOGRAPHY .....</b>	<b>149</b>
<b>APPENDICES.....</b>	<b>150</b>
Appendix 1: Participant Interview Consent Form.....	150
Appendix 2: Focus group discussion consent form.....	152
Appendix 3: Observation guide.....	153
Appendix 4: Interview guide for documentary film directors and producers .....	154
Appendix 5: Guide for conducting an interview with a person living with HIV/AIDS or a health professional.....	155
Appendix 6: Focus group discussion guide.....	156
Appendix 7: Transcription of the interview with Mr. Inganga (a documentary film producer).....	158
Appendix 8: Interview data transcription from the interview with Mr. Arnold Oloo a Public Health professional.....	164
Appendix 9: Transcription of Interview with Madam X (A PLWHA) .....	171
Appendix 10: Transcriptions of FGDS- Psycho-Social Support Literacy Group ...	182
Appendix 11: Research Approval by Kenyatta University .....	216
Appendix 12: Authorization from NACOSTI for Research.....	217
Appendix 13: Permit from NACOSTI to Conduct Research .....	218
Appendix 14: Authorization from County Commissioner, Siaya County.....	219
Appendix 15: Authorization from County Director of Education, Siaya County ...	220

## LIST OF FIGURES

Figure 1.1 Conceptual Framework .....	35
Figure 2. 1 Maria’s house in the background (Courtesy of Fishers of Pain).....	51
Figure 2. 2: Maria’s malnourished and sickly child (Courtesy of Fishers of Pain)...	56
Figure 2. 3: Residence of a family living with HIV/AIDS (Courtesy of MSF, Dying of HIV in 2017). .....	60
Figure 2. 4: Mary Achieng; living with HIV/AIDS (Courtesy of Mercy in Action).	61
Figure 2. 5: An unnamed woman seated at the reception baym (Courtesy of Mercy in Action).....	63
Figure 2. 6Figure 2.6 A Medium Close-Up Shot of the woman at the reception bay (Courtesy of Mercy in Action). .....	63
Figure 2. 7: Visiting with an HIV/AIDS patient (Courtesy of MSF -Dying of HIV in 2017).....	67
Figure 2. 8: HIV/AIDS patient is helped by medical personnel to sit up.....	68
Figure 2. 9: The image of an HIV/AIDS patient in a hospital ward.....	68
Figure 2. 10: An emaciated HIV/AIDS patient in a hospital ward.....	68
Figure 2. 11: A paralysed HIV/AIDS patient admitted in hospital (Courtesy Dying of HIV in 2017). .....	75
Figure 3. 1: Timothy Otieno, standing beside the grave of an HIV/AIDS victim (Courtesy of Fishers of Pain).....	88
Figure 3. 2: Devastation of HIV/AIDS; a fresh grave outside a deserted homestead (Courtesy of Fishers of Pain).....	103
Figure 3. 3: A family affected by HIV/AIDS cooks on traditional three stones (Courtesy of Mercy in Action). .....	104
Figure 3. 4: A permanent house on the left is deliberately avoided (Courtesy of Okumu-Mercy in Action). .....	104
Figure 3. 5: Interview against a backdrop of the partly ruined semi-permanent house (Courtesy of Okumu-Mercy in Action).....	104
Figure 3. 6: Bushy hospital environment and crowding (Courtesy of; Okumu-Mercy in Action).....	105

Figure 3. 7: The torn beddings point to social status of patients visiting the facility (Courtesy of Dying of HIV in 2017). .....	106
Figure 3. 8: a scally and wrinkled skin of a HIV patient in hospital (Courtesy of Dying of HIV in 2017). .....	107
Figure 4. 1: Winney, an HIV/AIDS patient with alcerations on her mouth in hospital ward (Courtesy of Dying of HIV in 2017). .....	111
Figure 4. 2: An HIV/AIDS patient in a hospital ward is fed through a tube in his nose (Courtesy of Dying of HIV in 2017).....	112
Figure 4. 3: A patient body muscle is wasted due to HIV/AIDS (Courtesy of Dying of HIV in 2017). .....	112
Figure 4. 4: Image of an HIV/AIDS patient in advanced stage if the infection (Courtesy of Dying of HIV in 2017). .....	113
Figure 4. 5: An elderly lady down with HIV/AIDS (Courtesy of Mercy in Action). .....	121
Figure 4. 6: Wounds allegedly caused by HIV/AIDS (Courtesy of Mercy in Action). .....	125
Figure 4. 7: Jack Otieno in his farm harvesting maize (Courtesy of Mercy in Action).....	126
Figure 4. 8: Karen Adhiambo, a widow sensitises the public on HIV issues (Courtesy of Fishers of Pain).....	128
Figure 4. 9: Alice inside the permanent house we have no full visual of (Courtesy of Mercy in Action). .....	131

## OPERATIONAL DEFINITION OF TERMS

- Able-bodied:** Healthy persons free from any ailments HIV/AIDS.
- Advocacy:** Creating awareness on positive living with HIV/AIDS.
- Affected:** People with blood relationships to persons infected with HIV/AIDS.
- Boda Boda:** A form of transport where motor cycles are used to ferry people from place to place.
- Documentary Film:** An educational short motion picture production on real issues in society.
- General Public:** People in society in which persons infected with HIV/AIDS live.
- Jaboya:** Sexual relationship between a fisherman and a fishmonger.
- Infected:** People living with HIV/AIDS.
- Lost to find:** People who have defaulted on ARVs and cannot be traced for treatment.
- Others:** Persons infected or affected by HIV/AIDS in the society.
- Mobile Cinema Van:** Vehicle fitted with movie screening equipment and screen films/documentaries from place to place.
- New positive:** People who test positive to HIV/AIDS for the very first time when they visit a testing center.
- Positive living:** Accepting HIV status and leading a normal life.
- Survival Sex:** A form of prostitution to meet basic needs.

## ABBREVIATIONS

APSSLG	Adult Psycho-Social Support Literacy Group
APSSG	Adolescent Psycho-Social Support Group
AIDS	Acquired Immune Deficiency syndrome
ART	Anti-Retroviral Therapy
CHW	Community Health Worker
HIV	Human Immune deficiency Virus
FGD	Focus Group Discussion groups
KHCP	Kenya HIV/AIDS County Profile
KHDS	Kenya Health Demographic Survey
KMCC	Knowledge Management and Communication Capacity
KNASP	Kenya National HIV/AIDS Strategic Plan
M	Moderator in the FGDs and Interviews
MSF	<i>Medicins Sans Frontieres</i>
NACC	National Aids Control Council
OIP	Oyugis Integrated Project
P	Participant respondent
PLWHA	People/ Person Living with HIV/AIDS
PMTC	Prevention of Mother to Child
POV	Point of View
PSSG	Psychosocial Support Group
PWID	People who Inject Drugs
UNAID	United Nations Program on HIV/AIDS
WOFAK	Women Fighting Aids in Kenya
WHO	World Health Organization

## ABSTRACT

Although there is sufficient knowledge on HIV/AIDS, the disease has continued to cause devastation in society. The larger Nyanza Region has recorded a high HIV/AIDS prevalence at 15.1% with Siaya County recording 21% HIV/AIDS prevalence. The deep-seated resentment of people living with HIV/AIDS has been perceived as a factor in the spread of HIV/AIDS which has been portrayed as a death sentence. Since documentaries play a key role in providing information to the public, this study interrogated the agency of documentary film in advocacy that highlights positive living with the virus. It interrogated three areas of documentary film making which included characterisation, documentary voice, imaging and depiction through cinematography, scripting and editing as well as the narrative styles which include structure, plot and dialogue. Being a qualitative study, it did obtain data through FGDs, in-depth interviews and content analysis. The researcher employed semiotics and reception theory in undertaking the study, and through these theories, reading of texts was made possible. It was thus established that every filmmaker has a message they intend to advance, either consciously or subconsciously as they entertain or inform. The study found that People Living with HIV AIDS (PLWHA) have been characterised as having poor health and living on the compassion of others. The study also established that PLWHA cannot be identified from their physical looks, and neither is death an absolute end to an infected person. The study observes herein that the documentary film production on HIV/AIDS, do impact on the perceived role of the films as vehicles for advocating for positive living through cinematic explorations. The study then concludes that filmmakers must not mislead the audiences by assigning a point of view that is biased and inclined to reflect negatively on certain people and places. Researchers and filmmakers will find this study useful as it may offer guidance on how to reimagine telling the story of PLWHA to the world through documentaries. The findings will also contribute to the body of knowledge on producing documentaries touching on PLWHA.

## CHAPTER ONE: INTRODUCTION

### 1.1 Background

The power of moving images to communicate effectively across different demographics and social backgrounds is not in doubt. Carroll (1985) avers that film is widely accessible across social cultural boundaries in so far as everybody is familiar with reality. In this point is an assertion that carefully composed, selected and combined images through professional editing have the capacity to bypass language barrier, which often is a major hindrance to effective communication (Carroll, 1985). Hodes (2007) avers that the value of film in relation to other types of mass media lies in its verisimilitude. This is what Carroll (1985) explains, that films have the power to present the viewer with a picture of what appears to be reality.

MacIsaac (2017) asserts that TV and news channels as well as movies have a substantial influence on people's everyday lives. This observation concurs with Diang'a (2013) who avers that the medium of film showcases life in its real form, one which the viewer easily identifies with. A reason Moore, Onsomu and Abuya (2014) observe easily instigates discussions among people over sensitive issues in media than in their own lives. Mungai (2018) avers that, film, whether it be a documentary or drama is motivated to communicate something in the ecology of the filmmakers' community. As such, it likely takes some position around the frontier of change as designed to either move forward or to photograph it for us to see as it is.

As regards HIV/AIDS, filmmakers globally strove to voice their contribution through various film genres. *Pili* (2017), directed by Leanne Welham, is a feature film set in rural Tanzania. It tells the story of Pili, a poor HIV-positive single mother of two, who

ultimately prostitutes herself without protection so as to gain financial independence. UNAIDS (2018) asserts that the makers of this film intended to show the plight of women living with HIV in deplorable conditions. Upon premiering, they stated that they aspired for anonymity and to protect the women from stigma. However, they did report on the cast, giving plausible information that more than 65% of the cast were women living with HIV/AIDS (UNAIDS, 2018).

Kerubo (2015) studies *Shuga*, a TV Drama series established in 2009 to harness the power of mass media in HIV/AIDS edutainment. She observes that the characters in *Shuga* live bright and sassy lifestyles. Following a similar trend common in most media, Kerubo (2015) observes that the causes for HIV/AIDS infection are highlighted as: sexual involvement with multiple partners, sexual exploitation, and drug abuse. These facts lead to aspersions that probably those involved in these traits are the ones at risk of infection. Tomaselli (2009) observes that a popular South African music TV station '*Channel O*', while intending to encourage faithfulness as a way of fighting HIV/AIDS, identified people living with HIV/AIDS as promiscuous in a society that likened HIV/AIDS infected people to dirt that needed cleaning. This eventually influenced the public's perception of isolating people living positively with the virus.

In the feature film *Love for Life* directed by Changwei Gu (2011), a 'Hollywood love story and medical docudrama' according to Hanson (2020, p. 93), labours to portray the struggle for acceptance of people living with HIV/AIDS in a remote village in China. This story follows the struggle of Zhao Deyi and Shang Qingin's love story and last moments of happiness. According to Zuo (2014), *Love for Life* is an attempt to re-tell and un-stigmatise the disease through the use of sensual tactility, sentimental

convention, and melodramatic performance (p.209). However, Deyi's suicide leaves questions for the spectator - is there really hope for one living with the virus? This was the concern this study sought to point out, being prevalent in films. In yet another film, *Inside Story* directed by Rolie Nikiwe (2011), Kalu a young footballer dreams of playing professional soccer. His life dramatically changes when he gets exposed to the HIV virus. As Kalu faces aggression on the outward, the sci-fi filmmakers depict the raging battle of his body cells. The film takes us through Kalu's struggles even to his eventual success as he achieves his dream despite his status.

*Freddie Mercury: His Tragic AIDS Story (2016)* a Docu-drama directed by John Fothergill, illustrates the story of the legendary and iconic rock figure Freddie Mercury whose secret carefree life is said to have exposed him to HIV/AIDS. According to the film, he lived a precarious life of drug injection, gay relations and unprotected sex, traits associated with the virus. In the documentary, a popular journalist is depicted as having declared HIV/AIDS a case of suicide, a declaration that works against positive living.

Another film, *Passing the Torch – Film 3 (2018)*, a South African short documentary film by Staffan Hildebrand was intended to shed light on issues surrounding HIV/AIDS. It was meant to raise awareness and to attempt to re-establish commitment and conversation around HIV/AIDS (AIDS Foundation, South Africa, 2021). However, the voice it carried did cast aspersions on the eventual end of an HIV/AIDS infected person – death.

Running on a similar strand, Kenyan documentary films like *Dunia ni Mbaya (2001)* by Kibaara nto Kaugi, *Deadly Catch (2005)* by David Gough, and *Sio Mimi (1989)*

and *Silent Epidemic (2011)* by Raphael Tuju among others, presented horrifying images that left the audience in shock. The images relayed were those of wasted bodies, skin ulcerations and inflammation of reproductive organs, ostensibly caused by HIV/AIDS. Rwafa and Rafapa (2014) aver that since HIV/AIDS symptoms are not always obvious, directors have a challenge to handle the theme with care lest film images be used to send wrong signals about the nature and manifestations of the disease. Whatney (1990) as quoted in Rwafa and Rafapa (2014) states that, the use of horrific presentations creates ‘phobic visuals’ that promote fear and hopelessness for the infected individuals.

Aitken and Dey (1998) on the growth of the HIV/AIDS film genre wondered whether these films could be used to improve communication skills, only time would tell. Unfortunately, it then appeared over the years that the films being produced were doing more harm than good to the plight of the infected. Kerubo (2015) asserts that there was very little impact if any, that HIV/AIDS media campaigns were noted to be making. It is worth noting the concern by Omuyoma (2016) that for there to be a behavioural impact, the messaging should be done with the aim of improving audience understanding that leads to the desired action. Such is the core of documentary films, even to coin elements of positive living, a dimension that has been wanting in many of the available films.

Hellandendu (n.d) states that at the height of the denial of AIDS in Nigeria, the Ministry of Health resorted to producing *Dawn of Reality (1992)*, a documentary film intended to enlighten the masses on HIV/AIDS. The documentary then focused on convincing the masses who thrived in disbelief “the existence of HIV/AIDS to believe and protect themselves from the deadly intractable disease” (p. 146).

Hodes (2007) states that the documentary format is particularly seductive as it claims to depict the truth. Indeed, Hicks (2007) affirms that documentary cinema in its approach to information, persuasion and communication is like a newspaper which processes and distributes factual information. UNAIDS (2004) observes that in putting HIV/AIDS on the news agenda and also encouraging relevant leaders to take action, documentaries became a key element in media involvement in reporting the epidemic. The report observes that in 2003, England's BBC, China Central Television, Spain's Radiotelevision Espanola, Time Warner Network's HBO in the US, Indonesia's Metro TV as well as Moscow's NTV included documentaries on HIV/AIDS in their programming bulletins. Documentaries having acquired an elevated sense of legitimacy in the mind of the viewer (Hodes, 2007) would therefore be instrumental in instilling desired beliefs about the subject of HIV/AIDS. In 2016, the Chinese Health Ministry supported a proposal to combine a feature film with a documentary as essential elements of a wider multimedia HIV/AIDS public health education campaign (Hanson, 2020).

It is therefore upon this observation that gives credibility to the deployment of documentary films in the fight against HIV/AIDS, especially when in need of eliciting dialogue. It is presumed that as people watch documentaries on HIV/AIDS, genuine discussions will ensue. This concurs with Mclane (2012), whose assertion is that it is a documentary filmmaker's intent to increase our understanding of, our interest in, our sympathy for their subjects, and perhaps our future actions regarding a certain trend or behaviour. This is the point that positions documentaries as better placed in playing an effective advocacy role on HIV/AIDS issues.

Hart (2002) posits that film offers a unique opportunity for enlightening audience

members on issues of HIV/AIDS. However, he further notes that a significant degree of homophily must first exist between individual audience members and the characters in such films/documentaries for them to be effective at getting the audience to personalise the danger of HIV/AIDS and readily engage in preventive measures. In this case, homophily refers to the level to which people with HIV/AIDS in documentaries are similar in meaningful ways (age, race and sexual orientation) to the audience viewing them (Rogers & Shifield-Rogers, 1999 as cited in Hart, 2000). In other words, the presentation of the HIV/AIDS in films/documentaries is key to the way the information is perceived by the target audience.

According to WHO (2016), by 2014 the world had been losing 1.2 million people annually due to HIV/AIDS-related deaths. Closer home, NACC (2016) affirmed that HIV/AIDS accounts for 29% of adult deaths annually and 20% of the deaths among children aged below five years. The report blamed HIV/AIDS for lowering the country's per capita output to 4.1% with an estimated 71034 new infections among adults annually and 6613 new infections among children. It identified men who have sex with men (MSM), female sex workers and people who inject with drugs (PWID) as the most affected by HIV/AIDS. It is unfortunate that such people have the least access to prevention, and treatment as their behaviors are stigmatizing and even criminalised (NACC, 2016).

According to Kenya Health Demographic Survey KNBS (2014), widespread stigma and discrimination of people living with HIV/AIDS are the two key reasons identified as adversely affecting the willingness of people to be tested and to adhere to Anti-Retroviral Therapy (ART). KNBS (2014) observed that there is sufficient knowledge on HIV/AIDS with 52% women and 66% men reporting comprehensive knowledge

on HIV/AIDS. Kenya AIDS Indicator Survey 2012/2014 points to a regional variance in HIV prevalence among adults ranging from 15.1% in Luo Nyanza to a low of 2.1% in Northern Kenya (NACC, 2016). Even at regional level, there is variance in prevalence per county. KNBS (2016) puts Siaya County at 24.8%, 4.2 times higher than the National prevalence with women comprising 26.4% and 22.8% for men while Homa Bay County is at 26% prevalence.

KNBS (2016) notes that by 2015, 126,411 people were living with HIV, Siaya alone giving 8.6% of people living with HIV/AIDS in Kenya. Moving through West Yimbo Ward in Bondo Sub County, one is faced with the reality of the devastation of HIV/AIDS on families. From Misory village to Nyenye, Uhanya, Kanyibok, Siungu, Honge, Got Agulu and other beach line communities tell a similar story of shuttered lives. According to Arnold Oloo, the Clinical Officer at the Usenge Dispensary, the damage done by HIV/AIDS in this area and beyond deserves serious intervention. Oloo (Personal Communication, July 20, 2019) avers that despite efforts by the government to battle stigma, it still is a great challenge to date, as the majority of PLWHA cannot freely disclose their status. Matsika (2013) in a case study of Harare's Hatcliffe Extension Suburb on the need for positive living among people with HIV/AIDS, stated that in some instances, people are forced to leave their homes or change their daily activities due to disclosure of their HIV status. He further observes that there are cases where people have been murdered after disclosing their status.

Since there seemed to be sufficient knowledge on HIV/AIDS in larger Nyanza region, yet that has not reflected in reduction in resentment of PLWHA, there is need to establish the salient issues of HIV/AIDS as portrayed in Kenyan documentaries. This study therefore did interrogate how HIV/AIDS has been depicted in selected

documentary films, while intending maximum benefit to the PLWHA as an advocacy tool for positive living.

## **1.2 Statement of the Problem**

Documentary films communicate by the use of visuals and sound, making them ideal for advocacy to both the literate and illiterate in the society. This mode of communication becomes vital in relaying messages on a social issue such as HIV/AIDS. Since the 1980s, many documentaries have been produced in Kenya as a way of mitigating the spread and effects of HIV/AIDS in communities. Many such documentaries have focused on Siaya and HomaBay Counties which have borne the brunt of the disease. According to NACC (2016), Siaya County remained at the top of the HIV prevalence rate recording 24.8% against the National average of 5.9%. High intolerance to people living with HIV/AIDS is also reported in the county. Therein lies the need for scholars to interrogate these documentaries by analysing their aesthetics and communicative value so as to ensure that they are sending the right messages in the best possible manner through a critical and independent inquiry. As such, there is a need to understand their agency in responding to the social and community needs of people living with HIV/AIDS. This study therefore did set out to interrogate characterisation, voice and visual depiction as used in selected documentaries in advocating for positive living with HIV/AIDS.

## **1.3 Objectives of the Study**

1. To identify and examine how characters living with HIV/AIDS have been portrayed in the selected documentary films in their attempt to advocate for positive living with HIV/AIDS.

2. To evaluate how documentary voice has been used as agent of advocacy for positive living in the selected documentary films on HIV/AIDS.
3. To establish how HIV/AIDS visual imaging aids or inhibits the depiction of positive living among the infected, affected and non-infected in the selected Documentary films on HIV/AIDS.

#### **1.4 Research Questions**

1. How have the characters living with HIV/AIDS been portrayed in the selected documentary films with regard to advocacy for positive living with HIV/AIDS?
2. How is documentary voice used as agent of advocacy for positive living in documentary films on HIV/AIDS?
3. How does HIV/AIDS visual imaging aid or inhibit the depiction of positive living among infected, affected and non-infected in the selected documentary films on HIV/AIDS?

#### **1.5 Assumptions of the study**

1. Character portrayal is a vehicle of messages for positive living in documentary films on HIV/AIDS.
2. Documentary Voice can be used as agent of advocacy for positive living in documentary films on HIV/AIDS.
3. HIV/AIDS visual imaging in documentary films depicts positive living among infected, affected and non-infected.

## **1.6 Significance of the study**

With the introduction of anti-retroviral therapy, the number of people living positively with HIV/AIDS in communities is increasing by the day. These members of the society must find their place to make meaningful contributions in the society, as most of them are professionals in their respective areas of expertise. If not handled well, the increasing numbers of people living with HIV/AIDS will be a burden to the society they live in. They are also likely to spread the virus as they seek a sense of belonging and love, away from the normalcy of stigma and isolation.

The findings of this study therefore shape future depiction of HIV/AIDS in documentary films to effectively communicate messages of hope that act as agents of positive living for the infected and or affected. The findings also inform future visual imaging and narrative styles in documentary films on HIV/AIDS that advocate for positive living with HIV. These findings add to the body of audio-visual communication knowledge with regard to HIV/AIDS advocacy requiring action.

## **1.7 Scope and limitations**

The research was confined to Siaya County of Kenya, focusing on Yimbo West Ward in Bondo Sub-County. The study further limited its population to three social support groups operating at Usenge Dispensary. The study analysed only three documentary films with a focus on one ethnic community, which may not be representative of other communities due to cultural diversity.

## **1.8 REVIEW OF RELATED LITERATURE AND THEORITICAL FRAMEWORK**

### **1.8.1. Introduction**

This section looked at literature from previous studies on the depiction of HIV/AIDS in documentary films. The section is divided into three parts; Characterisation in documentary films on HIV/AIDS, Voice in Documentary films on HIV/AIDS and visual depiction of HIV/AIDS in documentary films to foster positive living.

### **1.8.2. Character Portrayal in Documentary Films on HIV/AIDS**

According to Paula (2020), cultural productions around HIV/AIDS do carry a discourse that is still laden with stereotypes and prejudices. She observes that in blaming women for the spread of the pandemic, the Mainstream media during the 80s classified women with AIDS in two groups; 'safe' or 'dangerous'. The documentary film *All Affected: Aids and the Family* (2016) by Ingolo Wa Keya, advances this theme of blame on those infected with HIV/AIDS on women falling into a circle of sex predators. Hodes (2007) observes a similar trait while studying South African documentaries. He observed that, even though majority of the films aim at eliminating the isolation of PLWHA, this is often not supported by the visual images or the narration which are often laced with moralisation and attribution of blame. He further asserts that, media representations of HIV/AIDS present it as coming from moral decay in the society, and PLWHA as wasted bodies awaiting death.

In Paula's analysis of the documentary *DiAna's Hair Ego (1989)* and *(In) Visible Women (1991)* both by Ellen Spiro, she observes that the characters' resolve to make a positive impact on their communities often arose when they realised their communities were being portrayed negatively, as well as lacking or were receiving incorrect information about HIV/AIDS. Paula (2020) further asserts that while seeking community identity and empowerment, Spiro presents the real-world effect at the same time contesting dominant narratives about HIV/AIDS. Having established from these studies that activist art as well as advocacy art practices in documentaries can be efficient in the fight against AIDS and stigmatisation, this study sought to identify the advocacy elements in character portrayal of PLWHA in the selected documentaries. These studies observe that the eminent characterisation of PLWHA in film often outweighs the hope they claim to communicate. Rising from this observation, this study set out to look at how PLWHA are depicted in selected Kenyan documentaries while intending to advocate for positive living.

Ismael, Karu and kamarulzaman (2016) posits that HIV/AIDS is a problem with deep economic consequences often leading to debts as the infected and or affected are denied the ability to engage in gainful economic activities. In the preface of his book; *HIV/AIDS: A Very Short Introduction*, Whiteside (2008) while agreeing that HIV/AIDS does not discriminate observes that HIV/AIDS is a disease for the deprived and the powerless because it seems to find easy ground among the poor, be they poor nations or the poor individuals in rich Nations. Parker (1994) concurs observing that once the virus gets into a community, it tends to travel the path of least resistance of those who are poor in the community. Learning from these studies, this research thus

aspired to establish how PLWHA are characterised in the sampled Kenyan documentary films, regardless of their status.

Cooper (2015) asserts that stories portrayed in films are powerful advocacy tools for creating social change. This implies the assertion by Hode (2021) that Mozambican filmmakers resorted to address the HIV/AIDS crisis domestically through crafting narratives that Mozambicans could associate with. This became a counter move to the popular Western concept of HIV/AIDS filmmaking, even moving away from the narrativisation of women's subjectivities, thus resulting in the emergence of a cinema of action driven by humanitarian and pedagogical objectives.

In her analysis of *Looking*, Cooper (2015) observes that by challenging the way HIV is characteristically portrayed, *Looking* moved away from the tradition that originally dictated HIV discussions. With that, it instead rewrote the narrative regarding issues surrounding HIV hence altering how HIV is portrayed through the media, and subsequently, its discussion today. Despite the positive mentions, Cooper (2015) observes that HIV among gay men is still sadly a case of irresponsible risk-behaviour, an issue of great concern. Premising from these observations, this study sought to establish portrayal of characters with HIV/AIDS in the selected documentaries.

### **1.8.3. Voice as an Agent for Positive Living Documentary Films on HIV/AIDS**

There is a lot that comes to mind in the question of voice in documentaries. According to FitzSimons (2002), documentaries have a voice of their own, that is, the means by which a particular point of view is made known to the public. Ramesh (2017) argues that the plotting in documentary films should lead to calls for action from the audience. As such, he observes that the way information is presented to the target

audience is as important as the message formulation itself. Of notable essence here is the fact that, the message is of utmost importance, since the power of a documentary ostensibly lies in its point of view, which is the message of its maker, intended to drive forth a certain line of thought. FiltzSimons (2002) asserts that the voice of a documentary is the means by which a particular point of view is made known to the audience by the producer. He adds that the voice of the documentary comes from the selection and arrangement of sounds and images to create logic. This study sought to identify the point of view of the selected documentaries with regard to advocating for positive living.

According to Nichols (2001), the voice of a documentary is the argument of the film director regarding certain elements of the historical world in which he/she lives. He argues that the voice of a documentary is not restricted to what is said verbally on screen, and can be said to speak about this world through both sounds and images. Keil (2014) then affirms that this voice is different from the literal voice which springs from voice-over narrations. According to Onen (2021), it can be employed as a narrative element since it has an effect on the narrative style and the mode of the documentary. This is what Nichols (2001) further asserts that the voice of the documentary can make a case or present an argument, hence convey a point of view. To this effect, this study sought to examine what essential and underlying message the selected documentaries do rely on, through their ensemble in advocating for positive living.

Lo, Berry and Liping (2020) assert that cinematic text is haptic, which implies that it can be felt in the body. In this regard therefore, it is important to draw a critical example from Hanson (2020) concerning the hybrid documentary-film developed

from the footage of the film *Love for Life* and actual interview recordings of the cast and crew. Hanson (2020) asserts that;

One of the reasons the Chinese government likely supported making *Love for Life* is because of its focus on sick villagers who contracted HIV, considered an ‘innocent’ or ‘legitimate’ way from the ‘moral disease’ perspective. No gay people, sex workers, or intravenous drug users enter the narrative of either the novel or the film.... By contrast, most Anglo-American films devoted to the HIV/AIDS epidemic were located in major cities and focused on the gay population, prostitutes, intravenous drug users, and other people considered to engage in high-risk behaviours. (p. 90).

Emerging from this citation and as propelled by the documentary is the assertion that China considered HIV infection through illegal blood trade a nobler way of contracting the disease as compared to the issues of morality as advanced by other countries. This dangerous conception according to Ekpenyong (2007), is a product of some documentaries (and films by extension) wittingly or unwittingly compromised their theoretical and ideological precept of dealing with truthful actualities. Since every documentary has a point of view which it tries to propagate, it emerges that for ‘*Together*’, it is moral sanity that appears glorified even in the wake of irregularities pertaining to infection of the pandemic.

According to Kombo, Sariola, Gichuru, Molyneux, Sanders and Elst (2017), in 2013 Kenya Medical Research Institute (KEMRI) in Mtwapa-Kenya, made a documentary called *Facing Our Fears*. Through Facilitated Film Viewing (FFV), Kombo et al. (2017) engaged communities in HIV/AIDS research involving Lesbians, Gays, Bisexual and Transgender (LGBT). In their findings, they did note that, that documentary was seen as a strong visual communication tool with the power to enlighten, educate and even persuade people by instigating discussions with the potential to reduce stigma related to homosexuality. Kombo et al. (2017) further

affirm that, LGBT being a sensitive topic in Kenya, the members of these organisations exuded confidence in the documentary's ability to provide an opportunity for dialogue between them and the wider community about same sex relationships while acknowledging their existence. Observing the findings by Kombo et al. (2017), they fail to bring out the potential of documentary films as tools of advocacy for hope to people living with HIV/AIDS, irrespective of LGBT status.

Macheso (2016) posits that the biggest dilemma faced by HIV/AIDS positive persons is how they are to face the general public, since living with HIV/AIDS has been rendered 'queer'. This observation is drawn from the concern in the findings that the cast in the documentary might not be prepared for the eventualities in the event the documentary goes public. This study thus endeavored to understand how selected Kenyan documentaries advocate for positive living with HIV/AIDS for the infected and the affected.

Hart (2002) asserts that the public has a lot of faith in the media, and what the media says influences the audience in a particular direction concerning an issue at hand, hence the need for care to avoid misleading the audience. While agreeing to the effectiveness of mass media in communicating HIV/AIDS messages to the masses, Omuyoma (2016) states that emphasis should be placed on understanding of the communicative messages. When messages are not packaged well, the media may easily fall victim to miscommunication.

Hodes (2007) posits that, efforts to fight stigma around people living with HIV/AIDS have most of the time yielded the opposite effect, fueling stigma against those living positively with HIV/AIDS. Through visual images used and accompanying narration,

PLWHA are portrayed as hopeless and in some instances blamed for the infection. These studies by Hart (2002), Omuiyoma (2016) and Hodes (2007) provided a catalyst for this study where the voice was analysed for its role in communicating the desired message in documentaries.

Rukambe (1999) asserts that documentary films can be used to give power to infected individuals to live positively with the virus. In his discussion of the documentary, *Emma's Story*, Rukambe (1999) avows normalness in living with HIV/AIDS. Emma, the main character in the documentary advances hope for positive living despite one's HIV positive status.

Through *Emma's story*, despite offering a common-sense resolution that HIV positive persons are as normal as those without HIV/AIDS, he observes that their normal life is 'mythical'. One is left to wonder then, what exactly is the point in advancing some sort of false hope? This perhaps is the fuel to the observation by Swindells, Mohr and Justus (1999) and Abasiubong, Ekot, Bassay, Etiobong, and Edyang-Ekpa (2010) that there are deeply engrained negative and resentful attitudes towards people living with HIV/AIDS, such that even when positivity is intended, negative strains in messaging are noticeable.

This takes us to the assertion by Aitkin & Day (1998) that films on HIV/AIDS are ultimately about dying, and that they fail to deal with the truth that one can live positively with the HIV virus. This study sought to understand the message delivered through the sampled documentaries on their reflection of PLWHA and to advance the opinion that documentary films can be used to effectively communicate HIV/AIDS messages while presenting the reality that one can lead a positive life.

Malagasi (2015) in the study of the film by Maneno Mtawali *'The Test'*, a Malawian film on HIV/AIDS, observes that HIV/AIDS positive persons view themselves as lesser human beings than the rest of the society. Indeed, Fife and Wright (2000) affirm that, HIV positive persons in most cases usually condemn themselves. They contend that the nature of stigma depends on whether the individual can be blamed for the illness and, the potential consequences of the illness on other members of the society. Abasiubong et al (2010) affirms that such depiction forms a major barrier to social affiliation and integration of HIV/AIDS positive persons in society.

Malagasi (2015) also observed that HIV/AIDS is projected as a stigmatising disease, subsequently denying PLWHA the right to socialization. While these studies amplified negativity associated with PLWHA, the current study sought to examine how voicing in local documentary films impact on positive living with HIV/AIDS as well as how it can be used as a key element in advocacy for positive living with HIV/AIDS.

#### **1.8.4. HIV/AIDS Visual Depiction in Documentary Films**

Osome (2021) observes that documentaries intend to influence either consciously or subconsciously. With that in mind, it is notable that they can be used to achieve an idea in mind which could be social, political or cultural (Mungai, 2018). This is what Diang'a (2013) posits, that what is filmed and how it is packaged have a great influence on how the transmitted message is understood. She adds that while trying to establish meaning out of the mise-en-scene, a spectator has to pay close attention to the setting, props, costume, performance and even lighting. As such, Osome (2021) further asserts that there exists a kind of coalition between documentary practice and

social change. In the case of HIV/AIDS filming, Paak (2014) avows that filmmakers have created a global visual image of what HIV/AIDS is. Osome (2021) thus points to the need to choose or design the visuals in any story in a way that complements and advances the narrative, of course with the aim of opening up discussions without the possibility of stigma. These observations affirm the place of the documentary in inspiring necessary debates towards issues of grave concern as HIV/AIDS visual depiction is in documentary films. This study thus endeavored to examine whether the visual content in the selected documentaries did correspond with the intended meaning of the documentaries by virtue of the discussions they elicited.

Osaigbovo and Wood (2013) affirm that film is considered very influential and seductive in convincing and communicating ideas on HIV/AIDS, and that in showing the effects of HIV/AIDS, it helps bring the disease into reality, and people believe more in what they see on screen. They further observe that in order to reduce all forms of discrimination, it is essential to show infected/affected persons and to have them share their experiences so as to create awareness and to advocate for positive living.

Osaigbovo and Wood (2013) place emphasis on showing the infected in films, the study doesn't, however, speak on the visual aspect of depicting HIV/AIDS. This is key in HIV/AIDS advocacy considering the assertion by Paak (2014) that most well-intentioned films unfortunately dehumanised their subjects through depiction of despair when documenting the pandemic, through the use of stereotypical images of suffering; people dying, villages in devastation and impoverished children. While agreeing that a person's private suffering may draw attention to the issue of HIV/AIDS, it also comes with a compromise on the dignity of the people involved. These stereotypical images used to represent HIV/AIDS have resulted in fixed

symbolic representation at the expense of personal situations. As such, this study sought to establish how visual depiction of the infected advocates for positive living with HIV/AIDS.

On studying the effectiveness of '*Uri Mu Ufa*' a Malawian film, Malagasi (2015) asserts that Malawians formed a stereotype that HIV/AIDS infected persons are sickly and very thin in body frame. This is what Hart (2002) had observed, that the shared social understanding of HIV/AIDS has resulted from stories on HIV/AIDS in the media over time, and that cumulative trends identified in film under certain circumstances on HIV/AIDS, significantly influence the way audience members perceive and respond to HIV/AIDS infected people when they meet in real life.

Malagasi (2015) further point out that such stereotyping and 'othering' has led to the unchecked spread of the HIV virus as one cannot tell an HIV positive person from looks. In this then, he sadly avers that film has failed to present living with HIV/AIDS as a normal existence. In reality, the number of people living positively with the virus is increasing by the day. This study thus was premised on the observation that; the media largely influences handling of people living with HIV/AIDS through particular presentations. This study then explored visual depiction of HIV/AIDS in selected documentaries and its effect on positive living with the virus among infected, affected and non- affected in the society.

Watney (1992) asserts that the confining of HIV/AIDS to certain people and/or places does play against the very role of the documentary meant to fight HIV/AIDS. Hart (2002) affirms that in the early years of HIV/AIDS in America, it was associated with the gay community, implying that the other groups and individuals were safe from

exposure. Ismael, Karu and Kamarulzaman (2016) noted that in Sudan, HIV/AIDS was blamed on women who would then suffer rejection by their families, face the burden of blame and shame as well as lose their entitlement to family property. As a result, testing HIV positive had been equated to a death sentence with older parents of HIV positive persons too frightened to disclose their children's HIV status.

Matsika (2013) affirms that women were neglected, isolated and abandoned even by close family members upon disclosure of their HIV status. As observed, this then developed failure to disclose one's positive status which then resulted in continued spread of the virus involuntarily by the infected as can be noted of Pili in the film *Pili* directed by Leanne Welham (2017). This study hence sought to look at ways in which film documentaries could be used more effectively in demystifying the fear in people associated with HIV/AIDS, some of which is unfounded.

### **1.8.5. Synopsis of Documentaries Selected for Study**

#### **1.8.5.1. Dying of HIV in 2017 by MSF (2017)**

In trying to satisfy the objectives of the study, three documentary films were used, namely, *Dying of HIV in 2017* by Medicins Sans Frontières (MSF), also known as 'Doctors Without Borders'. The documentary was produced at Homa Bay district hospital in 2017. MSF is an international humanitarian medical non-governmental organization of French origin specialising in the provision of health services.

The documentary opens with a shot of Winney Atieno, an HIV/AIDS patient at Homa Bay District hospital lying in bed with doctors surrounding her bed. Dr. Berna Gurer explains how Winney was started on medication with late-stage HIV, which had weakened her immunity making her vulnerable to infections. The camera then moves

to another patient by the name of Akunda also lying-in bed and many others. At this stage, Dr Gurer explains that many others are in the same condition as Winney. The voice over comes in to explain that HIV continues to kill people at a time when Anti-retroviral drugs are plenty. The narrator points out that in 2016, more than 1 million people died of HIV/AIDS. Dr Gurer wonders why people are dying in large numbers from HIV/AIDS like before the introduction of ARVs. At that point, a text in bold comes on the screen: 'Dying of HIV in 2017'. An attendant to a patient lying on bed seems to be staring at the text. We are then introduced to a shot of the hospital as patients come in.

The crowding at the reception is shown as an officer calls out patient files, to go see the doctor. Dr David Maman comes to explain that 15 million people are on ARVs worldwide and the mortality is either due to adherence problems or medication failing. The narrator then explains that specially tailored care is needed for patients whose treatment is failing. Dr. James Abwao explains that the majority of people they get at the hospital, already know their status. He adds that either they have been on ARVS for a long time, and they are failing, or they defaulted, or have an adherence problem and therefore are prone to opportunistic infections, which he says is a challenge in the ward.

The voice over explains that though it is believed that if one is on ARVs, one will live for long without falling sick, the truth is that the journey for people with HIV is strewn with pitfalls. At this point we are introduced to a woman who was chased from her home due to her HIV status. In an interview, the lady explains how she defaulted in the process as she could not access her medication. She ended up being paralyzed from the waist downwards due to the interruption of the medication.

The scene moves to a HIV/AIDS couple home visit by social workers. The patient is in a temporary structure, the husband brings out her medication for inspection by the visiting team. The patient explains that if the medication is taken well, one goes on with life as normal. He explains that when many people get better as a result of the medication, it is mistaken for total healing, a situation that makes the victims leave medication. He observes that virus only comes back with more force.

We are taken back to the ward situation, where we see desperate patients, young and old, women and men, lying in bed as the narrator pronounces that the other challenge is identifying patients whose treatment is failing. She goes on to explain why it is important to obtain results as fast as possible for people infected with HIV/AIDS. At this point we are shown shots of different testing tools at patients' beds. Dr. Maman explains that the process of diagnosing opportunistic diseases must be accelerated to win the fight against HIV/AIDS infections with special emphasis on tuberculosis and cryptococcal meningitis, the two most common opportunistic infections. Shots of patients who are not able to support themselves are then introduced in the documentary.

Away from the hospital scene, we are taken to a market scene as the narrator announces that there is another challenge of the sick that are not able to reach the hospital and have never tested for AIDS. At 6:30: 00, the documentary moves to Central Africa hospitals where HIV prevalence is very high. Here the narrator explains that there is very little access to testing and counseling. Mr Tanguy Andigbia, a health promoter, explains that patients come to hospital when they are very weak while others don't afford to go to hospital.

The documentary focused on HIV patients already at the AIDS stage at the Homa Bay District Hospital. It followed the journey patients have gone through to reach the critical stage of being bed-ridden. The documentary explains what needs to be done to avoid getting to the AIDS stage in the journey with the disease. The documentary does not hide the fact that HIV/AIDS patients will die from the disease even in the era when Anti-Retroviral drugs are readily available. The documentary ends in a hospital scene where doctors attend to patients who appear to be in an advanced stage of HIV/AIDS.

The documentary is relevant for the study as it provides a glimpse of what those infected with HIV/AIDS go through. Persons infected with HIV/AIDS are prominently used in the documentary, which directly talks to the research objective number three on visual depiction and imaging of characters living with HIV/AIDS in documentaries and objective two on voice of documentaries on HIV/AIDS.

#### **1.8.5.2. Fishers of Pain: HIV Situation in Homa Bay County (2016)**

The documentary was produced in 2016 in Rachuonyo Sub-County of Homa-Bay County. The documentary focuses on the devastating damages of HIV/AIDS on the society fabric. Timothy Otieno, the producer/director is a KTN TV producer who specialises in health documentaries focusing on HIV/AIDS, a social problem destabilizing families in the society.

The documentary begins by driving through the dusty roads leading to the remote village of Karachuonyo. The camera pans through the village to reveal homesteads that have little human occupation, and where we have people, we find elderly women and little children. The narrator, Timothy Otieno explains that the virus has nearly

wiped out the entire community. The narrator then provides data of the HIV situation in Homa Bay County where the prevalence rate stands at 26% against the national prevalence of 5.6%.

The producer then introduces interviews of personal experiences with HIV/AIDS beginning with 52-year-old George Onyango explaining how many people have lost their lives to HIV/AIDS in the village. The director then asks a leading question; ‘So this disease is almost wiping out the entire village?’ To which George answers in affirmative noting that in every home, you must get somebody who has lost a loved one to HIV/AIDS. The crew is then led to an empty homestead whose occupants have allegedly died of HIV/AIDS. George then tries to provide an explanation for the high prevalence, attributing it to double registration. He explains that when they move through homes, they don’t get new infections while the prevalence rate remains high. The director is not convinced by the explanation, a position he does not hide.

The narrator then leads the documentary to another homestead whose only sign of previous occupation is a freshly dug grave. The scene moves to another homestead where we get a twelve-year-old girl, Jane (not her real name) standing next to another freshly dug grave bearing the remains of her mother. The mother died on the roadside on her way from hospital. We are then moved to Jane’s 92-year-old grandmother who now stays with her. The 92-year-old Syprina Amolo reveals in an interview that she does not know what killed her daughter. The story moves to 82-year-old Agatha Onditi who laments the problems she finds herself in due to the death of her son and daughter-in-law. She has lost four of her five children to HIV/AIDS. The 82-year-old Agatha is now a guardian to five grandchildren, a situation she finds difficult to deal with.

The narrator states that a total of 182,000 people live with HIV in Homa Bay County with 15,000 new infections every year. At 0:09:00 minutes, the narrator introduces anti-retroviral drugs in the fight against the virus, but with a disclaimer; the residents are too poor to buy the drugs. Karen Adhiambo, a community health worker living with HIV/AIDS, brings in an explanation as to how HIV/AIDS is high in the community. She attributes it to survival sex due to poverty in the community. At 0:10:13, the producer moves the documentary to the beach where he introduces the angle of sex for fish in the spread of HIV/AIDS. Calvin Otieno, a fisherman says, negotiations for sexual favors are done while the fisherman is still in the waters, confirming the assertion of sex for fish. Zahra Hassan, a program officer with WOFAK weighs in by saying women are ill equipped to negotiate for safe sex.

An interview with Maria, a woman who lives in the vicinity of the beach reveals the vulnerability of women in the hands of fishermen who exploit the women's poor economic ability. The narrator introduces a theme of rejection as he explains how Maria's husband abandoned her on learning of her HIV status. A scene of another woman whose husband died and now lives under the threat of being thrown out by the husband's relatives reinforces the rejection theory for HIV/AIDS infected people. The director then moves the camera to several homes with little or no sign of human habitation.

The documentary brings out the reality of devastation caused by HIV/AIDS to families, as a result of death caused by the virus. Visuals of many homesteads left either without human habitation or managed by small children are many. The burden carried by elderly women due to deaths caused by HIV/AIDS is also revealed in the

documentary. The documentary ends by giving a glimpse at how the virus is spread through the infamous '*jaboya*', (sex for fish) trade on the shores of Lake Victoria.

The documentary was taken for the study as it gives a portrayal of one who gets HIV/AIDS as immoral, poor, ignorant and hopeless. Many talking heads admit to getting into relationships to fend for their families not minding the consequences due to their poverty. The documentary speaks to the three objectives of the study.

### **1.8.5.3. Mercy in Action (2014)**

The final documentary used for the study was *Mercy in Action* (2014) by Stephen Okumu. The documentary was sponsored by Oyugis Integrated Project run by Shirikisho centre in Oyugis. The project was established after a need arose to help people suffering from HIV/AIDS and orphaned children left after their parents died from HIV/AIDS. The documentary begins with a map of Kenya indicating where Oyugis is located. Graphic still photos are used to show wounds on the feet of people infected with HIV/AIDS. The wounds appear cancerous as they don't seem to heal.

Personnel who seem unprofessional and ill equipped as they lack protective gear like gloves when dressing the wounds are attending to the sick. Bro Leo qualifies this when he says novices were attending to the wounds. The camera moves to the villages where homesteads are uninhabited allegedly as a result of death from HIV/AIDS. Bro. Vincent explains that they moved in as brothers to help the people as the death toll rose. The narrator explains how Oyugis Integrated Project moved from just cleaning wounds to a fully-fledged health center to provide a holistic approach to the problem of HIV/AIDS. Jane Atieno, a beneficiary of OIP services, explains how the center has

helped them by subsidizing medical fees. Shots of patients being attended to by medical personnel are then shown, as well as those of counseling sessions.

The scene moves to a visit to a patient who is not able to reach the hospital as the narrator explains the importance of home visits to HIV/AIDS patients. Alice Atieno, a mother to of HIV/AIDS patient being visited, explains how it was easier to handle her sick daughter when she was able to walk. She explains how even the boda boda riders have abandoned her. She explains that her daughter has to be carried from one place to another. A clip of the patient who seems out of her mind is shown. The scene ends with the mother sadly looking at her daughter. Different clips of patients collecting their medication from the center are shown.

We then move to the social department where elderly grandparents are seen receiving cash to help orphaned grand children under their care. Boniface Mambo of the social department explains that the department ensures that the infected live a normal life. The narrator points out that the center does not run an orphanage but enables orphans from the HIV/AIDS pandemic to live with their loved ones, including providing for their education. We see children fitting school uniform as this goes on.

We then get to Tony Onyango and Catherine Atieno, students under the support of OIP in an interview narrate how OIP has helped them. Br. Thomas then comes in to say the center gives the orphaned children more than what their parents would have provided. The narrator then explains how the center involves those who have acknowledged their status to reach out to others who are afraid of coming out. Mary Achieng is one such person who spreads the message of positive living among other women in her locality. The center then formed therapy groups for women where they

can discuss among themselves and encourage each other. We are shown some of the groups in session. The documentary ends with some of the investments the therapy groups have yielded, including goat keeping and dairy cattle to supplement their income and nutrition.

This documentary was considered for the study as it dwells on the vulnerable situation the affected and infected people find themselves in. The documentary has characterised people affected and infected with HIV/AIDS as requiring mercy to survive. They have no life outside shirikisho. Even after OIP initiated income generating projects for affected families, the documentary still ties their survival to Shirikisho. The documentary also links the suffering of the elderly to HIV/AIDS as they are turned into caregivers at the stage when they should be enjoying their sunset years in peace. Visual images used speak of desperation.

### **1.10.0 Theoretical and Conceptual Framework**

This study employed the use of two theories: Reception Theory and Semiotics Film Theory.

#### **1.10.1 Reception Theory**

Reception Theory emphasises the interaction between the audience and a work of art in generating meaning (Elmo 2013). Davis (2003) adds that a work of art is an inert object in the absence of the reader. It is therefore the reader who brings the text to life each time he/she interacts with it. Reception Theory has its origins in Stuart Hall's encoding and decoding model of communication. According to this model, meaning is encoded by the sender and decoded by the receiver, and that the encoded meaning may be decoded to mean something other than the intended (Hall, 1980). The particular position taken by the audiences largely depends on their life experiences, often relating to social class position and on specific interpretative repertoires at their disposal.

Main proponents of reception theory include Stanley Fish who observed that the meaning of any work of art is not intrinsic but relies on the reader. In other words, in the absence of the reader, a work of art has no significance. Wolfgang Iser is another proponent of reception theory. He avers that audiences project meaning, a meaning that they require of the text or work of art depending on their world view (Iser, 1978). The historical background and past experience of the audience largely determines the meaning generated from a work of art. Davis (2003) on the other hand, while advocating for reception theory, believed that no effort should be made in interpreting a text for the reader as meaning is generated each time an act of reading takes place.

According to Morly (1992), audiences do not come to the moment of viewing ‘culturally naked’ they come to the text carrying already and thinking within their own set of cultural contexts and frameworks derived from their social and cultural situation and backgrounds (p. 92).

The theory was best suited for the study to understand how spectators view and derive meaning from documentaries on HIV/AIDS. As stated by Hall (1980), the audience take divergent positions when reading a text depending on their world view and hence the meaning generated is dictated by this context. This means the reader links previous knowledge to the text in deciphering its meaning (Davis, 2003). The study is interested in the meanings generated by the audience as they interact with documentaries on HIV/AIDS, hence the choice of the theory to guide the research.

The fact that audience members interpret messages depending on the social context in which they find themselves, the theory assisted in understanding how spectators in different social economic situations interpret the depiction of HIV/AIDS in documentaries. The theory was vital in understanding how respondents reacted to selected documentaries resulting from the meaning they generated after watching the films. Since respondents (interviewees and FGD participants) had watched the documentaries, the study did consider their responses as genuine and authentic social feedback that constituted meaning and understanding of the films. Their responses were therefore considered as a representation of communal understanding of HIV/AIDS in the documentaries. The meaning was understood as socially owned and transmitted to the researcher through the responses.

### **1.10.2 Semiotics Theory**

Eco (1978) defined semiotics as the study of signs. In that definition, he perceived that a sign is anything which stands for something else. According to Eco (1978), a sign can take the form of words, images, sounds, gestures and objects. Leech and Onwuegbuzie (2008) did consider semiotics a science that explores relationships between signs and their intended and specific meaning. According to Goharipour (2019), semiotics dictates what constitutes signs and how they are governed. According to Zlatev (2018), meaning hence becomes the relationship between the recipient of a sign and their personal experience of the world around them. Meaning is created when the recipient makes sense of the sign by connecting by connecting and interacting. With their environment. This thus implies that this theory consists of the sign, the context and the meaning.

A sign consists of both the form it takes in physical reality and referred to as a 'signifier' and how it is interpreted, known as the 'signified'. Context on the other hand consists of aspects in a conversation or interaction that provide relevance in a particular exchange (Bowchar, 2018). The relevance helps the recipient to make sense of the exchange and hence derive the intended meaning. The main proponents of the theory were Ferdinand de Saussure (1857-1913) and Charles Sanders Peirce (1839-1914). Saussure was a Swiss linguist who studied the meaning of signs within a community while Pierce was an American philosopher who studied how signs shape our understanding of the physical reality at an individual level.

Semiotics considers the relationship between the signified and the signifier a crucial part of communication to either deduce surface meaning or concealed meaning.

According to Saussure, a sign is something delivered by someone with a purpose and specific intentional meaning (Yakin & Totu, 2014). It therefore goes that in communication, signs used in the form of images, words, gestures and sounds have an intentional meaning intended by the producer. Reeper (2013) avers that no object or word has no meaning. He asserts that one cannot see or read something without associating it to some idea. Signs in film may therefore be taken as the thinking of the filmmaker on the subject at hand.

When discussing filmic signs, Reeper (2013) observed that though conventions are used to indicate an established way of doing things. When used on characters in film, they shape how the audience think about the characters on screen and can easily turn into stereotypes. These stereotypes fail to represent reality and can be harmful to how audiences perceive the world, he added.

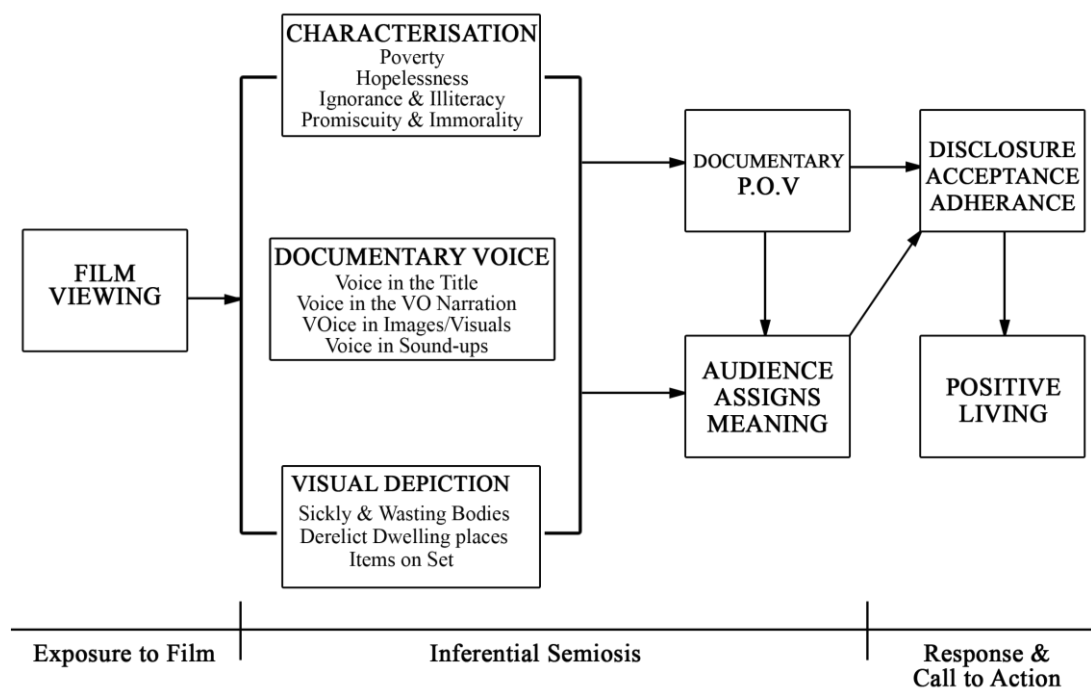
It was therefore important for this study to understand signs, codes and conventions as used in documentaries under study to understand the hidden meaning of the text, and if the signs communicated the meaning the author had.

### **1.10.2 Conceptual Framework**

The conceptual framework provides the relationship between independent, dependent variables and mediating variables. The character assigned to people living with HIV/AIDS, the voice and visual images used in documentaries have a direct impact on positive living with HIV/AIDS. Horrific presentation of HIV/AIDS through character portrayal, voice and visual images creates fear in the infected and the affected, therefore giving a negative view on living with the disease. As the audience watch documentary films, characterisation, documentary voice and visual depiction

may determine the meaning attached to the text. Positive characterisation, appealing visual depiction and voicing may lead to disclosure and adherence which in turn results in positive living with HIV/AIDS. Rwafa & Rafapa (2014) stated that ‘use of phobic visuals creates fear and hopelessness’, a position that does not support positive living with HIV/AIDS. In arriving at a conclusion based on filmic evidence as well as audience reasoning, viewers can be drawn to take action and respond either positively or negatively to the designed meanings or the perceived meanings. Audiences might also be influenced by the documentary’s POV or may as well ignore it and deduce their own meaning as they view the documentaries for either entertainment or information.

*Figure 1.1 Conceptual Framework.*



### **1.11.0. Methodology**

#### **1.11.1. Introduction**

This section discusses the methodology used in carrying out the research. The following sub-sections are discussed; research design, study location, target population, sample population, data collection tools, data collection and data analysis.

#### **1.11.2. Research Design**

This is a qualitative study and used focus group (FGD) discussions, in-depth interviews and critical content analysis to collect data. The qualitative research aims to understand, explain, explore and clarify situations, feelings, values, attitudes and beliefs of people (Kumar, 2014). Creswell (2014) avers that qualitative data seeks to explore and understand meanings individuals or groups of people attach to social or human problems.

The problem of HIV/AIDS being a social issue, it was important to understand the meaning people attach to documentaries on the topic of HIV/AIDS in relation to characterization, documentary voice and visual depiction and imaging. Qualitative research method was therefore best suited to yield the required results. Kombo & Tromp (2006) define research design as the outline that is used to generate answers to the research problem. It is an arrangement of conditions for collection and analysis of data. According to Kothari (2004), research design is the blue print for collection, measurement and analysis of data. Qualitative research designs are more flexible as they may use multiple methods to extract answers to the research question

### **1.11.3. The Study Location**

The study was conducted in West Yimbo Ward, Bondo Sub County of Siaya County of Kenya. Yimbo West Ward lies at latitude -0.066990 and longitude 34.057990. Yimbo West ward and by extension Siaya County, is inhabited majorly by the Luo community. Kombo & Tromp (2006) observe that selection of research site is essential as it influences the usefulness of the information produced. This area was selected due to the devastating effects of HIV/AIDS on families. At the Usenge dispensary there are two main Social Support Groups whose members are drawn from the larger West Yimbo Ward. These are the adolescent PSSG group and Adult Psycho-Social Literacy group, which include a sub group of Prevention of Mother to Child Support Group.

### **1.11.4. Sampling**

Sampling is the process of selecting a number of participants from a population such that the selected group contains characteristics representative of the entire population (Kombo & Tromp, 2006). Kothari (2011) refers to a sample as a collection of units chosen from the population to represent the whole. Lack of human resources, high cost and population dispersion are some of the reasons researchers can't study the whole population. Saunders et al (2003) observes that it is impossible to collect data from all members of the population owing to restrictions of time, resources and access. This necessitates sampling where a representative group is picked to represent the whole population. Mugenda (2008) advises that the sample must be carefully selected to represent characteristics in the entire population. Mugenda & Mugenda (2003) suggest that a sample of 10% of the sample frame is acceptable to represent the whole

population. The first part involved sampling of documentary films to be used in the study while the second sampling provided the population to form focus group discussions and in-depth interviews.

#### **1.11.4.1. Population for FGDS and Sampling Technique**

The study population for FDGs comprised of people living with HIV/AIDS in West Yimbo Ward of Siaya County. This number was 2486 according to Oloo (Personal Communication, July 20, 2019), the clinical officer at the Usenge Dispensary. The number was compiled from the four health facilities operating in West Yimbo Ward. Study population is the full set of samples under study from which the study sample is drawn (Saunders, 2003). Mugenda (2008) on the other hand, describes sample population as the entire set of people, objects, items, or cases with similar characteristics. The sample frame for FDGs was registered members of the two social support groups operating at the Usenge dispensary; Adult Psycho-social Support Literacy Group (APSSLG) Adolescent Psycho-social Support Group (APSSG) with a total of 165 registered members. The sample frame for the FDGs was therefore 165 registered members of psycho-social support groups. According to Mugenda (2008), sample frame refers to a list of members within the population who can be sampled.

Stratified sampling was used to divide the sample frame into two stratas of adolescent psycho-social support group and adult psycho-social support literacy group based on age. The adolescent group ranged from 12 years to 17 years while the adult group ranged from 18 years and above. Stratification was important to provide an atmosphere in which free discussions could take place considering the age difference. Of the total 165 people, the adolescent Psycho-social Support Group comprised of 21

members while the adult Psycho-social Support Literacy Group comprised of 144 members. Mugenda & Mugenda (2003) aver that a focus group should have between 6 and 15 people to yield meaningful results. Edwards & Holand (2013) observe that FGD are useful in discussing sensitive topics such as sexuality since they provide a comfortable environment for people to open up. They argue that disagreements in FGDs lead to participants defending their position, thereby providing more clarification on issues under discussion. Mugenda & Mugenda (2013) aver that a sample size of between 10% and 30% is representative enough of the population to generalise findings. Since the number of adults is 144, the researcher used 10% of the total to come up with a focus group discussion for APSSLG;

$144 \times 10/100 = 14.4$  people. The figure is rounded to the nearest whole number giving 14 participants for the APSSLG focus group.

Purposive sampling was then used to select the 14 people for the FGD depending on previous exposure to health documentary films and availability to participate.

For the adolescent psycho-social support group, the total number after stratification was 21 members. The researcher took the maximum 30% from Mugenda & Mugenda (2013) formulae to get the focus group for the discussion.

$21 \times 30/100 = 6.3$

This was rounded-off to the nearest whole number, 6, people for the Adolescent FGD.

Purposive sampling was then used to select the appropriate sample from the 21 members based on previous exposure to health documentaries and availability to participate. Purposive sampling is where the researcher settles on cases that can provide the required information needed to address the objectives of the research

(Mugenda, 2008). May (2001) on the other hand describes purposive sampling as a method where a sample is selected based on well-known and useful characteristics.

#### **1.11.4.2. Population for Films and Selection Criteria**

Due to the huge number of documentaries on the subject of HIV/AIDS on the market, it was difficult coming up with a definite number as a representative of the film population. The researcher came up with selection criteria to help in identifying documentaries that qualify for the study. For a documentary to qualify for the study, it had to have been produced, screened on national and/or local television or published online between 2010 and 2018. This duration was considered as a way of remaining relevant to current trends in the manifestation of HIV/AIDS.

The second consideration was that the documentary had to be at least 70% of content touching on Luo Nyanza. This was to resonate with the study location of Yimbo West Ward of Siaya County, dominantly inhabited by the Luo community. Thirdly, the documentaries had to have a strong characterization and depiction of HIV/AIDS. Finally, the study considered short documentaries of between 5 to 20 minutes. The sample frame for the study included HIV/AIDS documentaries available on-line and those produced by community-based organizations and are accessible to the community. After watching 80 documentary films on HIV/AIDS, 30 of them met the selection criteria described above which formed the sample frame for documentary films for the study.

The study used Mugenda & Mugenda (2013) formulae of a sample size of between 10% and 30% being representative of the population. Since the sample frame for films is 30 documentary films, the researcher used 10% to get the sample size as follows;

30x10/100=3 films

The film sample size was therefore 3 documentary films.

Purposive sampling was used to select the following three films from the sample frame. *Dying of HIV in 2017* (2017) by Medicines Sans Frontieres (MSF), *Fishers of Pain: HIV Situation in Homa Bay County* (2016) by Timothy Otieno, and *Mercy in Action: Oyugis Integrated Project* (2014) by Stephen Okumu. An explanation is given below on how each film qualified for the study.

*Dying of HIV in 2017* (2017) focused on the visual depiction and imaging of persons living with HIV/AIDS. HIV/AIDS is seen in the body of the infected. The documentary is given a voice through the life experience of the infected. This tied in very well with objective two and three of the research on visual depiction and imaging and voice of the documentary. That is how the documentary was sampled.

*Fishers of Pain: HIV Situation in Homa Bay County* (2016) dwelt more on the character of persons living with HIV/AIDS, hinting at what might have caused the ailment. It also addressed the visual depiction and imaging as well as the voice of the documentary relating to HIV/AIDS. This qualified the documentary for the study, having met the selection criteria set as it addresses the three objectives of the study.

*Mercy in Action: Oyugis Integrated Project* (2014) addressed visual depiction and imaging of people living with HIV/AIDS both negatively and positively. The documentary voice also came out clearly on what living with HIV/AIDS is like in the society. These factors qualified the documentary for the study after it met the selection criteria as it addresses objectives number two and three of the study.

#### **1.11.4.3. Sampling for Interviewees**

Expert sampling was used to identify four participants for in-depth interviews. Mugenda & Mugenda (2003) do single out interviews as a way of giving respondents a chance to express their views, on an issue, while at the same time contributing to solutions. The interviewees included a director/producer of documentaries on health with emphasis on HIV/AIDS, a person living with HIV/AIDS for the last 22 years who is also a policy maker, a clinical officer at Usenge dispensary who on a day-to-day basis deal with HIV/AIDS Psycho-social support groups and an HIV/AIDS counsellor who is also living with HIV/AIDS. The researcher settled on the four interviewees as they have worked closely with people living with HIV/AIDS over a long period.

Through expert sampling, the researcher settled on Mr. William Inganga, a health documentary film producer with Kenya News Agency. Mr. Inganga has produced documentaries on HIV/AIDS since November, 2007 with the first production from prisons featuring on the world Aids Day of December 2007. He has produced several documentaries through the changing times of the HIV/AIDS experience. From 2007 to 2011, he ran a weekly slot on Kenya Broadcasting Corporation (KBC), *It Begins with You*, which later changed to *Beyond the Epidemic* on the same channel. He also ran another weekly slot on Kenya Television Network (KTN) by the name of *Mending the Ribbon* from 2011 to 2013. Both looked at HIV/AIDS through a human face. This wealth of knowledge was key for the study which led to Inganga being picked on as the film producer to be interviewed.

Madam X (not her real name) was sampled for her wealth of knowledge on HIV/AIDS issues, despite being a person living with HIV/AIDS. She was diagnosed with

HIV/AIDS in the year 1998 and later faced rejection from her husband. Her will to live and fend for her children kept her going. She responded well to medication and became an advocate for people living with HIV/AIDS with a message; there is life after HIV/AIDS. Since then, she undertook the role of counseling people living with HIV/AIDS with the aim of encouraging positive living with HIV/AIDS.

The clinical officer selected for the interview was Mr. Arnold Oloo. He works with the social support groups at the Usenge clinic. He interacts with PLWHA on a daily basis. Part of his duty is to help PLWHA accept their status and live positively with the virus. He was therefore in a better position to talk from a clinical point of view, the effectiveness of communication through documentaries.

Ms. Rose (not her real name) is the community health volunteer. As a person living with HIV/AIDS and involved in supporting social support groups at the Usenge dispensary, it was important to get her input. Since participants are her clients on a daily basis, she was best suited to validate the information.

#### **1.11.5. Data Collection Methods**

The study used both primary and secondary data. Primary data came from content analysis after watching documentaries under study, FGD and interviews. Secondary data came from books, periodicals and journals. The secondary data helped in validating findings from the study by way of comparison.

##### **1.11.5.1 Observation Guide Method**

The researcher used the observation method to critically analyse content as presented in the documentary films under study. The guide helped in understanding the choice

of characters in documentaries on HIV/AIDS. This guide helped gather data on characterisation, visual depiction as well as voice of documentaries on HIV/AIDS, as presented in the documentaries under study. The guide was also used in recording non-verbal responses by the participants as they watched the documentary films to get their reaction to different scenes as presented in films.

#### **1.11.5.2 Focus Group Discussion**

There were two focus groups, APSSLG and APSSG each holding three FGDS, one after watching each of the films under study. A total of six focus group discussions were therefore held. As members of FGDS were HIV/AIDS positive, the method was used to collect data on characterisation, visual depiction and documentary voice as perceived by PLWHA. The moderator used the guide to help participants not to go out of topic. Opportunity was given for a preview whenever a participant requested. Data on expectations of participants on characterisation, visual depiction and imaging and documentary voice was also collected using the method.

#### **1.11.5.3. Interview Guide**

The researcher used unstructured interviews to collect data from respondents. The interviews sought to get information on characterisation in the documentaries on HIV/AIDS under study, visual depiction used in these documentary films and cinematography in projection of the same and how the same impacts on the meaning or the voice of the documentary. Information from the interviews was recorded in audio. The recordings provided a fall back in case the researcher missed out on any information. The recorded information was transcribed during analysis for comparison with the notes taken during the interview.

### **1.11.6. Data Analysis**

All data was analysed and presented separately. The data was presented in the form of descriptive, interpretive and evaluative statements.

### **1.11.7. Validity and Reliability**

For the study to yield valid results, the researcher took time with the respondents as a way of gaining their confidence before data collection began. During this period, the researcher sought to explain the purpose of the research to the selected sample population to allay any fears that may lead to invalid data. Data obtained from FGDs was compared with what came from detailed interviews to check for any inconsistencies. As the same group watched the three films under study at different times, it was easy to detect any false words during FGDs. Mugenda and Mugenda (1999) explain that validity is the degree to which results obtained from data analysis represent variables of the study. Nassiuma, (2000) explains that validity of a research outcome refers to the extent to which what is observed reflects what is expected.

### **1.11.8. Ethical Considerations**

For this study, the researcher started off by getting an introductory letter from Kenyatta University to collect data. The researcher then introduced the subject of the study to the participating community giving details of how data collected was to benefit the objectives of the study. The researcher then requested consent from willing members of the community to participate in the study. Confidentiality of the participants was assured by not attaching names to given information. Documentary films used for the study were obtained from YouTube, which is an open platform, accessible by the general public. Characters in these documentaries are therefore

assumed to have consented to their names and images being used as the documentaries are in the public domain. Marianna (2011) defines ethics as a branch of philosophy that deals with the dynamics of decision-making concerning what is right and wrong. She goes on to state that informed consent leads to participants getting involved in research when they have information on possible risks if any and benefits of the research.

### **1.12. Conclusion**

This chapter looked at the background of the study focusing on the journey of HIV/AIDS worldwide and Kenya in particular. The background led to the significance of the study at the moment.

The chapter further looked at the available literature on the subject of HIV/AIDS and how documentary films have been used as tools of advocacy. Most literature has focused on the suffering people infected and affected with HIV/AIDS go through.

The theoretical and conceptual framework in this chapter also presented the guidelines on how the study interpreted the data, as well as underscore the role of the audience in creating meaning to any text.

This is a qualitative study which employed a mixed method research design where different tools were used to collect and analyse data. Purposive sampling was used to select documentaries for the study and participants for focus group discussions. The study location was Usenge sub-county in Siaya County of Kenya.

The next chapter analysed selected documentaries in relation to the first objective on characterization of HIV/AIDS in documentary films.

## **CHAPTER TWO: PORTRAYAL OF CHARACTERS WITH HIV/AIDS IN DOCUMENTARY FILMS**

### **2.1 Introduction**

This chapter sought to identify and analyse the portrayal of characters in the sampled documentaries. It then presents and discusses the findings of the same in relation to the research objective one. The chapter identified instances of positive and negative character portrayal and also examined how characters have been used in documentary films on HIV/AIDS with regard to advocacy on positive living.

### **2.3. PLWHA Characterised as Poor**

This study observed that the three sampled documentaries have dominantly characterised PLWHA as poor and in an economic crisis. Moore, Onsomu and Abuya (2014) observe that there are individuals with negative attitudes toward PLWHA due to the level of social stigma they accord them. In the opening scenes of *Fishers of Pain* (2016), dusty roads in a setting dotted with mud-walled houses are accompanied by the narrator's announcement that this road leads to the remote village of Karachuonyo, a place he refers to as 'the epicenter of a pervasive virus sweeping swiftly across Homa Bay County' (0:00:55,17). In the assertion that the disease is sweeping swiftly through the villages, an impression is given that people are at the mercy of HIV/AIDS.

In *Dying of HIV in 2017* (2017) the images outside the hospital characterises the localities in Homabay in two forms; the alleged homes of PLWHA are characterised by semi-permanent houses with mud walls (04:00), second, the fairly permanent

structures are superimposed on the narration speaking of the sick who have never been tested and would probably die of HIV in their houses (06:17 – 06:28).

*Mercy in Action* (2014) strives for positivity to a large extent, however, there are still several instances that link poverty to PLWHA. This documentary posits that the infected and the affected live in grass-thatched houses and semi-permanent mud-walled houses (03:07, 03:41). These filmmakers have attached PLWHA to semi-permanent, grass thatched and mud-walled houses which they have unanimously employed to symbolise poverty. This observation concurs with the assertion by Tsikhungu (2014) that such footage of mud walled, grass thatched houses often portrays the image of poverty. With that, it is concluded that the dwellers of such homes are poor HIV/AIDS victims, an assertion that may not be reflective in actuality.

According to Whiteside (2008) and Parker (1994), by linking HIV/AIDS to poverty, one asserts that the virus indeed tends to follow the path of the poor, be it at individual or country level. These poor people are then perceived as the least resistant in the society, hence they tend to bear the harsh effects of HIV/AIDS. The following paragraph discusses instances that portray poverty besides housing as mentioned in the preceding paragraph. These findings concur with what Hodes (2007) pointed out that depictions of HIV/AIDS in films is often an antithesis to their assumed objective of battling stigma. It is these instances that hence assert the filmmakers' POV that HIV/AIDS is a poor man's disease, despite the claim on advocating for positive living.

In *Dying of HIV/AIDS in 2017*, PLWHA have also been depicted widely as illiterate. The only vocal character living with HIV/AIDS who happens to be a patient in hospital cannot express herself in English (03:28). The same occurs in *Mercy in Action* (2014),

several instances where PLWHA as well as the affected are interviewed, their inability to speak English is seen in their choice of Dholuo; in *Fishers' of Pain* (2017), the same observation is made as several instances of talking heads who are PLWHA as well as the affected persons do not use English or rather struggle in their use of English. With regard to these documentaries, a specific strand of knowledge has been propagated, maligning PLWHA and according to them a voice in the Dholuo language and primitive English and Kiswahili (as in the case of *Fishers of Pain*) whereas informational figures are given English, better Kiswahili and even French (as in the case of *Dying of HIV in 2017*). This observation concurs with an assertion by Hymes (1996) that what education ascertains in an individual with regard to linguistic competence and community membership is often in relation to pursuance of a *lingua communis* which has become an instrument of class hierarchy and discrimination. Furthering on this assertion, he avows that;

Language has been a central medium of cultural hegemony. Class stratification and cultural assumptions about language converge in schooling to reproduce the social order. A latent function of the educational system is to instil linguistic insecurity, to discriminate linguistically.... while appearing open and fair to all... All have equal opportunity to acquire membership in the privileged linguistic network. If they fail, it is their fault, not that of the society or school.... The widespread sharing of cultural assumptions about language has rendered their particularity almost invisible. (p. 84)

In this assertion, it appears that Hymes (1996) affirms the point that in real life, language becomes an entity created by its users. The findings of this study ascertain hence that this has become key in enabling cultural stratification, since literacy has a standard language. This concurs with Cambridge Assessment (2013) assertion that the importance of literacy is attributed to two main reasons, the links with economic stability and individual well-being.

Indeed, as ascertained in this study, the essence of literacy for the PLWHA in a community has affected their positions by enabling social exclusion through an intelligent form of ‘othering’. This concurs with Tett (2006) that literacy has been equated with success in life, bearing traits such as being educated, having a job and having access to the good things that are valued highly in society which indicate a healthy of life. To this end, then, it appears that the languages used in the sampled documentaries, besides Dholuo, have been posited as languages of civility and literacy, a privilege of healthy people, the elite and urbanites, not PLWHA, village dwellers, the poor and the unschooled; a people of a certain niche in society.

The study further identified instances from the sampled documentary films where thin bodies associated with PLWHA are said to suffer from nutritional deficiencies. In *Fishers of Pain* (2016), PLWHA are shown as largely suffering from malnutrition and anaemia (05:48). *Mercy in Action* (2014) characterises PLWHA as having also been associated with malnutrition (21:01, 22:20). Something else stands out vividly when images of Oyugis town are displayed in *Mercy in Action*, that, as alleged HIV/AIDS persons were dying in the villages, the town’s active life slowed down. This thus links HIV/AIDS to a dwindling economy and subsequent poverty both communally as well as individually. This opinion concurs affirmatively with Ismael et al (2016) that HIV/AIDS is a problem with deep economic consequences. All features identified in this section give a portrayal of communities immersed in poverty, with the impression that the poor are the ones dying from HIV/AIDS. These concurs with the assertion by Paula (2020) that cultural productions around HIV/AIDS are often stereotypical bearing prejudices in their discourse, and that the eminent characterization of PLWHA in film often outweighs the hope they claim to communicate.

This study thus observes that the general belief that HIV is a disease for the poor arises from the way it has been portrayed in many documentaries centered on poor people in the society. Inganga (Personal Communication, July 17, 2019) suggests otherwise, stating that;

Going back to the factors that contribute to the prevalence of HIV, it is true there are chances that the poor can easily contract HIV but at the same time there are quite a number of poor people who have taken precautions against infection. Still, we must know that there are rich people who are very reckless with their lives. In fact, chances are that they might be more vulnerable to the spread of HIV than the poor. It's a complex issue where we cannot really say that it's just the poor who are more vulnerable than the rich. It depends on the factors that contribute to the prevalence of HIV among the two groups.

In this observation there lies an assertion that there is a definite bias in most documentaries inclining towards 'othering' the poor as the propagators and incubators of HIV/AIDS. To this end, the study endeavored to identify specific instances where filmmakers of the sampled documentaries intending to communicate advanced notions of HIV/AIDS being associated with the poor. The subsequent section analyses specific characters identified to give an explanatory variable to the observations arrived at here.

### **2.3.1 Maria; The epitome of poverty in Fishers of Pain**

Maria, not her real name, is a 34-years-old single mother with nine children. In the subsequent paragraphs, the study analyses a specific instance in the characterisation of Maria. Looking at how the filmmakers have portrayed Maria, a clear image of poverty is painted in the viewership. When considering her house and homestead in general, mud-walled semi-permanent houses dot the compound with her grass thatched house in the background of her interview with Timothy and Cecilia.

The setting of Maria's home paints the full picture of what her socio-economic status seems to look like. This then dictates how we are to perceive Maria's characterisation in poverty. This is affirmed by Dusabe (2019) who affirms that set components also do play a big part towards the story's build up and can thus influence the direction of the entire plot, informing how the characters behave, as well as dictating how themes in the narrative evolve. As she is introduced to us, the narrator speaks of her plight as she is shown picking firewood in the compound as well as sweeping the compound with a homemade broom. A close look at the house in the picture, one can see the state of its dilapidation despite its repair being a nearly 'zero budget' initiative.

*Figure 2. 1 Maria's house in the background (Courtesy of Fishers of Pain).*



As earlier noted, that poverty has an attachment to literacy, it was essential that the study look at Maria's state of HIV/AIDS literacy. The filmmakers portray Maria as a carefree HIV/AIDS positive woman willing to infect anyone regardless of the consequences. Consider the following excerpt from her interview;

**Maria:** Ukienda huko, saa zingine kama unaenda kununua samaki unapata watu wengi huko wanasema madam we ni mzuri unaongea nayeye unapata kitu kidogo kama samaki saa zingine ni pesa unaenda kununua gorogoro unasiaga unakula, hio ndio maisha sasa.

(Sometimes when you go to buy fish, you get so many people who complement your beauty, then you talk to them and

eventually you get something little, it could be fish and sometimes money which you can use to buy maize for your meal. That is the current lifestyle.)

**Interviewer:** Hautaogopa kwamba unamuambukiza labda, amahio hata yeye hajali?

(Won't you fear that you may be infecting that person, or doesn't he care too?)

**Maria:** Sahii sitaogopa ndio nikule.

(In order to eat, I won't fear.)

This negative portrayal positions PLWHA as deliberate propagators of the virus. Maria is characterised as a promiscuous PLWHA who has no regard or knowledge of her implacable actions resulting in serious consequences due to the severity of her condition, and the risk it places her sexual partners in. In drawing this assertion, the study concurs with Dusabe (2019) that there will always be a way in which people make meaning of the world based on popular beliefs. In Maria's case, the filmmakers paint a gruesome image that little is left to bargain with as regards her deadly character born out of poverty. Maria's apparent poverty is depicted as positioning her in the direct path of HIV/AIDS. This observation concurs with Parker (1994) that the poor are often the highway of the virus the moment it gets into the society. In this regard, Maria seems to have found herself in a situation where she has to survive by giving herself sexually to those ready to provide for her needs.

Since the study sought to ascertain what was considered key to the spreading of HIV, it was established that there is prevalent lack or neglect of cautionary education regarding HIV/AIDS. Madam X (Personal Communication, July 12, 2019) avers that;

They talk about the Jaboya systems. It's all about fish and sex. The women who go to buy fish, have to have sex with the fishermen. So when you genuinely go to buy fish you may not get unless you sleep with those people. Which is not good because

you don't know their status and now you are involving yourself in sexual activities with them, hence the spread of HIV.

This observation concurs with the observation by Sileo, et al. (2019) that HIV fatalism among fishermen perceivably develops from the response to the nature of exposure to their occupational vulnerabilities. As regards the assumption on 'Jaboya System', a FGD participant who happens to be a fisherman also observed that;

Fish for sex is a common activity apart from wife inheritance that makes people contract HIV.

This observation pointed to an assertion that despite fish for sex being a main factor, it was not the only contributor to HIV prevalence. Madam X (Personal Communication, July 12, 2019) further observed that;

Lack of information and the fact that fishermen have money enables them to take advantage of the young poor girls in the villages as well as the widows. Because most of them are not from the Lakeside, having come from other areas for fishing with nobody knowing their status, they become a loose trap for the villagers.

Other respondents during the FGD session noted that the poor are more vulnerable due to many problems they face. Consider the following statements;

Hapo kwa umaskini na HIV, maskini atakuja sana kwa sababu atakuwa re-infected kama anatafuta kulisha watoto wake na kujilisha.

(On poverty and HIV/AIDS, the poor will be more affected as they struggle to fend for themselves and their children).

Another participant observed that;

Ni rahisi kwa maskini kupata HIV kwa sababu atakuwa exposed. Watu ambao wanaukimwi na wanapesa watampatia favours na ni lazima afanye vile wanataka.

(It is easy for the poor to get HIV/AIDS because they are exposed, the rich who are HIV positive will offer favours to them, and they have to reciprocate by agreeing to their demands).

In Maria's case, this situation of poverty seems to have transcended time, from the time she was still probably in marriage to this time in her life after her husband abandoned her, leaving her with nine children to fend for. This life of promiscuity might be assumed as being the reason for her infection and potential reinfection with HIV/AIDS. This is quite in line with Selikow (2002) that, a combination of poverty with the current consumerist culture can potentially lead to the spread of HIV/AIDS.

As observed generally, the management of HIV/AIDS requires good nutrition which might not be easy to come by in poor resource settings. In Maria's case, the filmmakers portray her as so poor that she cannot provide medical care for her ailing daughter (see figure 2.2). The narrator (0:14:18, 16) asserts concerning her that;

When you have *nine* mouths to feed, issues such as medicine take a back seat.

This child is associated with HIV/AIDS based upon the poor health as has been displayed. The pimpled and wrinkled skin and the visibly poor body mass have been assumed as indicative of malnutrition, other factors notwithstanding. To this, participants observed that there was indeed a challenge with health and nutrition for PLWHA in poor settings; however, not every one of them or those in such environments exhibited malnutrition and wasted bodies. Consider the following observations from the FGDs, one participant noted that;

Physical appearance, aneno ka ngeny gi healthy... donge majority mar jo beach go to healthy.

(Considering their physical appearance, I observed that the majority of them are healthy. Most of those people who are at the beach look healthy.)

In this observation lies the assertion that the physical appearance of the body should not be the determining factor that accords healthy status upon an individual. Another

participant with regard to Maria's alleged inability to access a health facility for her ailing daughter observed that;

What is coming out on PLWHA like us from the picture conflicts with reality because if this film was done in 2016 and that mum has nine kids, it means she was attached to a health facility.

This observation in relation to Maria affirms that she must have received medical guidance from a health facility to have successfully brought all her children to this life bearing in mind her HIV/AIDS status. It is therefore discriminative to assume that healthy living is entirely out of question to the poor PLWHA as has been projected in her case. Another participant also stated that;

It should not be that anybody who looks emaciated is equated to HIV/AIDS positive status. It is discrimination. How can he say that the kid has HIV, and she has not been taken to hospital?

In this statement is a cry against the continued generalisation and assumptive portrayal of the sickly and malnourished bodies as being HIV/AIDS carriers.

Where blame is to be placed on the HIV patient, it appeared as though adherence to ARV medication was the greatest challenge observed. Oloo (Personal Communication, July 20, 2019) observed that;

When someone takes drugs, they seem okay, when you default, your health definitely deteriorates.

Indeed, circumstances that enhance defaulting are observed to be springing largely from stigma. This assertion agrees with Sileo, et al. (2019) that the observable fundamental barriers to HIV care is significantly associable with higher HIV fatalism in communities with a high HIV/AIDS burden. This defaulting and forfeiting medical care in the end manifests in poor physical health since the lack of proper medication affects the wellness of the PLWHA.

Figure 2. 2: Maria's malnourished and sickly child (Courtesy of Fishers of Pain).



To this end, the study observes that the hegemonic portrayal of PLWHA as poor plays a great risk in creating the possibility of a discriminative audience. This audience then becomes part of the public ascribing HIV/AIDS to particular segments of the society, resulting in unchecked spread of the virus by people who don't fall in the 'othered' segment. As has been observed, HIV/AIDS does not discriminate, and all can get infected, be they rich or poor. Inganga (Personal Communication, July 17, 2019), posits that;

People from poor communities are easily reachable. They can easily be convinced to tell their story. The rich worry more about their status in the society due to stigma attached to HIV/AIDS. It is therefore not easy to get them to tell their story.

Similar sentiments were also observed by a participant during a FGD session who stated that;

Sio eti ukimwi ni wa maskini, matajiri hawakufi kwa ukimwi kwa sababu wanakula vizuri, wanameza dawa vile inatakikana. Sio rahisi kupata statistics za matajiri wenye wana ukimwi compared na maskini.

(It is not that HIV/AIDS is for the poor, the rich don't die of HIV/AIDS because they eat well, and take medicine as scheduled. It is not easy to get statistics of the rich with HIV/AIDS like it is for the poor).

These observations affirm that though many documentaries have focused on the poor, it does not necessarily mean that they are the only ones affected by HIV/AIDS.

Indeed, the study observed through the FGDs that the message of HIV/AIDS and the poor in the society resonated well with respondents. The following observations were made by participants during the FGD sessions, a participant stated that;

Mtu akishapoteza bread winner, itabidi utafute kila mahali ili watoto wakule na wewe pia ukule, hio ndio umaskini na ndio inasababisha mambo haya yaenee Zaidi.

(When one loses the bread winner, they are likely to turn to any available means so as to get food on the table, and that is what poverty is, and it is a factor in the spread of HIV/AIDS).

Another participant observed that;

Wameeleza kuwa hii ugonjwa ni ya watu maskini pekee na sio hivyo.... So it's like kutokua na kazi pia inaeza fanya mtu aingie kwa jambo la usherati ili upate kitu.

(HIV has been defined as a disease for the poor which is not right. It appears that the lack of a source of income may also cause someone to get involved in prostitution so as to get something).

Another participant yet again observed that;

Ng'ato nonyisa chieng' moro ni jomomeyo emanigigino molooyo kata jo modhier.

(Someone once told me that the rich are more infected than the poor).

Another participant also noted that;

Wan waneno ni wadhier koro adhi e dho nam mondo achiu denda ne jaboya ayud pesa adhi apidh godo nyithindo, lakini ng'amomeyo gimokoso onge.

(We feel we are poor and so I prefer to go to the beach and give myself to the jaboya so as to get money to feed the children, but the rich have no lack).

As noted, these observations do not by any means amount to HIV/AIDS being a disease for the poor in the society as filmmakers have characterised it, that is, as Dusabe (2019) posits 'how they have revealed the personality of a character' (p. 30).

We are, however, driven to the understanding that getting people from well-to-do

families talking about their journey with HIV/AIDS is very important in advocating for positive living. This is perceived a vital step since the invisibility of HIV/AIDS among the rich as regard the form of the body can be an essential portrayal of positive living. However, difficulty in achieving such an observation arises from what Inganga (Personal Communication, July 17, 2019) observes that;

If I were to get a person in the health sector maybe a nurse or a doctor who is living with the HIV, I would cover that story, any media house would want to use but, it is very difficult because of what will happen to the patient of such a doctor if they were to know that their doctor is living with HIV. It is very difficult to convince them to tell their story.

This observation affirms that the better-off in the society are protective of their status and may not easily feature in documentaries. Regardless of such assumptions and realities, in order to achieve a balance in advocacy for positive living, society need to deliberately feature HIV/AIDS in all its segments.

### **2.3.2. Dying of HIV in 2017- Poverty in a family living with HIV/AIDS**

In the documentary *Dying of HIV in 2017* by Medicins Sans Frontieres (MSF), images of patients lying in hospital beds covered in torn beddings are seen. At 0:02:05,03, we see a clear view inside the ward. The paint on beds is falling off. At 0:02:12,17, the cinematographer gives the view of the reception area of the hospital with wooden benches and overgrown grass. The waiting bay is also crowded with patients. When social workers visit an HIV/AIDS patient (figure 2.3), we see a temporary structure they live in; the house is poorly lit and very cramped with a wooden table (0:04:00,00). At 0:05:48, 16, a medical officer explains the challenges they face as they deal with HIV/AIDS patients;

We are working with people who are extremely weak, they are malnourished and anaemic. We have to treat very severe

infections as fast as we can. And at the same time, we have to work on rebuilding their immune systems. This is complex in extremely poor resource settings.

The situation presented above is symbolic of poverty for people living with HIV/AIDS, 'a serious financial hardship' as Moore, et. al (2014) refer to it. The director is proving a point when images of torn bed sheets, overcrowding at the reception and peeling off paint are used when featuring people living with HIV/AIDS. It is a way of apportioning the disease where it 'belongs', the poor in the society. A visit to a family living with HIV/AIDS reveals the conditions PLWHA reside in. The house is squeezed with old wooden furniture. The occupants, husband and wife, look emaciated and drained of energy as they walk supporting themselves on the wall and table. Except for poor housing and the unhealthy-looking body, the couple is encouraging as the husband tells of good progress with their medication.

HIV/AIDS is not synonymous with poverty and desperation. In an era where people have been living with HIV/AIDS for decades, it becomes paramount to create an environment where they feel accepted and appreciated. This then becomes a way of integrating them in the society by removing the psychological stresses that come with negative portrayal. This role can be played well by documentary films depending on the plotting. Documentaries on HIV/AIDS should not fall victim to the observation of Paak (2014), where they dehumanise people living with HIV/AIDS instead of giving them hope.

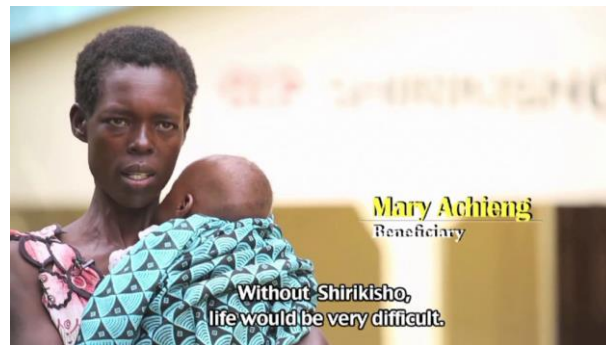
*Figure 2. 3: Residence of a family living with HIV/AIDS (Courtesy of MSF, Dying of HIV in 2017).*



### **2.3.3 Mary Achieng stands out in the face of HIV/AIDS-Mercy in Action (2014)**

Mary Achieng looks healthy and confident as she narrates her life with HIV/AIDS, a testimony that life after testing positive with HIV is a possibility. With her portrayal, this documentary gives an alternative voice to the formulaic narrative that HIV/AIDS equals death for PLWHA. Though Mary appears to tie her life and survival to Shirikisho, she does not show desperation associated with PLWHA. Hart (2002) observes that cumulative trends identified in media often shape how the public perceives and responds to people living with HIV/AIDS in real life. Since media shapes how the public perceive and react to issues in real life, there is need to be careful when documenting HIV/AIDS. The public should not be made to believe they can tell a PLWHA from looks as it can lead to unchecked spread of the disease by people not displaying the picture presented in media. With the introduction of ARVS, individuals look physically healthy despite being HIV positive.

Figure 2. 4: Mary Achieng; living with HIV/AIDS (Courtesy of Mercy in Action).



What ties Mary to the tug of poverty is her insistence that life in the absence of Shirikisho would be a nightmare. When people infected with HIV/AIDS come out and speak on camera, it demystifies myths associated with HIV/AIDS where PLWHA are expected to be poor and hopeless. This way, Rukambe (1999) puts it that HIV/AIDS infected persons, are empowered to pick up their lives towards a mythical normal-ness. She is projected as a person not ashamed of her status, she goes around counseling others still living in denial.

#### **2.4. Characterisation of hopelessness in documentaries**

The documentary *Dying of HIV in 2017* (2017), the title of the documentary spells hopelessness. The same to *Fishers of Pain*, and *Mercy in Action* (2014). The titles of these documentaries seem to imply that the infected need mercy to survive, that they can at best thrive on the compassion of other people. In other words, what they seem to communicate is that they are actually living a hopeless life. This kind of selective and targeted communication of some sort of unbearable life, according to Stamm (2018) produces a mode of cinematic representation suitable to the devastation of health, life, and body that was the AIDS crisis.

In *Mercy in Action* (2014) for instance, at 00:06:18 – 00:06:22 and 00:17:15 – 00:17:17 a short sequence presents a distraught woman dressed in a blue dress. In the first sequence the narrator explains that;

HIV treatment and care is still at the core of the health centre's work.

Observing that sequence, it begins from the shot of a VCT sign with a drop-down arrow, then jumps to the shot of this lady with a sign 'laboratory' framed above her head with an arrow pointing to an inner room. After this shot comes that of the general group in a wide shot. In the second sequence, as her face is magnified on the screen, the narrator states that;

The social department ensures that people who are affected receive proper counselling.

This sequence lies between distraught images of perceived HIV/AIDS patients before it, and the image of a jovial man. At this juncture, I must draw attention to a critical observation that in the first sequence the narrator is female whereas in the second sequence the narrator is male. Should we hereby assume that this was employed for an aesthetic function? No. It seems blatant that the first sequence is presented as objective, driving towards a free will in the choice of whether to receive the treatment and care or not. In the second sequence, a subjective voice, biased in its will power of choice is heard. This subjective push seems to have been placed a deliberate plot point in between distress and positive living, with the possible implication that the hopeless must be pushed through proper counselling at all cost. It appears as though the perceived patients have no other option but to fall in line with the objectives of the facility, whether at will or not. That instance of zooming in on the face is indicative of its identity as the representation of HIV/AIDS, Stamm (2018) avers that the freezing of a portrait is reminiscent of, as well as an iconic image associable with the

face of the pandemic. She further asserts that such kind of identical representation mirrors the proliferation of media images that portray queer bodies as dangerous at worst and pathetic at best. In regard to this study, the danger perhaps lies in the manner in which the framing of the medium close up is superimposed on the subjective narration and pathetic in the sense in which free will is at first suggested to them in the objective narration (See Fig. 2.5 and Fig. 2.6). As a result of such portrayals, Stramm (2018) avers that these bodies are thus rendered docile and vulnerable to the public's gaze and consumption, yes, perhaps for prejudice or sheer enjoyment. In this hopelessness, PLWHA have characteristically been reduced to a representation of the virus and the disease, and subsequently danger and death.

*Figure 2. 5: An unnamed woman seated at the reception baym (Courtesy of Mercy in Action).*



*Figure 2. 6Figure 2.6 A Medium Close-Up Shot of the woman at the reception bay (Courtesy of Mercy in Action).*



In *Fishers of Pain*, at 0:00:55,17 and 0:01:05,07 subsequently, the narrator states that;

The remote village in Karachuonyo constituency has become the epicenter of the pervasive virus .... The virus has nearly wiped out the entire community.

The two statements point to a worrying state for PLWHA. If the virus is sweeping swiftly across, it is symbolic of no escape. When combined with the next statement where the virus has nearly wiped out the entire community, it becomes connotative of people living at the mercy of the disease. Such sequencing spells doom for people living with HIV/AIDS and by extension, the entire community.

At 0:06:00,11 the documentary reveals a young girl left in the hands of a frail 90-year-old grandmother Siprina Omollo who has allegedly lost all her children to HIV/AIDS.

In her interview, she states that;

Mtoto yangu nakufa na ukimwi. Anawacha watoto tano, sasa mimi na shida kabisa, hata chakula hakuna, siwezi kulima shamba, nasikia mbaya sana.

(My child died from HIV/AIDS and left five children, I have a lot of problems, even food is a problem, I cannot till the land, and I feel very bad).

The narrator then adds that though Siprina is taking care of orphaned children, she is in need of a caregiver herself. When the camera moves to a close-up of Siprina's wrinkled hands, it is seemingly intended only to show how vulnerable she is.

This is closely followed by another story of 82-year-old Agatha Onditi who has lost all her children to HIV/AIDS and now takes care of her grandchildren (0:08:11, 20).

In Agatha's interview, she laments that;

Kama mimi iko na watoto tano sasa, nafanya nini

(I have five children at this age, what can I do)

The situation would be different if there was an alternative for the parents. The two grandmothers, Siprina Amollo and Agatha Onditi are so economically challenged that

providing for the young children placed under their care is evidently a burden. By leaving their orphaned children to these economically challenged octogenarians these filmmakers advance the hopelessness of those affected by HIV/AIDS.

As much as it is a reality that the aged take care of the orphaned as a result of deaths occasioned by HIV/AIDS, the cases must not be as desperate as portrayed in documentaries under study. The effect of such depiction on PLWHA is that of self-pity as they imagine what awaits their children in the event they die. As observed by Inganga that HIV/AIDS does not discriminate (Personal Communication, July 17, 2019) it could not be that all orphaned children are left in the hands of hopeless elderly. This characterisation may seem deliberate on the part of the filmmaker to assign the tag of hopelessness to PLWHA. Responding to a question about whether she fears HIV/AIDS, Maria responded as follows (0:13:27,13);

Saa hii, sitaogopa, ndio nikule, saa zingine watoto wanaongea, mama nini, mama nataka pesa, uko nastress meengi, unasema tu wacha niwache hii dawa...nikufe, na kifo hakuna, unakonda tu, unasikia vibaaya.

(As for now, I will not fear, I have to eat, sometimes children are so demanding, you get so stressed, you just want to die, but even when you stop medication, you don't die, you only grow thin and feel very bad).

One participant observed in Maria's case that;

Maria's case inakuonyesha ile hali ya mtu mwenye ako na virusi ni mtu hana tumaini kabisa.

(For people living with HIV/AIDS, Maria's story spells hopelessness).

As Maria narrates her predicament, the interviewer gives a sympathetic pose as he keenly listens to the tale. He holds his chin and silently gazes at Maria.

The makers of this documentary had the right of choice as to what images and messages to pass across in the documentary; however, the choice of these images as well as those of the other deserted homesteads send a message of no hope for PLWHA.

The documentary has utilised images of patients who appear in advanced stages of fighting HIV/AIDS. Oloo (Personal Communication, July 20, 2019);

What is being brought out in the documentaries is that they are using characters that are in stage 4 HIV. Most of the patients who live with HIV are not in the end stage because of the effective ARVs. So in the documentaries I usually see them focusing mostly on those people who are in the end stage of HIV and this is not actually the reality on the ground.

Hodes (2007) concurs with this assertion, affirming that even though documentaries on HIV/AIDS are meant to offer hope for people living with HIV/AIDS, the visual images in such documentaries have rather portrayed hopelessness. When Dr Burner talks of the situation of Winney Atieno, a patient in the hospital, she tells of Winney having been in the hospital for two years, yet her situation has continued to deteriorate. The doctor fails to explain the reason as to why Winney's situation is not getting better. The failure to provide facts leading to weakened body as in the case of Winney may send a wrong message to infected persons who are not yet in Winney's situation. One easily wonders why he/she should struggle with ARVs if the end is predetermined. The doctor while explaining the situation of Winney ends with an ambiguous question;

I don't know why patients are still dying in large numbers like before, when there were no ARVs?

As has been demonstrated, the doctor understands that non-adherence to ARVs prescribed way of administration leads to failure of medication. She also understands that late diagnosis is a problem with handling HIV/AIDS. Failure to provide such vital facts in the documentary only acts to create hopelessness in PLWHA, more so when

the statement is followed by visuals of gravely ill patients. Since media has an influence on decision making in society (Osaigbovo & Wood, 2013) assert that, the filmmaker should go an extra mile to provide the educational role of the documentary when dealing with terminal illnesses such as HIV/AIDS. When left unexplained, as in this case, the documentary ends up doing more harm than good, as Hart (2013) puts it.

*Figure 2. 7: Visiting with an HIV/AIDS patient (Courtesy of MSF -Dying of HIV in 2017).*



The narrator affirms the state of hopelessness when he says that another problem is identifying patients whose treatment is failing (0:04:40,24). How hopeless can a patient be having the realisation that treatment indeed fails at times? It is without help at such a point. At this point we are shown the intricacies that go into testing for opportunistic diseases when the immune system is weakened. At 0:05:29,07, we are given visual images of gravely ill patients.

*Figure 2. 8: HIV/AIDS patient is helped by medical personnel to sit up.*



*Figure 2. 9: The image of an HIV/AIDS patient in a hospital ward.*



*Figure 2. 10: An emaciated HIV/AIDS patient in a hospital ward.*



*(All photos courtesy of MSF -Dying of HIV in 2017)*

These images seemingly appear to have been used to strengthen the point of hopelessness in the fight against HIV/AIDS. Now the question one would ask is: What impact will such kind of productions have on people who have already been infected

with HIV/AIDS? In my opinion, this will only act to dampen the hopes for people who have chosen to live positively with the virus. This line of production leads one to believe that documentaries are made with a fixed mind on what the target audience should consume, a position that can easily lead to miscommunication. It gives credence to the plea by Hart (2002) when he calls on filmmakers to free themselves from the trap of the early years of the HIV/AIDS pandemic to accurately serve the information needs of the target audience.

*Mercy in Action* (2014) curves out hopelessness in the following varied ways as identified in the documentary. First and foremost, the survival of PLWHA as well as the affected shown to be based on the mercy from the Catholic brothers and sisters. The narrator starts by stating how village after village buried loved ones, we are then shown close-up shots of small children in isolation wearing sad faces. A close-up of an elderly woman picking on her nails is shown. She appears to be in deep thoughts. Mary Achieng, an HIV/AIDS patient confesses that she doesn't know where she would be if OIP had not come to her aid. She states that;

Kama Shirikisho haingekuwa, sijui ingekuwa aje.

(If shirikisho were not here, I don't know how it would have been).

This affirms that she thought her life had come to an end the moment she was diagnosed with HIV/AIDS.

Elsewhere, Mary Atieno, a nurse at the local hospital, says the virus weakens the body to the level that patients are not able to come to the facility, and thus, they organise to visit them at their homes. We are then shown the image of an elderly woman lying in the grass not able to walk, implying her inevitable hopelessness. This concurs with

the observation by Stamm (2018) that, human bodies have been made to appear to function merely as screens on which the 'truth' of AIDS, which is otherwise equated to death is made to materialise.

Documentaries are meant to educate audience members on topical issues at hand, a fact that the documentary *Mercy in Action* (2014) can be said to have done only in part. When the nurse Mary Atieno says the virus weakens the body to a point where patients are not able to come the facility, she is stating a fact. The filmmaker needed to follow up and establish reasons as to why the weakening of the body occurs. It is the explanation that will help PLWHA have reason to look forward to tomorrow since it is also a fact that not all people infected with HIV/AIDS end in the situation the lady lying on the grass is in. When information terminates at the hopelessness of the lady lying in the grass, the documentary fails to excite the audience to action as part of its mandate (Osaigbovo & Wood, 2013)

Mary Anyango comes in next by saying her daughter has to be carried from place to place. She adds that even the Boda Boda riders have refused to attend to her. This observation affirms Moore, et. al, (2014) that to a great extent, supportive families often experience some type of disruption to their normal life due to the financial strain caused by the disease as well as stigma. Madam Anyango expresses the helpless situation she is in. It is not lack of money but isolation of her family by the rest of the society. Taking her daughter to hospital is a tall order as the only means of transport, Boda Boda, has declined to attend to her.

Further into the documentary, the narrator states that the elderly are given Ksh. 1000 to help them take care of the orphaned children under their care. Magdalene Anyango

confesses that life would be unbearable without the help they receive from Shirikisho. Boniface Mambo, head of the social department at Shirikisho points out that the department started to journey with the people (read HIV/AIDS positive) who are suffering. Bro Andrea adds that;

When parents die, the children remain, they need hope; you cannot stand to see children not going to school; children scavenging for food.

This statement is followed by close-up clips of sad children in isolation. For Catherine Achieng and Antony Onyango OIP restored hope for them by paying their school fees at St. George's Secondary School.

Though the documentary has dealt more with the suffering HIV/AIDS has meted on the society in Oyugis, there is much to be admired from the lives of the characters involved. While we have images of orphaned children dressed in tattered clothes, the children look healthy, a sign they are well-fed. People like Onyango live with the virus but appear happy with their family. Even as he agrees that Shirikisho has helped him, he can be seen working hard on his farm of maize to feed his family. This was replicated in many parts of the documentary where characters infected with HIV/AIDS are seen either individually or in groups doing something for themselves. During FGD discussions, participants were encouraged by the fact that PLWHA are not entirely dependent on handouts. This is what one participant observed;

Hata nimeona baba mwingine akifanya kazi yake shambani vizuri sana. Sio kungoja tu kusaidiwa.

(I can see a man working very well on his farm, yet he is HIV/AIDS positive. You don't have to wait for handouts).

When situations are portrayed as not so very hopeless, it paints a picture that PLWHA can succeed in life, in their endeavors and not be entirely dependent on others. The dependency syndrome portrays people living with the virus negatively heightening

self-stigma. As Hart (2000) observes, documentaries will only be effective in communicating HIV/AIDS messages if characters in such productions display characteristics similar to audience members.

## **2.5. PLWHA Characterised as Social Misfits**

Characterisation of PLWHA as social misfit also emerged as a troubling concern from the sampled documentaries. This has been depicted to be the reason for the hostility meted against PLWHA, especially women. Indeed, this observation concurs with the assertion by Moore, et. al (2014) that fear and violence may at times accompany disclosure to a partner that one is positive, and that in Africa, HIV positive women were more likely to have a violent partner. When it comes to gender, it was observed that the documentaries' point of view has largely been inclined towards women becoming victims of aggression, hostility and blame. These issues then lead to violence and, in some cases disinheritance.

The sampled documentaries appear to be advancing this negative practice against people living with HIV/AIDS by portraying most as not fit to coexist in the society (Matsika, 2013). In *Fishers of Pain* (2016), this notion is propagated through an unnamed woman's portrayal, she states that her house was burned after her husband died of HIV as the community wanted her to leave the homestead. Here is a snapshot of the interview (0:15:14, 01);

**Interviewer:** Wenyaji wa kijiji hiki walichoma nyumba yako kwa sababu hawakutaka uendelee kuishi huku?

(Residents here burned your house because they did not want you to continue staying here?)

**Interviewee:** Kwa maana bwana yangu amekufa, sasa walikuwa wanataka mchanga iwabakie.

(Because my husband was dead, they wanted to take his land)

**Interviewer:** Sasa ati walikueleza wanangoja ile siku utakufa?

(They told you they were waiting for the day you would die?)

**Interviewee:** Kwa maana... siniliitwa hata maiti... we ni maiti sasa unafanya nini hapa.

(They were wondering what I was still doing around yet I was already a corpse).

The violence faced by this lady puts her in a difficult situation where she has to fight for her space instead of taking care of her health. In the same documentary, Maria's husband abandons her due to her HIV status. Such experiences often end up instilling fear among HIV positive women. Such a concurrence was observed in a woman during the FGD, she stated that;

Kama mimi personally, baba ya mtoto wangu hajui niko na ukimwi kwa sababu nasikianga tu vile anaongea juu ya watu wako na ukimwi, siwezi ata kumwambia.

(As for me, the father of my child doesn't know that I have HIV because of the way he speaks of PLWHA, I can't dare to tell him.)

When someone goes through such a challenge domestically and then sees it again propelled in films, it compounds his or her fears. This is in line with Aitkin and Day (1998) observation that watching documentaries on HIV/AIDS increases fear for the infected and affected. Though such occurrences might be common in the society, they ought not to be in documentaries advocating for positive living. Moore, et. al (2014) avows that research in African countries established that HIV positive women may sometimes delay informing their partners because of the fear of physical abuse. This observation concurs with Greef et al. (2008) that disclosure is key to positive living with HIV/AIDS. The lack of it as a result of potential violence or hostility limits voluntary and regular access to medical care due to psychological and social stresses.

Rising from this observation is an assertion that, PLWHA are not fit to be part of the society and should be avoided, segregated and done away with, or considered under very strict terms. This observation concurs with the conclusion by Ismael et al. (2016) that, women suffer rejection by the community they live in due to their HIV/AIDS condition. In the documentary *Dying of HIV in 2017* (2017), we meet a lady patient in the hospital ward (Fig. 2.10) whose HIV/AIDS condition caused her husband to chase her from home, even pelting her with stones. Subsequently, her situation worsened as she could not access her medication, she states as follows (0:03:24, 24);

He stood at the *door* and said he did not want to see me near the house. So, I couldn't get in to take my ARVs. I tried to dodge my way in, but he started hurling stones at me. When I got back home in January, I started taking my ARVs again. I had become disabled and had no energy. I am paralyzed from the waist downward.

The study also established that it appears as though many people do not have access to the right information on the transmission of HIV/AIDS. Herein, hostility meted on PLWHA by the public is assumingly brought to life in this concern. The hostility of this woman's husband made her adherence to medication a challenge that eventually led to her paralysis. This has been the conventional way of HIV/AIDS portrayal and that is how the public now define HIV/AIDS. As a result, the myriad voices of what HIV/AIDS is should be recognised, especially, when they move away from the conventional way the public have been made to know the disease (Paak, 2014). As the world moves, so should the media in relation to HIV/AIDS.

Figure 2. 11: A paralysed HIV/AIDS patient admitted in hospital (Courtesy Dying of HIV in 2017).



In the documentary *Mercy in Action* (2014), Judith Anyango (0:09:55, 20) the caregiver to Alice, an HIV/AIDS patient states that;

When Alice was *stronger*, I could get a motorbike to take her to hospital, but since she became immobile, even the boda boda riders shunned her because she had to be carried from one point to another. So, the riders don't come here anymore. When the health center staff come, they bring a message, a message that consoles both of us.

This statement confirms to us that, besides the consoling visits from OIP staff members, this home receives no visitors. The care giver is alarmed that even those services she could pay for are difficult to come by because of her daughter's HIV/AIDS condition. Her family is isolated and denied essential services. This line of exhibition creates fear in PLWHA and can potentially lead to two things; one is poor quality of life due to psychological stress as is exhibited in the documentary through failure to attend medical appointments, and second, more spread of HIV as the infected will not disclose for fear of rejection and hence continue life as normal.

## **2.6. Ignorance and HIV/AIDS devastation**

The study observed that lack of information as depicted in the sampled documentaries makes management of HIV/AIDS a toll order for medical personnel. Positive living

is thus impacted negatively in such an environment of ignorance. When considering the area of adherence in taking ARVS, many characters living with HIV/AIDS have been depicted as having abandoned medication after they assumingly began to feel better, out of belief that they are completely healed. In *Fishers of Pain* (2016), Dr. James Abwao asserts that;

Many people we receive at Homa Bay district hospital already know their status and are *on* ARVS. The problem is, most have defaulted and therefore are getting opportunistic diseases, which is a challenge in the wards.

Elsewhere, an HIV/AIDS patient (0:04:1, 00) affirms this stating that;

Like me, I started on ARVS and got better. I thought I was cured and could do my job. *When* you get better, you imagine you are already healed and as healthy as everyone else. You don't know the drug has only weakened the virus.

These observations affirm the filmmaker's voice that there seem to be a deliberate thought towards the end that PLWHA are ignorant of the requirement for enhancing their personal wellness, and hence, they end up deliberately putting others at risk.

In *Fishers of Pain* (2016), Karen Adhiambo, a community health worker explains that when a husband dies, their widows flock to the lake for survival. They hook up with fishermen to whom they sell sex in exchange for either money or fish. She attributes this to the rise in HIV infections in Homa Bay County. Elsewhere in the documentary, Ms. Zahra Hassan the program coordinator of Women Fighting Aids in Kenya (WOFAK) (0:12:22, 08), points out that women do not have safe negotiating skills in terms of using condoms;

For example, you know that your man is having extramarital affairs, but when he comes home, you don't have that bargaining power that I need to protect myself.

Many of the cases we come across in the documentary *Dying of HIV in 2017* are as a result of not taking drugs in the prescribed manner, an observation that concurs with

Osaigbovo (2013) that points out the fact that HIV infection is connected to lack of access to correct information. In this case, access to the correct information concerning the use of ARVs which have the capacity to keep an infected person in a near-normal healthy condition when taken well. When they stop taking drugs, the virus attacks with more vengeance, putting them down.

Karen Adhiambo, a community health worker then points out that women indulge in sexual liaisons at the lake without minding the HIV/AIDS status of their partners. Such narrow reasoning has arguably facilitated the rapid spread of the virus in the community. Ms Zara Hassan further observes that women need to be empowered with the necessary information if the war on HIV/AIDS is to be won. In these findings lies an assertion that even in cases where women face hostility due to their HIV/AIDS status, it is largely due to the lack of information.

## **2.7. Characterization of Children as orphans due to HIV/AIDS**

The characterisation of children is expressed in two of the documentaries, *Fishers of Pain* (2016) and *Mercy in Action* (2014). In the documentary *Mercy in Action* (2014), a particular scene begins with a shot of children who are poorly dressed with no adult in site (0:03:36, 10). This is followed by single close-up shots of children emotionally disturbed with very sad faces. A scene of an elderly woman with children follows, they are apparently cooking in the open on the traditional three stones. A grandmother is seen leaving the house with three children.

We are later shown three women seated on the veranda (0.03:51, 19). These women are shown holding their chins and probably in deep thoughts, with them are children in uniform, an indication perhaps they may be out of school for lack of school fees.

Ismael et al (2010) observes that families affected by HIV/AIDS are forced to cut down on education spending resulting in illiteracy. These depictions dominantly repeat through several sequences that feature orphaned children with their struggles revolving around upkeep, school, clothing and general nutrition and octogenarian caregivers. A participant observed during a FGD that;

Watoto hao ambao wazazi wao wamekufa kwa HIV wako  
sentenced kuishi na nyanya zao.

(Those orphaned children have been sentenced to live with their  
grandmothers).

This documentary assertively paints a picture of suffering children, who are allegedly orphaned by HIV/AIDS. They are dressed in tattered clothes, which is an indication of the quality of life they live. They look sorrowful, pitiable, lonely and dull hence completing a portrait of suffering. It is assumed life would be different if their parents were alive. It is, however, common knowledge that this kind of life is not a preserve of the orphaned in the society, regardless of the cause. As an assumption, this documentary has however labeled all parental deaths as caused by HIV/AIDS. It has also subsequently stratified the orphaned as a people that cannot survive without compassionate helps.

Though this assumption may be true for some orphaned children, it is irresponsible to generalise such predicaments as the way of life for all orphaned children. Oloo (Personal Communication, July 20, 2019) observes that;

In my facility here, I have kids who are orphaned, but, then when  
you look at them, they are well taken care of.

In the interest of advocating for positive living, it should also not be assumed that all orphans are a result of HIV/AIDS as the filmmaker seems to communicate.

In the documentary *Fishers of Pain* (2016), the plight of orphaned characters is seen from the words of the 90-year-old Siprina Omollo and the 82-year-old Agatha Onditi.

In relation to fending for her grandchildren, Agatha says that,

Sasa hivi kama mimi niko na watoto tano nafanya nini.

(At this age, if I have five children, what can I do).

Agatha laments that she has no strength to till the land so as to get food for the grandchildren. Siprina on the other hand has resigned to fate. She has one granddaughter to take care of, and she notably states that;

It is only God who can take care of her; I have left it to Him.

Children left under these grandparents are bound to drop out of school if help fails to come their way. Catherine Atieno, a student of St George's Secondary School, gives testimony to this as she states that;

When I finished standard 8, my uncle took me to stay with my grandmother, but before I joined form one, that uncle died, it forced my grandmother to search for me a scholarship but in good luck, she found one of the members working with Shirikisho, she talked to her and that person agreed because I had finished standard eight, it would have ended like that, because there was no school fee (0:14:45' 07).

This testimonial seems to dictate that orphaned characters who fail to get sponsorship to school are therefore tied in the cycle of poverty through illiteracy, which in turn pushes underage girls from such families to engage in premature sexual relationships for survival, a thing that aids the spread of HIV/AIDS.

## **2.8. Conclusion**

This chapter has addressed the issue of characterisation in documentary films on HIV/AIDS and how it impacts on positive living with the virus. Whereas documentaries have characterised PLWHA as poor, it has come out that HIV/AIDS

does not discriminate, and therefore all sectors of the society are at risk of infection. Confining the disease to particular segments of the society can result in a false feeling that the rest of the society is safe from contracting the disease. Documentary films have a key role in enlightening members of the public of this reality so as to avert unwarranted spread of the pandemic. PLWHA have also been characterised as hopeless, people who do not have a future. It has come out that continued portrayal of infected people as hopeless only heightens fear among PLWHA and cultivates stigma, even self-stigmatisation. As tools of advocacy, documentaries should help the public with information that draws them away from hopelessness.

This chapter has also established that when viewed as social misfits, disclosure of HIV status becomes a problem leading to unchecked spread as individuals seek a sense of belonging in the society. Resultantly, stakeholders need to relook at characterisation of PLWHA in documentaries to reap expected benefits. As a powerful tool of communication, the public have faith in what is communicated through documentaries and hence the need for factual positions to be reported to all the audience to make informed decisions.

Finally, it can be noted that there definitely are many cases of people positively living with HIV/AIDS and contributing immensely to the economy. Such are messages that need to come out in documentaries alongside desperate cases. Ultimately, the infected must be aided to understand that there is life after contracting HIV/AIDS.

The ensuing chapter presented and discussed findings on documentary voice in relation to HIV/AIDS advocacy.

## **CHAPTER THREE: DOCUMENTARY VOICE AS AN AGENT OF ADVOCACY FOR POSITIVE LIVING IN DOCUMENTARY FILMS ON HIV/AIDS**

### **3.0. Introduction**

This chapter looked at voice of documentaries from the perspective of what is verbally said on screen otherwise referred to as ‘up sound’ of characters, voice-over narration and selection as well as the arrangement of visual images. It is said that an image is worth 1000 words. According to Chandler (2005), Semiotics is invaluable if we wish to look beyond the manifest content of texts such as films. In this chapter, the titles of the sampled documentaries will also be discussed in relation to what voice they carry.

### **3.1. Voice in documentary title**

According to semiotician Peirce (1991), the act of thinking by itself, is often a process of interpreting signs. In light of this assertion, the study sought to critically look into the filmmakers’ POV as displayed in the titles of the sampled documentaries. Braha & Byrne (2011) classifies titles broadly as credits and then asserts that, when seen as actors on stage instead of just titles in the foreground, then we can imagine them to do anything that you want them to do, as long as you direct them. They point out further that, these titles can also interact with the characters, taking on their traits, thus becoming the real actors on stage, and the human characters just puppets. Without doubt therefore, the title of a documentary introduces the audience to contents of the documentary, thereby telling them of what they are to expect in the event they decide to either watch the documentary or not.

The title creates in the audience a desire to watch the documentary by being either literal or figurative in its implication of the packaged content. According to Chandler (2005) figurative language is that which doesn't mean what it says, as such, it contrasts literal language which is purely denotative. It should thus be noted that the title sends a message to the target audience even before they come into contact with the body of the documentary. What leads the audience to either take the documentary from the shelf or not is the voice of the title. In the analysis of the titles of the sampled documentaries, *Dying of HIV in 2017 (2017)* points to death as the main content of the documentary. The same to *Fishers of Pain (2016)* points to pain as a by product of fishing while *Mercy in Action (2014)* points to a people under compassionate living. The three titles do not assert positivity for people living with HIV/AIDS. As has been observed, these titles do convey doom for people living with HIV/AIDS. They are thus likely to put off the target audience, as they may already feel condemned for living with HIV/AIDS.

When watching the documentary *Dying of HIV in 2017 (2017)*, one would assume from that title that all victims of the virus in the documentary are actually dying, or are destined to die at some point in the film. However, none of them dies despite being portrayed in bad physical shape. The expectation of death as pointed in the title fails to materialise, and as a result, the title *Dying of HIV/AIDS in 2017* becomes both misleading and misplaced in a documentary where no death is reported. Consider the following observations by FGD participants;

Title imekuja tofauti na kitu ile tunaona kwa sababu picha inaonyesha treatment of AIDS lakini title inasema dying of AIDS.... picha haijatuonyesha vile watu walikua wanakufa in 2017.

(The title does not speak to what we have seen in the film. The film is about AIDS treatment while the title is about death. I expected to see people dying but the film has not shown anybody dying of HIV/AIDS in 2017.)

Another participant noted that;

*Dying of AIDs in 2017*, the situation I am seeing, and the title is very different. Maybe they are giving it a picture as people who do not understand what happens in the life of an HIV/AIDS patient. The title does not fit the documentary.

Another participant also observed that;

Mimi sijui kama tunaongelea 2017 ama 2007.

(Are we talking of 2017 or 2007?)

According to Álvarez (2020) media is not monolithic, it has the potential for resistance, dissonance, and readings against them. The reactions are in conformity with Hall (1980) assertion that audiences may at times take an oppositional reading to what the author meant. Rising from the observations pointed above, it is an outright indication that the participants noted with objection the fact that the producer has a set mind that anybody infected with HIV/AIDS will eventually die. This is contrary to reality where people have been living with HIV/AIDS for decades without any sign of death. This kind of voice does spell doom for people living with HIV/AIDS.

In *Mercy in Action* (2014), the title puts the infected in the category of people who need compassion, sympathy and pity. Álvarez (2020) concurs, thus affirming, that we understand AIDS in the language by which it is constructed, and that there is nothing further outside the text since we only exist and conceive our reality within the margins of discourse presented before us. This in itself dehumanises PLWHA as a people without a future, as they have to be dependents of OIP in order to survive. The interesting thing is that when you watch the documentary, you come across people who are determined to live positive. People, who are working hard to feed their

families. During focus group discussions, this seemingly appeared to be the only documentary that participants identified with. In reference to Jack Otieno, a character living with HIV/AIDS who is captured on his farm harvesting maize, one of the participants in FGD had this to say:

Hii picha ya leo vile nimeona ni mzuri sana. Inaencourage wagonjwa. Hata kama unapewa dawa, unendelea na kazi yako kawaida. Nimeona mbaba mwingine akifanya kazi yake ya shamba kama kawaida.

(Today's documentary is very good. It is an encouragement to people infected with HIV/AIDS. Even when on drugs, you still go on with your normal chores. I have seen a man tilling his land as if he wasn't sick.)

Haifai eti kama mimi nikipata ugonjwa, sasa unakaa tu, hapana, inafaa unaendelea na kazi zako.

(It is not good that when you are diagnosed with HIV/AIDS now you just sit there doing nothing. You should continue with your normal duties. These people have decided to do something extra for themselves, just like in this facility here, you don't have to fully depend on handouts).

This is not said of somebody whose survival is dependent on mercy. The title is therefore not in tandem with the visual images used in the documentary. The voice of the title is that of people who cannot survive in the absence of external help. This thus becomes a stereotypical creation in concurrence with the assertion by Malagasi (2015) that, audiences can easily form stereotypes around HIV/AIDS. On the contrary, these characters have formed self-help groups, which have led them into small-scale businesses. They therefore appear able to support themselves accordingly.

The title *Fishers of Pain* (2016) portrays fishermen in a bad light; it seems to imply that instead of going for fish, a delicacy from the lake, they instead fish for 'pain' in the name of HIV/AIDS. FGD participants observed that;

Title yake ni stigma, inaongelea watu ambao, hawaajibiki.

(The title is stigmatising; it speaks of people who are not responsible).

Another participant observed that;

Hii title haifit with hio content.

(The title is not in line with the content of the film).

Another one still observed that;

*Fishers of Pain* can attract one to watch the documentary, but on watching it, you get very little of fishing in that movie.

As noted from these observations, it can be affirmed that the expectation of the viewer is cast out the moment they engage the content of the documentary. The title implicitly communicates immorality on the part of fisher folk on the beaches of Lake Victoria. In concurring with Osome (2021) that documentaries intend to influence either consciously or subconsciously, it is duly noted that the filmmaker intended to advance notions of immorality, hence achieving the creation of a perceived immoral culture among the fisher folk community. Fishing is a noble cause and should not be condemned, as it is a trade that cannot be wished away. The documentary does not give us a direct connection that gives evidence of that pain ascribed to fishermen. In the case of Maria who has HIV/AIDS, just as are all other cases of PLWHA, it is not evidently stated if they got it from the lake, and even if she did, she is neither a fisher lady nor a fishmonger, indeed, no evidence is given of a fisherman nor fishmonger contracting HIV/AIDS due to fishing activities.

As has been observed regarding the documentary titles of the sampled films, the study affirms that the title is therefore not reflective of the contents of the documentary. I thus draw concern to the fact that concurs with Chandler (2005) that, in everyday life, our attention is often drawn to an unusual metaphor, such as these titles critical quip the observations made in this section. Having been enticed in some way to view these

documentaries, audiences would eventually be brought to the realisation that by far and large, the voice of the title and the voice of the body differ.

### **3.2. Narration voice as voice of documentaries**

The narration voice is considered as the dominant voice of documentaries; it is pre-determined by the filmmaker, and intended to achieve a certain objective, that is, to advance a particular point of view. It is the explanation that comes from the producer to aid the audience understand the documentary better. It therefore stands for the position the producer of the documentary has taken.

#### **3.2.1 Narration voice as bearer of News of Death**

In the three documentaries under study, it has come out that death and HIV/AIDS cannot be separated. In *Fishers of pain* (2016), we are introduced to empty homesteads where parents have allegedly died from HIV/AIDS. As earlier on observed, at the very beginning of the documentary, the narrator states that the area has become the epicenter of the deadly virus. Further in at 0:01:05, 07, the voice over comments that;

The scattered homesteads share a unifying history that HIV/AIDS has nearly wiped out the entire community.

The narrator gives the impression that the virus causing HIV/AIDS is uncontrollable, hence sweeping through the community mercilessly and without discrimination, driving it towards extinction. The audience is then made to perceive that all death emanates from HIV/AIDS, and they are thus in danger, for it seems only a matter of time before the virus catches up with them, hence subsequently - death. This documentary thus gives a voice of death for people infected with HIV/AIDS when juxtaposed with the observation that nearly every family has lost someone to

HIV/AIDS (0:03:02,00), which is indicative of an unsafe community on the verge of extinction. Consider also this opinion;

So this disease is almost wiping out the entire community?

At 0:03:06,15, in reference to George the CHW, the narrator avers that;

George is not an ordinary health worker; he has borne the brunt of HIV/AIDS. Four of his brothers have died of HIV/AIDS.

Coupled with other instances, the narrator is seen as advancing the notion that AIDS is indeed an outright killer. At 0:04:48.10, the narrator avows that there exists very little human contact due to the scourge of HIV/AIDS between the two neighboring villages in Rachuonyo sub-county. At 0:06:12,11, Siprina Omolo, a grandmother who takes care of her orphaned grandchildren is portrayed as stating without certainty that all her children have apparently died from HIV/AIDS. At 0:06:56, 04, the narrator asserts concerning Agatha Onditi, another octogenarian, that she apparently lost all her four children to the disease. At 0:05:04, 03 the narrator states that he is currently standing by the graveside of the latest victim of the HIV who passed on just two weeks earlier (Fig. 3.1). The producer through narration is categorical that the little human contact in the villages is as a result of death from HIV/AIDS.

By singling out George, a CHW, who has allegedly lost four of his brothers to HIV/AIDS, it is telling in itself that George should know better how to deal with HIV/AIDS since he is a health worker, yet four of his brothers have died. By stating that George is not an ordinary citizen, it is a signifier of the danger the community is faced with. Chandler (2007) states that even the most realistic signs may not be what they appear to be. It therefore follows that by reference to George as not being an ordinary person in the community, the narrator seems to suggest the gravity of the

problem the community is faced with through the scourge of HIV/AIDS. It would therefore appear from the narration that regardless of circumstances, the ultimate end of a person infected with HIV/AIDS is death. Even in picking George to comment on mortality, it should be noted that George is not a health professional, and therefore, he cannot be taken as an authority to comment on the cause of death in the villages.

Rising from the observation raised above, it can only be concluded that the filmmaker may have started the production with a fixed mind on what he wanted to convey that HIV/AIDS is a killer and, therefore, the higher the number of graves, the more credible his tale becomes. Rising from these FGD observations, it is eminent that such portrayals in the documentary voice are not reflective of the known truths. Homa Bay County has been noted as one of the places where HIV/AIDS advocacy was highest.

*Figure 3. 1: Timothy Otieno, standing beside the grave of an HIV/AIDS victim (Courtesy of Fishers of Pain).*



*Mercy in Action* (2014) brings out HIV/AIDS as the cause of death. In its opening minutes voice over at 0:03:40, 00; the narrator states that;

Adult population vanished and children were orphaned,  
grandparents took charge of caring for the grandchildren.

The word ‘vanished’, is inferential to the assertion that the ‘adult’ population did disappear. By innuendo one may thus equate HIV/AIDS with death. That voice is hence reflective of how dangerous HIV/AIDS seems to be.

In the documentary *Dying of HIV in 2017*, the narrator asserts the possibility of death due to infections in advanced stages of HIV. At 0:05:33,02, the narrator asserts further that;

Teams will continue to receive gravely ill patients and many will die shortly after arriving, medical care is a real challenge.

It must be observed that this statement has been affirmatively stated in a hospital setting, which should be the last call of hope for people living with HIV/AIDS. When the voice of death is sounded in such an environment, people with HIV/AIDS tend to have nowhere else to run to. Further on, the narration goes on to say that (0:06:17,00);

There is another hidden side to AIDS, the sick who don't manage to get to hospital. Either they have never been tested for HIV or they have never had access to antiretroviral. They remain out of sight and will highly likely die in their homes.

The documentary seems to be telling us that the sick are ignorant of their situation, and as a result, they are likely to die in their homes. Combined with the previous statement, either way, in a medical facility or at home, it has been projected that death is waiting for people living with HIV/AIDS. The producer has failed to sensitise the audience on what they need to do, so as to live a positive life with HIV/AIDS. The documentary's POV deliberately projects people living with HIV/AIDS as destined to die. As a medium with influence on the perception of audience on social issues (Hart, 2002), documentaries need to go further and explain HIV/AIDS fully for audience to understand what they need to do to live with the virus. It is not enough to project the desperate situation in the journey with HIV. Documentaries should go further and provide solutions to social issues, a position documentaries under study have failed to bring out.

### 3.2.2 Narration voice and Immorality

Through the sampled documentaries, the POV has also been noted to be pointing towards immorality. In the documentary *Fishers of Pain (2016)*, immorality is first mentioned at 0:08:58,13. Consider the following excerpt;

The genesis of HIV/AIDS is the show line of Lake Victoria. Here young fishermen and ladies engage in a very dangerous trade of fish for sex. The trade *jaboya* is what many attribute to the spread of HIV in the region.

The narration goes on at 0:10:46 stating that fish is not the only commodity on sale at the beach. In these depictions, the narrator seems to be of the view that HIV/AIDS is spread from the sexual engagements of fishermen with the women at the beach. These assertions are indicative of women trading sex. Of grave concern is the association this statement is given with the idle women standing beside a stall at the beach (Fig. 3.2). By juxtaposing that narration and the image of these two women, the filmmaker aims to ascertain the point that it is beyond fish trading, another dangerous trade that plays right into the trappings of HIV/AIDS. Intuitively, they are to be considered as prostitutes or rather commercial sex workers.

A critical assessment of the scene in context depicts no outright link between the women at the beach and prostitution. These women are decently dressed and not in the company of men perse. The narration assumes however that all women who go to the lake are looking for sexual partners, a position that may not be necessarily true. To illustrate this concern vividly, consider the narration at 0:11:25,00;

Women here engage in sexual relationship with fishermen to get their daily shawl of fish.

This statement is very categorical. It suggests that all women in the fishing industry are immoral and given to wanton sex on or off its demand. When combined with the statement that follows at 0:11:36:00 stating that;

For women here, it does not matter how much money you have, if you don't back up your sale in bed, you go home hungry.

When the narrator stresses that for a woman in the lake region, it does not matter how much money you have, it puts all women in the same category of selling sex. The narration is categorical on the source of HIV/AIDS to the community as being the shores of Lake Victoria and does not acknowledge many other locations. Paak (2014) argues against ascribing particular localities with the disease as it creates a false impression of innocence for people who do not fall in those places despite their wayward ways. In light of this documentary's implication, people in nightclubs and red-light streets watching this documentary are likely to sit pretty, continue in the risk behaviours while assuming HIV/AIDS is a preserve of beach goers. It must be ascertained that the life on the beaches is not the sole cause that fuels the spread of HIV/AIDS. It needs to be categorical that it is not the only source, nor is it obvious that you get HIV/AIDS by associating with beach activities. During FGD sessions with Adult Psychosocial Support Literacy Group, it came out that HIV/AIDS is not a preserve of the lake region. A participant observed that;

Ukweli ni kwamba boya iko kila mahali, hata kama ni butchery, iko, shamba ya mboga ukienda boya bado iko. Anataka mboga mingi na anatoa pesa kidogo, huyo mtu atamuweka kando na wataelewana, not only fishermen, unanielewa?

(Truth be told, 'jaboya system' is everywhere, in the butchery, you will get a jaboya, in the farm, you still get jaboya, she wants more vegetables but has less money, the farmer will pull her aside and they will agree, so it is not only fishermen, do you understand?)

This observation points to the fact that sexual favors in the 'jaboya' or what they refer to as 'customer' system can be traced to all spheres of the socio-economic life. They thus observed that the fight against the spread of HIV/AIDS should not be confined to the lake as other segments of the society may be affected to a larger extent than the lake.

Based on the portrayal in the documentary, decent people found near the lake may easily be mistaken for prostitutes looking for company. As a result, therefore, the fishing community faces more marginalisation, thus making them more vulnerable to irresponsible sex life.

### **3.2.3 Narration voice and Ignorance**

In *Fishers of Pain* (2016), ignorance has been brought out in the way HIV/AIDS is said to be spreading at the lake. When the narrator states that young men and ladies engage in sex for fish, it is intended to communicate that they are ignorant of the dangers posed by HIV/AIDS. The voice of the documentary in such a statement is that of assumed ignorance on the part of fisher folk and the lake line dwellers who may think they are enjoying life only to be infected with HIV/AIDS.

In the documentary *Mercy in Action* (2014), the narrator states that the disease was thought to be an act of witchcraft brought about by going against cultural norms. Judith Anyango states that her daughter was taken to Tanzania for 'treatment' because they thought she was bewitched. She however confirmed that there was no cure (0:01:51,00). But for a documentary that was done in 2014, such a line of thought was not necessary as information about HIV/AIDS was available to the community courtesy of Shirikisho. As such, the line of witchcraft was not relevant at that point in

time. This voice seems to have been forced into the documentary for the purpose of fulfilling the desire of the producer, who seemingly wanted to portray ignorance on the part of the people infected with HIV/AIDS.

In the documentary *Dying of HIV in 2017*, ignorance is expressed by the characters infected by HIV/AIDS when they go for medication too late. Consider this excerpt from the narration (0:01:10,00);

Winney was admitted to hospital in Western Kenya with late-stage HIV, meaning HIV has attacked her immune system. She is extremely vulnerable to infection.

Indeed, HIV can be well handled in the event that patients go to hospital early, before they develop full-blown AIDS. The reality, however, is that most patients seek medical attention when the virus has weakened the body and are now immobilised, a result of ignorance, and in return, this makes it very hard for medical officers to manage the patients. At 0:01:30,00, the narrator states that;

In the nearby bed, Akunda and others like her are all in the same situation. Their stories are different, but they face the same situation where HIV continues to kill when ARVs are in widespread use.

The voice in the narration is that of ignorance on the part of these infected characters that they have neglected the effective use of ARVs which are life-sustaining drugs intended to help boost the immunity of people living with HIV/AIDS. PLWHA are able to live a normal life when they adhere to the doctor's prescription in taking drugs on schedule. For the audience who is informed of this fact, dying of HIV/AIDS would definitely be a product of ignorance.

Ignorance is also expressed when a lady, (name not given) is chased out of her home due to her HIV status. The lady defaults in the process leading to paralysis. Many people have the misconception that HIV/AIDS is a result of unfaithfulness in the

family. This ignorance breaks families that would have been strong, increasing the suffering of the infected in addition to stigmatization. Such voice should be used together with voices of well-informed people living with HIV/AIDS to avoid generalisation. The voice over has projected infection and death arising from HIV/AIDS to ignorance of those infected with the virus.

### **3.3. Documentary voice in up sounds of talking heads**

Talking heads are the characters that speak in documentaries, giving sound bits and could be the people with information the filmmaker wants. The role these talking heads play in the documentary decides whether they provide a voice for the documentary or not. If the characters and the role they play resonate with the audience, then what they say is key to the message passed by the documentary. Their influence in the society is also a factor in whether their voice will count in the overall message of the documentary projects. In the documentary, *Fishers of Pain* (2016), the up sounds used give the voice of poverty, desperation, immorality and evident lack of proper nutrition for people living with HIV/AIDS. At 0:09:21,16 Karen Adhiambo a CHW exemplifies this in her observation stating that;

Kwa hii jua hakuna chakula ya kutosha, sasa mtu anaweza meza dawa na akose chakula ya kukula. Sasa itafanya mtu atafute mpango ya kando ili apate chakula alishe nayo Watoto.

(With this hot sunshine, there is not enough food, one can take drugs and lack food. This makes one to engage in side relationships to fend for the children).

This assertion that even getting food for most victims is difficult presents a situation according to her that leads most women to prostitution. Her statement points to a concern that apparently, all widows do turn to the lake for 'fish for sex' trade (*jaboya*) to survive.

Boya maana yake ni customer kwa kijaluo, huyo ni customer ukienda unataka kununua samaki, mpaka ukue customer. Sasa mimi ni mvuvi utakuja kwanza tushike ucustomer kwanza, hapo ndio mimi nitakwambia mimi ndio nitakua nakupea samaki lakini kwa njia ya aina hii na hii na hii.

(Jaboya means a customer, to do business with anyone you need first to be a customer. In the fishing industry, it is the same, we must create customer relations before the fishing business.)

This observation asserts that one doesn't necessarily have to have sexual relations to acquire fish. Indeed, a guided walk through Yimbo West ward revealed widowed women who are successful business personalities in other spheres. It could actually be noted that it is the minority who turn to the lake for the infamous 'fish for sex' trade. When Karen is made to associate HIV with immorality, being an influential and accepted peer educator in the community speaks volumes concerning the social status of the people concerned. The audience can very easily believe what she says. The filmmakers seem to have used Karen to show where they have intended to lay the blame in the spread of HIV/AIDS. Her endorsement of unfaithfulness thus seems deliberately directed for a perceived outcome.

Deliberately avoiding interviewing women in the fishing industry seems to have been aimed at muting the voices of the accused, with the ultimate end to project HIV/AIDS as a self-inflicted problem. This kind of programming deliberately prepares for the creation and advancement of a voice in documentaries that isolates PLWHA from the rest of the society, hence working against positive living with the virus.

In another instance, as observed in the previous chapter concerning Agatha (see 2.4), her complaint leads one to again blame people infected with HIV/ADS for creating problems for the aged in society. Any audience cannot ignore the age of Agatha.

When one combines her age and the tone with which she expresses her complaints, it gives a very strong message of people infected with HIV/AIDS causing anguish to the elderly.

In the documentary *Dying of HIV/AIDS in 2017*, it is Dr. David Maman's complaint in his up sound that evidently shows the stand point of the documentary voice. He avows that if the patients at the hospital were from well off families, maybe they would not die from HIV/AIDS. The statement at 0:05:48, 16 talks of poverty on the part of the people living with HIV/AIDS as being so loud and evident. It should be observed that a word from a medical doctor is often taken very seriously. When he says it is very difficult to deal with HIV/AIDS in poor settings with minimal or without resources, he seems to have sentenced a majority of his audience to death, whereas the documentary is supposed to sensitise the community in which it is produced even before it gets to other regions. Another instance from that documentary presents Tangui Andygbia a MSF health promoter who states that;

Patients come in very late; others prefer to stay at home while others can't afford to go to hospital. Due to insufficient bed capacity, patients are discharged before they are healed to create room for other critical cases.

That many people prefer to stay at home for lack of resources to access medication is of grave concern. Tangui's statement shows that the community is poor, and that is why the hospital does not have sufficient facilities. Patients are forced to discharge before they are healed to create space for more critical cases. This is a very strong message to people living with HIV/AIDS. When they hear the message from people infected and service providers on what they have to face, it discourages instead of encouraging them towards positive living with HIV/AIDS. After watching the documentary and listening to Tangui, patients may not see any reason for going to the

hospital if they will be discharged before they are well enough simply because the hospital does not have enough bed capacity.

In the documentary *Mercy in Action* (2014), the voice of poverty, desperation and dependency continues to come out through talking heads. Brother Vincent of OIP says;

OIP was started mainly to cater for people who were infected with HIV/AIDS and support them in other ways, and that is why we started the medical department, social department, and agriculture department.

Brother Vincent explains that they needed to be all round for their assistance to have meaning. He notes that with the economic position of the community, medication alone would not assist. The agriculture department was started to take care of nutritional needs of the community, while the social department was to assist them come up with ventures that would enable them to generate income. At 0:16:45,00 Brother Thomas, the deputy head teacher of St. Georges Secondary school says;

We actually provide them with more than their parents would provide.

When the teacher imagines that the school is providing more for the students than what their parents would, one is left to believe that the individuals referred to are extremely poor, that school becomes not only an educational center but a haven, far much better than home. The statement is tantamount to bragging about their ability, which they outrightly perceive is over and above that of people infected and affected by HIV/AIDS. The dangerous notion is propagated deliberately by the filmmaker's blatant failure to follow up these claims on provisions by the school. The filmmakers seek out the beneficiaries of OIP who allude to this similar strand. At 0:14:45,00

Catherine Atieno, a student of St. Georges secondary School under sponsorship of OIP affirms that;

My mother sort for me scholarship from Shirirkisho who took me to form one. My education would just have ended like that.

Tony Onyango, another student also under sponsorship confirms that;

I think I would have been told to repeat so that I can get good marks for the government or Equity to sponsor me.

Such voices of desperation project PLWHA as beggars whose survival and family welfare depends on outside help. This kind of voice from the documentary calls for sympathy for the affected as well as the PLWHA. Perhaps the voice of a person living with HIV/AIDS and in a position to help others would have been more acceptable for those living with the virus, but this is probably left out deliberately. One participant observed that;

Kama hii ni kudiscriminate eti mtu mwenye amekonda, mtu hajiwezi.

(Anybody who looks emaciated is equated to HIV/AIDS positive status, which is discrimination.)

This observation depicts the dissenting view with the projected POV. It is observed that people living with HIV/AIDS were not as desperate and poor as has been predominantly indicated in most documentaries.

Another voice the filmmakers have projected from talking heads is that of death for people living with HIV/AIDS. In the documentary *Fishers of Pain* (2016) at 0:01:46,08, George, the CHW leads the producer through the community but only shows him instances where death has occurred. Consider the following excerpts;

Huku juu, kuna boma bwana alikufa, akawacha bibi akawekwa kwa dawa, akawacha dawa, aliporudi hospitali nyingine, pia akafa (0:01:46,08).

(This upper side, there is a home where the husband died, the wife was put on drugs which she defaulted, when she went back to drugs again, they could not work, she died)

Kila boma, lazima upate mtu amekufa kwa ajili ya ukimwi.

(0:03:02,06).

(In every homestead, you must get somebody who has died from HIV/AIDS).

The documentary through George paints a picture of HIV/AIDS killing indiscriminately. In a peculiar instance at 02:29,53, the interviewer appears to have set up George in giving out a directed response that favors the picture that the filmmakers desired to paint. Consider the following excerpt;

**Timothy:** Within this whole area, of say 50m by 50m how many households can you count and say have lost a family member through HIV/AIDS?

**George:** Almost ten (10) or twenty (20), karibu maboma ishirini (20), ninahakikisha.

(... about twenty homesteads, I can ascertain.)

It is unrealistic that more than 20 homesteads would fit in a 50-meter square area. In this regard, to point such an interviewee towards responding to such an ambiguous question from a seasoned journalist is indicative of a predetermined outcome. So, when George says that every home has lost somebody to HIV/AIDS, it communicates the preconceived seriousness of the problem at hand that seems to have been predetermined for screening. Another citable instance was seen at 0:05:37, when the 16-year-old Jane stands next to her mother's grave and says;

She was taken to hospital, was discharged and on her way home she died on the roadside.

In this observation, the filmmakers point to the need for empathy from the audience.

In return, they would naturally connect with the message of death. Indeed, it is natural

for people to identify with the plight of minors and, therefore, the voice of the minor next to her mother's grave cannot go unnoticed and hence strengthens the documentary a voice, in this case, on the matter of death.

At this point, it may be asserted that the decision to use the affected or infected with HIV/AIDS to do the communication was intended for the purpose that the audience be directed to identify with the message. This concurs with Carroll (1985) that in explaining the process of documentary making said that, through careful image selection and combination, the editor is able to project the image desired by the filmmaker at the appropriate time to the audience. It can thus be affirmed that the filmmaker was therefore selective even of the up sounds so as to drive their point about the deaths of Karachuonyo people as resulting from HIV/AIDS.

Paak (2014) states in affirmation that directors on the pandemic of HIV/AIDS have concentrated on nothing else but projection of despair for people infected with the virus. Indeed, when George, the CHW tries to explain that the continued high prevalence rate for HIV/AIDS in the region is as a result of double registration by people who default from one hospital to another, the narrator disputes while insisting that George's analysis is not sufficient to explain the high prevalence rate. Such a line of thought only acts to direct attention to the wrong areas when addressing HIV/AIDS while real issues identified by those who work closely with the community persist. Oloo (Personal Communication, 20 July, 2019) concurs with George's observation stating that;

Patients move from facility A to facility B without any transfer letter and when they get to facility B, they are initiated into ARVs as new patients. This lost to follow patients are the ones who create a wrong impression of high prevalence rate in Nyanza. It is very difficult to find a real new positive nowadays.

This observation points to the fact that it is very difficult to get the right prevalence rate of HIV/AIDS in any part of the country as a result of defaulters who move to other facilities and register as new patients.

In the documentary *Dying of HIV in 2017* Dr. Berner Gurer of MSF says;

ARVS are available, diagnostics are available, so the question is why HIV/AIDS patients are still dying.

The statement observed above baffles, just the concern that a doctor is asking such a question when they are to explain to the infected why people with HIV/AIDS are dying. This statement from the doctor communicates the existence of some sort of definite, incomprehensible death for people infected with HIV/AIDS. Again, that question goes ahead to show that even doctors do not understand how to deal with the HIV problem. Dr. James Abwao then comes in with an explanation for the deaths, suggesting that;

Most patients are on ARVs. Either they have been on ARVs for long and they are failing or failure to adhere to schedule.

No reason is then given as to how or why ARVs fail when used over a long period of time. The voice of Dr. Abwao's statement may therefore be misleading, as it is outrightly frightening. If a doctor puts doubts in the only drug that patients know of as the solution to HIV/AIDS, it blows out any little hope for positive living that they may still be harboring. Clearly, there seems to have been a need for further clarification by the filmmaker for people living with HIV/AIDS to benefit from the communication. As observed in Hart (2002), media has a lot of influence on the direction taken by the public on issues of public interest; there was, therefore, a need for the filmmaker to have gone further to explain the way out for people infected with

HIV/AIDS. What should they do to escape imminent death? As it is, the message only serves the producer who has a fixed mind that HIV/AIDS kills.

In the documentary *Mercy in Action* (2014), death is alluded to by a talking head at several points. At 0:03:27,22 Brother Vincent says;

It was very sad, especially for us brothers. It was sad for us to see people dying... It was sad and that is what made us start helping these people.

From the projected voice, it is these deaths that led to the opening of OIP, and these deaths were as a result of HIV/AIDS. Up sounds in this documentary did not dwell much on the voice of death. As observed in FGDs people living with HIV/AIDS identified more with this documentary for the positivity in the characters used.

#### **3.4. Documentary voice in visual images**

A picture speaks volumes, hence the saying that a picture speaks 1000 words. This study considered all imagery as viable data for discussion in three dominant categories namely; death, poverty and wasted bodies. As has persistently been observed in the prior analysis, the dominance and probability of death continues to be visible in the images and visuals used in the three documentaries. *Fishers of Pain* (2016) paints the most gruesome image of that assertion, in it, we are introduced to homesteads whose occupants are allegedly dead and thus we are shown grave after grave (See Fig. 3.2). According to Sileo et al. (2019), their study among Ugandan fisher folk affirmed that HIV fatalism is associated with increased engagement in transactional sex. For this documentary, it appears the filmmakers took a run with such a strand without having done relevant research to ascertain thoroughly the issues amounting to these deaths. As a result, therefore, these graves apparently speak implicitly on what awaits people living with HIV/AIDS, death.

Figure 3. 2: Devastation of HIV/AIDS; a fresh grave outside a deserted homestead (Courtesy of *Fishers of Pain*).



Visual images from the sampled documentaries also bring out the voice of poverty for people living with HIV/AIDS as has also been dominantly explored in the previous sections. In *Fishers of Pain* (2016), those images of dusty, untarmaced roads with dirt everywhere and semi-permanent dwellings, dotting the face of the geographical set are presented as a preserve of the poor who have been characterised as HIV positive. This voice isolates HIV/AIDS as belonging to the poor in the society, an assertion supported by Parker (1994) when he says that the poor offer the least resistance to the spread of the disease. This voice will therefore not be resonating with people in upmarket villages, not withstanding their moral life. The documentary therefore affirmatively ascribes HIV/AIDS to the poor and desperate in the society.

In the documentary *Mercy in Action* (2016), we are shown images of grass thatched and ruined semi-permanent houses as well as those of grandmothers cooking in the open on the traditional three stones in cluttered environments (See fig. 3.3). There are also images of children in tattered clothes in a costume setting that advances communicating poverty. Elsewhere, when health workers visit an HIV/AIDS patient, the filmmakers deliberately avoid a good permanent house in the compound to only show a toilet, and then move into the house (See Fig. 3.4 & 3.5).

*Figure 3. 3: A family affected by HIV/AIDS cooks on traditional three stones (Courtesy of Mercy in Action).*



*Figure 3. 4: A permanent house on the left is deliberately avoided (Courtesy of Okumu-Mercy in Action).*



*Figure 3. 5: Interview against a backdrop of the partly ruined semi-permanent house (Courtesy of Okumu-Mercy in Action).*



In other images where the houses were semi-permanent, the producer gave visual images of those houses, especially the ruined ones in which the occupants lived. In the case of this one, the beautiful permanent house is deliberately avoided. In fact, in a subsequent shot, the caregiver is interviewed on a backdrop of a semi-permanent mud

walled house which is then followed by a jump cut to the patient's room which apparently seems to be inside the permanent house (0.09:37 - 0.10.07). It can then be affirmed that the reason behind such a filmmaker's POV is that people infected with HIV/AIDS are supposed to be poor and not owners or residents of good houses. This affirms the concern pointed out by Daniels (2019) that an image of a ruined house may be seen as a sign that has escaped from history, and it thus becomes the object of contemplation because the past itself cannot be contemplated. That indeed is the voice evident in the images in this documentary, which we are to give critical thought to: the state of living of those PLWHA, the bushy surroundings of the hospital, an entrance overgrown with grass as well as an overcrowded waiting bay, all communicating a place for treatment of the less fortunate in the society. Pictures of torn beddings also voice the poverty of the victim (See Fig. 3.6).

*Figure 3. 6: Bushy hospital environment and crowding (Courtesy of; Okumu-Mercy in Action).*



In *Dying of HIV/AIDS in 2017* (2017), the voice of poverty continues to dominate imagery through the careful selection of semi-permanent homes in association with PLWHA, as well as rural dwellings. There are many angles the filmmakers would have chosen to avoid the torn parts of the bed cover, but, they decided to show the torn areas anyway. This is proof of selectivity among documentary filmmakers so as to

project a particular POV, hence, ascribing poverty, lack and the denial of better amenities thereof to PLWHA.

*Figure 3. 7: The torn beddings point to social status of patients visiting the facility (Courtesy of Dying of HIV in 2017).*



The documentary *Dying of HIV in 2017* capitalises on images of patients in very bad state, this study christens them ‘wasted’ bodies. These images showcase patients being helped to sit, or being fed through tubes. There is no single image where a patient is able to do things for him/herself. A participant observed during FGD that;

Pichini mokol mokuongo gi nyisowa gima HIV nyalo result to. Then an gi yie kata geno ni the next pictures dhimiowa ni to kikao medication kisengee ni in gi tuo, odonje ei medication, ang’o ma adhi bedo.

(These images to us are depicting what HIV can result to. I am hopeful that the next images will show us what would result from adhering to medication after knowing you are positive).

Another participant observed that;

An pichni go nomora, nkech negigolo jomodhero saidi ma nenre ni okigcham yath maber.

(Those videos were good because they had thin people which implies that they are not adhering to medication).

Even when confronted with such images, it was observed that for an initial warning on the damning results of HIV/AIDS to an ignorant patient, that would make sense, however, that should not have been the point of emphasis all through. Showing wasted

bodies dominating the screen is uncalled for when actually advocating for positive living.

*Figure 3. 8: a scally and wrinkled skin of a HIV patient in hospital (Courtesy of Dying of HIV in 2017).*



During his interview, Oloo (Personal Communication, 20 July, 2019) observed that;

We have very effective ART treatment. And with all the publicity from print and electronic media that HIV is getting, especially in areas of high prevalence like Siaya County, that is not the true depiction... it is just a smaller percentage of those that are in that area.... There are people that if you meet them out there you won't even know they are positive... but I wouldn't lie, I wouldn't also object that there are some in that state, but these are just a few cases. Even in my facility, I have some few cases. So I think the characterisation and what is actually on the ground is not the exact thing.

This observation points to the assertion that, the documentary used images of the minority patients who are in advanced stages of HIV/AIDS to generalise on the portrayal of the state of PLWHA. Contrary to the affirmation by Daniels (2019) that the primary aim of documentary filmmaking is to provide authentic evidence of historical events, such depictions play the nasty role of propagating stereotypical perceptions filled with prejudices against a certain 'other' people. Now, therefore, this study observed that regardless of what experts might think of such displays of wasted

bodies, vies vie reality, a majority of audiences might have already been influenced to hold that particular line of thought as deliberately projected by the filmmakers.

### **3.5. Conclusion**

This chapter analysed voice in documentaries under study from the position of documentary title, narration voice, voice in talking heads and, finally, voice in visual images used. It has come out that the title is key as it is the first thing the audience interacts with. The titles of documentaries under study have projected a voice of desperation for people infected with HIV/AIDS. It has, however, come out that the titles do not speak to the contents of the said documentaries.

From the narration, it has come out that death is inescapable for people infected with HIV/AIDS. The many graves and diminishing adult population in the community are all associated with the devastation of HIV/AIDS. This has been done despite lack of direct connection of these deaths to HIV/AIDS.

The narration voice has also alluded to immorality at the shores of the lake as the only source of HIV infection and ultimate death in the community. This is despite the fact that HIV/AIDS does not discriminate. People who do not fall in the said environment can easily assume false immunity as they are not in the ‘danger zone’. The reality is that HIV/AIDS cannot be confined to particular regions.

The narration voice has also linked PLWHA as ignorant and uninformed. By alluding to carefree sex in the fish for sex trade, it is indicative of ignorance of the danger of HIV/AIDS and its mode of transmission. It is, however, noted that the same voice fails to educate the audience out of their ignorance. Therefore, even after watching the

documentary, the audience is still in danger of repeating the same mistakes while those who are HIV negative may still fall in the same trap of ignorance.

The voice of poverty has come out loud in talking heads. Talking heads have projected HIV/AIDS as a preserve of the poor in the society. It has however come out that HIV/AIDS affects all in the society irrespective of social status. Ascribing the pandemic to segments of the society creates the wrong impression that the disease is selective and hence there is need for balance when making productions on such sensitive issues.

The voice in visual images used has presented desperation for PLWHA. Emaciated body is characterised with HIV/AIDS. This is despite the fact that HIV/AIDS no longer manifests in looks. With the introduction of ARVs, people have been living 'healthy' for ages without losing weight as was in the introductory years of the disease. When such information is taken as the true position, the likelihood of unchecked spread of the virus is imminent. From the foregoing, care needs to be taken when making productions for the right voice to be projected.

The next chapter looks at visual depiction in documentaries and how they impact on positive living with HIV/AIDS.

## **CHAPTER FOUR: HIV/AIDS VISUAL DEPICTION IN DOCUMENTARY FILMS**

### **4.1. Introduction**

This chapter sought to examine visual images used in HIV/AIDS documentaries and how they impact on positive living with the virus. Findings are then presented and discussed in relation to the third objective which sought to establish how HIV/AIDS visual imaging in documentary films depicts positive living among the infected, affected and non-infected in the selected documentary films on HIV/AIDS. Both negative and positive images were analysed and discussed in connection with positive living with HIV/AIDS. Hode (2021) avows that the human body is a social construct. As a result, society judges human health from the way the body looks, and since HIV/AIDS has been associated with wasting body muscle, audience members are likely to make conclusions based on the way the body is portrayed in films.

### **4.2. Visual images of characters infected with HIV/AIDS in documentaries**

Veraz-Diaz & Toro-Alfonse (2003) assert that, the body is a constant visual image in social human interactions, and the way in which it is presented has a bearing on how it will be interpreted. This section therefore looks at how the body being projected as the vehicle for interaction of human beings enables people to experience the HIV/AIDS epidemic. This therefore means that the public will judge what HIV/AIDS is from the way the body looks like. This hence places importance on how filmmakers present HIV/AIDS bodies in documentaries, meaning that the public will judge what HIV/AIDS is from the way the body looks, hence the importance placed on the visual representation of HIV/AIDS in documentaries.

The documentary *Dying from HIV in 2017* has presented people infected with HIV/AIDS as desperate, emasculated and depending on others for survival. The documentary starts by introducing Winney Atieno as a very weak patient who is not able to sit upright by herself. She is assisted to sit up in bed by medical officers (0:00:15,00). We are then presented with a close-up shot of Winney revealing ulceration on her mouth. She presents a very sad face, apparently of a somber mood (See Figure 4.1).

*Figure 4. 1: Winney, an HIV/AIDS patient with alcerations on her mouth in hospital ward (Courtesy of Dying of HIV in 2017).*



Shortly after, there is a shot of Akunda, another HIV/AIDS patient who wriggles in pain in bed. It is followed by another shot of an emaciated lady sitting up in bed. The scenario is replicated throughout the documentary as all patients appear to be in a bad state. They are emasculated and drained of energy. At 0:01:40,01 we are taken to a man who is not able to feed on his own. He is fed through pipes connected through his nose (*Figure 4.2*). His face is expressionless.

*Figure 4. 2: An HIV/AIDS patient in a hospital ward is fed through a tube in his nose (Courtesy of Dying of HIV in 2017).*



We are then given another image of a man who lies in bed holding his head in his hands, ribs protruding and his face blank (*Figure 4.3*). At 0:05:03,07 the production moves the viewer to the image of a patient who cannot attend the call of nature by himself and has a urinal plastic bag fixed on him. The film ends with a scene where doctors perform tests on an emaciated woman who appears to be in pain (see figure 4.4).

*Figure 4. 3: A patient body muscle is wasted due to HIV/AIDS (Courtesy of Dying of HIV in 2017).*



*Figure 4. 4: Image of an HIV/AIDS patient in advanced stage of the infection (Courtesy of Dying of HIV in 2017).*



The images presented in the findings highlighted above are of suffering HIV/AIDS patients whose emaciated bodies in hospital beds are testimony of stereotypes accorded to PLWHA. This stereotypical observation concurs with Macheso (2016) whose study revealed that, filmmakers have often created stereotypes in the representation of PLWHA. While agreeing on exposure to the HIV/AIDS in the society, Macheso (2016) avers that, good communication should debunk such stereotypes in countering stigma. Indeed, stigmatisation is a product of stereotypes. Oloo (Personal communication, 20 July, 2019) did point out that;

I think what filmmakers usually depict from the documentaries I have watched is what they aim to get from the ground, and I don't really think they help in destigmatising HIV/AIDS.

FGD participants did also concur with this observation pointing out that;

It is good to tell people something real, ile kitu inaenda kuangaliwa huko inje. Hio picha inaonyesha treatment ya wale watu, ata labda wangekua ni ugonjwa ya malaria, si ati walikua wanakufa, walikuwa wanatibiwa.

(It's good to tell people the reality that the film is going to be shown elsewhere. Those images are showing people under treatment, perhaps for malaria, not dying people, they weren't dying.)

These observations affirm that those visual images used in the documentary films could be assumed as representative of people living with HIV/AIDS. Wartney (1992) as cited in Hart (2002) asserts that, those stereotypical presentations of HIV/AIDS breed confusion against people who may not be displaying similar symptoms. In early years of HIV/AIDS, such images of wasted bodies had become the norm since there was no medication and diagnosis wasn't so easily available as today. Unfortunately, anybody with such a frame of body would be taken as suffering from HIV/AIDS. Such was considered normal, and the public would interpret images as such. Today you are likely to get people living with HIV/AIDS whose physical appearance is no different from anybody else in the society.

It must be noted that PLWHA in society would like to see a reflection of themselves in the characters used in documentaries on HIV/AIDS (Hart, 2002). Such shortcomings are likely to deal a devastating blow to the value placed on documentaries. In advocating for positive living, consider the following excerpt from an FGD session;

**Moderator:** These films are to educate the public on HIV/AIDS, concerning the characters used, their physical appearance, the environment in which they live, what it tells you, is it giving you the true picture of what HIV is today?

**Participant 1:** Mimi sijui kama unaongelea 2017 ama 2007.

(Are we talking of 2017 or 2007?)

**Participant 2:** It is good to tell the truth, let us not lie that in 2017 Kenya was still so backwards.

**Participant 3:** Kwa mtu Yule hana HIV akiona hio filamu, inapatia fikira ya picha ya mtu ako na ukimwi kama mtu tofauti nayeye. Mtu hamezi dawa anaona kama mtu ako na HIV na anameza dawa atafika tu kwa kiwango ya mama

yule ako kwa hospitali. Na kama mtu analive positively kama mimi inaniogopesha.

(When someone who is HIV negative watches that film, it creates impressions that a PLWHA is different from him/her. Someone who is not on medication sees the HIV positive person on ARVs getting to that point as that woman at the hospital. It also instills fear in someone who is living positively like me).

From the above observations, participants point out that if one fails to adhere to prescribed medical schedules, HIV/AIDS will affect their health, hence driving them towards the possibility of resembling those gory images. It should also be observed that over reliance on the use of such images in documentaries may end up dehumanizing PLWHA while they had set out to give hope as Hodes (2007) observed.

Oloo (personal communication, 20 July, 2019) asserted that;

The narrative I get from HIV documentaries is that HIV/AIDS is still a killer, but from what I see every day dealing with people infected with the virus, very few people die from HIV. I think going forward we should start getting documentaries that talk about positive living with HIV/AIDS. Documentaries have shown people who are in the end stage of AIDS, stage 4. You don't get people in stage 4 anymore on the ground. People are using ARVS.

Though the situation has changed due to the use of ARVS, most productions on HIV/AIDS have continued with the same narrative of HIV/AIDS as a killer disease.

In reference to these images, a FGD participant stated that;

Pengine ni mimi naishi dunia nyingine, lakini mimi naishi hapa nyangera. Ukitaka kurelate hiyo kitu, unaona na jirani yako, na sijaona mtu aina hiyo kwa environment hii nimeishi. Hio sio situation iko kwa ground saa hii.

(Maybe it is me who lives in a different world, but I live here in Nyangera. If you want to relate with this issue (read HIV/AIDS) you look at your neighbour, and I have not seen the likes of those in the documentaries in this environment. That is not the situation of HIV/AIDS on the ground at the moment).

Another participant also observed that;

Maybe walikuwa na nia ingine, maybe ya kutafuta aid kwa njia ya HIV, which is not fair kwa sababu 2017 sifikiri kama unaeza kupata kwa ward zaidi ya watu kumi wamedefault.

(Maybe they had a hidden agenda, maybe soliciting for aid by using HIV, which is not fair, because in 2017 you could not get more than 10 people in a ward who have defaulted).

Still on that, another participant observed in shock that;

Mimi niko shocked kuona documentary hiyo na mahali imechukuliwa kwa sababu mimi nilikuwa na mgonjwa 2005 na nilikuwa nachukwa dawa HomaBay. Hali haiwezi kuwa hivyo wakati huu.

(I am shocked to see this documentary and where it was produced because in 2005, I had a patient and was going for medicine in HomaBay. The situation cannot be like this in 2017).

A teenage participant observed that;

Lakini kama unatumia picha ya mtu hana hope, inafanya mtu hata anaogopa ati, hivi ndivyo nitakuwa hata nikimeza dawa.

(If you use an image of a person who has no hope in life, it creates fear, that this is how I will become despite using ARVs).

As Hawkes (2003) puts it, the nature of any element in any situation has no significance by itself. Its value is determined by its relationship with other elements involved in that situation. It then implies that the visuals presented to the public are viewed against the prevailing situation of HIV/AIDS in society. In the event presentations in films fail to resonate with what is on the ground, the production fails to communicate the expected message. No wonder then, respondents failed to identify with visuals as presented in the documentary *Dying of HIV/AIDS in 2017*.

The feeling that the documentaries were made with other intentions other than sensitizing on HIV/AIDS is an indication of failed communication, which works

against the noble goal documentaries are supposed to play. Another respondent is shocked that such a documentary was produced in Homa Bay in 2017. According to Morly (1992), audiences come to the moment of viewing thinking within some cultural context derived from their social and cultural situation.

These social and cultural situations influence the meaning arrived at when viewing productions on HIV/AIDS. Information falling outside this cultural context may lead to oppositional thinking to the supposed meaning as demonstrated in responses above. This finding concurs with Hodes (2007) observation that the essence of a documentary lies in its verisimilitude, a fact that makes it relate to the audience. It is therefore important for a deliberate effort to be made in establishing this verisimilitude for documentaries to impact on the target audience.

Another participant also noted that it is not bad to use images of patients in a bad state of health, but insisted on proper explanation as to the reasons for the same;

Inafaa wakifanya hizo documentaries, waeleze kinagaubaga, amefika hiyo stage kwa sababu gani?

(When producing the documentaries, they should explain properly why the patient has reached the particular stage of AIDS).

This view is supported by the adolescent FGD when they say, patients are in a bad state because of not following the instructions on medication. Another discussionant added that;

Hiyo stage mtu anakuwa tu kama hamezangi dawa, na umefanya vizuri kutuonyesha hio coz hio inaweza kutuencourage na hata kama mtu ako hali hiyo, unaeza kumuambia afanye hili ama hili ili akuwe healthy

(A person can only reach late-stage HIV/AIDs when he/she is not taking medicine, and you have done well to show us this documentary because it has encouraged us and even if

somebody is in that stage, you can tell him/her to do this or that to be better).

Participants understand the role ARVS have played in improving the health of infected persons. They are not passive consumers of information. Morly (1992) in reference to reception theory stated that audiences come to the point of viewing thinking within their own cultural context, which influences the meaning they attach to films. As they interacted with the films, they attached meaning to them.

Participants could not comprehend how in this time and age, patients of HIV/AIDS could still be in the situation of characters in the documentary *Dying of HIV in 2017*. Rogers and Shifiel-Roger (1999) as cited in Hart (2000) observe that, documentaries can only impact when a significant level of homophily exists between individual audience members and characters in the films. While respondents who were HIV positive looked healthy, those in the documentary under study were sickly. Although it cannot be ruled out that some patients will appear sickly, it is important for documentaries to be clear that it is not the norm for people with HIV/AIDS to be that sickly. As a matter of fact, the study noted that it is important for other voices on the subject of the pandemic to be heard, especially if it debunks the conventional way HIV/AIDS has been commonly known (Paak, 2014). Inganga (Personal Communication, July 17, 2019) points to one such a way in advocating for positive living through the long story telling technique stating that;

There is nothing wrong in using images of people who are down with HIV/AIDS. It would, however, have more impact if one were to use long story telling form of productions. This will involve getting the patient when his/her health is badly off and follow up with images of the same patient progressing with medication and, finally, when he or she has improved due to medication.

This observation points to the assertion that he finds no problem in using pictures of people whose health is down. However, that ‘long story telling’ he asserts, by trailing the life of a patient from the sickly condition to an improved well-off state will intently give the patients hope in taking medication. It can then be deduced that the emaciated body is the hopeless stage in the fight against HIV/AIDS and if the documentary does not move the viewer from this stage to the next stage where medication has worked, it will not have done justice to the viewer. His observation is indicative that this is one of the ways you can show that there is life after HIV/AIDS, hence contribute towards positive living, an element that Hode (2021) refers to as humanitarianism in film.

Inganga (Personal Communication, July 17, 2019), further opines that this class of filmmaking, while exploring familiar literature of regional specificities of HIV/AIDS epidemiology does reveal what is perceived as important intersections between a pedagogical public health film and community action. Therefore, as we can deduce, it is a reality that HIV/AIDS drains the body of its good health as portrayed in documentaries under study. However, it is very key to move the viewer from the hopeless state to a position where medication has worked. Such a technique of production as stated by Inganga (personal conversation, 17 July, 2019) will instil hope for PLWHA as it advocates for life even after infection with HIV/AIDS.

The emphasis placed on wasted bodies for PLWHA has the potential of sending a wrong message that people who physically look ‘healthy’ are free of HIV/AIDS. Such people may not seek HIV screening as they are assumed to be negative, being different from the portrayal in documentaries. A participant observed that;

Hii ni kudiscriminate eti mtu mwenye HIV amekonda, mtu hajiwezi.

(It shouldn't be that anybody who looks emaciated is equated to HIV. It is discrimination).

Another participant observed that;

Kama kuna picha mzuri tuweke kwa akili ya watu wengi.

(If good images are available, let's have them inculcated in viewers' minds.)

As observed by the participants in the above instances, this deceptive portrayal often causes perceptions that an HIV/AIDS positive person must be desperate. Categorically, there is no apparent need to continue bombarding audiences with those pictures of lost hope. This concurs with the assertion by Coile (2017) that time has indeed come in which we ought to ignite a very different conversation, such as depicts advocacy against blame and stigma.

In the documentary *Mercy in Action*, a gravely ill HIV patient, living in poverty as deduced from the environment is visited by social workers. That scene brings us to a man and his wife, both of whom have their body muscles wasted and do walk by supporting themselves on the table in the room (0:3:58,12). Another image purportedly of an HIV patient outside of the hospital setting is that in which a lady is seen lying hopelessly in an unkempt environment by the roadside (See Fig. 4.5). Without doubt, these images and those similar to these create a certain phobia that inspires unease among PLWHA. This concurs with the observation by Rwafa & Rafapa (2014) that, since HIV/AIDS does not manifest physically on the one who carries it, interpretation of symptoms of who is HIV positive is a contested area in the creation of meaning. This contestation is advanced in their assertion that the effect of the continued use of horrific images cultivates the creation of phobic visuals that promote unease among the infected. In that regard, this study observed that, as much as there are hopeless individuals in the society as a result of HIV/AIDS, it should not

be taken as the norm. Positive living can be attained, just as Hodes (2007) observed that documentaries ought to move away from stereotypical visuals so as to serve its target audience's information needs.

*Figure 4. 5: An elderly lady down with HIV/AIDS (Courtesy of Mercy in Action).*



As Osaigbovo & Wood (2013) puts it, showing people who are living positively in films, and having them share their personal experiences will put the pandemic into context and may change the way the public responds to the same. The assertion by Osaigbovo & Wood (2013) is alluded to by discussants who pointed out that if people infected with HIV/AIDS are positively used in documentaries, it might help change society's perspective of those infected; one participant observed that;

Kutumia picha ya an individual yule maybe is doing well and taking ARVs is good.

(To use a picture of an HIV/AIDS individual whose health looks perfect is good)

Another one added;

Ukitumia picha ya mtu ako na virusi, anameza dawa na anendelea vizuri ni mzuri kwa sababu inaweza kubadili vile watu wanatuona na wajue ya kwamba ukimwi sio death sentence.

(Use of somebody with the virus and on drugs whose health looks good is important because it will change the way people look at us and also know that HIV/AIDS is not a death sentence).

Another participant still added that;

The other lady, if you look at her utaoa she's positive but ukimwona she is healthy.

(Looking at the other lady, even though she is HIV positive, she looks healthy).

These findings reveal a disconnect in communicating HIV/AIDS messages in documentary films. From these submissions, it can be noted that PLWHA are not happy with the projection of HIV/AIDS in documentaries, and their voices are proof that even though the disease exists, one can lead a near normal life in society with the disease. The assertion in such submissions is that visual productions can go a long way in changing the perception that people living with HIV/AIDS are skinny and 'unhealthy'. This observation concurs with the affirmation by Mambrol (2018) that the audience project the meaning they require to the text or work of art depending on their world view.

A participant in one of the FGD sessions pointed out that, her husband is not aware of her HIV status because she is afraid of his reaction to disclosure. She observed that;

To me picha ya an individual yule maybe is doing well and taking ARVs would be very good. But considering that stigma, mimi personally, baba ya mtoto wangu hajui niko na ukimwi kwa sababu nasikianga tu vile anaongea juu ya watu wako na ukimwi, siwezi ata kumwambia.

(According to me, the image of positive living would be very good, but considering stigmatization, even the father of my child doesn't know I am HIV positive, there is a way he speaks about HIV positive people that makes me shy away from disclosing to him.)

The husband of this lady is likely to be ignorant of the fact that one can live positively with HIV/AIDS without infecting the partner. Such information should come out in productions for the communication to be wholesome. This non-disclosure puts the

husband of this particular participant at risk for he may not understand why she insists on the use of protection during sexual intercourse. The situation would be perhaps different if the husband was accommodative of people living with the virus.

Documentaries under study appear to have been selective on the information passed over to the audience. Even *Mercy in Action* (2014) which has many instances of positivity, has stuck to the narrative of death for people infected with HIV/AIDS. In an interview with Madam X (Personal Communication, July 12, 2019), a lady who has lived with HIV/AIDS positively for the last 18 years, she observed that it is good to use visuals of HIV people whose bodies are healthy as a sign that you cannot tell a person living with HIV/AIDS from their physical appearance.

People still believe that a person with HIV/AIDS should be very thin, emaciated, sickly, malnourished and all that. Now somebody like me, you stand there and say you have HIV/AIDS. Nobody will believe you, they think you are using HIV/AIDS to turn them off.

This explains the need for a shift in visual images used in HIV/AIDS documentaries. The public should come to terms with the fact that you can have HIV/AIDS and still look as healthy as anybody else, what Osaigbovo & Wood (2013) would call ‘the other voices of what HIV/AIDS is’. Availability of ARVs changed the visual picture of PLWHA and ‘films should serve present information needs away from phobic images of yesteryears’ (Hart 2002). The belief that persons living with HIV/AIDS are thin and unhealthy from looks is overtaken by events and if maintained can easily fuel further spread of the virus. While advocating for positive images when communicating HIV/AIDS messages in documentaries, it must be cognisant that danger lies in miscommunicating HIV/AIDS from what it really is. The devastation of HIV/AIDS to a person’s health must always be brought out while the ability of life after

HIV/AIDS infection when one adheres to doctor's instructions should also come out as a message of hope to the infected. Inganga (Personal Communication, 17 July, 2019) advocates for long story telling where the infected is captured from the time of poor health to the point when the health has improved and the person is living positively. In this case, the evolution is presented to the audience step by step giving hope to the infected that they can regain their health.

In the documentary *Mercy in Action* (2014), we are shown many people with bad wounds on their feet at the beginning of the documentary. Close-up shots of wounds on the feet of patients are shown to the audience (see figure 4.6). The wounds are associated with HIV/AIDS as Bro. Leo puts it;

When we noticed the wounds were not healing from the inside, we noticed that this had to do with AIDS, so we later discovered this was AIDS (*sic*) (0:01:26,15).

The narrator categorically says that, the only reason they concluded it was AIDS is due to the fact that those wounds were not healing. Having been produced in 2014, when there was widespread knowledge on the characteristic symptoms of HIV and the widespread knowledge that assumptive diagnosis is uncalled for, the setting forth of a narrative based on such a picture was not particularly necessary. More so, considering the fact that this film was being created in the age of anti-retroviral therapy. Affirmatively speaking, it is wrong to associate people with HIV/AIDS as having wounds that don't heal, as the filmmakers have done, unless, by justifying that that has resulted consequentially due to the patient neglecting the use of ARVs.

*Figure 4. 6: Wounds allegedly caused by HIV/AIDS (Courtesy of Mercy in Action).*



The fact that the producer uses black and white photographs from the archives, for his illustration, is an indication that he could not get footage of people with wounds like the ones he used at the time of production. The question one would ask is: was it necessary that such stock footage be used? This study ascertained the fact that that was not entirely needful. Subsequently, this is what Hart (2002) had observed noting that filmmakers have refused to shift from what HIV/AIDS was known to be many years ago. This is an indication that production scripts are made with a fixed point of view, irrespective of the context in which it will be screened. As audiences interact with such text and decode it in their cultural context, it fails in its educational purpose and only serve as entertainment material.

Another visual image is that of Alice who is visited by social workers. Alice is perceivably losing her head as she laughs alone without proper cause (0:10:01, 23). The producer again brings out the danger one gets into by contracting HIV/AIDS. Through these images, people with HIV/AIDS are presented as losers with no future as they are associated with a myriad of problems.

The documentary then introduces individual shots of HIV/AIDS patients who live positively with the virus. Jack Otieno, Janet Atieno and Judith Anyango are as healthy as any other person. Jack Otieno, who had lived with the virus for nine years by the

time the production was done, looks very healthy and happy as he narrates his HIV situation. The scene at 0:7:33,18 is very encouraging as he is seen happy with his children checking their school assignment, later on we even see him in his piece of land harvesting maize (See Fig. 4.7). Jack explains that it was tough for him before he joined Shirikisho as getting drugs was not easy, pointing out that by then, ARVS were not as freely available as they are today. The image of Jack was welcome by discussants who noted that HIV status does not render somebody a beggar. For PLWHA, the scene is encouraging as it offers the possibility of life after HIV/AIDS, as such, other infected people may aspire to be like Jack, since he is likely to excite interest in PLWHA to know what he has done to attain such good health despite his HIV status. The scene may also alter the way the public relate to people infected with HIV/AIDS as they may not be considered dangerous to the society (Osaigbovo and Wood, 2013).

*Figure 4. 7: Jack Otieno in his farm harvesting maize (Courtesy of Mercy in Action).*



Participants also observed how hope can be rekindled when PLWHA work together with the rest of the society as positively brought out in the documentary *Mercy in action* (2014). This is what they observed;

I have seen a society that has accepted people living with HIV/AIDS. This is very encouraging for people with the virus.

Another participant observed that;

Tunaona wale wenye hawana visusi wanasaidia wale wenye wana visusi, for example hapo kulikuwa na mama mwenye alikuwa mgonjwa, hangeweza kuenda hosi, mimi naona health workers wanatoka hosi wanamletea dawa nyumbani, unaona at times wanamsaidia kufanya mazoezi hadi tunaonyeshwa vile wanamsaidia kusimama. Hio inaonyesha love, upendo. Wanaencourage wale wana virusi na hio ni mzuri.

(We see those without HIV/AIDS helping those infected with the virus, for example there is a lady who is sick and who could not go to hospital. I see health workers come from hospital to bring her medication. We see how they are helping her exercise; we are even shown how she is being helped to stand. This is a show of love. It encourages those living with the virus).

Another one also observed that;

Nawale walikuwa wanapatiana dawa walikuwa na mapenzi, hawakubagua ati huyu ni mgonjwa, walikuwa wanapatia moyo na wanasema hiyo ugonjwa unaweza shika mtu yeyote, sio wao pekee yao. Hii ni mzuri sana inaencourage mtu.

(And those who were giving medicines had a lot of love. They were not discriminative of the sick, they were giving them hope and said HIV/AIDS can get anybody, it is not only them).

These engagements in gainful activities are noted as inspiring acts that raises hope and the will to live positively. This warm relationship between the infected, affected and the rest of the society was encouraging to the participant as has been noted, as opposed to *Dying of AIDS* in 2017 and *Fishers of Pain* which appeared to emotionally weigh down participants. This had also been observed during the screening, that, participants reacted differently to documentaries as they watched them, hence drawing different interpretations on the same subject. Davis (2003) avers that, meaning is generated in context each time an audience interacts with the text. *Mercy in Action* (2014) despite the instances of negative portrayal had many instances of positive messages as well as visual images, something respondents were happy about since it inspired positive

living. The summary of their observations could therefore be considered to affirm that being HIV positive does not make one useless in society.

For positive living with the virus to thrive, advocacy documentaries that dwell on acceptance and integration of people living with the virus are necessary. The reason for non-disclosure as observed in this study is based more on the treatment meted on people living with the virus, and this concurs with Paak (2014) that, the lives of the PLWHA are shaped by how filmmakers represent the disease in productions.

In *Fishers of Pain* (2016), Karen a CHW, states that she began community engagement and sensitisation after realizing her HIV/AIDS status. That was after the demise of her husband through the virus. She looks healthy and happy even as she distributes condoms as she sensitises the public on the dangers of HIV/AIDS (See Fig. 4.8). She confesses that after the death of her husband and co-wife, she resolved to work with the community to fight HIV/AIDS.

*Figure 4. 8: Karen Adhiambo, a widow sensitises the public on HIV issues (Courtesy of Fishers of Pain).*



In another instance, Maria who is depictedly ashamed of her HIV/AIDS situation hides her face from cameras as she narrates her case. Though her health does not appear to have deteriorated, she lives in poverty. We are then introduced to her daughter (refer

to Fig. 2.2) who looks sickly and skinny with wrinkled and ulcerated skin. Maria's daughter is perceived as being HIV/AIDS positive. As established from the findings of this study, it is not a sight one would like to be associated with.

Through Maria, HIV/AIDS is presented as a disease of shame that people should not identify you with. Mdege (2020) observes that films can be very powerful ideological tools that can influence the way people conceptualise their problems and/or solutions. Indeed, as a result of that shying away from the camera, it did paint an indication that she has not accepted her status and, therefore, the community might not be aware of her condition. This must be noted as creating fertile ground for spreading the virus to others, just as she had alluded to in that interview. One of the participants during FGD observed that;

Sasa naona kama wameficha uso wa yule mama. Sio vizuri kwetu kama PLWHA. Inaonyesha ni kama bado ukimwi is unacceptable in society. Ningependa kama naongelea HIV/AIDS status yangu, nisikuwe penalised.

(I see they have hidden the face of the lady with HIV/AIDS. It illustrates that HIV/AIDS is still unacceptable. I would like a situation whereby when I disclose my HIV status, I am not penalised).

This observation affirms that, this documentary brings out shame as a product that comes with getting infected with HIV/AIDS. Such images are not good for positive living as audience members will also be convinced that it is shameful to identify with HIV/AIDS. The imagination of reaching such a level is what leads many people to hide their status from the public. From the findings, it emerged that people infected with HIV/AIDS are not happy when their condition is projected as one of despair.

### **4.3. Visual pictures of dwelling places for people living with HIV/AIDS**

Most documentaries have linked people living with HIV/AIDS with poor and pathetic living conditions. The following arguments have been advanced through implication of what is perceived they are communicating. Mdege (2020) affirms that buildings do speak of affluence, development and prosperity. In the documentary *Mercy in Action* (2014), a grandmother is shown with children huddled around her. In the background, there is a mud walled house with an open door, the inside looks dark.

Further, at 0:02:21,05, three HIV/AIDS counsellors talk to young men in the background of a mud-walled house. The camera takes an angle that reveals the incomplete part of the house. At 0:03:42,08, the plotting dissolves to the grandmother with four children cooking outside a grass thatched house on traditional three stones. At 00:09:30 – 00:09:50 the filmmaker seems to deliberately avoid a permanent house in the compound to focus on a caregiver seated on bricks. It then moves to a scene inside the house to the scene where Alice is seated on a bed and then leans forward to stand while supporting herself on the window grill.

Come to think of it, as the health officers drove into the black gate, they found Judith her caregiver seated on bricks beside a permanent house they avoided, then taken for an interview on the backdrop of a semi-permanent house. Definitely, there was something in communication, images speak in concurrence with Makela (2006) that montage is the language of cinema. This framing out that permanent house is thus seemingly well-planned for the achievement of certain predispositions.

Mdege (2020) avows that in some instances films build on the assumption that images of suffering can stir up compassion in viewers, a catalyst for positive change.

However, it should be noted with concern that that does not appear as being the objective in the framing of these sampled documentaries. This assertion is drawn from the fact that the study did observe that where houses were mud-walled and grass thatched, the filmmaker was quick to display, but when it came to the good house, it was avoided and juxtaposed with the ‘producer friendly’ housing concept (See Fig. 4.9 and Fig. 4.10). Through the dwelling places associated with people living with HIV/AIDS, the filmmaker has continued to project PLWHA as poor. In this, therefore, they are assumed not to be able to afford good houses to live in.

*Figure 4.9: Jack Otieno’s residence (Courtesy of Mercy in Action).*



*Figure 4. 9: Alice inside the permanent house we have no full visual of (Courtesy of Mercy in Action).*



In the documentary *Fishers of Pain* (2016), again, people infected and affected with HIV/AIDS are projected as the poor who cannot afford good housing. One would ask: is it true there was no single good structure in the whole village, even it does not

belong to PLWHA or the producer decided to go on a 'hunting spree' for those poor structures only? And if so, why? Perhaps to emphasise the point being subconsciously driven that PLWHA cannot live a good house, symbolic of a normal life. This observation concurs with the affirmation by Osome (2021) that how a story is told can definitely influence social perceptions. The third documentary, *Dying of HIV/AIDS in 2017*, is done almost entirely in a hospital setting with torn beddings, crowded wards and an unkempt environment. The only place where a patient is seen outside the hospital is when social workers visit a patient at 0:04:00,00. Again, it is a semi-permanent house, visibly seen as small and dark from the inside.

As has been noted, the filmmakers of these sampled films appear to have deliberately linked PLWHA with the worst troubles in society. As such, they do not have good roads, they cook in the open, and they stay in dirty environments and dilapidated houses. Such visualisation degrades and dehumanises people living with HIV/AIDS. For positive living to be attained, it is good for the makers of documentaries to deliberately go for success stories of people living with HIV/AIDS positively.

#### **4.4. Conclusion**

This chapter examined visual depiction of HIV/AIDS in the selected documentaries and their linkage to positive living. It has been observed that PLWHA have been portrayed as having unhealthy bodies with wasting body muscles. This is in disregard of the contribution of ARVs in the fight against HIV/AIDS. As such, there is a need to appreciate that HIV status cannot be diagnosed from physical appearances and as such, the association of HIV/AIDS with emaciated body frames could be misleading.

PLWHA have also been visualised as poor from the dwelling places linked to them. They are pictured in dilapidated houses, some of which are falling apart. This is tantamount to the assigning of HIV/AIDS to the poor segment of the society disregarding the fact that the pandemic does not discriminate. Such portrayal may lead to unchecked spread of the virus in affluent sections of the society.

PLWHA have also been visualised as desparate, hopeless and suffering. Though this cannot be ruled out, documentaries should not generalise such as the norm for PLWHA. It has come out that long story telling technique is the way out of such technicality.

The next chapter presents summary of findings, conclusion and recommendations of the study.

## **CHAPTER FIVE: SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS**

### **5.1. Introduction**

This chapter presents a summary of major research findings, conclusion and recommendations of the study. This is achieved by restating the key observations and findings arrived at during the study. This chapter also links the findings of this study to relevant fields of expertise for consideration for practice, policy and further studies with a view of responding to the various troubling concerns on positive living with HIV/AIDS as well as suggesting a viable way forward henceforth. This chapter is thus a reflection of the entire study. In order to address these, the researcher outlines this section under the findings of every objective.

### **5.2. Summary of Findings**

The summary of findings were based on the research objectives/questions as had been presented at the start of the study.

#### **5.2.1 Character Portrayal in HIV/AIDS Documentaries as Vehicles for Positive Living with HIV/AIDS**

The first objective intended to identify and analyse character portrayal in documentaries on HIV/AIDS as vehicles for advocacy for positive living. The study established that all the selected documentaries depicted PLWHA in a certain consistent manner. In these documentaries, the results from critical content analysis have shown that the selected documentaries aligned HIV/AIDS with the poor in the

society. This arose from the observation that these documentaries were deliberately filmed in environments that linked PLWHA to the poor in society.

The situation and condition of PLWHA has also been portrayed as coming from moral decay in the society, and subsequently, it is assumed that the PLWHA's appearance in the wasted bodies awaiting death is a just course, deserving of their carefree lives, a due punishment of some sort. Rising from the study's observations, it is thus arrived at that the filmmakers ended up doing more harm than good in the bulk of the negative portrayal, while intending advocacy for positive living. It is also essential to observe here that, despite all the negative portrayal, the study, however, did establish that HIV/AIDS does not discriminate. As such, anyone in the society can be infected irrespective of their socio-economic status or positions in society.

It was further established that living with HIV/AIDS does not automatically result in poor health. As a result, therefore, the study observed the need to redefine the way documentary films on HIV/AIDS are produced. In it, therefore, asserting the gains made so far in the wake of ARVs, since it is now very possible for PLWHA to lead a normal healthy life as long as they adhere to the prescribed ARV therapy.

### **5.2.2 Documentary Voice as an Agent of Advocacy for Positive Living with HIV/AIDS**

The second objective sought to evaluate how documentary voice has been used as an agent of advocacy for positive living. In advancing their point of view, the sampled documentaries were observed to be having their own voice, the message the filmmakers intended to drive across, irrespective of the mise-en-scene. From the verbal sound emanating from the documentaries, this study took note of the following

regarding the point of view the selected documentaries with regard to advocating for positive living. It was established that the voice of death has predominantly been associated with people living with HIV/AIDS despite the gains in ARVS. These findings thus give credence to the observation by Malagasi (2015) that film has failed to present living with HIV/AIDS as a normal existence.

Nevertheless, the study arrived at the observation that HIV/AIDS is no longer a death threat as projected by filmmakers. The findings of this study also affirmed that the sampled documentary films advance a narrative of irresponsible sex as the cause of HIV/AIDS. HIV/AIDS has herein been presented as a preserve of the fishing community, propagated through the *jabo* system of 'fish for sex'. It was however established that '*boya*' actually implies 'customer' and has been stereotypically and irresponsibly pinned to the spread of HIV/AIDS to the fishing industry.

The study also observed that the voice of desperation and hopelessness is so prevalent that it is projected from the effects of HIV/AIDS or from financial difficulties associated with PLWHA in those documentaries. To this, the study established that infection with HIV/AIDS does not put one in a special category of the 'othered' as the documentaries have purported. On the other hand, the study observed that PLWHA are simply exposed to the same problems in the society like anybody else. As such, they too have the capacity to be productive and industrious like the rest of the community they live in, even to overcome poverty, poor health and malnutrition.

### **5.2.3 Visual Depiction of HIV/AIDS in Documentary Films**

The third objective sought to establish HIV/AIDS visual depiction in documentary films in positive living among the infected, affected and non-infected. Analysis of the

sampled films pointed to the fact that PLWHA are visualised as bed ridden and desperate, presenting them as being in a state of dependence upon the compassion of others. The study also revealed that the continued use of horrific visuals instils fear and hopelessness in people living with HIV/AIDS. Since the study was intended to examine whether the visual content in the selected documentaries did correspond with the intended aim of advocating for positive living, it was established that the incorporation of positive images resonates well with PLWHA, however, they were observed as largely lacking in the documentary films.

The findings of this study further established that despite documentaries associating HIV/AIDS to wasted bodies, an individual's HIV/AIDS status is not discernible from physical appearance. The study revealed that associating HIV status to frail and emaciated body frame is misleading, and this conforms to Paak (2014) observation that documentaries have failed to show anything else other than depiction of despair in relation to HIV/AIDS. The findings of this study alluded to the fact that, in order to reduce all forms of discrimination against PLWHA, it is essential to show infected/affected people across social status, and to have them share their experiences so as to create awareness and to advocate for positive living.

This study also observed that Kenyan documentaries failed to do due diligence in advocating for positive living with HIV/AIDS. In order to create a shift from simply documenting HIV/AIDS through the motion picture to being partakers of social change, the study observed that stereotyping and 'othering' has to be put in check since one cannot tell an HIV/AIDS positive person from their physical looks. It was noted that since film does influence audiences either consciously or subconsciously, stereotypical images used to represent HIV/AIDS have resulted in a certain element

of fixed symbolic representation at the expense of personal situations in striving to give HIV/AIDS a face. This study thus established that visual depiction of the infected must be well thought out since HIV/AIDS advocacy is key to positive living.

### **5.3. Conclusions of the study**

This study has shown that documentary film on HIV/AIDS is an essential tool in advocating for positive living, especially through the kind of message it projects through its voice. The production techniques employed in the sampled films have shown that every filmmaker has a specific message they intend to deliver, whether or not it resonates with common knowledge. However, in the event that positive living has to be achieved, it is resoundingly evident that proper packaging of the documentary on HIV/AIDS has to be fashioned. This ought to be done while bearing in mind the desired outcome, since images projected through documentary films often do have a substantial effect on the popular built imaginations of perceived audiences. Arising from this study on the interrogation of documentary films as a tool for advocacy for positive living, several conclusions were adduced;

- i. The study has taken note of the fact that the makers of the selected documentaries have characterised HIV/AIDS as a disease for the poor in the society. In this portrayal, both the infected and the affected are characterised as poor people. This is despite the fact that AIDS does not discriminate and can get anybody infected irrespective of their socio-economic status. More so, when documentary filmmakers link HIV/AIDS to fish for sex at the shores of Lake Victoria, it easily characterises the infected as prostitutes who ought to be blamed for the prevalence of the pandemic. The assigning of the disease to a particular segment

of the society is in itself misleading, as it creates a false impression of safety to the rest of society who do not fall in the 'othered' category.

- ii. Though ARVs have made it possible for people living with HIV/AIDS to lead a near normal life, documentaries have continued to voice death as the resulting consequence in their end to being infected. This makes it hard for the society to relate to the productions when put in context as has been observed in this study that there exists a great chance for PLWHA to live a normal and productive life. Most of the participants observed that it was indeed possible to live a normal life and succeed in life even when living with HIV/AIDS. These observations arose in objection to the persistent voice of death as propagated in the documentaries from a point of view.
- iii. The study has noted that documentary films can be effective as tools for advocating for positive living with HIV/AIDS. This is so because, when well-packaged, they provide a unique window for people to have a dialogue through creativity. By so doing, such dialogical opportunities allow for audiences to expose and share their personal beliefs, culture, and experiences to one another. Indeed, as also observed, documentary films have an extraordinary capacity to expand our reality on this issue of HIV/AIDS.
- iv. The study concludes that, those visual images of HIV/AIDS in documentaries have largely reflected hopelessness. Most of the participants agreed to this observation having interpreted the visual images in the documentaries as having a biased and unfair depiction of persons living with HIV/AIDS. In these documentary films, characters living with HIV/AIDS are portrayed as bed-ridden and wasting away with no hope for recovery. The environment in which they reside in is a setting with pathetic and poor housing, as well as poor roads. In their

hopelessness, they are also portrayed as dependant on the mercy of others through hand-outs. In disagreeing with such depictions, participants did observe that such a continued display of imagery does reflect negatively on PLWHA hence advancing stigmatisation, which is a hindrance to positive living.

#### **5.4. Recommendations**

This section presents recommendations of the study which if adopted may help improve communicating HIV/AIDS messages through documentaries. Generally, it is recommended that documentaries should shift from negative narratives to more positive narratives that promote positive living with HIV/AIDS. Specifically, the study recommends the following;

##### **5.4.1 Recommendations for practice**

Producers of documentaries on HIV/AIDS should be open minded as they go to the field. This will help create a shift from negative characterization to the reality of what HIV/AIDS is on the ground.

The study proposes a shift in documentary practice, where the documentary filmmakers ought to stop ascribing the HIV/AIDS pandemic to particular groups of people and places. The voice of documentaries should be clear of ‘othering’ and aim at sensitization of the reality that HIV/AIDS can get anybody, whether rich or poor, and it is also not a death sentence.

The study also recommends that future productions on the subject of HIV/AIDS should evolve with the times to reflect the development of the situations surrounding HIV/AIDS in the current period in time. This will allow for narration and the use of

imagery that the audience can identify with, hence it will help to personalise the message of the pandemic. For this to be achieved, filmmakers will then have to do due research before commencing their production.

#### **5.4.2 Recommendations for policy formulation**

This study recommends that key stakeholders such as policy makers, religious leaders and relevant arms of government be drawn together for an all-inclusive discussion to deliberate on proper doctrines, beliefs and practices. This will ensure that there is one key voice as regards PLWHA as well as the HIV/AIDS subject. In advancing a common point of view among the influential and key opinion leaders in the society, it shall be possible to arrive at consensus building among the various players in formulating a common policy towards fighting HIV/AIDS.

#### **5.4.3 Recommendation for further studies**

This section presents recommendations for further studies that should be undertaken in the future on the role of documentaries in advancing positive living with HIV/AIDS.

Arising from concerns within this study that PLWHA would sometimes deliberately refuse to disclose their status, this study proposes a need to conduct studies on the educational function of documentary films in aiding disclosure so as to advance positive living with HIV/AIDS.

Since the study observed that HIV/AIDS has largely been depicted as a poor man's disease, and therefore the rate of mortality has been attached to issues of poverty, the study recommends that extensive studies also need to be undertaken on how wealthy

families cope with HIV/AIDS. This will help either allay or confirm the notion that HIV/AIDS is a disease for the poor.

This study also observes that the aged have been significantly placed largely at the fore front of the battle against HIV/AIDS, more so as the affected persons left to care for the alleged HIV/AIDS orphans. Arising from this therefore, this study reconmmends that further studies ought to be undertaken regarding the aging characters used in HIV/AIDS documentaries and their effect on advocacy for positive living. This is to understand the position and the role of octogenerians in HIV/AIDS campaigns, this should also focus on the aspects of orphaned stereotypes in the fight against HIV/AIDS.

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## APPENDICES

### Appendix 1: Participant Interview Consent Form

**Research project title:** Interrogation of Documentary Film as a Tool for Advocacy for Positive Living with HIV/AIDS in Yimbo West Ward of of Siaya County- Kenya

Thank you for agreeing to participate in this research project. The interview will take approximately one hour. We don't anticipate any risks associated with your participation, but you have the right to stop the interview or withdraw from the research at any time. This consent form is necessary for us to ensure that you understand the purpose of your involvement and that you agree to the conditions of your participation as detailed below;

- The interview will be recorded and a transcript will be produced.
- The transcript of the interview will be analysed by Benedict Wasiche Were, the researcher.
- Access to the interview transcript will be limited to the researcher and academic colleagues, and, other researchers with whom he might collaborate as part of the research process.
- Any summary interview content, or direct quotations from the interview can be made available to the public through publications and conference presentations.

Your identity will however, be kept anonymous to maintain confidentiality.

By signing this form I agree that;

I understand that I am free to contact the researcher with any questions I may have in the future.

Benedict Wasiche Were (Researcher): Signature \_\_\_\_\_ Date \_\_\_\_\_

Participant's name \_\_\_\_\_, Signature \_\_\_\_\_ Date \_\_\_\_\_

### Contact Information

If you have any further questions or concerns about this study, please contact the following:

1. Benedict wasiche Were (Researcher); Tel. 0723-503-811/0733-818-106; email [benwasichewere@gmail.com](mailto:benwasichewere@gmail.com)

2. Dr. Emmanuel Shikuku (Supervisor); Tel 0715526114; email address: shikuku.emmanuel@ku.ac.ke
3. Dr. Zippora Okoth (Supervisor); Tel. 0722-446-990; email: okoth.zippora@ku.ac.ke

## Appendix 2: Focus group discussion consent form

**Research Project Title:** Interrogation of Documentary Film as a Tool for Advocacy for Positive Living with HIV/AIDS in Yimbo West Ward of Siaya County- Kenya

Researcher Name: Benedict Wasiche Were

This study is focused on the role of documentary films on HIV/AIDS in mitigating the effects of HIV/AIDS in society. The discussions will focus on cinematography, character and characterisation, setting, narratives, and choice of subjects as they relate to creating meaning for the audience. Information obtained from this discussion group will be treated with confidentiality and used for academic purposes only. The group members will watch the films before the discussions are done. Each session is expected to take a maximum of two hours. I thank you for agreeing to be part of the FGD.

In signing this consent form, I agree to the following statements:

- I have read the information sheet related to research and understand the aims of the project.
- I am aware of the themes to be discussed from the documentary films under review.
- I am aware that I will remain anonymous throughout the data reported and that I have the right to leave the focus group at any point.
- I am fully aware that I am not obliged to answer any questions and that all answers will be given at my own free will.
- I agree to have focus group discussions recorded on video or audio and transcribed after the discussions.
- I am aware that I will not benefit directly from participating in this focus group discussion.

Participant \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

Researcher: Benedict W. Were      Signature \_\_\_\_\_ Date \_\_\_\_\_

### Appendix 3: Observation guide

Item for observation	Description	Notes
<b>Characterisation.</b>		
Identifying the infected and affected		
Thematic concerns in characterisation		
<b>Documentary Voice</b>		
Narration voice		
Talking heads		
<b>Visual Depiction</b>		
Visual images of the infected		
Visual images of the houses		
Set components		

#### **Appendix 4: Interview guide for documentary film directors and producers**

- i. For how long have you been directing and/or producing health documentary films? How has it been?
- ii. Please briefly discuss your motivations for producing documentary films on HIV/AIDS.
- iii. What factors influence your choice of people/characters through whom to tell the story?
- iv. What message did you have in mind when producing the documentary, and was its purpose achieved?
- v. Briefly tell us why you would choose a particular setting over another in producing documentary films.
- vi. What would you say about other productions you have seen on HIV/AIDS?

**Appendix 5: Guide for conducting an interview with a person living with HIV/AIDS or a health professional**

- i. What came to your mind when you saw the title? In relation to positive living with HIV/AIDS
- ii. What would you say about the images of HIV/AIDS positive people used in documentary films?
- iii. Briefly comment on the role played by talking heads and informational figures in HIV/AIDS documentaries.
- iv. What is your take on the plotting and story line in documentary films on HIV/AIDS?
- v. Are documentary films, in your opinion, addressing or exacerbating the problem?
- vi. How else would you present messages about HIV/AIDS without triggering stigma in the affected?
- vii. As you deal with social support groups, are films part of what you use for advocacy?
- viii. What do they detest most in documentary films on HIV/AIDS?
- ix. According to you, does watching documentary films isolate or integrate HIV/AIDS positive people in society?
- x. Briefly share your take on the narrative projected in documentary films on HIV/AIDS.
- xi. In your honest opinion, are documentary films on HIV/AIDS successful as a tool of advocacy on HIV/AIDS?
- xii. What would be your advice for future productions on the subject of HIV/AIDS?
- xiii. Would you kindly comment briefly on the circulation of documentary films on HIV/AIDS in Kenya?

## **Appendix 6: Focus group discussion guide**

I thank you all for accepting to be part of the discussion group today. The goal of today's meeting is to watch four documentary films on HIV/AIDS and analyse them for characterization, the voice/narrative advanced, and the effect of these documentaries on the relationships of the infected/affected in society. The information we give in this discussion has one soul aim: to improve documentary film productions to help in advocacy for HIV/AIDS. We will take a maximum of two hours for this session. For us to save time, the following are basic rules to keep in mind as we conduct the session:

- i. Speak freely but do not interrupt others.
- ii. Every answer is right.
- iii. Everyone is expected to be an active participant.

All feedback remains anonymous. In order to maintain anonymity, I request that anything discussed in this room is not to be repeated outside of our session.

### **1. Introduction**

Before we start, let us have a round of introductions. Please say your name and briefly explain what you do.

### **2. Screen the documentary films**

#### **3. Interactive session**

- i. Briefly discuss the title of the documentary. What came to your mind when you saw the title? In relation to positive living with HIV/AIDS.
- ii. Discuss the plot of the story and how HIV/AIDS was presented.
- iii. Discuss the presentation of characters in relation to HIV/AIDS. Look at the physical appearance, angles of cinematography, and narrative he/she advances; is it one of hope or despair? Discuss his/her dialogue in relation to other aspects of communication in the documentary, i.e., image, lighting, narrative, space/place.
- iv. Discuss talking heads or information figures in the documentary films. What narrative are they advancing in relation to the image projected of the HIV-

positive character? Analyse the message-advanced intentionally or unintentionally through the narrative against the intention of the documentary.

- v. Discuss the issue of stigma in light of these documentary films. Where do you place people infected with HIV/AIDS in these documentary films?
- vi. Finally, briefly discuss the HIV/AIDS documentaries' circulation and the implications therein.

## **Appendix 7: Transcription of the interview with Mr. Inganga (a documentary film producer)**

**Moderator:** The topic of my research, as I mentioned to you earlier, is the interrogation of documentary films as a tool of advocacy for positive living with HIV. So, basically, we are looking at documentaries on HIV and how they can be used better in advocating for positive living with HIV. So maybe, as a beginning, you can tell a bit like how long you have been doing... you've done documentary films on HIV.

**Participant:** Well, I began this journey of storytelling on HIV/AIDs and tuberculosis mainly in the year 2006, and to be specific, in October. To be specific, this was as a result of having been invited by Internews in Kenya to embark on the production of stories in that particular category of storytelling. And over the years, I have gone to quite a number of places within the country to produce stories on HIV/AIDs and tuberculosis. Within four years, I had produced over 60 stories in those categories.

**Moderator:** Fine, you have already answered the second question on the motivation for producing the same, and perhaps now the third question will be what dictates your choice of the characters to use... Your choice of who to use is dictated by HIV positive characters.

**Participant:** First of all, we need to recognise the fact that editors for television stations or even newspapers have had this notion that HIV story telling is tired in itself, and therefore, for me to come up with a story on HIV, or AIDS, or Tuberculosis for that matter, it has to be something unique. So, I look at how unique the story is. I can give you an example of once when I went to Butula to do a story on HIV. It was a story about an 89-year-old man living with the virus. I reasoned that since Kenya's democratic and health surveillance is based on the age bracket of 16–64 years, what about those over that age bracket? Does it mean that we don't have Kenyans who are beyond that age bracket who are living with HIV/AIDS? So that in itself made that story quite a unique one. This was an 89-year-old person living in Butula, Busia County, who was living positively with that virus, and indeed, when I took it to the media houses, there was no question that this was a unique story. So, I like to ask myself, "What is it that has been told about HIV that has not been told before?" That dictates my choice... my choice.

**Moderator: Among the characters to be used?**

**Participant:** Yes, how unique is the story? If there is nothing new that I am going to get from that story, then I don't go ahead. There are quite a number of things that I analyse. For instance, if I were to get a person in the health sector, maybe a nurse or a doctor, who is living with HIV, I would cover that story. That is a story that any

media house would want to use, but now it is very difficult to get because what would happen to the patient of such a doctor if you were to know that my doctor is living with HIV? Of course, I believe that they are aware, but then it is very difficult to convince them to tell you their story. So, the more unique a story is, the more I will go for it.

**Moderator:** Fine, uhm, you've talked about that issue of a doctor. Of course, there are some. We are told that HIV/AIDS is something that anybody can get, even health officials. I don't know... How would you, or rather, how would such a story influence the public towards positive living with HIV if you were to get such a character?

**Participant:** You see, anybody could contract it and the fact that healthcare givers are, you know, at the core of offering care to patients means that if they can give their story, then it would reflect the fact that they too are at risk. We have had very many cases where medical personnel have asked for proper remuneration in order to compensate them for certain ills that occur within their medical fields. So once they open up, of course, it will bring out the idea that everybody, even in the health center, needs to be even more careful in trying to contain the spread of that condition.

**Moderator:** As you do HIV documentaries, as you get out, or rather come out with an idea that this is the story you are going for, what message is normally in your mind as you go out to do that documentary?

**Participant:** Well, first of all, HIV is a condition, not a disease, and my message normally is to those who are watching, look at these characters in these stories. They are infected. They've accepted what they can't change; there are other conditions outside where patients or people living with those conditions should accept what they can't change as well. Accept what you cannot change. That will constitute part of positive living. You accept your condition and learn as much as you can from it and how to survive with it. And then, of course, it's also a psychological issue because if you are overly concerned about it, chances are that such a person is not going to feel well. But if they have that positive perception that it is not a death sentence, so to speak, then, of course, it will be easier for them to cope in life.

**Moderator:** So, what is that? What I'm probably implying is that, in the back of your mind you have a thought to bring out a positive message.

**Participant:** Exactly.

**Moderator:** Do you usually achieve that in your work?

**Participant:** Sometimes we do, and I would like to think in terms of Butula. I've done quite a number of stories in Butula, and Butula is the only place I've visited in this country where people maintain positive living. They talk freely about HIV/AIDS.

Even if you were to go there. Of course, I went through an organization called LARIB, and when I went there for the first time, I just took my notebook and pen, just to interview the director of RIB. RIB is an organization that deals with several issues having to do with HIV/AIDS, child molestation, and so on and so forth. I was actually shown quite a number of people who were living with that condition. Of course, they have different clubs for people living with HIV. We have mothers, fathers, and even youths. Different age groups who are living with that condition talk freely about it. But of course, there are others who are quite apprehensive about opening up, so they keep it to themselves. In some communities, well, it worked to demonstrate through pictures and through story telling, that indeed there are people who have accepted their condition and, well, that is not condemnation to them, so to speak.

**Moderator:** Just as a producer, you have two situations: you have somebody who is ready to tell a story from their rich background and another one who is ready to tell a story from their poor background. Which one would you easily go for and why, in relation to positive living?

**Participant:** First of all, people who come from poor communities are easily reachable; they can easily be convinced to tell their story. Those from rich backgrounds find it very difficult to reach them. I'll give you an example. There was a time I went to Kwale while I was doing a story on tuberculosis; I met a woman who was struck very much by that disease—tuberculosis. Unfortunately, she was so poor that she didn't even have food, but nonetheless, she was willing to tell her story. She was put on very heavy drugs and because she didn't have food, we empathised with her. So, at times, it reaches a point where because of that empathy, you do what you can, but for the rich, it's quite difficult, maybe because it's very difficult to reach them and perhaps they worry about their status in society. What if it's known that they are suffering from this condition? If you look at an ailment like the cancers that you have been hearing about, well, even the rich and those who are high and mighty have started coming out, some of them advocating for it to be declared a national disaster. We are yet to hear of a prominent person or a rich person coming forward and saying that they are living with HIV.

**Moderator:** There has been this belief in many that HIV is a disease for the poor because of the way it has been portrayed in many documentaries that have come out. They have centered the poor people in society, which is now saying that those who don't belong to that category feel like it is a disease for them, not us. Which ends up now exposing them and also the poor feeling that this is our disease, not theirs. And that's why I was bringing up this question: do you think it would stamp that message that HIV is for all of us if we were to use the rich in bringing out the story of HIV?

**Participant:** You see, we would have to go back to the factors that contribute to the prevalence of HIV. I believe it is a matter of behavior change. At present, there are

chances that the poor can easily contract HIV, but at the same time, there are quite a number of poor people who have taken precautions against infection, and at the same time, we must know that there are rich people who are very reckless with their lives. So, the fact that they are reckless means that they are exposing themselves to the possibility of being infected. In fact, chances are that they might be more vulnerable to the spread of HIV than the poor. But if you look at what the poor sometimes do, like in the fishing industry, you had cases where we had fish for sex. Like the shores of Lake Victoria, Infact, I have quite a number of colleagues who have produced such stories. Of course, if fishermen travel from home for several hours or days, even in the waters going to nearby islands within the lake or elsewhere fishing, they expose themselves to a greater risk. There are some who come with a lot of fish, but for them to sell to certain retailers, they demand sex, so it's a complex issue where we cannot really say that it's just the poor who are more vulnerable than the rich. It depends on the factors that contribute to the prevalence of HIV among the two groups.

**Moderator:** In your own honest opinion, have HIV/AIDs documentaries achieved positive results in advocating positive living?

**Participant:** Well, I believe it has because if these stories had not been aired, I think it would have been worse. We had media houses that have had a little program on HIV/AIDS over the years that have contributed to it. We had Mending the Ribbon by KTN, which used to come every Sunday at prime time, and we've had Beyond the Epidemic on KBC, but before that, it was all as it begins with you. I contributed quite a number of stories to those two channels, and there are many times when these stations will be dry that they will have to call me and ask, "Might you have something for us for this field?" Of course, if I had, I would give them. So, these were weekly programs that were sponsored by various organizations. It was a sure slot that come Friday at prime time at KBC, you would have a program ranging from 5 minutes, sometimes even to 8 minutes. KTN is the same. And they had very committed journalists who were going out on a weekly basis looking for something fresh to be aired. And there are quite a number of organizations that sponsor journalists and encourage them to specialise in those particular fields. The advantage of being specialised in a particular line is that a journalist becomes more adept at reporting those issues, and it had reached a point where there were more than probably 200 reporters in the country who were going out to produce various stories on HIV/AIDs. Virtually all the stations had a group of journalists who were going out. And you see, the fact that we had dedicated time on television meant for such programs must have been a new fact. I had been engaged by the AIDS control unit of the prisons department, and I went to quite a number of prisons within the country, covering stories on HIV and AIDs. It reached a point where I became one of the very few journalists in the country to gain access to any prison within the country. And the AIDS control unit would take my productions, especially after being aired, and use

them in forums such as workshops or even shows at various prisons. So, I believe they have had some impact.

**Moderator:** I would take you slightly back on one question, or rather, a clarification. There is the use of people who are living with HIV in documentaries. As you know, we now have people living with HIV/AIDS and you cannot even tell that Kennedy or Tony or Ng'ang'a has HIV, while we are positive. While there are those who are down with the disease, or rather, with the condition. Most documentaries use those who are down. Again, this is just an opinion. In your own opinion, do you think those pictures dehumanise people living with HIV/AIDS and stigmatise them more than if we were to use the others?

**Participant:** I wouldn't say so, and let me give you a case study. For the sake of illustration, I'll go back to tuberculosis. I did a story on tuberculosis where there was a person who had suffered from tuberculosis and had recovered. So, what this lady does is that she visits one Manyatta after another in Kajiado County, tracing any person who has defaulted on the tuberculosis treatment. When she finds them, she persuades them to resume their medication because there is a danger of that tuberculosis developing into MDR TB (Multi drug resistant TB) and, according to the Ministry of Health, it takes at least Ksh. 2M to treat MDR TB. If it goes beyond that, it develops into XDR TB (Extremely drug-resistant Tuberculosis). It is almost impossible to survive with XDR TB. So, in short, what I'm saying is that this lady does something quite noble and there are some that she finds that are taken back for treatment and, with time, they recover. So, we are talking about a category of storytelling that is known as "long form storytelling." It does no harm to use somebody who is down. This person has all the breakout symptoms of HIV; I don't see anything wrong with that. But what is this person doing? Is this person on medication, so we need to have journalists who are committed to making follow-ups? Even if it means following such an individual for one, two, or three years so that you show the transformation, I believe that would be a more powerful documentary. Yeah, we need to have journalists who are committed to making constant follow-ups so that they show both sides. We began three years ago, taking an arbitrary duration, and one year later, this is how this person looked, one year later, this is how he looks healthy. He's working. He's taking care of his family. He's farming and engaging in other activities. So, you saw that turn around? There is nothing wrong with that as far as I am concerned. I've done it, at least from a tuberculosis point of view, and I believe the same can be done in HIV stories.

**Moderator: Finally, the final one.** Please comment on the circulation of HIV/AIDS documentaries.

**Participant:** I remember when this condition was quite new in the country. We had ACE-communications that was then run by Raphael Tuju, and back then HIV was still

very new. But this farm went ahead and set the pace for the production of HIV/AIDS stories. Back then, we had a number of cinemas and various television stations that were airing and broadcasting such stories. We also had documentary film services, which is now a department of film services. It had quite a number. We had the national AIDS control council that would get productions from various media houses to screen. But I don't think the circulation is quite adequate. The reason being, as I mentioned earlier, most people think it's a tired story. But of course, the public needs to be reminded of the importance of such a subject, especially to be aware that if you are reckless, you might, or rather, if you don't take precautions, you might be affected.

**Moderator:** Thank you so much for your time.

**Participant:** You are welcome.

## **Appendix 8: Interview data transcription from the interview with Mr. Arnold Oloo a Public Health professional**

Note: This interview was carried out immediately after a documentary film had been shown to some participants of which this professional health care provider was part of.

**Moderator:** Thank you for taking time off your busy schedule to first of all organise for us and also be ready for us to have a session with you. I know that you deal with social support groups like the one we just had. Are films part of what you use?

**Participant:** films?

### **Documentaries or films**

**Participant:** No. Right now, we don't really use films. Specifically, documentaries, but we use things like pictures, flip charts, and things like that, but films right now in my facility, it's not really a part of it.

**Moderator:** What could be the reason for that?

**Participant:** I think the main thing is maybe support from the partner, because now there is no support from the partner. Our partner is able to just provide print media but not electronic means like this. I think it's mostly because of the cost implications.

Do you think films would do better in training to bring out the HIV impact?

**Participant:** Yes, definitely it has a positive impact when just like the session we had with the people who have just left, I was even surprised at how they usually talk. I think I will be using documentaries to depict HIV in any way that would have a positive impact. Defaulting and all that have a positive outcome.

**Moderator:** Do you generally watch documentaries

**Participant:** Yes, I am a very big fan of documentaries.

**Moderator:** That's good. What is your take on the narrative being projected in HIV documentaries? It may not be necessarily what we have watched today.

**Participant:** The narrative that I usually get is actually quite different now that I'm a big fan of medical documentaries, especially for HIV. the narrative now is that HIV is still the killer disease that is narrative still brought out but to me as a person who handles people who live HIV each and every day most days of my life you find that is not there actually, most people HIV there very few people die from diseases related to HIV/AIDS, By the say of the films it is still the same narrative that HIV is a killer

disease but the of example the one we have seen today there aspects that try to bring out the HIV is something you can live with for a very long period of time as long as you take drugs the earlier documentaries are still depicting to HIV as a killer disease but to the ground what is happening right now is that these people don't die from HIV, every few cases but I think and hope moving forward we are going to get documentaries that will now talk about positive living with HIV/AIDS. That's ok

**Moderator:** If we partake of the characterization of the characters we are using in documentaries,

**Participant:** Let me talk about what we saw today. You see, from what is being brought out, people are orphaned, and when they are orphaned, they are left with old people to take care of them. Well, even in my facility here, I have kids who are orphaned, but then when you look at them, they are well taken care of. What is being brought out in the documentaries is that they are using characters that are like, you know, people with end-stage disease, end-stage, and stage 4 HIV, which is like what I just said earlier. Most of the patients these days who live with HIV are not in the end stage because of the effective ARVs. So, in the documentaries I've seen, they usually focus on people who are in late stages of HIV, which isn't the case in reality. Let's take a look at some of the patients who come to the studio; most of them you wouldn't recognise if you met them outside. So about the characters that most documentaries use, I think they're not a true representation of what is there. They are not using the true representation. Well, there are those cases that are still there, but they are not that many. Yes

**Moderator:** Does watching documentaries of people living with HIV/AIDS, after watching these documentaries, do they feel more part of the society or more isolated?

**Participant:** That's a tricky one because we really have to get exactly what they have to say. This is what I think, when they watch these documentaries, I think it's a wakeup call to those people who are on drugs and maybe had thoughts of defaulting and all that. When they see the type of characters that are brought in, if you don't take your drugs well you will be like that. So, it doesn't take them away from the community, I think it makes them accept that they are living with these. You were talking about positive living it makes them accept the fact that yes, they have HIV/AIDS but there is hope that if they take the drugs they can do well. So, I don't think it takes them away, it integrates them.

**Moderator:** There are what we call "talking heads" and "informational figures" in documentaries. This may not be, now if we were talking about HIV/AIDS documentaries, this is not the person living with HIV. Maybe he is a doctor. The guy giving the voice over. What would you say of the message they pass out when they

are commenting on HIV? Generally, on the ones we've watched, we are not tying you on any. We are not tying you down to anything.

**Participant:** Okay, these people in the voiceover, as you've said, I think they are people who are doing research and what they comment is exactly what they find. So, your question is, are they?

My question is, are they helping destigmatise HIV? That's another way of putting it.

The information they give: does it advocate for positive living, or what image does it paint?

**Moderator:** That is the first one we watched. If I take you back to the first one, I'm not directing your thinking. (*Laughs*) Otieno says, the other guy was taking him around. George

In his view, they moved into homes and they don't get new infections, but the prevalence for Homabay County continues to rise. According to George, it is people defaulting here and moving there, so they register afresh, according to George. But Otieno insists that it is not enough to explain the rise in the prevalence of HIV/AIDS.

Well, the voiceover, I think what they usually say, from the documentaries I have watched, they are just trying to depict what they get from the ground. And if it really helps to destigmatise, no, I don't really think they help to destigmatise HIV/AIDS because what they usually get from the ground, just as I said earlier, what they purport to get from the ground and what is in the facility in the community is something different. So, you know, when like, for example, the example you have just given still says "no, that is not the real picture of what is here," I don't think if they rally to help to destigmatise HIV/AIDS

**Moderator:** Let's talk about the images used of people living with HIV/AIDS in the documentaries. Most of the images I agree with you are like a follow up, of course, to what you've just said. It's like a wakeup call sometimes, something like that. Most of the time we are receiving images of people suffering in documentaries. I don't know the ones you have watched. Is it a true reflection of what HIV/AIDS is today? Now as a medical officer you've dealt with

**Participant:** Yeah, we are in 2019; and just as I have said we have very effective ART treatment. And with all the publicity with all the print and electronic media that HIV is getting and especially in areas of high prevalence like for example Siaya County, that is not the true depiction, I think when these people go to, when they create the documentaries am not saying, most of the documentaries that we get they are usually of people who are very much inculcated, they cannot be able to move, they live in absolute poverty which is not the true representation it is just a smaller

percentage of what everyone that is in that area. So, these characters that are used in these documentaries they are not, actually it's like an inverse proportion of what is actually at the ground because I walk with them each and every day. There are people that even if you meet them out there you won't even know that someone... but I wouldn't lie I wouldn't also object that there are some, there are only just a few cases who are usually represented, even in my facility I have some few cases who are, you see someone very much exact way, but they have their programs that are coming up that are helping the patients. So, I think the characterization and what is actually on the ground is not the exact thing.

**Moderator:** So, in line with that, since the biggest challenge that people living with HIV face is usually stigma, do these documentary films seem to address this problem or do they even make it worse? We say what we've just discussed is some form of false representation of the actual situation that is on the ground.

**Participant:** Well, I think that I wouldn't say that they really make them, I don't think that what they are showing in the films would actually help. They are not really. I think the damage was already done, as they started depicting HIV/AIDS in the earlier centuries. They are still doing it. The damage is already done. People expect that when you show them a film of HIV/AIDS you will show them people who are thin, people who are emaciated and for most of the patients who come to... people have taken up, people are coming out saying ok we have HIV/AIDS there are drugs that are helping and they are taking drugs. So, the films what they are doing I think there is no effect to me, there is no effect that the current documentaries what they are showing is making about helping to reduce the infection, I think there is actually no effect because the damage is already done, they started showing films of people who are thin emaciated until this day and time they are still using the same thing. People will see and say no that is not what is actually there, people these days are taking drugs, people are dying with HIV, so no effect

**Moderator:** So, do you believe there is a way to present the HIV/AIDS message without increasing stigma? And still make it even more effective.

**Participant:** Yes, I think there is. Let me tell you something, right now in the whole sites that are supported by CDCs, we want to eliminate the virus by 2030, so right now we are getting those people who were previously on drugs who stopped. We want to put them on drugs so that there is suppression. You know, when there is suppression, there is elimination. So that is what CDC is moving into that is what we are doing in the facility. So, if the documentaries can also pick the same message, you see, the same message of now we want to eliminate HIV/AIDS, let it not still bring out the question of HIV/AIDS is a killer disease, those people who have AIDS are very thin which is not a true representation of what is on the ground. If they can pick the message into some, you want to eliminate HIV/AIDS by 2030, now these are the

steps you are going to take. So, when you are on drugs ensuring you take you drugs well, there will be viral suppression by that time. I think that is what they should do. Not just taking HIV/AIDS to be a killer disease. That they are showing us areas where everyone has died, *kuna makaburi kila pahali (laughter)* I think they should move away from that. They should also start giving people who live with HIV/AIDS, tell them that they will be okay if they are on drugs yes, if you take your drugs well you will live longer, give us example of people who have lived for a very long period which clearly are not there, they are not shown now. Give us examples of people who have lived with HIV for a very long time, show us a homestead that probably everyone has HIV/AIDS; everyone is working, nice homestead, things like that. That will help reduce the stigma of HIV/AIDS. But what they are showing right now just as I said no if but to some extent it would cause some stigma. Yes, just like that.

**Moderator:** Yeah, I think you have already answered a few of the questions there. He's already answered the question about the success tool and future production (laughter). Yes, I think that is what we would do. I think we would pretty well sum up, unless you have something... On circulation, yes, on the distribution of documentaries on HIV/AIDS. What is your take on that? Are they available to the masses, or do we think they are? What is your take on that?

**Participant:** Yes, let me pick on the group that we had earlier said that there is a representation of a good percentage of people who stay around. I think they are available to at least a good percentage of people. Just a small percentage are not able to access it. Regarding the documentaries and their circulation, I think they are available. Yes, they are available.

**Moderator:** Any other business? Oh, no! There is something about the issue of the Jaboya system's prevalence as it is, let alone the way it has come out in the discussion, as it is, and as it has been propelled by the media, that the Jaboya system is only about the fisherman and the woman fish vendor, and that this is the only cause in communities along the lake shore. In your experience dealing with such cases, what is the picture of prevalence? Is it only as a result of that, does that paint the real picture, or is there something different?

**Participant:** Actually, the issue of Jaboya if I was a policy maker, I wouldn't even allow it to be mentioned because it is not something that is there. It is not clearly something that is there. Well there are a few cases but not the true indication of what is there in this age and time. Well, when HIV started that is when I was still a young boy the early 80's that was what was happening. The Jaboya, HIV/AIDS got the Jaboya system not the other way round, no. HIV/AIDS got the Jaboya system. So, there you want to get fish you have to give sexual favors, that was there. But the media, the government and the NGO's have tried to create awareness of how HIV/AIDS is spread and they got the main thing around the lake shores is the Jaboya

System. Right now, let me tell you this thing called Jaboya is non-existent. Yeah. Its's just the notion that people had a long time ago that is still here. And about the issue of prevalence, getting there is something called a new positive. A new positive is someone who was not known their HIV status and when they come to the facility, they are tested they have a positive result. That is a new positive. In this age and time getting a true new positive is so hard.

So that is based on George, when George in the documentaries says, "When you walk around, there is no new infection."

Yeah, he was saying when you walk around the houses, around the communities, there are no new infections but that the prevalence is still high. That is the exact thing that is still happening. You will find that... So, I had a patient in this facility, Usenge Dispensary. I worked for two years, and probably after a year or two, I was transferred to a different facility. There are those patients whom I left in Usenge dispensary and at Usenge dispensary they are called a lost to follow-up. A lost to follow up is someone who started drugs then akaenda akapotea, now when you move to the next facility you find the same person. Not he didn't move from facility A to facility B with a transfer letter, he just moved to facility B and just told the "I have never known my status, I was tested and is initiated into care." So that will get the issue of prevalence going high. That's why CDC is coming and saying, if you have people called lost to follow up, you have to look for them and you have to find out where they are. Now, before you initiate a person into treatment, you really have to be certain that this is true positive. So, about the issues of prevalence, I wouldn't say that there is so much prevalence in HIV/AIDS, what we need to move to know is just containing the disease. It's not spreading so much

**Moderator:** That's good. It's good for discussion because it will shed some light. Personally, we had a problem with that part of the information because, further on, when Timothy insists and says that cases of what you are explaining do not justify the prevalence. It tells us what you have just said, that they do good research, yes, but they do not do good research in relevant places. So, what they come up with is not a true depiction of what is on the ground.

**Participant:** And also, another thing right now, CDC is doing a study. It is called rescency. They are trying to, for example, when you get a new positive client, you have to draw blood, take the blood samples to Kiambu, where they have to do studies. The studies will show that there are blood tests to show when this person was likely infected. Has this patient ever been on drugs, or not? So, I think the...

**Moderator:** You said that is called?

**Participant:** Recently, this is what they are doing right now. It's still in the early stages, we are still getting new patients then we take samples so on that we want to see when exactly or what period of time was this patient likely infected, has this patient ever been on drugs or not. I think now this when it comes out this will really help us to

**Yes, there is the issue of prevalence.**

**Participant:** Yes. Also, this is of areas where there is a lot of fishing going on, and let me tell you what happens. You get a fisherman he goes deep into the sea, someone is caught anenda anfungwa Uganda, goes to Uganda for almost three months, you know in our facility we will be looking for the person but we will not find him. This patient when he comes back stigma ya kushikwa Uganda sijui nini, he moves out of Usenge goes to a different beach. You see the livelihood is in the beach. He moves from Usenge goes to a different beach probably in Uganda.

**Moderator:** So even just being arrested stigmatises you?

**Participant:** It does. I hear they do so many crazy things in Ugandan prisons. So, when someone comes back, there is a lot of stigma. So, they move from one island to a different one. And you know in the movement to the next island, when someone takes drugs, mtu ako sawa, when you go to Uganda maybe two months, your health definitely will deteriorate.

**Moderator:** Your health defaulted for two months.

**Participant:** Yes, now you have to go to a different facility and do what? To be tested again. So, the issue of prevalence does.

**Moderator:** You don't even disclose

**Participant:** You don't disclose, because when you move from facility A to facility B, the clinician who was helping you has to write a transfer letter, so it is known to the other side what was being done, especially if you were on first-line or second-line HIV drugs, yeah. Those are the issues that affect them. So, I believe the issue of prevalence is kidogo, and I recall hearing in Luo Nyanza when I was growing up that there was a lot of HIV/AIDS so that more funding could come so that watu wafanye nini? Wapate kazi (*laughter*)

**Moderator:** So that explains the other part of the narrative, that it is a Luo man's disease.

**Participant:** Yeah, so they scale up the prevalence so that there is a lot of money coming up with the NGO's so that watu wapate kazi.

## **Appendix 9: Transcription of Interview with Madam X (A PLWHA)**

**Moderator:** Thank you for accepting the invitation to this interview. After watching those films, what's your take on the productions generally?

**Participant:** They are good. I can say they are good they are informative, educative and they also encourage those who have despaired in life. When they watch them, they get an insight of taking precautionary measures not to involve in illicit activities that may bring them down. May be getting opportunistic infections.

**Moderator:** When you look at the story and how the story flows in this documentary what would you say with regard to the observation that you have just made.

**Participant:** This one is talking about the infected people who visit hospitals when they are at an advanced stage. So that means that their immune systems have gone down and helping them is not very easy. Yeah,

**Moderator:** Now just in relation to the first statement, the documentary is educative, informative and now we are just following it up on that storyline, the flow of that story, the message that is coming out of that story, that is what we want you to relate. Not necessarily on this documentary, but HIV/AIDS documentaries generally. This one we were just giving to you to jog your mind a bit. Not that your comments will be based on this one only.

**Participant:** As I have said, they are educative for those who do not know their status, as they will be encouraged to go and find out their status and may start early medication when their situation has not worsened. For those who are already affected now start behavior change. Nutrition and such kind of things; there are things that can maintain their health status.

**Moderator:** In this documentary, there are these people who are positive. What is your perception of how they are...? What would you say about how the images of the people living with HIV/AIDS have been depicted in these documentaries?

**Participant:** Before you answer, I need to clarify it further. What would you say about that choice of the characters infected with HIV/AIDS in HIV documentaries?

**Moderator:** I can still say it's good... Explain.

**Participant:** I told you yesterday when... before I went public about my status, I had just been diagnosed with HIV, so I did not talk about my status, so the facilitator that brought the video about the... he was the first person to disclose and also get infected while in Uganda. So, personally, I got encouraged and said if this person has managed to live with HIV, why not me? Then later on, I went to see John Muriuki and another person was Sylvia Wanjiru. And apart from me, many others got encouraged that we

thought about disclosing, and that's how we started going public, talking to the people who were infected and also making referrals.

**Moderator:** Just a follow up to that. What encouraged you there? The documentary about Lutea

**Participant:** The positivity within, behavior change, and we also talk about drug adherers. Prone to medication,

**Moderator:** From that documentary, did you see that his life had changed for the better or that the image of him projected was that of somebody down?

**Participant:** He was down initially; he started when he was very down. And then he later on they got to where he was able to walk. In fact, he was bed ridden. So, the stages, the developmental stages of how he started are what encouraged me also. Mmmh. So I said if he was badly off that is if he was able to move from stage 1 to where he was now talking to people, then living with virus is possible. So that is when I decided also to go public and talk about myself. Yes

**Moderator:** What was his image, if I may ask...? I was more interested in that. In that documentary. What was his image at that point when now he's talking to people? You said he started when he was talking to people.

**Participant:** The image was good compared to the earlier stages. At least he had improved because the first image showed that he had an oral rash, he was very thin, and he was still restricted, but now he was able to talk through the film, nobody could tell that he was sick. So, this was a big encouragement to those of us who watched the film.

**Moderator:** So, at the very least, you were encouraged by the fact that you had seen him down and now you couldn't tell if he was sick.

**Participant:** Yes. And it was from stage to stage, first stage, the way he was moving with treatment, that this was what he was sharing. The things he was supposed to do, even nutrition, what he was supposed to eat and what he was not supposed to eat. Consistent use of condoms is a must if you must have sex.

**Moderator:** There are these characters in documentaries called "talking heads" or "informational figures." This is not the person who is leaving with HIV, but rather the other people who may be clinical doctors, community health workers, or caregivers.

**Participant:** Yeah, In the documentary, they are there. What would you comment on the role they play? The words they say...

**Moderator:** In terms of the information they give, About HIV/AIDS

**Participant:** They give good information. Depending on what they talk about. They talk about different issues. So, if you ask me which one it is, I might be able to tell you.

**Moderator:** If I may expand on the section of the films I gave you...We are talking about HIV at the Lakeside... At the lake shore, the Jaboya system... Yeah, you must have watched some of them on the Jaboya and whatever, comment on that.

**Participant:** Yes, Jaboya, I wrote a story about Jaboya and the Lake System, because I'm from the Lake.

**Moderator:** Okay. now you must have watched some documentaries of the same

**Participant:** yes

**Moderator:** Like when reporters are talking and the kind of information they give, the voiceover

**Participant:** They do good work. Yeah

**Moderator:** Expound a bit like on the how HIV spread. What do they say?

**Participant:** When we talk about what happens in the lake region, most people may not know, but now...

**Moderator:** I just want you to base it more on what they say. Of course, most of the people may not know, but...?

**Participant:** They are discussing the Jaboya systems about fish and sex. The women who go to buy fish are They are what? They have to have sex with the fishermen. These people who sell fish, that is what is called the Jaboya system. So, when you genuinely go to buy fish, you may not get it unless you sleep with those people. Which is not good enough because you don't know their status and now you are involving yourself in sexual activities with them, hence the spread of HIV.

**Moderator:** Now, as a person living with HIV, do you agree with that assumption that people at the lake get HIV because Because of fish for sex,

**Participant:** That is a common activity, yes. It's true, apart from the wife's inheritance, fishing for sex is a common activity that makes people contract HIV.

**Moderator:** Yes

So that is the main reason, but not the only one.

**Participant:** It is the primary

**Moderator:** At the lake, what other activities do you think could lead to HIV prevalence?

**Participant:** Lack of information and also the fishermen; they have money, so they take advantage of the young poor girls in the village, the widows. Because the majority of them are not from the lake. They have just come from other areas, but they go fishing. Nobody knows their status. My mother was born with She didn't know this person, and both of them died. Mmmh. So, you find most of the homes, especially the ones we've seen, there are no people because of HIV.

**Moderator:** But of course, your mother was not inherited as a result of Jaboya's.

**Participant:** No, not that of Jaboya. But these people are there. They come as fishermen, and now they get used to the village, until they become as if they were born there.

**Moderator:** They get assimilated into the village.

**Participant:** yeah

**Moderator:** Still, if I dwell more on the Jaboya because it is an aspect of the field that we are studying, I will ask more because it is critical. Do we have women who do genuine fishing business without getting involved in it?

**Participant:** And the men who do it

**Moderator:** How do you comment on that? Comment more on these women: a little bit more about these women who do genuine business without involving themselves in Jaboya parties in the fishing industry.

**Participants:** They do well.

**Moderator:** How?

**Participant:** Because they get what they want but these others because they involve themselves in sexual activities not knowing the status of the other person, now they get infected and when they are sick the business may not continue but these others will prosper because they stick to their business

**Moderator:** Something that is emerging in the documentaries that we are studying and generally in society is that the major problem faced by people living with HIV is stigma. Are documentary films, in your opinion, addressing these issues and changing society's perception of stigma, or are they exacerbating it?

**Participant:** They doing well but they continue doing it because the stigma is still there. Stigma is very high. And that is why people majority they don't want to talk about their status in the society even at work place anywhere stigma is real.

**Moderator:** So, when you say that stigma is real and still there, according to you, when people who live with HIV/AIDS watch these documentaries, do they seem to isolate them from society or integrate them?

**Participant:** They isolate them, especially in the rural areas where awareness is not so much kama like in town. You find it is not even possible for one to take medication at the nearest hospital, but you prefer to travel far for medication, and sometimes they don't even have the fare to get them to those places. As a result, they are the default.

**Moderator:** I might ' If a person living with HIV/AIDS watches a documentary on HIV, after watching that documentary, does it make that person feel freer? Does it make that person feel more freely not this person living with HIV or even this person not living with HIV after watching this film? Do those documentaries change their perception of people living with HIV according to you?

**Participant:** Yes, it depends with an individual how you receive the message. Some watch and maybe they don't take action. Mmh. And some also watch and they take action, they say if this is what is happening, they say let me do this for a better life.

**Moderator:** What about the person who is not infected? The HIV-negative individualThe person has watched the HIV documentary and now I have watched it. For example, if I meet Tony and Tony tells me I am HIV positive, would the documentary make sense? According to you influence the way I look at and relate to you.

**Participant** Yeah, you will have received some information, information that now helps you relate to the infected person, so Yeah

**Moderator:** Like the films that I've used in educative documentaries, most of them are about HIV. I believe you have shared it with some people who are not HIV positive. Has it influenced their way of looking at you? Looking at people living with HIV

**Participant:** Yes, somehow. That's why I've said it depends on an individual. We normally have sensitization programs, but once we finish, some come out with negative attitudes. Like the way I look now, the majority are saying I'm not sick, I'm just for money. So, these are the attitudes I am talking about.

**Moderator:** So, according to the people, like those ones who should be HIV positive? According to them now, how would that person look?

**Participant:** They still believe that a person living with the HIV virus should look very thin. Mmmh

**Moderator:** extremely ill

**Participant:** Very sickly and malnourished and all that. You, like me, stand there and declare, "I'm HIV positive."

**Moderator:** They will. I would like to take you back a bit on something you mentioned when we were discussing, especially undeveloped places. You mentioned something about the image of the person living with HIV in the documentaries and in society in general that affects the person living with HIV such that they cannot even take their medication in particular hospitals that leads to defaulting. I'm a bit interested in getting a bit of knowledge on that if you could expound more on that.

**Participant:** That is, once again,

**Moderator:** Concerning the perception of a person living with HIV/AIDS and the stigma they face, which leads to them defaulting, even while on medication, and withdrawing from society.

**Participant:** As a result, this is a widespread stigma. But this person who is defaulting is now undergoing self-stigma. You know, we have self-stigma, stigma by association, mmh. So self-stigma is the one like maybe the way I am positive, I just think people are talking about me, so I am not able to get medication even though I am supposed to take it at 10, and because you are here, I cannot take it yet. This medication is supposed to be taken at 9, but it should be at 9, in the morning, or in the evening. That is where you are in a regime where you have to take 2 tablets; you come and take them, maybe at 1 or at 2. That is when one is abusing medication. It cannot help you. And that is why most of the people you see in their lives, their conditions deteriorate instead of improving. They are on medication that they're not prompt about. He doesn't adhere to medication. Otherwise, if one adheres to the medication promptly, there is no harm in getting a quality life.

**Moderator:** I think that's good. Now this is a question to you as an individual. (laughter)

**Participant:** It's okay

**Moderator:** What do you think you detest most about these HIV/AIDS documentaries?

**Participant:** "No no, to me I think they are good. They are good."

**Moderator:** Or perhaps what you feel might have been done better in those documentaries. Perhaps say in future production if a piece will be improved then... For example, you have just watched someone die of HIV/AIDS in 2017. When we came in, that is what we found running. What do you think could have been done differently to help the public get this message to help the people living with HIV/AIDS live positively? Even those who don't have HIV but they associate with people living with HIV/AIDS

**Participant:** Maybe you talk on various topics about behavior change or they start with knowing status is very important. Just knowing. When you know your status early it's good enough to take care of yourself that waiting until your condition deteriorates. Secondly there is behavior change. That's why I am saying you should talk of each topic differently.

**Moderator:** Personalizing

**Participant:** Yes. So, I've talked about---

**Moderator:** That is knowing your status and behaving differently.

**Participant:** And the importance of why people should know their status early. Adherence to medication means that you stick to the medication given in the hospital. Not that there is Loliondo when you start healing you go here.

(laughter)

**Moderator:** You dash to Loliondo.

**Participant:** Someone is selling immune boosters here. I don't know why Loliondo deceived a large number of people. And when they died, they left me here.

**Moderator:** There is this something you've mentioned, and I want to follow it up. I want you to briefly share your take on the narrative projected by HIV/AIDS documentaries. Just like many people will say all Kikuyus are thieves, that's a narrative, it's not true.

**Participant:** The narrative is that AIDS is for Luos.

**Moderator:** No now am talking generally in the documentaries, what is the story being sent out from these documentaries when you watch these when you are watching the documentary in HIV/AIDS

**Participant:** The comment? The generality that is given to HIV/AIDS documentaries. People say that they are informative.

**Moderator:** Not what people say, but what you watch and get out (laughs).

**Participant:** They are still informative, in my opinion.

**Moderator:** So, in your honest opinion, are HIV/AIDS films a success?

**Participant:** yes

**Moderator:** The proponent of positive living

**Participant:** yes

**Moderator:** Just expound a bit.

**Participant:** I think the majority have changed their behaviors after watching the documentaries, and even the infected, those who have despaired in life, get the courage to continue living after watching the films. Yeah

**Moderator:** That's good.

Others also take precautionary measures so as not to contract the virus.

**Moderator:** What do you think could be that taking on that precautionary measure? I believe you are talking about maybe the use of condoms.

**Participant:** That's behavior change, yeah.

Maybe you are sticking to one partner, if that's what you mean.

**Participant:** yeah

**Moderator:** What in this film could lead to that? What in the film could prompt that?

**Participant:** The things you talk about could make a person change their attitude towards what they're doing. Maybe if it is alcohol that is making him have sex without protection, he will stop taking alcohol, and the majority have done that. There are some who are also on medication and they still take alcohol. So, when they hear about the effects of alcohol and ARVs, they stop drinking. And the perception of condom use, you also discuss it, people believe, the majority believe, that when they put two or three together, they cannot burst, they cannot rupture, so that one you should also include. And also tell them that condoms are used consistently. Not that when you become familiar with it, you stop using it.

**Moderator:** So, in other words, you are saying that in these documentaries there is a message that is like, "If I don't do this, I'm going to be like this."

**Participant:** Yeah, so this is where a person now chooses, makes people choose what to do.

**Moderator:** So, documentaries bring a message of fear to the public. So that the audience doesn't want to be like the characters seen in the documentaries?

**Participant:** Yeah, they bring positive change.

**Moderator:** Let me just follow up on something you talked about earlier, but that's personal. How has disclosure helped you to live positive

**Participant:** Disclosure has really helped me because when people are talking about me, I don't feel it's something big. After all they talk and they get tired (laughs) and again you know disclosure starts from the family. I cannot go public before disclosing to my family starting from my children, my husband. Although it has effect but its good. Anytime am coming to work my children must ensure I take proper breakfast and when it's cold they remind me to take jacket, they can even bring to me, so maybe if I didn't tell them they may not know what am suffering from. They remind me "mom have you taken your medicine?" They know I take one drug in the morning at 8.00 so I wake up I find my son has prepared the breakfast; me I normally take hot water so there is hot water for me apart from the breakfast. It improves care in the family. And also encourage other people to take it normal. You see like in the ministry how many are we now? After I shared, that is when others decided to open up about their HIV status. Otherwise, you've seen people dying in this ministry; they don't want to talk about it. So, disclosure I think is good.

**Moderator:** As we draw to the end, i would like you to comment on the circulation of these documentaries, how easy are they for the public to access

**Participant:** They are rare. I don't think you are reaching everybody; these documentaries should go places, everywhere. Like I was talking to someone in Kisii, Kisii is terrible now, it's coming out with the highest prevalence. Some people are still not aware of HIV and how one should live with it. Like Taita

**Moderator:** How did you access them?

**Participant:** This is when we have sensitization programs.

**Moderator:** That is through workshops,

**Participants:** Workshops Yeah. That's why I said they are scarce.

**Moderator:** What are your thoughts on accessibility?

**Participant:** You should ensure they reach every county and spread even to the interior. Not now that you took it to Homabay and it remains in Homabay town. Yeah, and even having that, I don't know whether the mobile cinema is still there. Yeah, that is my recommendation.

**Moderator:** So, you suggest that mobile cinemas should show these documentaries at shopping centers?

**Participant:** Yeah, yes. You know people are even forgetting that HIV is there, like in our place they talk about 'ng'ombe inakufa na nyasi kwa mdomo" (A cow dies with grass in the mouth) (laughter) like ukimwi ni Malaria and they continue.

**Moderator:** I've just remembered something I wanted to ask but I just forgot. There is something that came up when he was asking about the popular narrative that is driven and he was trying to give an example of how society clowns on Kikuyus as thieves and then you talked about how HIV is for the Luos. Would you expound on that form of narrative a little bit? That perception? I might take to assuming that it is a bit cynical that I have actually heard such a statement before.

**Participant:** Yes, I have heard it. I was told when I got infected. A lady in the office just said "Ukimwi ni ya wajaluo" (AIDS is for the Luo Community). She later died of it; she didn't even seek medication she died in the house. That I May I had suffered hepatitis, I was weighing 29 Kgs I had oral rash and I was not able to walk. 2 years I was in the house. So, when I was coming back to the office you remember Markfalen Were?

**Moderator:** Mmmh

**Participant:** He was asking whether I was in the office, or whether I had come back from the house, and then the lady just said, "huyu hawezi pona." I told them, "She can recover, AIDS is a Luo community disease," so first, there was a time when we went to Nyeri with Kimani and I told them how many people were positive, and I challenged them, "I wanted to know." They just kept quiet, then I told them, "ukimwi ni ya wajaluo" (AIDS is for the Luo community), then everybody looked down. Kube, there was a person in this ministry who was positive with the wife, so when Mwaura sent me to talk to him, even the retired nini,

**Moderator:** Embu, the boss who was here the other day

**Participant:** That one. He was very sick, so through this sensitization, he went for the medication and he has retired, nobody knowing that he was sick.

**Moderator:** What do you think are the factors that propel such a narrative to spread faster?

**Participant:** Wife's inheritance

**Moderator:** As in this notion that ukimwi ni ya wajaluo' (There is the notion that HIV/AIDS is a Luo disease.) what do you think were the factors that propelled that narrative to move in the society.

**Participant:** I think people believe that Luos are not circumcised, so it is easy to carry the virus and there is also this issue of wife inheritance, which is very common in Luo.

**Moderator:** I don't know if I would be a bit biased, but from my taking of the documentaries I have watched, it could also be perhaps a factor. I'm just trying to brainstorm. It could be a factor of the fact that a pretty good number of documentaries on HIV/AIDs are actually in Luo land or have Luos as a subject.

**Participant:** It has Luos. Yeah, maybe this time you go to Central you want to see people dying of HIV because there are so many. Even if you go to the hapa Coptic, Kenyatta, you won't believe it isn't for Luos as they say.

**Moderator:** With that in mind, what is your advice for future documentary productions?

**Participant:** Future productions should cover every county, not just Luo Nyanza.

**Moderator:** There is this narrative following up on what you have said. I know we've concluded that ukipata ukimwi then jua tu wewe ni msherati (Once you get HIV/AIDS, you are a prostitute). What do you say about this?

**Participant:** It is a belief but that is not true. There are so many ways of catching AIDs, although the common mode of transmission is sex. So, if there are people talking about it, but according to me, now that I have information about HIV/AIDS, I know that is not the case. And the narrative you are talking about is why people are not talking about it. They fear being stigmatised as wewe ni msherati (that one is a prostitute). But once you know what you are doing and how you got the virus,

**Moderator:** Thank you so much. I know you are a very busy person.

## **Appendix 10: Transcriptions of FGDS- Psycho-Social Support Literacy Group**

### **FGDS- PSSG Session 1 Day 1**

**Moderator:** Jambo la umaskini imesemekana vizuri kutokana na hio filamu (Fishers of pain) ambayo tumeona kama Maria tuseme ya kwamba ni lazima watoto wakule kwa hivyo akaenda kwa bahari mtu akimwangualia na aseme wewe ni mzuri anakubali kwa vile watoto lazima wakule, Swali langu bado ni, ukimwi ni ugonjwa wa maskini?

(Maria's case is due to poverty to be able to feed her children.)

**Participant:** Nataka kujibu hapo kwa maskini na ukimwi, kwanza, nafikiri maskini atakuja sana, kwa sababu kwanza atakua reinfected kama natafuta kujilisha na kulisha watoto wake, atakua, kama ako na ukimwi ama hana ni rahisi kupata ukimwi kwa sababu atakua exposed kwa elements ya hawa watu wakonayo wakitaka kumpatia favours lazima pia anyenyekee afanye vile wanataka. Pili, watakufa sana kwa sababu, utameza dawa, sasa kama umeshachoka, huwezi enda kutafutia watoto wakule utameza dawa na haikusaidii kwa sababu huli, uko sawa na umaskini sababu hakuna mtu atakupikia au anakulisha ndio uwe unaendelea na dawa vizuri, utakufa, it's like a death sentence. Si ati ni ugonjwa ya masikini, matajiri hawatakufa kwa sababu watakua wanakula vizuri, wanameza dawa vile inatakikana, hakuna mtu atajua statistics za watu wako na pesa compared to maskini kwa sababu maskini ni wengi na situation yao inafanya, kwa sababu hawapati chakula vizuri, watahindwa kumeza dawa. Utakuta graves mingi kwa maskini sababu hawana njia ya kutoka kwa hio janga la ukimwi.

(The poor will be more affected than the rich as they get more re-infected in the process of struggling to provide for their families. When the rich give her favours, she has to give in to their demands. Secondly, they will die more as they may take drugs on an empty stomach which will not help them. It is not a disease for the poor, the rich are able to deal with the diet demands that go with HIV/AIDS and therefore will continue living well.)

Mimi nilikua naishi kwa town na saahizi nimekuja hapa nyumbani and it is very different. Town tukienda kuchukuwa dawa tuko wengi vile huyu amesema lakini hapa ni very few kwa sababu nafikiri mtu amechoka tu kwenda kuchukua dawa. Hana kitu ya kula, hajakunywa breakfast, anafaa ameze dawa asubuhi na usiku, ako na watu anamuaangualia atawacha kutumia.

Ya pili hapa baharini kuna umaskini na njia ya kupata pesa ndio inafanya hio cycle inakua vicious, haisaidii huyu mtu ako chini compared to hizo areas, sasa hata kama mtu anasema, baharini ukimwi itaonekana sana kushinda kule kwingine kwa sababu ya vile tuko. The economic activities zinafanya mtu hawezi toka, sasa kama umeshachoka wewe ni mnyonge sana mtu hatakuokoa hapo kila mtu anajishugulikia.

Ule mtu alikua anakupatia samaki hatakuja kukufuata kwa sababu hautampatia ile kitu anataka, utakufa. I also wanted to say something about the issue of poverty. It is not that poverty is such a big issue, but you can see from the film that that person talked like aliamua kuacha dawa ili akufe but kifo haiji.

(The lady left drugs so she could die, but death was not forthcoming.).

**Participant:** So inakua like, for most people there is this issue of disclosure. Then, somebody will go to a facility, apate mtu mwenye anamfahamu vizuri utapata huyo mtu hata kubali kuchukua dawa hapo. So, anaeza enda mbali kuchukua dawa huko. So anaeza enda mbali kuchukua dawa, and at the end of it anakosa nauli ya kuenda kuchukua dawa then anadefault.

(When one gets to a facility and gets a person who knows him, they will not take drugs from the facility. They end up going far off to get medication. They end up defaulting).

**Moderator:** Wameeleza kuwa hii ugonjwa ni ya watu maskini pekee na sio hivyo ni vile at time ukieda hospitali unafundishwa kuwa inafaaa before umeze dawa kuna kitu kwa tumbo at least ukule kitu, tajiri unajua hata kama anameza dawa anapata kila kitu, haezi kosa breakfast, na inafaa mtu kama ni mgonjwa anakula 4 meals per day at least 4 meals per day. Na wewe mwenyewe mtu maskini. So hii kitu, its like kutokua na kazi pia inaeza fanya mtu aingie kwa jambo la usherati ili upate kitu coz hauna kazi, hauna pesa, chakula mpaka ununue kutoka kwa pesa, na kama hauna pesa huwezi pata chakula, kwa hivyo sio eti watu wa boya pekee, mara eti uende baharini ndio upewe nini, hapana ugonjwa ni ya kila mtu, ni vile tu ukiaccept, udiscolse utajisaidia.

(HIV has been defined as a disease for the poor, which is not right. In hospitals, we are told you should eat before you take drugs. The rich can afford four meals per day and therefore have no problem with taking drugs like the poor, who cannot. Therefore, HI is not a disease for the poor, as alleged)

**Moderator:** Let us talk about the characters in the film. How have they been represented in the documentary?

**Participant:** Naona kama bado tuko mbali kama inchi na stigma, naona nikama wamefichwa, hawajaccept eti hii HIV iko is connected to something and that we should not even see that woman's face because tunaenda kureact may be negatively towards that woman. Hataki watu wajue status yake, anafunikwa inamaanisha bado tumefunika ukimwi vile nimeona hio picha, hatujakubali ukimwi kama ni ugonjwa kama cancer inaeza ua lakini it can be controlled, cancer inaua lakini ukimwi can be managed. Tunachukua ukimwi kama kitu chan... Imelinganishwa tu na sex peke yake, hakuna njia ingine uaezapata ukimwi, except kukua msherati katika hio filamu tumeona. Usherati pekee ndio njia tunaweza pata hiyo ukimwi.

(It is like we are still far behind as a country in the fight against stigma. By hiding the faces of the ladies, we have not accepted HIV as a disease like any other, just like cancer, which kills, unlike HIV, which can be controlled. The film has only linked HIV/AIDS to sex, it is linked to prostitution).

Sasa naona nikama wameficha yule mama niliona kama si vizuri kwetu kama PLWHA. That covering inaonyesha ni kama bado ukimwi is unacceptable in this society. That is what I saw.

(I can see they are hiding the face of that woman. It is not a good show for us with HIV. It only shows that HIV/AIDS is not acceptable in society)

I think you should work towards that; na ningependa pia nikiongea juu ya HIV status yangu, I don't have to hide him, nisikue penalised kwa sababu nilideclare HIV status yangu.

(I should not be penalised for declaring my HIV status).

Naona that is something that the government ama watu ambao is making those films to work on and make people who are watching understand that ukimwi sio death sentence, sio kitu ya kuficha kwa sababu next time mtu akipatikana nayo ataona this thing atajua people should not know if I say that

(The government and film makers should make the audience understand that HIV is not a death sentence, it is not something to hide so that people can be encouraged to disclose their status).

So hio kitu inafanya ukimwi inaspread kwa sababu sitataka mtu ajue hali yangu sababu hata kwa TV matu amefunikwa

(This thing is making HIV/AIDS to spread because I will not want people to know my status since even on Television, the infected are hidden). The person who was open was only the health worker, ee, she is the only one the rest were covered, even the child whose mother has died who is innocent probably she does not have HIV had to be covered probably because people will think she is a child of an HIV positive woman and so she has HIV. So, I'm thinking to make strides in fighting the epidemic, films should project HIV/AIDS as any other disease. Such that people don't get re-infected or infect others by accepting it is there, just like I can say I have cancer in front of you people and I get cameras on me so I'm thinking I have HIV should not be like I'm evil because I didn't know when I was getting it or where I got it, so I'm thinking that that is the message that the film gave me and it is not a nice one for people living with HIV like us.

**Moderator:** Anyone with a different view?

If you look at images of characters with HIV/AIDS in those films, look at their physical appearance. How have the films presented these characters with HIV/AIDS?

**Participant:** The story actually likes the ladies, like Maria's case. If I may talk about it, inakuonyesha ile hali ya mtu mwenye ako na virusi ni mtu hana tumaini kabisa,

(Maria's story is one of desperation for people living with HIV/AIDS. Someone who is maybe living just by the grace of God, but not because they are able to live on their own. So, they are giving us a picture of one with no hope, even for the following day, but that should not be the case. I think they believe HIV/AIDS is a condition, hii ni kitu unaishi nayo (something you stay with),

It's a tenant in your body, and it cannot control you. So, they are trying to tell us that it is what is controlling your life, that it is how you are supposed to live, but it is the opposite, haifai kua ndio inakucommand

(You should not be controlled by HIV/AIDS.)

It is up to you to command it. So that at least ata kama mtu ako na virusi ataona acha mimi nimeze dawa, dawa iokoe maisha yako because actually, ata tukiangalia sasa pale, I wish tungeona sura za hawa wamama coz they were showing us the back na wale health workers, the other lady if you look at her utaona okay, like she's positive but ukimwona she is healthy, you wouldn't like, kama ni kudiscriminate eti mtu mwenye amekonda, mtu hajiwezi

(I wish we could have seen the faces of those women because we are being shown their backs. It should not be like anybody who looks emaciated is equated to HIV/AIDS positive status. It is discrimination. "If somebody who is desperate is the person who is infected, then they are two different people. So, they should not give us those pictures of lost hope.

**Moderator:** Malnourished?

**Participant:** Yeah, malnourished because how can he, can he say that kid has HIV and she has not been taken to hospital. They are saying she has not been taken to the hospital because the

other kids are being taken care of. What that kid could be lacking is food. So, the picture is that someone who is HIV positive should be thin, so if you see a kid who is thin like that, he has HIV. Somebody who is watching that thing will get that picture that a kid like that, who is thin like that, has HIV. I'm thinking that there is some wrong information that the film is bringing about being HIV positive, and then, the environment was so hopeless. We saw a woman who was like crippled. She was the one taking care of her grand children. There are many women who are just walking

around and are very healthy, taking care of their grand children whose parents died. So, I'm thinking if you are making a film to pass a message, it should not be just as she said. It is not true that people who have HIV live like that. There are people who have other problems, and they live in the same environment. You should not depict people with HIV as the poor ones. It was a sad thing to see an elderly woman caring for her grandchildren, but that is not the message that should be sent out, that people who are hopeless are HIV-positive. It is not good. That message was not a good one. I don't like it.

**Moderator:** You are talking about the choice of characters and the environment.

**Participant:** And also, the defaming of the fishermen: I have lived in this community for more than 4 years. I see fishermen; I live with them. You choose to give omena. There are people who sell mboga. They can give you their mboga. So, you say, or the butchery guy giving you meat for a favor. It is not like fishermen are the people who are spreading HIV, because you could find some fishermen who are HIV negative. They could get the HIV from people, maybe they just socialised, but not really from fish. Most of them are single, maybe they've left their wives where they were. They want to socialise in the environment they are in and get the HIV from there, not from them giving women that disease. That message the fishermen think, I don't think it is the one contributing to HIV in the lakeside region.

**Participant:** I saw from the picture a desperate old lady whom I pity, and I really pity these guys because if they had been open and gone to take their drugs, they would not be desperate. I compare Martha with my mother. My mother is of her age, and I took the first steps to seek medication, and I'm still alive. So, I deduce from that point that we should be open when infected and rush for assistance. I pity Martha for this situation.

**The moderator:** In other words, you're saying that the film should advocate for something.

**Participant:** Openness

**Moderator: Transparency and**

**Participant:** **Because** one mother did not even know what killed her daughter-in-law. It means that the daughter-in-law came back home when she was already sick because the mother-in-law did not know what killed her daughter-in-law. So there is no openness within the family about people's status. That is why you heard that guy asking her if you think it is HIV that killed your daughter. She could be sure, but she is not sure. So, there is no... What we saw is that the family does not know the status of the members.

**Participant:** Naona kama adherence ndio poor, ndio ona hawa wote wanameza dawa, hawakai kama wale tumeona, ni adherence ndio poor, ndio inaleta hio kukufa.

(I think adherence is the problem; all these participants are HIV positive and taking drugs, and they don't look like the ones in the films. Adherence is the problem).

**Moderator:** In short, what you are telling us is that an HIV positive person must not always look like the ones in the video?

(Yes, everyone in the chorus)

**Participant:** Si lazima, si unaona hawa wote wako hapa they are HIV positive na haawakai kama wale, adherence ndio iko poor

(Not necessarily; as you can see, all of these people here are upbeat, but they don't resemble the ones we've seen in movies.) Adherence is the problem.)

**Moderator:** How has watching of this film helped reduce stigma or has it made it worse on your part?

**Participant:** An gi maneno kanyo kabisa stigma be nitie, emomio jogo chal kaka gin kamano.

(I have issues with stigma. That is why these people look like that.)

**Moderator:** Please give more details.

**Participant:** Anene ka gin gi luoro, kendo kaneno matuta kabisa ok gi yud puonja maber.

(They are stigmatised, and if I watched keenly, I realised they had not been adequately taught.)

Ok giyd puonj momiyu gineno kaka gineneo no

(Because they are not being taught, they appear the way they do.)

**Participant:** Chenye nimeona kwa hio film, kuna mama amekaziwa hapo akasema ati bwanake alikufa na HIV, familia yake ikajua bwana alikufa na HIV, nyumba yake ikataka kuchomwa, kumaanisha alikua na HIV, hio kuchoma nyumba pekee itafanya yani akue na uoga kuenda kuleta dawa. Inaeza fanya aache akue defaulter, akisha kua defaulter, baada yake ni kifo tu.

(I've seen a woman whose house was to be burned down because she was HIV positive; this alone will make you avoid drugs so that people don't find out about your status.)

**Moderator:** Are you saying by hiding my status I will not be disinherited?

**Participant:** Definitely, si utachomewa nyumba.

(Your house will be burned), you wouldn't want people to know, so you keep it a secret so that people don't know, and they don't discriminate against you because of your status.

**Participant:** Alafu itafanya pia, kwa hio film vile umeiona hautaenda kwa health center yako kwa sababu watu wanakujua huko, na hauna pesa ya kuanda Bondo, utakufa, kwa sababu huwezi kupata dawa, huwezi enda got Agulu utapata mtu anakujua hapo, huwezi enda Nyagera mtu anakujua hapo, hao ndio watu wanakujua hao ndio familia yako wanataka inheritance yako ya udongo, hautaenda kwa sababu watajua anytime unaenda kufa. So na tena huna pesa ya kuenda mbali, so stigma iko, watu hawajitokezei kuelezea status zao kwa sababu ya vitu kama hizo, mimi niko na rafiki yangu siku ingine alienda hospitali akaona mtu wanaomba nayeye kwa kanisa, akarudi ni vitu zenye watu hata kanisani, you should not have it. Hataki mtu wa kanisa ajue ako aje. Kwa sababu pengine anasikia akiwa kanisani ukiwa na HIV huyo ni shetani anakupunish. Sasa hataki wajue na kanisa ndio mahali inafaa twende tupate knowledge, unafaa uombewe upate spiritual nourishment. Huwezi kwa sababu aliona mtu wa kanisa na akaenda. Hakuenda hospitalini siku hiyo. Sasa hio stigma iko, it is entrenched kwa watu wenye wako na HIV.

(Stigma has led to many people defaulting on their medication. Many people will avoid going for drugs from facilities near them for fear of getting caught by people who know them. In the process, they go to far-off facilities that require transport. When they lack transport to take them to the far-off facilities, they default, affecting their health.)

**Participant:** Anto aneno gi mopogore, nitie jathieth moro aneno koting'o kondom. En owacho nango, ni jaode notho nyieke bende notimore nade, notho aeto eeto en othi eospital momiye yath to kando owacho maber ni kusawazisha maisha yangu. Kat de obed ni jok mang'eny ka okelni stigma, ni oo ma odhero, to nitie ng'at mor ma osekao ang'o moro maber moyie gi timre nade, gi kao yath ee to ngima ne bedabeda maber ma enbe oghi mopuonj anyuola gi omoko donge? Mano e maa an go.

(I saw something different. There was a health worker who had condoms. She said that her husband and co-wife died, but she opted to go to the hospital and was put on drugs that made her better. Even if there is an issue of stigma, that there are very thin people, there is also something that someone who can take a different better angle by

taking drugs to have a better life, and they too can teach their family and others, isn't it? That is what I had).

**Participant:** Aparo ni newawacho gimoro kionge, openness neewasewacho.

(We had discussed openness in your absence.)

**Participant:** Anbe anyalo medo, iwachoga ni seche ma wapuonjore ka adult's gimoramora ma ng'ato owacho to en nade, en kare donge? But maoni mag ji nyalo bedo mapogoreopogore donge? Ka luore gi pichni ma ayudo ekore but ayudo gi donge, mokuongo kochakore gi point mar mama ma idwa wan'ne ode donge? In'ee ni family gi neokdwa wang'o mama ni nikech ne engi okimwi kat nang'o en family gi noloose geno.

(I can add something as an adult while learning. It is said that anything someone says can be right, even though our opinions might differ. From the video I've seen first, starting from the point concerning the burning of the woman's house, maybe it wasn't just because she was HIV positive that the family had lost hope)

Negise koso geno kaluore ni chuur mama no notho nikech ma, maa otho nikech ma, koro gifeel niketch mama ni bende tuo, mama ni bended hi tho, koro is like mama ni wastes negi time ka to gidich gi loo no koro odni nidwa wang' mondo giridhi ang'o no loo donge? Kata maybe mwandu mama ni koro ne gin jogo maonge ni geno. Picha no nyisowa ni geno emanonge kanyo. Negionge geno ni ng'ano man gi kute nyalo dak kata years mane angoo no, maybe chuore no thoo go koro geno emaneonge kanyo donge?

(They lacked hope due to the fact that both her husband and co-wife had died and now that she was wasting their time whereas they were busy with the land, so they wanted to burn that house so that they could inherit that land plus her belongings. They did not have hope. That video shows that they had no hope. They had no hope that someone who is HIV positive could live many years beyond those which her husband had lived).

Alafu ne uwuoyo about wach mag pichni pichni, fine pichini mokel mokuongo gi nyisowa gima HIV nyalo result to. Then an gi yie kata geo n the next pictures ddhmiowa ni to kikao medication kisngee ni in gi tuo, odonje ei medication, ang'o ma adhi bedo donge, nikech mokuong omiwa scenario ni ka okitimo ma okitimo ma to idhi bedo infected to idhi end up ka koro the next dhi bedo ang'oo no, kidongjo e medicatoni ma ia dhere to ang'o mabiro next donge.

(You have spoken about the images. Fine these images brought to us are depicting what HIV can result to. I am hopeful that the next images will show us what would result from adhering to medication after knowing, you are positive.)

in fact seche mikao picha gi okwanyal kao ka maber lilo donge, nyaka waket pachji ni kae rach nyalo wuoke, kae ber nyalo wuoke, kae gi ma kmaa nyalo wuoke, koro pichas gi ikelo gi in stages, not only ni koro mokelni kata maybe jogi ohdarau jo nam, no, gimedo man nyiso wan ni sanasana kodokee lake region mae kaka olandre, kodok koni, mae kaka olandre but gimotimore march ni gikelo nwa mana side achile donge, to aparo ni gikelo side achiel ni nikech wadak e dho nam, aparo karo wan wamakore gi ngima mar ang'o ngima mar jo nam, emomoio ginbe gikelowa gi pich aila kore wakawe uru positively.

(In fact, as productions are done, you can only show good places. We must be shown that this can go wrong and that this can be fine. These images will be brought in stages. It should not appear as though they have despised fisher-folk, or that they are only trying to say that regarding the lake region, this is how it spreads. Unfortunately, they only focused on one side because we live by the lakeside. Since we live close to the lake, this video has been shown to us because our lives are reflective of the lakeside. So, we should take it positively because the truth is that that is what happens).

Koro ng'enyne awach ni gimaduon' ma wanyalo aa go ka en stigma gi discossure.

(So, the most important thing we can take away from that is stigma and disclosure).

E sida maduong man ka donge? Alafu awayudo ka puonj bende tin, donge

We've also noticed that they don't know much.

Atp mo gijaboya odio eluf kama, jaboya osemie rech gi besen infact onego obedni puonj mag HIV gi oter edho nam koro kata posters gi iba ibao kuonde ma gigi timore ma kata kiwuoth to ineno ka ng'ato oting' kondom, mano okmoni kao jaboy, ingeni kasekao jaboya to condom ni ka, donge, gigi onego bed ni, wanyiso jowa gi sama gia a, kafidhi loso pchini maeilo kagikelo momakore 190awah nam mano e gima dwadwar owachnwa ne jaboya, but koro puon ebdie, condom obedie to poverty to ni kamoro amora.

(At least at the beach, someone gives her Jaboya 1000/= and she is given fish in a basin. HIV education should take place along the lake-shores. There should be posters all over, at the point where these things happen, so that even as you walk around, you can spot people carrying condoms. That should not prevent you from having a jaboya; in fact, having one means you already have a condom. We need to tell these researchers that as they leave, as they go to prepare other productions touching on life by the lake shore, this is what we desire, that even if there should be issues on jaboya, but they must include teachings, condoms should be included and poverty is universal, its all over)

Ng'ato nonyisa 190awah u more ni jomeyo emnigineno moloyo kata jo modhier...

(Someone once told me that the rich are more infected than the poor.)

Ang'o 191awah u niketch wan waneno ni wachier dhi e dho nam mondo achiu denda ne jaboya ayud pesa adhi apidh godo nyithindo, lakini nyamomeyo gimokoso onge to nitie gima olak, niketch kodhinindo gotieno pache nie mwandu ne te , samoro time moyudo mobed gi chiege onge, okoro sa ma gi bet e bar cha, kouyda kama otieko mana koda totimre nade, kata okornomo gichiege to osetieke donge? Koro iwacho ni gi interact sanasana moloye an madwaro dhi sayo jaboya. Koro wawuoguru kawangeyo ni HIV en mar ji te but picture mokel kae ni kik wacontradite ahinya omiwa nikech angono Nigma wa olure gi edho nam ka luore gi kama puong ni bende nitie, de wan jo town do ketnwa pichni moluore gi ngima jot won. Omwnijore uru?

(Why is it that we feel we are poor and so prefer to go to the beach and give ourselves to the jaboya so as to get money to feed the children, but the rich do not have such needs? Their minds are on their wealth, to the point that they may not have time with his wife. So while relaxing at the bar, he might get a lady and have sex with her, and as he goes home, even if he doesn't have it with his wife, he's already satisfied. So it is said that they interact a lot more than the poor who have to spread jaboya. We should leave knowing that HIV is for all classes of people. Let us not contradict the video. We got it because we live in the lake region; if we lived in the city, we'd get one that reflects city life.

**Participant:** Physical appearance, anano ka ngeny gi healthy, koso? Kata mine motii motingo besende besende e dho nam ka, donge majority mar jo beach go to healthy. Mon mobore gi sukni ka dong gin halthy? Okoomiwa jomodhero ahinya. Koro an gima anylo medo ni gimoro ka gimoro ni gokang' kata ka gikelonwa pichini ma sad mokuong gi, wan gi geno ni next dhi ketowa somewhere erouru kamno.

Most of them look healthy, even the old women and those carrying basins by the beach as well as the women with lessos. Most of them look healthy. We have not entirely been given thin people. So, I am hopeful that the next video will put us somewhere)

**Moderator:** Let us move on to what other characters in the documentary are saying. These include the producer, Timothy Otieno, community health workers, and the chairman of the beach management unit (BMU). What is your take on what they said in the documentary? Is it encouraging or discouraging for people living with HIV/AIDS?

**Participant:** Ninaweza sema mwenye kutengeneza filamu alikuwa anafaa afanye research kidogo kuhusiana na vile HIV inasambaa, 191awah uku mimi nilidiscovers mimi ni HIV positive 2009 siku hizo singeweza kuenda hospitali ata kupewa dawa ya malaria kama hawajapima damu yangu sasa yule mtoto walikua wanasema

inaonekana ni HIV positive 192awah ilikuwa 2009 na sijui wakati walitengeneza hio filamu kwa muda gani.

(The producer needed to undertake some research on how HIV/AIDS is transmitted. I discovered my HIV status in 2009, and by then I could not get even malaria drugs before tests were done on HIV. When they say the child looks like she is HIV positive, the question is when was the documentary done?)

**Moderator: 2016**

**Participant:** Lakini mimi 2009 haungeweza kuingia hospitali na upewe 192awah uku kama kichwa inakuuma kama hujapimwa. Sa sijui mahali walichukua hii filamu kama hakuna health facility karibu ya kitu kama hio kufanyika ili mother to child mama asiwe anazaa mtoto ako na HIV, nilikuwa nafikiri hizo vitu zilikuwa important kwa msikilizaji au kwa yule mtu anaona hio filamu kujua is there hope for these children? Tena kitu nilikua naona ni wamegusia rights za wale 192awah wamesha loose parents 192awah hao ambao wazazi wao wamekufa kwa HIV? Wako tu sentenced kuishi na nyanya zao? Alifaa a research vile 192awah 192awah u 192awah itakua baada ya wazazi wao kufa, isikue mimi nikifa 192awah wangu wakibaki haawna 192awah ya mbele na nyanya yao ndio lazima awachunge kuna njia yenye hawa 192awah wanafaa wakue na hope nayo, alikuwa anafaa afanye research ya vile ule mtoto alikua, huyo mtoto aliniguza sana.

(In 2009, you could not get any medication before an HIV test was done. I don't understand how this documentary was made if we did not have any medical facilities to help the mother of the child avoid mother-to-child transmission. I thought such information was important for the audience to know what the unborn child of an HIV positive mother has. It should also not appear that orphaned children are forced to live with impoverished grandparents.)

**Moderator:** In other words, you are saying it is not only grandmothers who are desperate to take care of orphans.

**Participant:** I'm trying to say that what is coming out on PLWHA like us and the picture I was seeing was in a conflict, because I personally, in 2009, went for training, I had to be given a test first. You are telling me this film was done in 2016. In 2016, if that mum has 9 kids, it means she was in a health facility. Bring us one for the facility. It can help a lot, because when we gather here, we see what we have seen here. We discuss challenges and all the rest. To manage infection, we are all adults here. We know why we are here, the purpose of being here. If I... I would like all of us to discourage HIV/AIDS infection because we know why we are here and we want to stay much longer. Thank you.

**Moderator:** Now let us take a break for a few minutes, and then we will watch another film for eight minutes.

**FGD Day 1, Session Two:**

**Moderator:** Let us start with the title of the documentary. You can comment on the titles of both. The first one was called “*Fishers of Pain: HIV Situation in Homabay.*” The one you are watching now is called “*Dying of HIV/AIDs in 2017.*” That is the title of the documentary.

Let us talk about the title of the documentaries.

**Participant:** Title yake ni stigma, watu ambao, hawaajibiki, ukiwa mgonjwa unataka kujua status yako au ushaingizwa kwa 194awah u unadefault.

(The title is stigmatizing for people who are not responsible.)

**Participant:** An kaka aneno picha no aparo ni jogo dhi e pim late.

(From the video, I think those people go for testing when it is late.)

**Moderator:** What impression does the title give you even before you watch the film? What comes to your mind?

**Participant:** Like he has said, Fishers of Pain can attract one to watch the documentary, but on watching you get very little of the fishing in that movie, and in the second one, Dying of AIDs in 2017, the situation I’m seeing and the title are very different. Maybe they are giving it a picture, as people who do not understand what happens in the life of an HIV/AIDS patient. The title does not fit the documentary.

**Moderator:** Haifit documentary ya HIV wakati huu ama haifit kabisa.

Does it not fit the current HIV/AIDS documentary, or does it not fit at all?

**Participant:** Wakati huu.

(Present time)

**Moderator:** I think vile nimepata kwake, hii title haifit with hio content.

(If I understand you well, the title is not in line with the content of the film)

**Participant:** Hmm with content hazimatch.

(The film does not match the title.)

**Moderator:** Mwingine anayewaza tofauti?

(Anybody with a different view?)

**Participant:** Hapo title imekuja tofauti na kitu ile tunaona sababu picha inaonyesha treatment of AIDS lakini title inasema dying of AIDS, Si unaona umeuliza swali mpaka tukaangaliana 195awah? Tulikua tunashindwa tutaanzia wapi, kwa hivyo kama ni mambo ya kukufa by AIDS, maybe by 2007 or 2017, hii inaonekana kuna watu hawakua wanafuatana na mambo ya hospitali kwa hivyo hio hospitali inahusika na mambo ya treatment na kupima pia. Sasa kama hawakua wanafuatana 195awah 195awah nilikua nadhani watu wakufe lakini picha haijatuonyesha vile watu walikua wanakufa in 2017.

(The title does not speak to what we have seen in the film. The film is about treatment, while the title is about death. (I expected to see people dying, but the film has not shown anybody dying of HIV/AIDS in 2017.)

**Moderator:** What message do you get when you watch this film?

**Participant:** Nami nemeona nikukosa kumeza dawa, defaulters.

(The problem is non-adherence to drugs.)

**Participant:** Mimi niko shocked kuona hio documentary na mahali imechukuliwa kwa sababu nilikua na mgonjwa wangu 2005, zamani kila mtu alikua anaenda Homabay kuchukua dawa, kama mtu anajua safari ya HIV vizuri, kitambo Homabay peke yake ndio walikua wanapeana ARVS. Watu walikuwa wanatoka Kisumu na kwiongenepo wakienda Homabay kuchukua dawa. Sasa hapo ndio NGOs ilikua inaleta dawa ya ARV. Sasa 2017, very many years later bado ward ya Homabay 195awah watu kama hao, imenidisapoint na imenishock. Nafikiria journey ya HIV from vile watu wa sensitization waliingia Homabay mpaka saa hii inafaa ikue ime-impact hiyo community hata imechange hio community kushinda community zingine kwa sababu hao ndio walikua watu wa kwanza kupata ARVs. Kama haijafika ata Kisumu, watu walikuwa wantoka hata Kisumu kuenda Homabay kuchuku dawa. Kama mtu anajua kitu chochote, hivyo ndio ilikua, it was very expensive kwa sababu lazima ukue na transport ya kuenda Homabay na kurudi na saa zingine uko na mgonjwa hawezi kaa lazima ulale kwa sababu watu wako wengi, kama hio ndio situationa saa hii, iko mahali wanaenda wrong. Kwa mafikirio yangu, they are dwelling on maybe the wrong thing. Kwa sababu kama watu walipata 195awah uku Kisumu nafikir ukienda Kisumu unaweza kupata utofauti, watu wako na that stage ya AIDs ni watu kidogo nafikri, hata kwa area zile zilipata dawa baada ya Homabay. Sasa kulingana na hitrory yangu ya kijua mtu alikua mgonjwa wakati wa nyuma na akapelekwa Homabay, hiyo video imenishtua kama kuna watu wako kwa hio hali in 2017.

(I am shocked to see the film and where it was documented. I had an HIV patient in 2017. By then, all patients used to take drugs from HomaBay. Now in 2017, many years later, do we still have patients in HomaBay looking like that? I am disappointed and shocked. The sensitization that has been done in HomaBay should be having a greater impact than any other community in Kenya. If that is the position in HomaBay now, then something somewhere is wrong. In my opinion, I think they are dwelling in the wrong area).

**Moderator:** These films are to educate the public on HIV/AIDS. Considering the characters used in the films, their physical appearance, and the environment in which they live, what does it tell you and is it giving you the true picture of what HIV is today? 2017 ni last year, sio mbali.

**Participant:** Mimi yangu inakuja different sijui kama unaongela 2017 ama 2007.

(Mine is a bit different. Are we talking about 2017 or 2007?)

**Moderator:** 2017 (everyone laughs, 2017)

**Participant:** Hakuna mzuri tuweke kwa akili ya watu wengi msiseme ati 2017 watu hawakua wanajua dawa mimi nilianza kutumia dawa 2010 kama nachukua kwa dispensary ndogo sio kama hii, huwezi sema ati by then, watu walikua wanatoka Kisumu wanaenda kuchukua dawa Homabay, 2017 ni jana, ndio sababu nimeuliza sijui kama mnaongea kuhusu 2017 or 2010. Ile kitu iko, ile kitu ilikua 2017 ndiyo hata tuko nayo mpaka saa hii, si watu walikuwa wanakataa kushikana na maneno ya dawa, vile watu walikuwa wanakataa kwenda kupimwa ata saa hii bado inaendelea. Ata saa hii kuna watu ukiwaona kwa manyumba zao, wakiona daktari anakuja wanatoroka, ama anafunga mlango, wengine pia wanafukuza examiners, wanasema wewe, mimi staki kupimwa enda zako anakufukuza kwa njia mbaya anakuambia enda zako. Kwa hivyo, ile kitu iko, vile treatment ya ukimwi ilikuwa inaendelea 2017 ata saa hii inaendelea. Kwa hivyo ile kitu muhimu ambayo nimeona, step tunapiga pole pole mwili pia inaendelea kuwa na nguvu kwa sababu tunazoea dawa, maisha pia inaendelea hivyo hivyo lakini tuseme challenge, it is good to tell people something real, ile kitu inaenda anagaliwa inje. Hio picha inaonyesha treatment ya wale watu, ata kama wangekua ni ugonjwa ya malaria, picha ni sawa tu kwa sababu inaonyesha kulikuwa na watu wagonjwa walikuwa wanatibiwa, si ati walikua wanakufa, walikuwa wanatibiwa kwa hivyo ile kitu kubwa, treatment ilikua inaendelea, maybe due to infections. Yea, ju watu wanazidi kupata ugonjwa. Na hio ugonjwa watu wanazidi kupata mpaka leo, kwa hivyo tuisiseme eti in 2017, mimi nilidisagree na hio, ee.

(Do not claim that in 2017, people were unaware of ARVs. I started on ARVs in 2010, taking drugs from a very small facility. By then people used to take drugs from

HomaBay. 2017 is just yesterday. It begs the question, are we talking about 2017 or 2010? The problem is we still have people who will not allow HIV counsellors into their homes. It is good to tell the truth, let us not lie that in 2017 Kenya was still so backwards.)

**Participant:** Mimi nataka kusema hiyo filamu imetengenezwa, maybe walikua na nia ingine, maybe ya kutafuta aid kwa nia ya HIV, which is not fair kwa sababu 2017 sifikirii kama unaeza kupata kwa ward watu zaidi ya kumi eti wame-default. Walikuwa na target ya kutengeneza hiyo filamu, na target yao haikukua ya kusaidia watu wako na ukimwi kwa sababu saa hii hata kila facility ata ile ndogo, iko na ARVs na kuna watu ata wanatembea kwa manyumba za watu kuhamasisha watu kuhusu ukimwi na kuwapima na kuwapea dawa pia. Kuna watu hata health workers' ndio wanawafollow na wanapelekewa dawa manyumbani, na tena wanafanya hata kupiga masimu kwa wagonjwa, mbona hujakuja hospitali leo. Kitu nimeona hapo ni vile yule amesema labda sii 2007, ni wakati ingine, sio sai sijui pengine mimi ndio naishi dunia ingine, lakini mimi naishi hapa Nyangera, ninaona, ninaishi na watu, unajua kama unataka kurelate hio kitu unaona na jirani yako. Sijaona mtu wa aina hio kwa environment ile nimeishi, na 2017 si mbali sini wakati tulikuwa tunapiga kura? Hakuna kitu imefanyika tofauti na saa hii. Kama ni county government walikuwa wanatarget iwapatie pesa pengine hio, maybe, lakini hio sio situation iko kwa ground saa hii.

(I think the film was made with an ulterior motive, maybe to solicit for funds which is not fair. I don't think in 2017 you get more than ten people in one ward who have defaulted. They had a target in making the film and the target was not to help PLWHA because in 2017 every facility had ARVs, even the small ones and we have officers who follow up to ensure adherence. Maybe the film was not made in 2017 but 2007 or it is me who stays in another world. I stay here in Nyangera and you can only relate these issues with what happening in your environment I have not seen anything like what we have seen in my environment and 2017 is just yesterday. The film is not representative of what is on the ground in relation to HIV/AIDS.)

**Moderator:** That was good news, as we also have an allegation that films are made to solicit money. If the image used was of a healthy-looking person like you, would it have given a more educative message or a discriminatory message like this one that they have used?

**Participant:** To me picha ya an individual, yule maybe is doing well and taking ARVs would be very good. But considering the fact that mimi ninameza dawa na kuna pengine bwana yangu hajui, that stigma, unajua nitakaa nawewe nanijue vile unafikiria kuhusu that person mwenye ako na ukimwi na nitajua nitakuambia ama sitakuambia, pengine baba yangu ananitegemea na najua fikira yake akijua nina uguwa na ninaeza kufa ile impact itampatia itafanya nisimwambie. Na kutumia picha

mzuri ya mtu anaendelea na dawa ni mzuri, lakini pia iko na disadvantage kwa watu wenye hawajui hali yako. Inataka kama amejitokeza kabisa sasa anataka ajue hali yake iko ivi, hajali, lakini watu bado wanaogopa kujulikana. Kama mimi personally, baba ya motto wangu hajui niko na ukimwi kwa sababu nasikianga tu vile anaongea juu ya watu wako na ukimwi, siwezi ata kumwambia, na kitu inanisaidia, hatuishi nayeye, tunaonananga tu vile kwa muda mrefu na saa ile tunakutana ninajua ninamprotect kwa sababu najua yeye hana, lakini naona vile anongea juu ya watu wako na ukimwi siwezi mwambia hali yangu sasa kutumia picha yangu tuseme ingetumika yangu mahali atakua atanishusa, niko na relationship na yule kumbe anakuanga hivi na amenificha, na si kwa kupenda kwetu, huwezi enda ukutane na kila mtu na umwambie unajua mi nameza dawa, unajua mimi niko na ukimwi!" hujui huyu mtu atakuchukulia namna gani, sasa kutumia picha ya mtu anendela vizuri ni mzuri, lakini vile tunaendelea vizuri hivi, kuna watu wengine pia hawajui tuna ukimwi.

(To me, the image of an individual on ARVs and doing well is very good. Before disclosure, I will gauge your feelings about PLWHA. If you talk negatively, I will keep it to myself because of the stigma. The use of a healthy-looking image is good but also has disadvantages for people who do not know your status. Like me, my husband does not know my status, and I can't tell him because of statements I've heard him make concerning PLWHA. The good thing is that we don't stay together. If a film with my image in it is shown and he sees it, it will cause conflict. You are always worried about the reaction to your disclosure.)

**Moderator:** Do you believe that there are PLWHA and have no problem with their images being used?

**Participant:** Kuna wengi nawajua lakini, nafikiri si rahisi...

(There are many, but it is not easy.)

**Moderator:** Are you saying if images of people living positively with HIV/AIDS and doing well were used, the message would have been more effective?

**Participant:** Wanafaa watafute yule mtu amekubali iwe pengine amepima akajua, pengine hafichi mtu, kama yule mama akasema hata watoto wake wote wanamletea dawa, inaonekana yeye ako free, na wamfundishe ile impact ya picha yake kuonekana pale, vile watu watamuona, wamuweke aware alafu watumie picha yake na atakua comfortable na picha yake kuonekana na itasaidia watu wengi. Watajua kumbe huyu namwonanga tu kumbe anafanana tu hivi, pia mimi acha nitafute usaidizi hii kitu inasaidia watu. Lakini kama unaonyesha picha ya mtu ule maisha yake hana hope, inafanya mtu ata anaogopa, hivi ndio nitafika hata kama nameza dawa, alafu ile perception ya yule alisema ati mtu anameza dawa anaenda vizuri anaona, nimeshapona vizuri anawacha dawa, pia kuna ujinga inaingia watu wakiwa wanameza

dawa. Unaona unaendelea vizuri umenenepa kushinda kitambo unawacha dawa unafikiri umepona. Hio pia wanafaa wafundishe watu, vile yule amesema, wafundishe watu hii dawa inapunguza tu hizi virusi lakini haimalizi. Watu wengine huwa hawapati hio, wanajua tu ati hii dawa lazima nimeze kila siku, sasa mbona wanawacha najua wanafikiri hii ni dawa ya malaria ukishaona dalili za malaria zimeisha unawacha. Hio pia inafaa ihamasishwe watu kwa sababu inaweza kurudisha watu kwa hio stage ya ukimwi, lakini kuonesha picha ya mtu anaendelea vizuri ni important.

(Just like the lady who said her children helped remind her about taking drugs on schedule, people must be educated on the impact of their pictures being used in videos before they are put in films. This will make others in the same state aware of the impact of adherence to drugs and may cause them to start on drugs. Use of people with no hope causes fear in the hearts of the infected. People should also be educated to understand that HIV/AIDS is not like malaria. When one starts on drugs, it is for life, not that when you get better you stop drugs. All in all, showing pictures of people living positively with HIV/AIDS is important)

**Participant:** Mi naona picha yenye film imetumia ni mzuri kuliko ya mtu ako mzima kama mimi juu kuna wenye wanasema ukimwi ni malaria, wakizidi kutuona vile tuko hivi wanakuambia ukimwi ni malaria na wakati amefunzwa na atawekewa hio picha anajua ukimwi sio malaria.

(The picture used in the film is better than when healthy looking images are used, since there are people who still believe that HIV is just like malaria. The film teaches such people the reality of HIV/AIDS.)

**Moderator:** What do you say about the respect of people living with HIV/AIDS? Do films dehumanise people living with HIV/AIDS? What do you say?

**Participant:** Ukimwi ni ugonjwa na ugonjwa ni ugonjwa hata iwe ni malaria ni ugonjwa unaona ukienda hospitali daktari wanakaanga na watu wangapi, sini mtu mmoja? Huwezi taka picha yako ionyeshwe ati wee ndio uko na malaria, uko na typhoid, hio tumekataa huwezi kubali picha yako ipigwe iende ionyeshwe kwa filamu ati wewe ndio uko na ukimwi hii ndio sababu kuna doctor's secret. kama mimi ni mgonjwa ninaingia peke yangu if not niko na next of kin, bibi yangu ndio anafaa ajue siri yangu kama hakuna bibi yangu, niko na ndugu yangu. Yule anaelezwa hii maneno yangu. Nakama mimi nimejitoa mwende munitangaze ati mimi niko na ukimwi, am I really normal? Hio inamaanisha hata mimi akili yangu haifanyi kazi na hata picha yangu ikipigwa ikienda kwa advertisement kama hizi ipelekwe ng'ambo sio hapa Kenya. Na hata ikiwa, mimi lazima munipatie kitu. Picha iende ngambo. Hapa Kenya utakua umenichafua zaidi.

(HIV/AIDS is a disease just like malaria. Nobody would like his/her picture to show that they are sick. That is what we are against. That is why we have a secrecy act in the medical profession. It is only my wife who should know. If my picture is to be used, then it should be abroad and I should be paid for that.)

**Moderator:** In documentaries, we still see the image of a person with HIV/AIDS. Do the films make you feel like you're a part of society, or do they isolate you from it? Does it create fear to integrate with society?

**Participant:** Kwa mtu Yule hana HIV akiona hio filamu, inampatia fikira ya picha ya mtu ako na ukimwi kama mtu tofauti nayeye, mtu mzima hamezi dawa anaona kama mtu ako na HIV na anameza dawa atafika tu kwa kiwango ya mama yule ako kwa hospitali ata kama ninatembea anajua sikumojia nitakua kama yule mama. Na kama mtu analive positively kama mimi inaniogopesha, nitajihamasisha nisiwache dawa yangu nifike kwa ile kiwango. Sasa inasaidia mtu yule unameza dawa kama mimi nisifike kwa kile kiwango lakini inafanya mtu yule ako inche kuona kama watu wako na ukimwi wanakaa tu vile yeye, unanielewa? Inasend messages tofauti kwa watu wawili. Mimi itanisaidia sitawacha dawa nifike pale kwa sababu najua amefika pale kwa sababu amewacha dawa na mtu yule hana ukimwi ataona ni kama sisi tuko hivyo tu. Hatajua yule amefika pale kwa sababu amefanya makosa hii na hii, atajua watu wako na ukimwi wako kwa pool moja na yule, sasa wakifanya hizo documentary waelezee kinaga ubaga amefika hii kwa sababu ya hii lakini si ati...

(When people not infected with the virus watch these films, they get the feeling that PLWHA are different from them. It is like even when one take ARVs, they will eventually reach the hopeless state. For somebody living positively like me, the video creates fear. It can help me not to default so that I don't reach that state. For the uninfected, the message might be that even with ARVs death is the portion for those with HIV/AIDS. They may not understand why patients had reached that state. The understanding will be that all people with HIV/AIDS are all in one pool.)

**Moderator:** The doctor has said that he does not understand why people are dying in large numbers...

**Participant:** Eeh alikua anafaa ajue ni kwanini imefika hivyo kwa sababu 2017 imepata kama watu wengine wameshameza dawa for 10 years, hawaja default and they are doing well. Sasa hao ni watu kidogo kati ya hawa wanatumia dawa ambao wamekataa kuingia njia za kumeza dawa na kutembea vizuri kama uko na HIV na kuangalia zile directions za daktari vizuri ndio imewafikisha pale, hawajaelewa hio picha vile inatakikana.

(The doctor should know why patients with HIV/AIDS are in such a pathetic state. In 2017, people who had taken drugs for more than 10 years said they had not defaulted

and were doing well. People in that state are very few. These are people who have refused to follow directions of the doctor on ARVs and should not like the fate of all infected people.)

**Moderator:** Do the films we have watched give you hope or present a hopeless situation for people living with HIV/AIDS?

**Participant:** Inaleta tumaini ju najua nikikosa kumeza dawa nitakua hivyo.

(It is also good to show the bad images as it will make us understand how bad defaulting on drugs is.)

**Moderator:** As someone living with HIV/AIDS, what thoughts come to mind when you watch the films? Talk, even in the local language.

**Participant:** Inatuencourage tu tuwe na bidii ya kutumia dawa vizuri usikuje ufike hio picha yenye tunaona.

(It encourages us to take our medications as directed in order to avoid experiencing what we have seen in the videos.)

**Moderator:** Anybody with an issue concerning the films we have watched and HIV, this is your chance, but for us, we are through for now.

## FGD Session 3 Day 2

**Moderator:** Thank you for coming today. How do you compare, or rather, how is the narrative that has come out, how has the story been presented? How has HIV been presented? HIV imejitokeza kwa namna gani? How did the story come out compared to yesterday's films? We are told people came with wounds and they thought it was HIV/AIDS and later on they concluded it was AIDS. That is what we are looking at.

**Participant:** Hii video yenye tumeona leo iko na matumaini sana, na inatuambia kuwa mwenye anaishi na virusi hafai a loose hope na inafaa pia aendelee na kazi zake za kawaida, si eti utegemee shirikisho, ambapo pia ni mzuri hiyo shirikisho inapatia watu matumaini ju inapeana usaidizi but ukiangalia kuna mshosho alikua na ng'ombe. Anakamua ng'ombe na anasema kuwa anauza na pesa zingine anasave na zingine ansaidia orphans wenye ako nawo. Sasa hii na zile zingine za pili zenye zilikua jana hii iko na matumaini sana, na haifai eti mimi nikishapata ugonjwa sasa unakaa tu, hapana inafaa unaenda hospitali unapimwa, ukipatikana na ugonjwa juu, hospitali nilikua naona kama mtu akienda anapimwa akipatikana na malaria anepewa dawa za malaria, yani wanahudumiwa vizuri. Sio kama ile yenye mtu anaenda anasema eti kuwa wako na defaulter's wengi, hapa kila mtu akishaanza kumeza dawa, mtu anasema kuwa, nilianza nikiwa hivi saa hii ninaendelea hivi na dawa inanipeleka vizuri. So hii ya tatu ni mzuri inapatia mtu hope.

(This video has a lot of hope for PLWHA. It is telling us that PLWHA should not lose hope in life and that they should go on with their lives and activities. Though Shirikisho is helping them, the other characters are also doing other things to help boost their lives. Compared to the other films we watched; this one is hopeful. We have not seen people who have defaulted on drugs. We are seeing people who are saying, "I started when I was like this and now, I am like this.").

**Moderator:** This video was done in 2014. What do you say about the characters with HIV/AIDS in the documentary?

**Participant:** This video the characters are people who have accepted their status. Naona kama the whole set up, there is no stigma. People are free it's a society that they can share kwa sababu pale, they even have these groups and there are support groups, wameanza hizo vitu za table banking, they are supporting each other despite the fact that wote, they are under shirikisho, they have also decided to do something extra so inatuonyesha tu that just like this facility here, whatever we are getting from this facility individuals can still come together you don't have to rely on handouts so it is an open society, it is not stigmatised society.

**Moderator:** On the characters? Are we getting or are they giving us people who are living with HIV who are desperate?

**Participant:** Naona wako na hope juu hata ukiangalia yule grandmother mwenye anakamua ng'ombe, alikua na hope, anasema akiuza maziwa pesa anasave of which nikumaanisha ako na matumaini bado kuna maisha mbele.

(I can see they have hope. We see a grandmother milking and she says that she sells part of the milk and saves the money, a show of hope for the future).

**Participant:** Hii video vile nimeona nimeona watu wako comfortable in their skin situation ile wanenda haiiaffect vile wanaishi wako na matumaini kwa watoto wale wameachwa nao, watapata masomo na wanawalisha vizuri kama watu hawana ugonjwa wako kwa society ile imewa-accept. Sasa wanajua kama uko kwa ile hali kuna watu wengine wana kushulikia pia unaweza kuelezea mtu, nimeskia mama mwingine akisema, akaita rafiki yake mwingine pia akiingizwa kwa program, kama ile impact ya shirikisho imefanya mama mwingine aweze kuambia mama mwingine kuja upate dawa hapa, sasa hio filamu inaleta hope kwa watu wako na HIV na hope kwa maana watu kama hawa hawana wasiwasi, wanaendelea na maisha yao hata kama is ya hali ya juu sana wako katikati lakini wako sawa, wanaweza kumanage. Na watoto pia nimeona ni wasafi wanaenda shuleni, wanapata uniform. Sasa nafikiri kitu kama hio shirikisho kama iko wale wanawake pia wanakutana peke yao wanafanya table baking hawarely kwa shirikisho peke yake wanajua pia hao wanafaa wafanye kazi kwa bidii walishe watoto wameacha nao. Nimeona kama ni video imeniencourage sana.

(This video shows people who are comfortable with their situation. They are people with hope. Even the children left in their care are well fed and in school. They are in a society that has accepted them. They are assured that somebody somewhere cares about their situation. The impact of Shirikisho has led a lady in the video to share her situation with another woman, encouraging her to join the program. The video is therefore encouraging for PLWHA. They are going on with their lives as usual. They don't rely wholly on Shirikisho for survival. The women have also formed social support groups to help them grow economically).

**Moderator:** Let us comment on the environment in which characters with HIV/AIDS reside.

**Participant:** The environment where they are living, we wouldn't say it's a desperate environment, because they are people who can do their things. Even to do their housework and run their businesses, Si watu wenye wanasaidiwa. As a result, their surroundings are very different from the ones we saw yesterday. The ones we saw yesterday were like "wale ni watu wanadepend on their care givers." But these are people who depend on themselves to do whatever it is they are doing. The environment is totally different. It's a comfortable environment.

**Moderator:** Does this video advance stigma or remove stigma for you as an infected person? Does it make you feel different from the rest of the community?

**Participant:** Kwa hio filamu yenye tumeona inatuondolea stigma kwa sababu nikama watu ambao wameaccept, sasa wanafanya kila kitu wakijua kwamba wako sawa.

(This video is good on fighting stigma as the characters have accepted their status and are therefore not held back by the infection.)

**Participant:** Hii video ya tatu inatuondolea stigma kwa sababu ukiwa kwa hiyo shirikisho group ama umeenda hospitali ukapatikana na ugonjwa unafuatiliwa hadi pahali unaishi na vile unameza madawa, sasa hii ni mzuri inakuencourage kabisa.

(This third video is very encouraging. If one is with Shirikisho and happens to be positive, follow-ups are made to where one lives to ensure drugs are taken on schedule.)

**Moderator:** Let us talk about other characters in the film. Those not positive for HIV, like the nurse, are now the ones I'm talking about. Can we comment on these characters and what they say in relation to PLWHA?

**Participant:** I came in late but I heard the people talking to the people who are not HIV positive. One of them said they accept them and they told them that HIV can infect even health workers. Those are words that are comforting to someone that has HIV. It showed some acceptance to some extent. What I've seen is a society that has accepted people living with HIV and is working to encourage them from that desperate situation to a place where the children of HIV positive people have a dream of becoming future leaders. That is what I saw from the characters who were assisting these HIV positive people. They accepted them, and they were treating them like any other person.

**Participant:** Nilikua nataka kuchangia kwa hio video, tunaona wale wenye hawana virusi wanasaidia wale wenye wako na virusi, for example hapo kulikua na mama mwenye alikua mgonjwa hangeweza kuenda hosi, mimi naona health workers wanatoka hosi wanamletea dawa nymbani, unaona kama alikua very weak na tunaona at times wanamsaidia kufanya mzoezi hadi tunaoneyshwa vile wanamsaidia kusimama, hio inaonyesha love upendo, waneconrage hao wenye wako na virusi na hio ni mzuri.

(I can see uninfected people helping those infected with HIV/AIDS. Even medical officers in the video are seen helping the sick with their exercises. They will even visit them in their homes. That is very good for those of us who are sick; it is very encouraging.)

**Participant:** Hii picha ya leo vile nimeona ilikua mzuri inaencourage wagonjwa, hata kama unapewa dawa, unaendelea na kazi zako kama kawaida, na wale wenye walikua wanapatia dawa, walikua na mapenzi, hawakubagua ati huyu ni mgonjwa, walikua wanawapatia moyo na wanawaambia hio ugonjwa inaeza shika mtu yeyote, sio wao peke yao. Sasa ya leo ilikua mzuri inaencourage mtu. Hata niliona mbaba

mwingine akiwa anafanya kazi zake vizuri kwa shamba. Kwa haindi, sasa ineam hata kama unatumia dawa, kazi zako pia unaendelea tu kama kawaida na dawa pia unaendelea tu vizuri na unakua tu normal like any other person mwenye hana virusi.

(Today's video is very good; it is encouraging to the sick. Even if you are using drugs, you are still able to carry on with your everyday activities. Those giving them drugs are doing so with love, not like they are being forced. I have even seen a man working on his farm of maize. This shows you are dependant on others for survival. You can provide for yourself like anybody else.)

**Participant:** The charactes like wale watu wenye hawana virusi wenye walikua wanasaidia hao wagonjwa... kuna like, they were showing us even the social department whatever they were doing, so it is just maybe that is their way of helping them out, but all in all everybody you are seeing there haungejua, hata wagonjwa, unless wakati amesema ye ni mgonjwa na uanapata hata madaktari, even the others who were there they are all out to help the patients, they are really giving them hope, and at the end of it all, Yule mama mwenye motto mdogo, unaona kama wakati alikua anaanza kuongea like, hakua anaongea akiwa comfortable sana, but the last bit when she's talking about telling a friend to go for testing na aanze kuchuka dawa, unaona kama sas nimtu ako na hope.

(The characters who are HIV negative are very good at helping the infected. You won't know who is HIV-positive unless he or she says so. The woman with a kid was not comfortable when she started talking, but at the end, when she is talking about advising others to go for medication, she looks very happy.)

**Participant:** Saa mane video chakre ne waneno ka nyathi moro ne ntie e osiptal, secondly dani ne wacho nii kanee tuo ochakre edala ne nyithinde nothoo, koro gin negiparo ni en juok, ma giringo nyaka Tanganyika ichak idwokadwoka jatuo ka yath onge tuo otamre dok kgoro bange ekanegifwenyo niketch tuo mar awang' be ne wang'o gi vidonda zilikua kwa miguu koro giwacho ni hapan, piny otuk giwach ni ka ng'ane ruom na nyier moko, kanegithie osiptal, kitu mzuri kwao, shirkisho ilikja andhty attended the hospital ma giyudo konyruok ma gichako dhi maber.

(As the video started, we saw a children's hospital. Secondly, that grandmother said that when the disease came into her home, her children started dying, and they thought it was witchcraft, which led them to Tanganyika, but they still came back with their patient. The illness wasn't going away. They also started having wills, and the community thought the family was being swept away. They then went to the hospital. Although Shirikisho was also helping them, they got assistance and were better off.)

**Participant:** An kamaneno onyiso wan i dongruok nie ping no kata gi kao yath laini ok gi nyis ka jo makao yath. Gi loso e dongruok kendo giloso e gi ma biro mbele. Aneno kaney ko wach ni oyudo gi moro t moro e okano biro rito go mbele. Ok gi nyis shida gi ahinya gin jo ma oherre.

(From what I've seen, the community is developing even though they are taking drugs. They do not appear, so they only talk about development and the future. I heard someone say that when they get something, they save part of it for the future. They do focus on their problems so much, and they love one another.)

**Participant:** Hi filamu ya leo inavutia sana, iko na mafundisho mengi kabisa na jambo ambalo naweza kuongezea ni ju ya masomo, kuna kitu ambayo imenifurahisha na hao watoto ambao wamewachwa hapo. Walikua bado na tumaini na masomo yao nikilinganishwa na shirikisho iliwafanya waka pata mafundisho mazuri. Sa hii nimeona ya kwamba hawa watoto vile walibaki bado walipata tumaini na wengi wao walikua wanameza dawa na masomo yao inaendelea vizuri sasa hio kitu imenifurahisha kabisa, ingawa tu nimeona manyumba ambayo walikua wanaishi hikukua mzuri lakini kwa ushirikiano ambayo walikuwa nayo iliwafanya wakakua watu. Sa ile kitu ambayo ningesema ni, hii video ya leo hii iko nahimizo sana kwa maisha yetu tukiona.

(Today's film is good as it has a lot of educative information. I am happy the orphaned children are still hopeful of good education though their houses are not in very good shape.)

**Participant:** Mar 2014 nni aneno ka en encouraging. Jogi gin jo am gi accept mayatima. Koro okgiketo gi ma desperate. Gi accetpt gi, gitio matek mondo kie odhi sikul jo gweng' bende nenre ni gin gi acceptance. Gitero jomoko, to ginyiso gi ber kao yath. Koro iterogi to iweyo gi e gate kanyo ka gidhi kao yath. Helth officer ka bende encourage jo tuo mondo ing'e sa mar kayo yah to kik itug kod yath, alafu oencourage ni kata mana in en tuo manyalo makko ng'atang'ata, kata mana nyaka health officers. Koro ing'eni omii tumiani nikech kata nurse ohudumia ii to kendo onyisi ni kik ibed gi luoro kata mana en, onyalo bedo affected. Oencourage ii so much, to kama intie ifeel mana ni in comfortable. Alafu the environment bende en agricultural, koro ineno ka gik moko magitimo timre maber

(This one is encouraging. These people have accepted the orphans, and they work hard to make sure they are in school. The community is also good. They tell their friends the benefits of taking medication. They take the sick to the hospital so that they can get drugs. The health officers also encourage the sick and give them hope. This is encouraging and comforting. The environment is also good for agriculture, so they do most things well.)

**Participant:** An adwa wacho ni aneno kama nyithi school wuoyee, awacho ni, aneno ni kata ka omwonyo yath to ok gichal jo mamuono yath, dendgi beyo okiyal ng'eyo koro okdabed gi luoro kabisa, pcha nokonyowa kata kaka ayude ni moia puong kabisa

(I want to say that from the statements of the schoolchildren, I've seen that even if they are on medication, they do not appear as so. They are very healthy. This video can not stigmatise me. It has made me learn something.)

**Participant:** Hio video tena nimeona maneno ya kanisa, jana tuliongea kidogo maneno ya kanisa inafaa iangalie maneno ya watu wako na HIV kwa sababu watu wanaingia kwa, church as a body ina watu wengi iki accept watu wako na HIV inaeza enda a long way kusaidia, hata kushinda health workers. Nona vile kanisa imeingilia hio maneno na ata watoto nikiwaona pale, hata kama hawajavaa vizuri, they are healthy na inaonekana pale, watoto wanapata nutrition mzuri sikuona motto malnourished, walikua wanonekana smart na hio kanisa ime encourage hio community ika accept. Unajua kanisa ikishakubali watu wengine hawana option. Wakishakubali kama mmoja wao sasa unaona wanakua na hope, wanaanza kufanya vitu zao vile inatakikana. Unaona wale wanawake wametengeneza body ile inasidia wanawake wazee wanaenda kupata kitu kidogo ya kulisha nayo watoto wale orphans, wanafanya wale wanawake wanaamaka wakiwa na hope ya kutunza watoto wale waliachwa nao. Groups wamesensitise watu wako na HIV wakutane, wazungumze na hao watu ukishakaa hivi tunaanza kuona weakness ya huy na tunaanza kuona vile tunaeza saidia kama mmoja wetu. Walikuwa wanafanya table banking, wanatembeleana, wanaenda na sabuni na sukari wanwach pale, wale watoto wanpata kitu ya kukula, nafikiri ndio maana walikua wanakaa vizuri, hawakukua desperate, sikuona mtoto amesimama kwa kaburi ya babake situation mbaya, niliona kama wale watoto wako na hope, walikua wanakaa right, hio film ni tofauti sana na zile tuliona jana.

(I've also noticed church-related issues in the film. If the church as a body has many followers, and if it accepts people with HIV/AIDS, it will go a long way towards helping us, even more than health workers. Because of the church, I can see children in the film. Even though they are orphaned, they are well fed. We do not have malnourished children. They are looking smart. The church has helped the community accept PLWHA. When the church accepts you, the rest have no option. The church has helped them come up with groups that help them relate to each other. They wake up with the hope that they will get something to feed the orphaned children under their care. The women do table banking. They visit each other and boost each other's households with their needs. I think that's why they look good and healthy. I did not see any children standing next to their father's grave. The children have hope. The film is very different from the ones we watched yesterday.)

**Participant:** Adwa penjo, nyoro ne wan gi pichni, moko ne wuoyo e wach jo boya, moko ne nyisowa pichin ma ji oran oran e osiptal, ji adi mane omor gi pichni ma nyoro?

(I have a question: we watched two films yesterday, one about Jaboya and the other about desperate images at the hospital. How many people were pleased with yesterday's films?)

Ji adi ma no mor gi pichni ma nyoro ka, ji neon mopogore donge? Wan gi ji adek, dong. To ji adi mano winjo lit ne pichni ma nyoro, ji adi mano winjo lit kane gineno pichni manyoro, waneno mopogore donge?

(How many people were pleased by yesterday's videos? We have three. We all perceive these films differently, don't we? How many feel pained by yesterday's film? Indeed, we all perceive these films differently.)

Waneno ma kawuono, ji adi ma pichni ma kawuono ni mooro, to ji adi ma pichni ma kawuon ni ochwanyo, owinjo lit koneno pichni makawuono?

(We have watched today's film. How many people are pleased with today's video? (Almost everyone) and how many are saddened?) (None.)

Sawa, nyoro donge ne awacho ni king'iyo pichni ma nyoro king'io the society ne nitie gi a lot of discriminatoni, infact pichni ma nyoro gi ma no miyo okelgi kamacha, a lot of information momakore gi HIV nepokosore e ang'o wa, kabisa kabisa e gwenge ka, koso? Neinyisowa yor ma kaka HIV landre go to gi kaka HIV nego dhano niketch neonge aang'o wa rageng', akia ni wawinjore. Akia ni adhi mangeny okalore ahinya (Wawinjo) Pichni ma nyoro neitemo nyiswa kaka HIV donjo, donge? Gi kaka olandore, to gi kaka onego ji donge? Lakini ne okonyiswa kibisa kabisa kaka inyalo genge gi wach mar ARVs donge? Kawuono inyiso wa weche madok kar ka ARVs, cre nd treatment, donge? manyiso ni kawuono inyisowa ni kata de bed ni nitie HIV to geno nyaka bdie, kia yath otigodo to kendo ko ti go eyo makare. Pichni ma kawuono nyiso wan i nitiere winjuok, nitie hearra, onge kwedo, nitie dongruok gik moko romre, bed ni in gi tuo, ionge tuo gik moko romre, jiomakore kamoro achiel, lakini pichni ma nyoro, kata miya cha donge uneno ka idwa wang' ode, idwa maye loo nikech ang'o en gi kute, manyiso ni nenitie discrimination, donge, lakini kawuono ineno ka jo ma ni go kod jo ma onge go makore kamoro achiel donge, grube mineno I form go, gin grube makelo geno kamoro achiel gin grube makelo dongruok gin grube majiuso jowadgi, koro kanyo donge waneno ber group? Koro kinyalo ngio picha ma nyoro, gi pich makawuono ere minyalo neon ni ber kata mineno ni rach kik ketie?

(Yesterday's films had a lot of discrimination against HIV infection and prevalence, and those involved did not have a lot of information on HIV. So the films were about how HIV is also killing people, and there was no protection from knowledge of ARVs. Today we are being told about issues that are related to ARVS, care and treatment, which implies that today we are being informed that even if there is HIV, there is still hope if you use drugs in the right manner. From today's video, there is love, understanding, development, and equality whether infected or not, but from yesterday's films, you saw that woman whose house would have been burned because she is positive. That tells you there was stigmatization, but today those people are united and they even have groups. These groups have both development and encouragement. Don't you see the essence of groups? So, between yesterday's and today's videos, which one do you find to be good or bad enough not to be used?)

**Participant:** An kawacho kenda, kipacha, picha onego obedi mabuogi momio ang'iamua ni kik ibed ka jomoko. Ibed scared enough ni okidwa bedo e situation cha ma okidwa ni ichopee kama ngat cha ochop, to oencouragi matin ma ineno ni intie gi

matumaini mar kiny okbuogi ka koro ahinya to omii hope ndii. Koro picha onego opuonjwa ka itimo makosa to inyalo chopo ka, ka okidhi maber to inyalo chopo ka, to ka idhi maber ot unyalo riworu mukel dongruok murit nyithindo mowe go kata ka in gi kute inyalo timo giki kikawaida kaka jomoko timo, ka iluo sheira mar muonyo yath, aparo ni mama mane nie e kitanda cha, okinyal kete e picha makawuono nyaka be ni okalo stages moko ma tiende ni nyaka oaccept ma oti gi yath maber owuogee kitanda cha odhi oriure gi jowetene okony nyithinde. Koro pich kata ka manyoro ka nobwogo wa lakini gitio tich mor, obwogo wa ma okwadwar ni wachop e stage cha okwadwar ni gi machal kamacha otimre nwa to kendo kawuono wan encouraged. Koro aweni nyoro ne en gima very important be omiowa light moro, ing'eni samoro an pokadhie osiptal aneno ji aila go, gintie gin kata Bondo, to okanyal access gi aneno gi mana e pich, koro an awuon katimo mistake, okadwa ni abedie situatoni machal kamano. To aneno kendo epicha makawuono aneno ni wanyalo riure mawakony ng'ato manpiny kata gi sabun gi sukari kawariwore ka group ma understandre ni wan HIV positive mondo wakony ng'ato, nyithindo ochiem, donge?

(In my opinion, the film we have just seen is scary because one would not like to reach the stage the character in the film has reached. It teaches us that if you default or fail to take the drugs at all, you will suffer like the person we have been shown. Though I may not have seen such people at the hospital, they are there, even in Bondo, and I would not like to make any mistakes that would make me live like the person in the film. From the film, we have also learnt that we can come together as HIV positive people to help each other, even with soap, sugar, and other household items, to enable us to feed our children.)

**Participant:** Ng'amachielo? (Anyone else?) Speaking on my own accord, the images should be scary so as to make me not desire to be like those people. You become scared to get to that point. At the same time, it is encouraging a little that you can have some hope for tomorrow. So, the images should teach us three things: if you make a mistake, you can end up like this; if you do not adhere, you can get here; but if you are pregressing, well, then you can unite and bring about development; take care of the children you have been left with; even if you are positive, you can live a normal life as long as you adhere to medication. That woman in that hospital does not fit the current situation. She must have skipped some stages. Now she must accept using drugs and she will get out of that bed and go back to take care of her children. Even if yesterday's videos scared us, we do not want to get there, so today we are encouraged not to go to that stage. I have also learned from today's video that we can also unite and help each other so that the person who is not able to feed their children can.

**Participant:** Gin gi puonj gite? (Are they both educative?)

**Participant:** Koro gi maduong en ni information mar kute.. yani ler matut omakore kod tho mar HIV oromo be ni odhi kila kona mondo atleast ng'ato ka ng'ato ongee ni

HIV ni en ang'o ere kaka anyalo yude, ere kaka anyalo lande to ere kaka anyalo geng'e donge? To kose yudo yath tanyalo genge kama to y ath ne owinjore atii godo nade donge? Pichni makawuono nyiso wa kuma wariee, kata nyathi sikul cha ni gigeno ni lek mare biro chapo kare, emomio nyoro nawacho ni kata obed ni magi lit tageno ni picha manext dhi miowa geo. Benedict, I dind't see nay film before, but I gused today's film will bive us hope and it is ture Nyoro ne onge gi ma aseneno but nomiwa pictures manyoro picha mar ario nyaka nedhi miowa hope. Koro in iwuon kaka in, e ngimani mar HIV be inyalanyala bet tipenjori ni an aseloko ji adi? Mae anenoka jo injili mar kanisa eingimana mar HIV nyaka nafweny ni andko kuto mag HIV ji adi maseloko, jiadi maseloko ngima gi, ji adi ma asegolo kama ma obedo somewhere, donge aneno kaka society ni tio?

(The greatest thing is the information that sheds light on the fact that HIV education needs to be spread all over so everybody gets to know about HIV, how it's transmitted, how it can be prevented, and once I have contracted, how I can adhere to medication. So those films of yesterday showed us the beginning; today's film shows us where we are headed. Even if yesterday's were scary, I had hope that the next would give us hope. Your individual life as PLWHA, you should ask yourself, how many people have I transformed from that situation to that?)

Alafu pichni ma nyoro ka no wuoye ko makore gi dhier sana, koso jogi be ni gi kute, be gi dhier ahinya? Nyoro nikech adhier aonge nyalo, adhi ir jaboya nyabyo nikech pesa na orem nyak walalre mondi eka abi akau rech donge, donge e gima watemo wacho ka? Kawuono be nitie kama dadhir ngatoni sijui an'o nikech an kod kute (Onge) donge ngufu na emomiyo koro mama cha nenyiedho? Yeah koro kawakao poverty ma warelake gi HIV kabisa is like wanyumore eibugo, donge? Koro onego wabed gi geno ni kata an kod kute to her nitie gi riwruok gi kila kitu to niti e kumwa head to. Nyoro datary nepenjowa ni ere kaka dhier omakore gi kute mag ayaki (mmm, yaeh) to newareson ni samoro kaka chiemo onge, kaka otm ang'o onge koro nyal mio amany yo machielo mamii ayud tuo, to koro kwuono waneno ka jogi riwruok magingo gidonjo e talbe banking gi share matin tin. Koro from table banking ng'ato nyalo nyedho, be nitie mwandu moro maopogore gi ngufu gi? Koro wawee kao poverty kabisa kabsia to wliere donge? Mano emomio ineno sani imedo jiwo wan i king'eni okinyal chopo bondo nkech fare, be nyangera ka minyalo wuotho donge, to kaluor bero Nyagnera nikech luoro to onego be ni ichopo ira mondo ijiwa donge? To kinyisa ni anbe mi nena ni ne an kama kam to ane yath to koro an kama kama donge ojiwa? Koro ka wan ka ji apar oromo kiny kwaduogo ka to wan ji adi? Pier ario, ngato ka ngato oloko ji adi adi? Nato achiel achile donge? Nikech information miyudo kae ni, you have to share, oken mari kendi, wawinjore? Koro ka ng'ato okeloni charuk ne, an chuora notho higa mokalo, gik maneango anyuola nomay te, an koro an man kama, ne adhi time maid ne ng'ato to kor wuo ot ni owacho ni nayka aabed kode achil eka obiro konya nono to okochulap pesa na, tawinjo ni en kod kute anenoga ka omwanyo

yethe moko ka, kor o anbe anenanena ni ayie abed kd achiel mondo ochula, ayud pesa makwoko ne nyithidan chiemo mondo akonyrago, dikonya nade?

(Yesterday's films were attached to poverty, but is that the case with these people? Due to poverty, yesterday, I'd go to a jaboya and, because I have less money, I have to have sex first before I can buy some fish. Isn't it so? Why is there such poverty today? Isn't it their hard work that is making them prosper? If we cling on to poverty, then we would appear to be falling into a pit. We must have hope that even if we are positive, if we unite, we will head somewhere. Yesterday we were asked about poverty and HIV, and we had varied reasons for that, like today, due to these people's unity and table banking they are able to share the little they have. They now have property from their efforts. We mustn't cling onto poverty. That's why we are now being encouraged that if you can't get a fare to Bondo, come to Nyangera for your drugs, where you can walk. If I can't come due to stigma, then you should encourage me. So, since we are coming here tomorrow, we should encourage someone that this information we have received is not only for you to share it, is it so? So if someone comes to you saying, "My husband died last year and my inlaws took away all my properties and I am as I am, so I went to work as a house girl for someone and the man of the house wants to have sex with me before he can pay me, yet I hear he is positive and I have seen him take some medication, so we must decide to have sex with him so that he can pay me and I can go buy food for my children so I can help myself, how would you advise me?")

**Participant:** Anyalo puonje ni kuriwore gi n'tcha, obiro yudo kute to maisha ne biro kethore nikech ka onego be orito nithinde kaka chuore ose tho no keno okdwa medore mzigo mr dhi rango yath okbi koney, otiatia matek oude kata loan kat e grop moro ochak timo ohande moro matintin ochk pidho go nyithinde mano e advice manyalo nyisi.

(I'd teach you that if you have sex with him, you will get infected and your life will be destroyed. Since you have orphans to take care of, do not add the burden of medication to yourself. You'd rather quit that job and get some loan to start a small business rather than work for an abusive employer.)

**Participant:** Chalna ni be pokongeyo, to ngato madwara ni anenega pilepile komuonyo yethe to awinjo ga kiwacho ni yedhe gi gin mag okimwi to chien to okanyal dok nikech anyuola oremba momaya gika te.

(I am yet to know my status and this man is on ARVs. I cannot go back home. The family has taken all my properties and chased me away.)

**Participant:** Anyalo advisi ni tich, kendo many kama chielo...

(I will advice you to quit that work and get another job...)

moloyo donjo e bur mineono.

(instead of falling into a trap that you are seeing.)

**Participant:** Chien ing'eni aonge geno. (Note that I have no hope back home.)

**Participant:** Kidongjo e bur ni to geno kor dhi bedo maonge kasa, nikech in many nyaka mii, in be kor idhi ir jal cha okochuno ni ka eaka nyaka itie, koro instead wee tich timany kamachielo to, kingima ikony go joka.

(If you fall into the trap, there will still be no hope. You will have to be given and that's why you went for that job. It's not a must that you work there. Instead, you can find another job. When you are still alive, that is when you can help the children.)

**Participant:** An kaka aneno kaka anyalo wuoyo dodu to okiwinj advice but, ingeni inyalo wuoyo dodu ngato to ngato wuoyo kodi gi ng'eyo mare nikech chien kucha ong'eyo ni ways onge ma into ing'e ni wach kende midway wachne ka to kong moro minyalo konye kata ki ngado ne rieke ni donje I group ma kama dipok gi mii pesa moro capital moro matin dipokichako go tiji moro madibed onge, koro anyalo advise because, anyalo wachone wach moro to chunye e wuon kaka owuotho gi ngere no, anyalo pimo ne ni koro ka tek ahinya to puonj nan i en ni odak kamoro omany tich kamachielo to kamano tek nikech inyalo judge yourself, you can use condom nikech okitiyatiya kod... nono, iti kode gi kondom.

(As for me, I can advise you and you don't here, so I know you have your own perception and that you cannot go back. Since I may not have any better help, I may advise you to join a group where they can give you some loans and you can start your own work. However, I recommend that you continue to use your own discretion. But I would ask you to find a place to stay and find another job, but if it is so hard, then just use a condom, since you should not just have sex without a condom.)

(Laughter)

**Participant:** An ingeni anyalo konyi ni, anyalo nyisi ni ka mano e yo ma nyaka iyud go pesa in bende noosedari onge kama di dogee, ibii mono wadaagi mondo adwar chama moro ma dwa yudie pesa mondo ichak godo ohandi moro matin matin kosave mos mos koduoko pesa.

(For me, I'd advise you that if that is the only way you can get money since you have also been chased away from your home, come let's stay together as I find a group where you can borrow money and start your business and save as you pay back the loan.)

**Participant:** An aparo ni anyalo nyisi ni we tijno nikech in gi nyithindo chien ikonyo donge? Koro an anyalo mana mii advice ni many grop minyalo donje, kisyudo group moro midonjee to nyalo mii kony, tinyalo yudo p esa michak godo bsiness, ichako go ohala ma kata inyalo loso pesa ti oro chien ne nyithindo kuone magintie, molooyo yudo tuo.

(I'd advise you to quit that job, find a group you can join, or one that can give you a loan so that you can start your own business and send money for your children's upkeep. That's better than being infected.)

**Participant:** Ineno ngima ma dhano odakie, ng'ato dak e ngima mohero ng'ato mandikko house maid, kapok unenoga, house maid, ena ena house maid, en kata imie mana business moro okobitiyo, odwaro kama ichulee, ingee ni ntie jok ma ni after employmet, ongee ni nyaka chule mishahara, to nitie ng'ato ma be nyasaye nomiye rieko, en onyalo jipanga kien, makata otimo gimoro kama, to oplan gimoro ni an kata katimo ma to dwa dhi nade koro wan wasebedokta gi jogo mandiko ga house maids gi kigole mimiye business to ofail nikech timo balancing mar stock more tame, koro chune ni nayaka obed house maid, but with house maid to boss more osehere wawachru I mar adiera boss ni oseheri, and boss is everything, ene pesa to maish en pesa, koro gi maber, kik owundre nikech dhano ma be chiemo ok dhoge ma inenoni en obende ogonga kata kineno kata ka boss onginene en wuon ogonga.

(People choose the life they live. A house maid is just a house maid. Even if you give her money to start her own business, it will collapse. There are people who just need employment, their mind is set on being paid at the end of the month, but there are those who can think outside the box on their own. Now let us just speak the truth, for a house maid's boss is everything. He has the money, and life is about money.)

**Participant:** We gombo kata boss, nikech sa ma ochiemo to owinj ka dende bende chwakore, koro boss manondiko, this is the right person manyalo dhi kode, nyaka ng'oyieayiea to mondo gi tii dok raboyunga ineno? Koro gimabedoga, kama complication bedo ga, kama ntie dhano to usharati to usharit moto tinde obiro ka, e mi winjo ka ng'ato wacho ni kawachako to nyak watim nade, pod nyaka wachakk timo hera kod royounga, but after all, raboyuanga koro iweyo, uwinjo gini, kae emakoro keloga pek ma mio kata jomo dak e ot raboyunga tamre, newachako tio godo nyoro kawuono keno walokre wachal jomochako dhi e test wang'e chal wa duto mae kama ntie effect lakini ng'ama miee pesa kata maa an ajanyisou ni a ja thum, asewuothe kuonde ma nyako kigolo 2000/= tidhiadhia kode nono, yani 2000 no oromo maisha mare, to 500 nyaka iti gi raboyunga koro solution in ene ni boss ni mae ng'a manyalo konyo nyako ni, koro nyaka oyie ayieya mondi, nyaka gicoperate tio moro ma kare to giti kod raboyunga kajomapuonjre ka mama cha odagi to ginylao differ nikech aseneno nyiri moko madhi elojings ka ma ka odhi gi ng'ato mang'ano otamre ni okodhitio kod trust, nyako no nyalo goyagoya uui maji chop ni kara en ang'o, owacho ni okonyal tio koda kamano inbe koro nyaka I care for your life. Omio solution en ni kama iyudie konyruok to nyaka ipar malong'o.

(But we should agree that she also has sexual needs. She eats, and after eating, her body warms up and she desires sex, not only with her boss, who she generally accepts on the condition that they use a condom. What often complicates issues is that people might start using condoms and then shun them even without having been tested. I always tell you that I'm a musician, and sometimes whenever we go, there are girls

whom you pay Sh2, 000 to have unprotected sex, while sometimes one pays Sh500 for protected sex. There are also girls at the lodgings who scream until people come in to hear the argument because she says she is careful with her life and so must the partner. So the solution lies with you because one must be careful with their life.)

**Participant:** Gi ma wia owil, iwacho ni jaodi nosetho to jogi no riembi dahero ni mondo odhi epim, nikech chalo ni en gi idea ni niteier yethe moko mimwunyoga mag HIV, ong'eyo nade, kata kokia odhi ong'e status ge modo obed ni ong'eyo chalne, koro kata ka koro oamua, nikech macha to boss ne dwa dhi miye pesa, oamua ni odwa dhi room gi ngatcha, oamua kongeyo status ne to oprotectre ee, ei project ge mar rango pesa no, kochue ni nyaka odhi orang pesa no, nikech ang'e ni boss kadhi miyi pesa to en gi upper hand, obo choose ni obiro tiyo kodi nade nikech ionge gi bargainin power sani, koro nyak ongee status ne mondi kapok odhi kaluore ni chuore nosetho.

(I almost forgot, you said that her husband died. I'd like to advise her to go for HIV testing. She appears to be aware that HIV positive people typically take drugs; how did she know that, if she has decided to get tested, she needs to know her status before proceeding with her search for money? You know, since it is her boss, he has the upper hand and he can use her as he pleases. She doesn't have the bargaining power against him. That's why it's important for her to know her HIV status beforehand, because her husband had died.)

**Participant:** Roho mar Nyasaye tio, nikech kanyo emane adwaro ni mondo upar, ng'ani oneo ka boss ne muonyo yedhe moke to oparo ni gin ARVs, ngam ne plko bedo gag i ng'eyo, kata ne poko neon goa gik miluong ni ARVs di no ng'ee nade ni gin ARVs ma ok no par ni gin yath pressure kata gin yedhe ang'o, donge? Koro mokwongoga, the fist step en ni to jaodi manotho ni dining'eyee gimanonege? Tuone nowuok e ang'o? Tuo ne nochakore kata nowuok e gine mane donge? The second step enni advice maman odhi ong'e cal mare, ka pok wadonjo e issues mag kondom and whatever advise mondo ong'e ang'owa, chal mare, Thridly wawach ni awuok positive, step mar adek en mar ang'o?

(The heart of God works, because there he wants you to think, "This person has seen his boss taking medication and he thought it was ARV medication. How would he have known that it was ARVs that he was taking?" He could have thought it was pressure medication or other medications. First of all, the people who know you, would they know what killed you? That disease was from where? That disease started and ended in which place? The second place is that the advice of this woman will look like hers. Thirdly, let's say that I turned positive. The third step is of what use?)

**Participant:** Okikao yath

**Participant:** Medication donge? Kaseng'e chal mara, tadonjo e thieth machon, donge? Sama asedonje e osiptal machako kao y ath ni step mar angwen adive mama ni mondo join gimilwongo ni psychosocial support goup koro seche ma osedonjo ka,

obiwo winjo ma ka ngato share. Donge ji biro share? Obiwo wijo kaka kila ng'ato share, ng'ani wacho mare, ng'ani wacho mare, obiwo winjo ni kare soamoro ng'ato ni gi lit moloyo mare no, mama no dhibedo encouraged to feel ni ok an kena. Nikech ing'e ni sama ne opimoni weche ka ingeni mamani nie darkness, ene silent world, gima on'eyo onge, koro mama ni iketee light, gima okao neon ler donge? Koro ibiwo yudo ka kiny mama ni biro bedo mentor mar ng'amachielo donge?

(I wanted you to think along those lines because she saw her boss take medication that she believes is ARVs. Anyone who has never seen or heard of ARVs cannot tell what they are.)

The first step of advice is to know how her husband died, then ask her to go for a test, and if she is positive, ask her to begin medication right away, and then the fourth step is to encourage her to join a psychosocial support group. Once she hears people opening up, she will realise that there are people whose experiences might be more painful than hers. You'll have put her Ni light in these now, and she'll be a mentor tomorrow.



## Appendix 12: Authorization from NACOSTI for Research



### NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY AND INNOVATION

Telephone: +254-20-2213471,  
2241349, 3310571, 2219420  
Fax: +254-20-318245, 318249  
Email: dg@nacosti.go.ke  
Website: www.nacosti.go.ke  
When replying please quote

NACOSTI, Upper Kabete  
Off Waiyaki Way  
P.O. Box 30623-00100  
NAIROBI-KENYA

Ref. No. **NACOSTI/P/19/38573/28150**

Date: **27<sup>th</sup> February, 2019**

Benedict Wasiche Were  
Kenyatta University  
P. O. Box 43844-00100  
**NAIROBI**

#### **RE: RESEARCH AUTHORIZATION**

Following your application for authority to carry out research on *“Interrogation of documentary film as a tool for advocacy for positive living with HIV/AIDs in Yimbo West Ward Of Siaya County-Kenya”* I am pleased to inform you that you have been authorized to undertake research in **Siaya County** for the period ending **27<sup>th</sup> February, 2020**.

You are advised to report to **the County Commissioner and the County Director of Education, Siaya County** before embarking on the research project.

Kindly note that, as an applicant who has been licensed under the Science, Technology and Innovation Act, 2013 to conduct research in Kenya, you shall deposit a **copy** of the final research report to the Commission within **one year** of completion. The soft copy of the same should be submitted through the Online Research Information System.

A handwritten signature in blue ink, appearing to read 'G. Kalerwa'.

**GODFREY P. KALERWA MSc., MBA, MKIM  
FOR: DIRECTOR-GENERAL/CEO**

Copy to:

The County Commissioner  
Siaya County.

The County Director of Education  
Siaya County.



**Appendix 14: Authorization from County Commissioner, Siaya County**

REPUBLIC OF KENYA



THE PRESIDENCY  
MINISTRY OF INTERIOR & CO-ORDINATION OF NATIONAL GOVERNMENT

E-Mail [cc.siaya@yahoo.com](mailto:cc.siaya@yahoo.com)  
When replying please quote ref. & date

COUNTY COMMISSIONER,  
SIAYA COUNTY,  
P O Box 83-40600

REF:CC/SC/A.31 VOL.III/32

**SIAYA**  
31<sup>ST</sup> MAY,2019

DEPUTY COUNTY COMMISSIONER,  
BONDO SUB COUNTY

**RE: RESEARCH AUTHORIZATION-BENEDICT WASICHE WERE.**

The person referred above from Kenyatta University has been authorized by the Director General/CEO, National Commission for Science, Technology and innovation vide letter Ref. No. NACOSTI/P/19/38573/28150 dated 27<sup>th</sup> February 2019 to carry out research on “ ***interrogation of documentary film as a tool for advocacy for positive living with HIV/AIDS in Yimbo West ward of Siaya county in Kenya***” for a period ending **27<sup>th</sup> February 2020.**

The purpose of this letter therefore is to ask that you accord him the necessary support as he carries out research in your sub county.

A handwritten signature in black ink, appearing to read 'Dennis Obiero'.

DENNIS OBIERO  
For: COUNTY COMMISSIONER  
SIAYA COUNTY

Copy to: Benedict Wasiche Were  
KENYATTA UNIVERSITY  
P.O BOX 44844-00100  
NAIROBI

County Director of Education  
SIAYA

**Appendix 15: Authorization from County Director of Education, Siaya County**



**REPUBLIC OF KENYA  
MINISTRY OF EDUCATION**

**State Department for Early Learning and of Basic Education**

COUNTY DIRECTOR OF EDUCATION  
SIAYA COUNTY  
P.O. BOX 564  
**SIAYA**

E-mail: cdesiaya2016@gmail.com

When replying please quote  
CDE/SYA/URA/10/VOL.1/116

Thursday, May 30, 2019

TO WHOM IT MAY CONCERN

**RESEARCH AUTHORIZATION – BENEDICT WASICHE WERE**

The above named person has been mandated to carry out research in Siaya County vide an authorization letter from National Commission for Science and Technology and Innovation Ref. No. NACOSTI/P/19/38573/28150 dated 27<sup>TH</sup> February, 2019. This research study ends on 27<sup>th</sup> February, 2020.

The research title is *“Interrogation of documentary film as a tool for advocacy for positive living with HIV/AIDs in Yimbo West ward of Siaya County – Kenya”*

Please accord him the necessary assistance in this County as he may require.

**JOSEPH K. WAMOCHO  
COUNTY DIRECTOR OF EDUCATION  
SIAYA COUNTY**

