The Islands of Kalangala District and Access to Antiretroviral Treatment: A Question of Human Rights and Global Health Justice

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Diana Bwette
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Members of the Examining Committee:

Dr. Jeff Handmaker
Dr. Rachel Kurian

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Inquiries:

Postal address:
Institute of Social Studies
P.O. Box 29776
2502 LT The Hague
The Netherlands

Location:
Kortenaerkade 12
2518 AX The Hague
The Netherlands

Telephone: +31 70 426 0460
Fax: +31 70 426 0799

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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral drugs
FDA	Food and Drug Administration
FFC	Fish Folk Communities
FHRI	Foundation for Human Rights Initiative
GHJ	Global Health Justice
HC	Health Centre
HIV	Human Immunodeficiency Virus
ILO	International Labour Organisation
MAAIF	Ministry of Agriculture, Animal Industry and Fisheries
MARP	Most at Risk Populations
MOH	Ministry of Health
NDP	National Development Programme
NGO	Non-Governmental Organisation
NSP	National Strategic Plan
PLWHA	People Living with HIV/AIDS
UAC	Uganda AIDS Commission
UBOS:	Uganda Bureau of Statistics
UNAIDS	Joint United Nations on HIV/AIDS
UNDAF	United Nations Assistance Development Framework
UNIDO	United Nations Industrial Development Organisation
UN	United Nations
WHO	World Health Organisation

Abstract

Antiretroviral therapy (ARV) is one of the most effective methods of treating and suppressing the human immunodeficiency virus HIV/AIDS a virus that attacks and weakens the human immune system. It is known worldwide for saving lives, preventing HIV/AIDS related illness and new HIV AIDS infections, thus keeping the people living with HIV/AIDS (PLWHA) healthy as long as they have adequate and constant supply of ARVs. Therefore the research will analyse the health inequalities faced by the Fish folk community (FFC) of Kalangala district created as a result of unequal access to ARVs within the public hospitals. This paper will examines the concept of global health justice and Article 12 of ICESCR to establish the violation of the right to Equal access to medicine as an integral right to the right to health by looking at the structural setting of the people living in Kalangala fishing communities and the government response to this population in regard to HIV/AIDS treatment.

Relevance to Developmental Studies

The right to equal access to medicine can be seen as integral to the right to health and is interconnected to many other rights, including the right to life, sanitation, education, and work, without which development processes are curtailed or can easily come to a standstill. Thus state's policies and programmes must always be tailor made to promote, fulfil and protect the right to health of their citizens in order to enhance economic social and political development. On the other hand, it is also important to analyse the interconnected of human right, global health just and development.

Key words

Kalangala fishing communities, antiretroviral drugs, health inequalities, right based approach and global health justice.

Chapter 1: Introduction

1.1 Problem Statement

"If we can bring a bottle of coke to every corner of Africa, we should be able to also deliver antiretroviral drugs"
- Prof Joep Lange[1]

Equity in health implies that every person can and should have the chance and potential "to attain their full health potential and, more pragmatically, that no one should be disadvantaged from achieving this potential, if it can be avoided" (Whitehead 1992: 7). However access to antiretroviral treatment is one of those needs that is proving hard to be attained by all who need it. Antiretroviral treatment being the main type of treatment for HIV/AIDS that boost the immune system and suppresses the HIV virus should be available even to the remotest and not easily accessible regions. It is not a cure but it can stop people living with HIV/AIDS (PLWHA) from becoming ill for about 10 years or more once they start therapy (Sabin et.al 2014: 51).

Early measures to stop the spread of HIV/AIDS in Uganda should imply a theory of change where the duty bearers learn from past mistakes to inform better health policies that support the level of treatment scale up for all those that need antiretroviral treatment (Kunihira et al. 2010: 120). In 1997 Uganda patterned with the Joint United Nations Programme on HIV/AIDS (UNAIDS) (WHO 2003: 2). The purpose was to advance free universal access to HIV/AIDS care and ARV therapy to HIV/AIDS patients within the country (Ibid: 2). In 2000 the Ministry of Health took up the obligation of ensuring access and availability of affordable antiretroviral drugs (WHO 2003: 2). In 2004 Uganda launched the Universal Access to Free Antiretroviral Drugs for HIV/ AIDS patients in the country. With the support of the World Health Organization (WHO), a National Strategic framework for expansion of HIV/AIDS care was initiated within the country to be "implemented within the framework of the National Health Policy and the HIV/AIDS Health Sector Strategic Plan" (WHO 2003: 2). Despite all the policy initiatives made, universal HIV/AIDS treatment is far from being a reality among the general population most especially where people are situate in places hard to reach and rural areas of the country like the islands of Kalangala District.

According to the 2012 Country Progressive Report on AID in Uganda, 540,994 people living with HIV/AIDS were eligible for treatment in 2010 and 577,000 in 2011, however only 77,768 were initiated on ART within the same year (Uganda Aids Commission 2012: 11). The United Nation Development Assistance framework (UNDAF) report of 2014, stated that "39 percent of people requiring antiretroviral treatment are accessing it and that for every 2 people who start to take antiretroviral drugs, another five people become infected" (UNDAF 2014:14).This means that those left out for one reason or the other could be victims of human rights violation and which is causing health inequality within the country.

This paper focuses on the fisher folk community (FFC) of Kalangala district in Uganda that is part of the Most at Risk Population (MARP) to HIV/AIDS besides sex workers, truck drivers, and men that have sex with men(UAC 2009:31, UAC 2012:40).Being geographically isolated, and

[1] This quote by the late prof Joep Lange who died in a plane crash on his way to the 20th International AIDS Conference in Melbourne, Australia held from 20-25 July 2014 (http://sciencespeaksblog.org/2014/07/20/aids-2014unaids-ending-the-aids-epidemic-a-new-target-for-hiv-treatment/)

a fishing community, research has showed that such communities are inadequately targeted with HIV/AIDS interventions (Allison and Seeley 2004, IRIN 2012, Opio et al. 2013, KMCC 2014, Indevelop 2014). Human rights are "rights to which individuals are entitled by virtue of being human beings" (Rodriguez et al. 2014: 3). People living in the island of Kalangala district have been conditioned to the fact that their location does not allow for their enjoyment and fulfilment of the right to health.

The time frame for this research covers the period of 2004 at time within which free antiretroviral drugs were introduced within the public hospitals and health centres by the government of Uganda to 2013 a time when Uganda's HIV/AIDS prevalence rate is said to be increasing at a first rate threatening a reversal of past gains(UNDAF 2009:14)

1.2 Relevance and Justification

Fisher folk communities (FFC) make a tangible contribution "by the fish industry to national economic development" (Opio et al. 2013: 1). Moreover, fishing "contributes to food security as well as income that boost the domestic product" (Opio et al. 2013: 1). It is estimated that the FFC fishing business contributes 6% to the national gross domestic product (Kiwanuka et al. 2014: 2). However, the location of Kalangala district on island geographically isolated from the mainland they are being left out on HIV/AIDS treatment programs. This is partly the reason as to why i claim that the right to health of people in Kalangala district is being violated due to the inadequate access to antiretroviral drugs. Thus this research will be an informative exercise showing how a shift from the rhetoric approach of policy implementation to a more practical approach of policy implementation and empowering victims of human right violations would deal with issues of health inequality. By drawing on the rights based approach and also relying on principles of global health justice to address this problem. This research is a contribution to the already existing research about the fishing communities as one of the most at risk populations to HIV/AIDS. However throughout data collection, it was discovered that most researchers write about the lifestyle of people in FFC and blame the high HIV/AIDS prevalence rate on their life style and implicitly attribute the inadequacy of access and availability of health services to the geographical location of islands. Hence It is prudent to show that human rights obligations that the government has towards its citizens have to be promoted, respected and fulfilled no matter their location in the country and lifestyle.

1.3 Research Objective

The objective of this research is to show how inadequate access to antiretroviral drugs within the country causes health inequality which is a violation of the right to health. Also to analyse how social determinants of social groups like fishing communities can be linked to health inequality caused by the inadequate access to ARVs and how Rights based approach and global health justice can be used to address the violation of the right to equal access to medicine which in most cases is considered as a health issue and not as a human right.

1.4 Research Question

How has the inadequate access to antiretroviral drugs in Kalangala fishing community amounted to a violation of the right to health?

1.5 Sub Questions

1. How can social determinants of social groups like fisher Folk communities be linked to health inequality and human rights violations

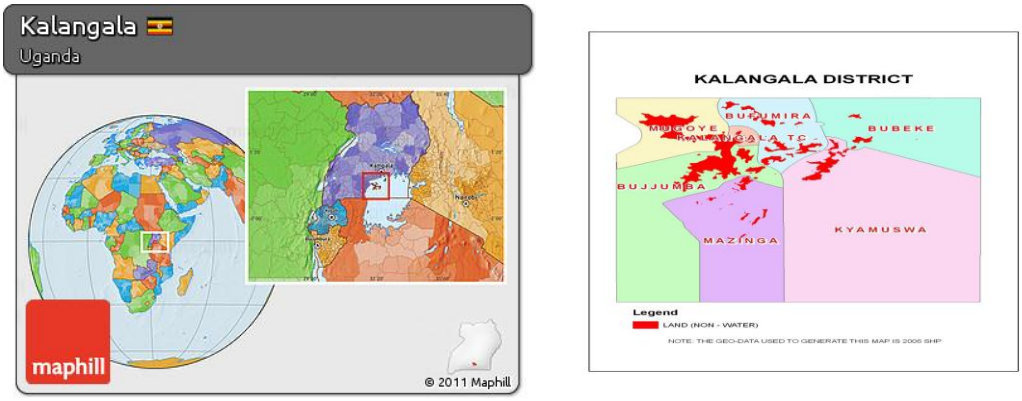
2. To what extent is there an integrated multi-sectoral response to equal access to antiretroviral drugs in Kalangala District?

3. How could right based approach promote equal access to ARV treatment to the isolated population of Kalangala District under global health justice fora?

1.6 The context of Kalangala District

There are many under prioritized districts in the country, however this research has chosen to limit its scope of study, and investigation in Kalangala district one of the many fishing communities in Uganda and also one of the districts where HIV/AIDS prevalence is reported to be higher than in the general population (Opio et al. 2013). Furthermore I have chosen this district as sample for the many other fishing communities facing the same problem due to their isolated location from the mainland.

Figure 1 Map of Uganda showing the location of Kalangala District



Source: (http://www.maphill.com/uganda/kalangala/location-maps/political-map/)

Kalangala Island was transformed into a district in 1989. It is located in the southern central Uganda. It is made up of 84 islands, 63 of which are inhabited. Kalangala is "made up of 2 counties, 6 rural sub counties and 1 town council" (Uganda Aids Commission 2003: 18). It is "bordered in the North by Mpigi District, in the East by Mukono District in the South by the United Republic of Tanzania and in the West by Masaka and Rakai Districts" (Ibid: 18). The district is "accessible by road through Bukakata (an inland port in Masaka district) to Luku, (an inland port in Kalangala district) using the Bukakata-Luku ferry" (Uganda Aids Commission 2003: 18).

The 2002 provisional census statistics show that Kalangala had a "total population of 34,907 with males being almost two thirds of the whole population" (Uganda Aids Commission 2003: 18) and as of today, the population of Kalangala district is placed at 66,300 by UBOS District Population Profile of 2011. The number of men out numbering women is said to have a great impact on sexual relationships and sexual practices; in that 'there is high competition for

women among men and commercial sex workers have exploited the sex gap and travel all the way from the main land to Kalangala landing sites to offer commercial sex service(SIAAP 2012:6).

1.6.2 Fisher Folk Communities (FFC) of Kalangala District.

Fishing communities are defined as, "s*ocial and economic groups of persons living together in a locality and derive their livelihood directly or indirectly from fishing activities*" (Opio et al. 2013: 3). They are said to consist of two groups; group one consists of the "specialist fisher folk who tend to be mobile or migratory; they can be found living temporarily in lakeshores and coastal villages or makeshift fishing camps, sometimes with their families, but often with other fishermen in all-male groups" (Westaway et al. 2007: 668). The "second group of fisherfolk are residents of lakeshore villages who tend to fish part-time or may not fish at all; instead they may own some fishing-related assets and depend on hired labor to do the actual fishing" (Ibid: 668). These groups may include "people who derive their livelihood from the lake shores and are engaged in fishing, marketing, and processing; they may also provide support services like lodging, food, and drink" (Westaway et al. 2007: 668).

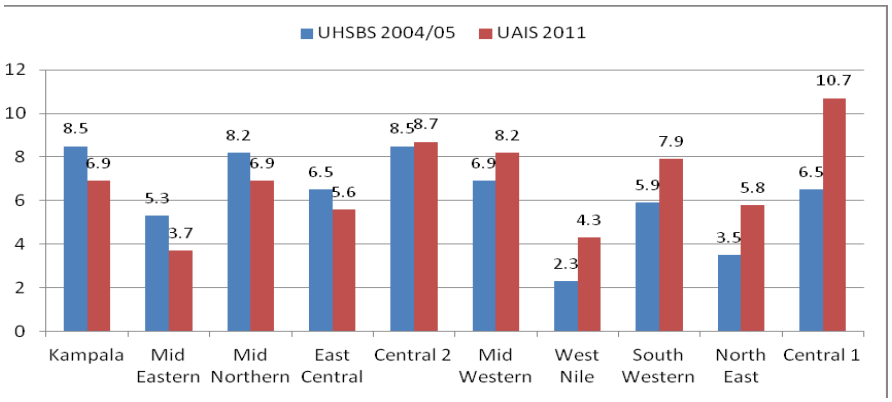
1.6.3 Health Services in Kalangala District

Kalangala consists of 84 islands, 56 of these have no health centers in that many patients have to cross over from one island to another in search of healthcare. It should be noted that Kalangala district has no referral hospital but instead 11 health centers and according to the Ministry of Health Norms, to adequately cover its population of 54100, it should have a total of 16 health centers (USAID 2010). Health infrastructures are limited, "most health facilities are understaffed and managed by nursing aides" and there are many medical staff who prefer not to live in Kalangala because of its remoteness (Uganda Aids Commission 2003: 20).

In total there are 10 health units in Kalangala, "two of these are health center level IV, 6 are health center III, and 2 are health center II" (Uganda Aids Commission 2003: 20). Kalangala does not have a "sentinel site, no VCT services, hospital and a functional laboratory to conduct HIV testing". The "nearest referral hospital is Entebbe (30-120km) and Masaka (40-114km)" (Uganda Aids Commission 2003: 20).

1.6.4 HIV/AIDS Prevalence Rate in Kalangala District

Table 1 Regional Variation in Prevalence of HIV, 2004/05 and 2011



Source: (Uganda Aids Commission 2012: 8)

The above table is adopted from the Global AIDS Response Progress Report: Uganda Jan-Dec 2012 and it shows the variations in prevalence of HIV, 2004/2005 and 2011. The case study area

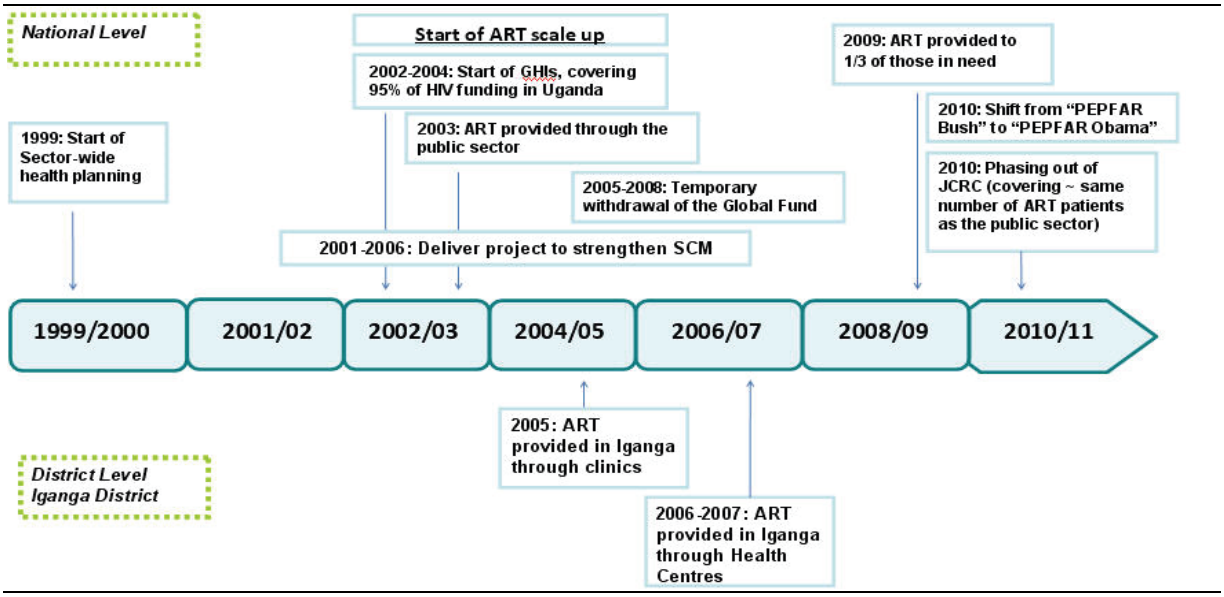
Kalangala District is located in Central 1 and has the highest HIV/AIDS prevalence rate (10.7%) as of 2011 (Uganda Aids Commission 2012: 8). Subsequently a research conducted by Kiwanuka et al (2014), found that "HIV/AIDS prevalence in the general population of fishing communities is about 4times higher than the estimated national incidence among adults in the general population in Uganda" (Kiwanuka et al. 2014: 6). The high prevalence is attributed to the life style of the population that lives around fishing communities which is characterized by a big number of commercial sex workers, fisher men with a lot of liquid cash to spend, lumbering activities and highly mobile population in search for fish, low levels of education and the isolated geographical location of fishing communities let alone Kalangala district (SIAAP 2012: 4).

1.6.5 Antiretroviral Drug Distribution within the Public Domain of Uganda.

Antiretroviral drugs became widely available in Uganda in 2004 when the Global Fund (i.e. Global Fund to Fight AIDS, Tuberculosis and Malaria), and PEPFAR (The President of the US, Emergency Plan for AIDS Relief: "…came in to support the provision of ART for people with AIDS" (Hardon et al. 2006: 262). These agencies "provided unprecedented multilateral support and enabled the scaling up of access to ART" (Ibid: 262). The support of these two organisations enabled Uganda government to provide ART to PLWHA through public hospitals and health centres free of charge to those patients that are in need of them.

The table below shows how scaling up started in the public sector of Uganda and the different players in the whole process. However as much as It is referring to another district (Iganga District), the same process applies to Kalangala district and any other districts within the country.

Figure 2 Major events during ART scale up in Uganda



Source: (Windisch et. al, 2011: 2)

According to Windisch, the supply chain of drugs in the national health system of the country is said to be weak, the "essential drug program lacks more than 50% of the funding it would need for the constant supply of the minimum care package" (Windisch et al. 2011: 2). Only "27% of hospitals and about 40% of other health facilities report receiving the requested quantities of essential drugs ordered through the National Medical Store" (NMS) (Windisch et al. 2011: 2). The Uganda Narrative Report of 2014, reports that 1,478 health facilities in all 112 districts

provided ART services and also the number of facilities providing ART increased from 407 at the end of 2011 to 532 by December 2012(Uganda Aids Commission 2014:22). It increased to 1,073 at the end of June 2013 and further went up to 1478 by the end of 2013(ibid). (Opio et al. 2013: 2) observed that most of the information about access to antiretroviral drugs is generalised in the whole of Uganda and information about fishing communities is lacking.

1.7 Methodology and Methods of Data Collection

The research is exclusively a desk study based on secondary data collected from different reports and literatures about the research topic. The literature review and secondary data was guided by the key words which included fishing communities in Uganda, HIV/AIDS, access to antiretroviral drugs in Uganda, right to health, rights based approach to health and also Global health justice. Internet search was conducted using google scholar to get different articles written about the research topic and articles on different website like The Lacent, Pubmed, Jstor, PlosOne were very helpful and Newspaper articles from Uganda. These key terms generated data from key authors like, Janet Saleey, Opio Alex, and Allison EH the have carried out and written about fishing communities, London Lesilie and different international law treaties with regard to Human rights and rights based approach to health and Jeniffer Prah Ruger, Grumskin and Sofia, among others that write about global health justice.

To further substantiate and backup the claims made during the research, documented empirical data from reports from different Uganda government entities was referred too. These included the Ministry of Health (MoH), Uganda AIDS Commission (UAC), Uganda Bureau of Statistics (UBOS) and other nongovernmental. International organisations that take up the initiative of carrying out research about HIV/AIDS and access to antiretroviral drugs were also mentioned. A quantitative analysis of the data collected from the different government reports was done to establish the HIV/AIDS prevalence rate in Kalangala district as compared to other districts and also to establish health service resource allocation and service delivery in the district.

Textual analysis and synthesizing of the secondary data collected in order to answer the research question was done by triangulating the finding with the theories of human rights, rights based approach to health, and global health justice. These inform the arguments and draw conclusions to the question and issues at hand. The analytical frame work was based on the principle of health inequality as put forward by Margaret Whitehead.

1.8 Challenges and Limitations

- Scheduling interviews with officials in the National Medical Stores and health workers proved to be difficulty. So this disrupted my initial plans of going to the field and it was quite a setback having to carry out a desk research that was not my initial plan.
- Insufficient reports and data with regard to fishing communities, government does not make enough effort to have disintegrated information with regard to fishing communities
- Last minute cancellation of skype interview and avoiding of phone calls that was quite expensive to make since they were international calls.
- Some of the important documents from the ministries where blocked by firewall so they could not be accessed.
- Delaying and frustrating tactics were applied on the research assistant I had employed back home to collect for me data from the ministry of health and the National Medical

Stores and as i kept waiting for the response a lot of time was wasted that could not be recovered and also I did not get the information I anticipated to get.

1.9 Structure of the Research paper

The research paper is made of five chapters as follows;

- Chapter One

Introduces the research problem, back ground information about Kalangala District, the research question and sub question, research objectives, justification and relevance and the methodology to be used in data collection and finally gives the challenges and limitations faced by the researcher.

- Chapter Two

Present and discusses the conceptual and theoretical framework of the right to health, the right based approach to health and then global health justice theories and elaborates on theory of health inequality and also justifies why these concepts and theories were selected for the paper. With this the researcher will be addressing sub question 1 of the research

- Chapter Three

This chapter will answer sub question one by analysing the link between health inequalities and the social determinants of health inequalities and risky behaviour of the fisher folk community (FFC) of Kalangala District. It also looks at The National HIV/AIDS Strategic Plan 2011-2015 and analyse whether its design and implementation prioritise the fishing communities' population as most at risk population to HIV/AIDS.

- Chapter Four

This chapter attempts to answer sub question two. It will analyse the role of multi sectoral in access to antiretroviral drugs in Uganda

- Chapter Five

This is the final chapter of the research paper. This chapter gives an analysis of the findings of the research in line with the theories of global health justice and rights based approach to health.

Chapter 2: Human Rights Based Approach and Global Health Justice Approach: A conceptual Framework

2.1 Introduction

This chapter explains the right to equal access to medicine as an integral part of the right to health as provided for by the different international treaties that Uganda is a signatory and also ratified them. The right health is also the basis for the claim being put forward in this paper. It then discusses the rights based approach to health as talked about by London Leslie which focuses on the obligations of the duty bearers owed to the right holders. The theory of global health justice as expounded by Jennifer Prah Ruger, draws on the different principles of health capability, human agency and human flourishing. All these will be analysed under the lens of health inequality as put forward by Margaret Whitehead.

2.2 Legal Framework of the Right to Equal Access to Medicine

Article 1 of the Universal Declaration of Human Rights (UDHR), states that "all human beings are born free and equal in dignity and rights" (United Nations 1948). The "right to health was for the first time laid down in the Constitution of the World Health Organization (WHO)" in 1946 (Maite 2012: 10). The WHO is the "directing and coordinating authority for health within the system of the UN" (Maite 2012: 10). The preamble of this constitution is to the effect that, "*health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition*" (WHO 1946: 1). The "right to health is not a right to be healthy", instead it is the right to different "entitlements and underlying determinants of health, such as potable water, adequate sanitation, housing, healthy occupational conditions and healthy environmental conditions" (Maite 2012: 9).

Subsequently the right to health was laid down in the 1948 Universal Declaration of Human Rights under article 25, paragraph 1, which stipulates that "everyone has the right to a standard of living adequate for the health and well-being of himself and of his family" (United Nations 1948). In 1966 the United Nations sponsored the development of the International Covenant on Economic, Social and Cultural Rights (ICESCR) and article 12 (1) recognizes "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" (UN General Assembly 1966).

The 1978 Alma-Ata Declaration provided that health is a "fundamental human right and that the attainment of the highest possible level of health is a most important world-wide social goal whose realization requires the action of many other social and economic sectors in addition to the health sector" (International Conference on Primary Health Care 1978: 1). Additionally, the Alma-Ata Declaration is of the view that primary health care includes the "provision of essential drugs" (Ibid: 2). WHO defines essential drugs as "those that satisfy the priority health care needs of the population. Essential medicines are selected with due regard to disease prevalence, evidence on efficacy and safety, and comparative cost-effectiveness" (Hogerzeil et al. 2006: 305). The right to have access to medicine is vital to prevent and also treat most diseases as well as the control of communicable diseases because it makes possible for people to reach their highest attainable standard of health (Hestermeyer 2008: 104). That's why in some countries where this right has been denied, courts have intervened to enforce it. For example the constitutional court of South Africa in the case of Ministry of Health Vs Treatment Action Campaign, court ordered the government to make Nevirapine, a drug preventing mother to child transmission of HIV,

more widely available[2].Also in neighbouring Kenya, the Kenyan High Court in the case of PA.O & Others v Attorney General & Another[3] the government of Kenya was advised to revise the Anti-Counterfeit Act because some sections of the Act threatened to limit access to affordable and essential drugs that included antiretroviral drugs[4].

Subsequently to clarify and emphasise the importance of the right to health as stipulated under article 12 of the ICESCR, the UN Committee on Economic, Social and Cultural Rights, drafted General Comment No. 14 of 2000 on the right to health and under paragraph 12 it enunciated that the right to health has four elements:

(a) Availability entails presence of "functioning public health and health-care facilities, goods and services" (UN Economic and Social Council 2000). Facilities will include "safe and potable drinking water and adequate sanitation facilities, hospitals, clinics and other health-related buildings, trained medical and professional personnel receiving domestically competitive salaries, and essential drugs, as defined by the WHO Action" (Ibid).
(b) Accessibility meant that health facilities, goods and services should be "accessible to everyone without discrimination", "within safe physical reach for all sections of the population" and must be affordable to everyone "including socially disadvantaged groups" (UN Economic and Social Council 2000).
(c) Acceptability means that all "health facilities, goods and services must be respectful of medical ethics and culturally appropriate" (UN Economic and Social Council 2000).
(d) Lastly "health facilities, goods and services must also be scientifically and medically appropriate and of good quality" (UN Economic and Social Council 2000).

In this regard, states have responsibilities to protect, promote, and fulfil the four elements that encompass the right to health falling short of fulfilling the obligations means that a right health has been violated and whoever is responsible for the violation has to be held accountable. Thus, Paragraph 47 of the UN General Comment No. 14 provides that, "*a state which is unwilling to use the maximum of its available resources for the realization of the right to health is in violation of its obligations under article 12"* (UN Economic and Social Council 2000). Furthermore, such "(v)iolations of the right to health can" take place "…through the direct action of states or other entities insufficiently regulated" by the state (Ibid).

2.3 Uganda Government Obligations under International Human Rights

As could be seen from UN General Comment No. 14 above, the right to health imposes obligations on countries that are party to the treaty. State parties to the ICESCR have the "obligation to respect, the obligation to protect, and the obligation to fulfil" the right to health to an extent commiserate with the available resources and level of development of a particular country (Maite 2012: 43). The obligations imposed onto states create a relationship between the state as a human rights bearer and individuals as rights holders (Tarantola 2007: 12). Thus the government of Uganda as a signatory to the different international treaties with regard to the right to health and also by virtue of incorporating the provisions of these treaties into the national laws has the duty to fulfil the following obligations to its citizens. The government of Uganda has ratified, adopted more so incorporated international human rights principles with

[2] FN Ministry of Health et al v Treatment Action Campaign et al 2002(5) SA 721(cc); 2002 (10) BCLR 1033(CC)(5 July 2002)

[3] High Court of Kenya at Nairobi Petition No.409 of 2009, http://www.saflii.org/za/journals/LDD/2013/8.pdf
[4] ibid

regard to the right to health in the national laws in order to promote and protect the right to health for its citizens (WHO n.d.: 1)

Paragraph 34 of General Comment No. 14 says that, states have an "obligation to *respect* the right to health by, inter alia, refraining from denying or limiting equal access for all persons ... and abstaining from enforcing discriminatory practices as a state policy" (UN Economic and Social Council 2000). Non adherence to this provision can amount to a violation of the right to health (Maite 2012: 45). The "provision of health services should be ensured to all population groups on the basis of equality and freedom from discrimination, paying particular attention to vulnerable and marginalized groups" (Tarantola 2007: 12). Further to this, paragraph 35 of General Comment No. 14 states that countries have the obligation to *protect* health care service by taking up measures that do not "constitute a threat to availability, accessibility, acceptability and quality of health facilities, goods and services" (UN Economic and Social Council 2000).

The third and last obligation found on UN General Comment No. 14 entails government to *fulfil* human rights by adopting proper legislative measures and "to adopt a national health policy with a detailed plan for realizing the right to health" (UN Economic and Social Council 2000). In this regard, states can adopt any measures to ensure the all people have access to health facilities.*(Ibid*) Furthermore the obligations of the Uganda government have been emphasized under section 27 part IV of the recently passed HIV/AIDS Prevention and Control Act (2014), the government of Uganda has obligations to;

a. "Ensure the right of access to equitable distribution of health facilities, goods and services including essential medicines on a non-discriminatory basis;
b. Provide universal HIV treatment to all persons on a non-discriminatory basis;
e. Promote awareness of the rights of persons living with HIV and duties imposed on persons under this Act;
f. Promote and ensure non-discriminatory participation of people living with HIV and AIDS in government programmes" (Government of Uganda 2014)

It should be noted that the right to health is not directly stipulated under the operational articles of the 1995 Constitution of the Republic of Uganda (as amend), though implicit references can be drawn from different articles of the constitution like article 22 which provides for the right to life and article 21 which provides for equality and freedom from discrimination (Uganda 1995).
Thus the framing of the right to health underlies the claim that the people of Kalangala district also have the right to health and the government of Uganda has an obligation to respect, protect and fulfill this right, failure of this, amounts to a violation of people's human rights which ought to be redressed.

2.4 The Rights Based Approach to Health

Hausermann (1992) as quoted in Marks (2005) defines a human rights based approach to development as one that, broadly speaking, "puts people first and promotes human-centred development, recognizes the inherent dignity of every human being without distinction, recognizes and promotes equality between women and men, promotes equal opportunity and choices for all (…), promotes national and international systems based on economic equity, equity in the access to public resources, and social justice and promotes mutual respect between people..." (Hausermann 1992 as cited in Marks 2005: 28). Hausermann uses this definition in relation to health to show how a human rights approach "addresses the structural causes of poverty…(e)conomic and social inequalities and inequities are observable through differential health status. Poor health frequently reflects poverty and social marginalization" (Ibid: 28).

Human rights approach should seek to empower the vulnerable people, giving them a voice and power to participate in decision making as a means to changing their vulnerability (London 2008: 68). A rights based approach to health offers a framework for practical development and implementation of health policies and programs in a manner consistent with human rights and provides solutions for the violation of the right to health (London 2008: 70). In her arguments, she advocates for the exercise of human agency and human capabilities by individuals whose rights are being violated or about to be violated and criticizes the way in which government substitutes it duties with NGO or community action while neglecting the protection of vulnerable people (London 2008: 68).

Furthermore she says that a right frame helps to judge rights, allows a much clearer opportunity to establish accountability by "defining who is a right holder, who is a duty bearer, and what the nature of obligation is" (London 2008: 68). Other than holding only the states accountable, health professionals could also be held accountable for violations because in some instances "if employed by a state party, a health professional may become the instrument through which the state violates the right to health" (Ibid: 68).

A right based approach to health focuses on how to hold duty bearers accountable, not only the government but also other stakeholders involved in ensuring the right to health. More to this the right based approach advocates for human agency as a way of empowering right holders to claim for their rights. Yamin (2009) States that, in a "rights framework people have the capabilities to develop their life plans through the exercise of human rights" (Yamin 2009: 6). This means that individual have to rely on human rights principle in order claim for their right from right holders and in most cases they are the people in power. Thus Yamin (2009) advocates for the participatory approach in policy making and implementation because she believes through participation different groups of people can air out their view that have always been suppressed by those in power (Yamin 2009: 7). She goes on to argue that "all affected parties should have an equal opportunity to be part of the process. The process is also to be transparent; the participants need to understand the information that is related to the issue at hand, in order to make the best possible decisions" (Yamin 2009: 8). As much as the participatory approach is criticized for taking into consideration opinions of only those that are in the participatory group, Bill Cook (2001) as cited in (Yamin 2009: 1), I still to agree with this kind of approach in realizing the right to health for the fisher folk communities in Kalangala because their grievances are the same thus their opinions are not any different. Thus while analyzing the rights based approach, the participatory approach to realizing the right to health will be one of the guiding principles as to how socially disadvantaged groups like FFC in Kalangala can realize their right to health. However in order to enjoy human rights communities have to have the knowledge about these rights. Kalangala District and its islands, largely isolated require a lot of rights advocates and community services to fully or partially understand what entails human rights. In this case, the right to health will require them to demand for the necessary health posts on the islands and would not have to depend on the mainland. Thus lack of valuable knowledge on human rights is costing them. A rights based approach to health is necessary in all communities if development is to be achieved. Healthy people produce and eagerly provide for their families and nation. However the scourge of AIDS is leaving many abled men and women bed ridden in the time and age when ARV drugs are available and different initiatives are being made to ensure access to ARVs. Commitment to empower communities and putting PLWHA first will ensure the fulfilment of the right to health and thus the success of the rights based approach on Kalangala's islands.

2.5 Global Health Justice Approach

Globalization is associated with the aggravation and acceleration of the spread of disease across borders, causing a very big challenge for states to manage on their own (Ruger 2009: 1). Hence the theory of global health justice advocates for ways in which health injustices and inequalities can be addressed and minimised among different states and also between states and their nationals (ibid:1). The global health justice approach embraces the concepts of health capabilities, health agency and health functioning as well as the efficiency of healthcare systems on responding to the needs of all the population without discrimination but rather with an aim at giving opportunities to all people to achieve their health capabilities (Ruger 2009: 264).

Jennifer Ruger was among the first scholar to develop a global health justice theory (Mugarura 2011: 16). She is of the view that 'in order to reduce health inequalities, countries with better health prospects should assist other countries which cannot achieve better health on their own' (Ruger 2009: 261). She expounds on health capability paradigm by focusing on equal access to health care and assesses the impact of health care on individuals capability to function while arguing that health capabilities should focus on reducing health gaps among different individuals irrespective of their race, class, gender and social status (Ruger 2010: 140-141). Ruger links the capabilities approach with the rights perspective when she argues for human flourishing and human agency as entitlements to all people by virtue of being human while advocating for respecting people's dignity. She states that, 'human agency constitutes human flourishing because people flourish by being able to make their own decisions and choices' (Ruger 2012: 36). On the other hand, health agency is the ability of people to make their own decisions involving their health in a favourable environment without injuring others (Ibid: 36).

While analysing the issue of health inequalities and health policy evaluation, Ruger (2009) argues that central health capabilities should be the focal point of global health policies to address health disparities regardless of social settings and location of the people(Ruger 2009: 7-8). She later on asserts that central health capabilities should be considered first before the non-central health capabilities while evaluating health policies (Ruger 2010: 76). Another term that was brought up due to more research on the health capability paradigm and health inequality is the *"shortfall equality method"*. Ruger (2009) explains that the *short fall* method considers a turn to proportional allocation and to partial equality through different lenses of equality as a means towards health care access (Ruger 2009: 269). This is so because there is no such a thing as equal right to health worse still equal access to medicine because of the different social settings in countries. The "shortfall equality [method] can be used to assess quantitatively how much a given society has realized its health potential and how much remains unrealized" (Ruger 2009: 269). Such measurements help in estimating how resources have been prioritised and maximised for the society's potential in achieving health possibilities (Ibid: 269). For the case of Kalangala fisher folk communities, the shortfall equality would serve as a tool to measure and investigate health inequalities compared to their counterparts on the mainland.

Ruger (2010) notes that health "capabilities represent the ability of individuals to achieve certain health functionings and the freedom to achieve those functionings" (Ruger 2010: 81). Thus the global health justice theory and rights framework aim at enhancing people's capabilities wherever they are therefore this theories will be relied on in analysis the ways in which government has facilitated individuals and societies that are disadvantaged by the inadequate access to antiretroviral drugs to exercise their health agency and functioning to achieve their central health capabilities. Furthermore these theories will be relied on to analyse the duties of different players like the government, civil society and individuals in achieving health equality.

2.6 Understanding Health Inequalities

According to Whitehead (1992) "equity in health implies that ideally everyone should have a fair opportunity to attain their full health potential and, more pragmatically, that no one should be disadvantage from achieving this potential, if it can be avoided" (Whitehead 1992: 7). Braveman and Gruskin (2003: 254) are of the view that there is equity in health when there is an absence of health disparities between dissimilar social groups (Braveman and Gruskin 2003: 254). Since equity means social justice or fairness, health inequalities are considered to be unfair and unjust since they further place groups of already underprivileged people "at further disadvantage with respect to their health" (Braveman and Gruskin 2003: 254).

Health inequalities should happen in an organised way capable of being avoided in order not to create variations among people (Whitehead 1992: 219). Health inequality must be "systematically associated with social advantages, and association must be important and persistent, not irregular" (Starfield 2001: 254). It should be noted that the unequal distribution of health care not only focuses on health care services but also other inter connected services that are vital for a functioning health sector (Braveman and Gruskin 2003). Le Grand (1982) as quoted in Whitehead (1992) is of the view that for health inequalities to be unfair it "seems to depend to a great extent on whether people chose the situation which caused the ill health or whether it was mainly out of their direct control" (Whitehead 1992: 6).Hence the existence of inequalities calls for equity in health care.

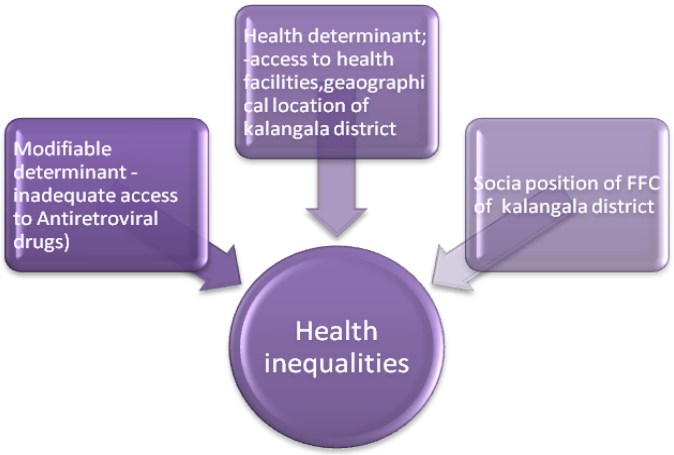
2.7 Measurement and indicators of health inequality

Braveman (2006) mentions that

> "Measuring a health disparity requires three basic components:
>
> (a) an indicator of health or a modifiable determinant of health, such as health care, living conditions, or the policies that shape them;
>
> (b) an indicator of social position, i.e., a way of categorizing people into different groups (social strata) based on social advantage/disadvantage, such as income, education, ethnic group, or gender; and
>
> (c) a method for comparing the health (or health determinant) indicator across the different social strata, such as a ratio of the rates of the health indicator in the least and most advantaged strata" (Braveman 2006: 187). This diagram is the researcher's creation showing how health inequalities can be measured. The diagram above shows how different social determinant like accessibility of health centre, education centres, social position and inadequate access to antiretroviral drug can lead to health inequality in a given society depending on the setting.

Identifying health inequalities between the disadvantaged fish folk communities of people situated in Kalangala district as compared to their counterparts on the main land will lead to analysing the causes of these inequalities in health and how the right based approach to health and global health justice principles can be used as tools for eliminating these health inequalities within the country.

Figure 3: Determinants of Health Inequality



Source: (Author/Based on Braveman 2006: 187)

Furthermore, in the later chapters, it will be analysed whether It is justifiable for people to miss out on essential treatment because of their social position in society. It should be noted that health inequalities faced by social groups like fisher folk communities involves injustices which are violations of the right to health. Also lack of basic health services and primary healthcare leads such children to grow up malnourished. The magnitude of health inequalities experienced on islands such as Kalangala needs to be further researched in order to come up with rapid solutions to provision of basic health care.

Chapter 3: Understanding the Social Determinants and Health behaviours of Fish Folk Communities

3.1 Introduction

Different authors and reports have showed that fishing communities are one of the most at risk populations to HIV/AIDS in Uganda (IRIN. 2012, Allison and Seeley 2004, Opio et al. 2013, Uganda Aids Commission 2012) The same evidence attributes social determinants as the main cause of the fisher folk community of FFC of Kalangala district from being left out from accessing antiretroviral drugs. Others say It is due to the risky behaviour of the FCC. Therefore, this chapter seeks to analyse the synergy between social determinants and health inequalities with regards to FFC of Kalangala district, and what the government has done to promote the right to health of the FFC of Kalangala district.

3.2 Social Determinants

Blas and Kurup (2010) claim that "structural determinants and conditions of daily life constitute the social determinants of health and that they are crucial to explaining health inequities" (Blas and Kurup 2010: 5). In addition, these can include the "distribution of power, income, goods and services, globally and nationally" (Ibid: 5). These factors affect how services are allocated thus shaping health care outcome and allocation of health care resources (Ibid: 5). It should be noted that social determinants like schools, access to health centres and roads and working conditions are interrelated services that affect access to health care services either negatively or positively and in the end can bring about health inequality among different social groups. Inequality in health is a term used to mean "systematic, avoidable and important differences" (Whitehead 1992: 5). The existence of conditions in a society that can be avoided due to some reason, cause health inequalities. According to Whitehead (1992) some of the determinants of health differentials are: "exposure to unhealthy, stressful and working conditions [and] inadequate access to essential health and other public services" (Whitehead 1992: 5). Thus It is prudent to analyse the social determinants of health in Kalangala district that include, health service centres, and education services and the life style of fisher folk. There needs to be a comparison study on fish folk community within African states in order to analyse the extent to which differences and similarities determine the social determinants. Such analysis can inform the basis on provision of basic healthcare services to search islands and locations. Social determinants are brought about by living, growing and ageing together in a given society as defined above, understanding how social behaviours can be improved would help in modifying and transforming negative behaviours to more acceptable healthy behaviours for generations to come.

3.3 Geographical Accessibility of Kalangala District

Geographical accessibility refers to the "relative ease (...) by which health services can be reached and utilized by a population when and where the services are needed" (Boscoe 2013: 143). Thus a shortage coupled with people travelling lengthy distances to access health services may limit access to health services and cause "possible geographic disparities in health service utilization rates" (Ibid: 143). Geographical accessibility can either be assessed through the "provider-to-population ratio (or supply-to-demand ratio)" which aims at analysing the geographical dissemination of health resources (Boscoe 2013: 145). WHO considers medicines to be geographically accessible if a facility is within 5km from an individual or one hour's walk (Kibira and Hasunira 2012: 26). It is further argued that health care requires adequate supply of health services available, where every person can obtain health care whenever needed (Guilliford et al 2002: 186).

Kalangala district is located in the southern central part of Uganda. As explained in chapter one, the most of the small islands are inhabited. However, with over 11 health centers, the data shows that to be able to control the situation, 5 or more HC are needed. Health centers need qualified personnel, but in this case, these are unavailable and/or unwilling to relocate due to geographical challenges (Uganda Aids Commission 2003:20). The government is doing their best to try and guarantee the delivery of health services, however regarding AIDS treatment, it is hard to say how equipped the HC are. Earlier information showed that there are no sentinel sites nor voluntary counseling and testing centers (VCT). On a positive note, the 2 health centers type IV, at least cater for HIV/AIDS patients are research by Kibira and Hasunira (2012: 20) showed.

More to this, health infrastructures and transport mechanism leading to the district are limited, most health facilities are understaffed or have no qualified health workers[5]. It was further discovered that, "drug delivery to districts can take about double the time foreseen and that It is difficult to get feedback from the National Medical Stores (NMS) on placed orders that make it hard to address potential bottlenecks" (Windisch et al. 2011: 3). More to this, Kalangala district is isolated and delineated from the main land and this makes accessibility to the island very expensive. According to the research carried out by Kibira and Hasunira (2012), high transport costs incurred during the delivery and accessing health services in Kalangala was identified as a major challenge in delivering health services to the district. Transport to Kalangala district is expensive and its time consuming to access the island. It takes about "*12 hours of a boat ride and when the lake is turbulent it might take days to connect to the mainland*" (Kibira and Hasunira 2012: 21). Peter Kyambade a MARPs coordinator at the ministry of health said that "*HIV interventions among fishing communities in Uganda remains low and a big challenge because most of the people stay in islands, that are hard to reach and lack health facilities"* (IRIN 2012). While doing secondary data collection I noticed that the biggest percentage of reports and articles attribute the 'poor health service delivery' to the geographical location of Kalangala district. hence the geographical location of Kalangala district in and isolated and hard to reach area is a factor that that is causing health inequality in the away that affects both service delivery and health seeking behaviours of the people in Kalangala district because they find it expensive to access health services. Some of them end up giving up on treatment while others move to towns were health services are easily accessible.

Uganda prevention efforts do not address structural barriers and neglect fishing communities (Indevelop 2014: 12). In the end these conditions have persistently placed the HIV/AIDS infected people like those situate in Kalangala district at a more disadvantaged side than their counterparts living in easily accessible areas of Uganda with regard to accessing health services. In some fishing communities, association members were angry that they and their needs were ignored by the government of Uganda and local governments even though their endeavours "feed Kampala" and are thus of economic importance[6]. They lamented that 'government sets more priority on the wild life in the national park than the fishing communities'.[7] Thus the in accessibility of Kalangala district makes it hard for both the service providers and patients to have access to antiretroviral drugs in Kalangala district. Such difficulties contribute to the fact that resources are accumulated in easily accessible areas of the country while others are under served thus causing health disparity between the fisher folk communities and those on the mainland.

[5] http://ntv.co.ug/news/local/10/oct/2014/kalangala-dispatch-difficulties-accessing-education-and-healthcare-islands#sthash.aRR7dtNr.dpbs

[6] Detailed Evaluation Findings across the NSP Thematic Areas http://um.dk/en/~/media/UM/Danish-site/Documents/Danida/Resultater/Eval/201401AnnexF.pdf

[7] Ibid

3.4 Education levels of the FFC of Kalangala District

Fulfilling the right to health entails addressing different interrelated issues like education that will impact on the health seeking behaviours of individuals and also a society as a whole. Tarantola (2007) is of the view that the "burden of disease is dependent on the unequal capacity of individuals to access information, understand the risks to which they have been exposed, and acquire the ability and freedom both to reduce these risks and to access preventive and care services when needed" (Tarantola 2007: 23). When people are educated, they are able to make good choices about their health, find information about their health, and engage in different activities that can enhance their wellbeing since they can comprehend the importance of being healthy thus work towards having a good and healthier life style (Barr et al 2011: 401). Education is a form of empowering people to be able to analyse good from bad, healthy to unhealthy, people also get know what the government and other stake holders owe them and they can easily organise themselves to achieve health needs and also take up the initiative to know about their health status. In brief, education is a tool for empowering people to charge and take control of their lives. It is stated that, through empowerment HIV treatment interventions will be successful (Barr et al. 2011: 401). I would say that the biggest percentage of health seeking behaviours is influenced by a persons' educational level.

Evidence has showed that Kalangala district is characterised by high illiteracy levels due to a big number of school drop outs that opt to go and engage in the fishing business with their parents at the time they are supposed to be in school. Findings show that majority of the population in Kalangala district has received only minimal or no education. According to a report by Kabira and Hasunira (2012) only 53% of residents in Kalangala had attained primary level of education (Kibira and Hasunira 2012: 9).

Table 2 Education levels in Kalangala District

Education Level	Frequency	Percentage
Never been to school	15	11
Primary/Junior level	71	53
Secondary	44	33
University	4	3

Source: (Uganda Aids Commission 2003: 13)

Surprisingly, the information in the table above is adopted from a report of the year 2003, however also current reports like the one of Kibira and Hasunira (2012) have the same information 12 years down the road. According to my observation as a Ugandan citizen, the primary/junior level is for age groups 6-12 year olds and secondary is from 13-18/19years and university level 19/20-24. Hence as per the findings above, the age at which an individual is much more able to comprehend and understand crucial matters about their health, is where the majority of students drop out of school. As you can see only 3% have attained university education and a bigger number of students drop out at secondary level too. More evidence revealed that 46 fishing landing sites were surveyed by the Lake Victoria Basin Commission (LVBC) in 2010, only seven (15%) had schools (KMCC 2014: 19). According to the above information, the district does not even have universities. It is said that in order to address health inequalities, the root causes of that inequality should be dealt with instead of relying on health care sector. Policies will not have an influence on people if they can't appreciate them (Whitehead 1992: 222). Education is one of the key factors of addressing conditions that create vulnerability

and by addressing the shortfall in education there will be change in the attitudes of the people in making choices about their health.

In Article 25 (1) of the UDHR the connection of living conditions and health is explicitly acknowledged, and it is noted that "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services" (UN General Assembly 1948). Therefore this provision calls on governments as duty bearers to exercise equitable distribution of health services within the country and other interrelated services like schools, roads and good sanitation. However, it should be noted that, not only health services are required for realizing the right to health but also other social determinants that are related to the realisation and enjoyment of that right. Thus I am inclined to say that social determinants are proxies to the right to health, as health functions are proxy to health capabilities (…) in that an impairment in an individual's health functions reduces his or her health capability' (Ruger 2010: 81). Thus the absence of one social determinant will hinder the supply of health services and cause health inequality. The argument above tries to propagate the fact that there is health inequality which calls for health equity; however it should be noted that equity in health is a fairy tale that we all dream of and fantasies about. Thus the right word to look for in health services most especially with regard to access to antiretroviral drugs should be fair distribution as according to need. Even advocates for eradication of health inequalities like, Margaret Whitehead dispute the fact that there can ever be health equity but rather advocate for fair allocation of health determinants so that people can access health care service. Hence (Marmot 2005: 1103) notes that the improvement on the status of the social determinants will also lead to the improvement of the health sector and service provision for societies.

3.5 Risky Behaviour of Fisher Folk Community (FFC)

A right based approach to health entails the rights holder to be part of the implementation of policies and also to actively participate in the realization of the right to health. Concerning this, I argue that the attitude attached to the character of fisher folk has led to service providers to neglect these kinds of people and less effort is used in ensuring equal access to antiretroviral drugs. A critical question was put forward by (Seeley and Allison 2005), of whether "occupational or social groups that pursue a high-risk lifestyle 'deserve' equal access to treatment?" (Seeley and Allison 2005: 693) and this is what seek to answer. Fishing communities are part of the occupational groups marked as MARPs to HIV/AIDS. Risk has been said 'to be a loss of fundamental interests which are not protected and which are potentially exposed to being harmed or that they are vulnerable to harm' (Straehle 2014: 198).The vulnerability of people in fishing communities is attributed to their life style. Fish folk are characterised as freckles, risk takers with a '*reckless attitude'* towards contracting HIV (Westaway et al. 2007: 664). Fisher folk are amongst the most vulnerable (and at risk of HIV) occupational groups because of their life style which is characterised by high mobility, irregular working hours, high consumption of alcohol, prostitution and remoteness from infrastructures that leads them to being left out on ARV treatment intervention even if programmes are massively scaled (Hemrich and Topouzis 2000: 90, Seeley and Allison 2005: 689). It should be noted that each country's most at risk is determined and defined basing on populations that are particularly vulnerable and key to the epidemic[8].

In addition to this, "fishing itself is a high-risk occupation and this may contribute to a culture of risk denial or risk confrontation among fishermen" (Westaway et al. 2007: 664). Thus some

[8] For more, see the World Health Organization's HIV/AIDS definition of key terms, June 2013. http://www.who.int/hiv/pub/guidelines/arv2013/intro/keyterms/en/

researchers have come to the conclusion that fisher folk communities are groups that are hard to reach with "long-term therapy and support" (Seeley and Allison 2005: 694). With such attitudes and perception, fisher folk community take less initiative in accessing the available health care service on the less taking the necessary measures of protecting against contracting HIV. Furthermore, other research has showed that the stereotype attached to people in fishing communities as freckles and risky taking fishermen, with high levels of prostitution "may stigmatize these communities as undeserving of support and care (...) [and has contributed to them being] left beyond the reach of prevention, treatment, and mitigation efforts" (Westaway et al. 2007: 666). Considering also the rampant migration of fish folk, consistency in health service provision for patients on ARVs will be difficult (Seeley and Allison 2005: 694). As analysed above, most fishermen are passers-by and hard to keep up with them in any given medical initiative. Not forgetting that AIDS patients require ongoing monitoring on the mode of treatment, other than that health service providers find it difficult to deliver services to untraceable people such as "geographically mobile, seasonal or long-term migrants or even, in some cases, nomadic" (Acheson et al. as cited in Seeley and Allison 2005: 690).

While some authors have raised the question of whether social groups that pursue a high risk lifestyle don't deserve equal access to treatment (Seeley and Allison 2005: 693), others argue that access would be determined by the availability of ART in a particular country (Kasper et al. 2003: 21) and Gilks (2001) says that even if government wanted to ensure access to such people, it will not have the necessary resources to access them and being a competitive environment for access to ART, the elite and those situate in easily accessible areas of the country will end up having the treatment thus causing further inequalities (Gilks 2001:14) 2001:14). However I am of the view that government has the obligation to full fill, respect and promote the right to health because human rights are universal with undue regard to a person's location status, race as long as they are human beings (Sabine et al. 2010:11). Therefore government should carry out its obligation regardless of the people's lifestyle and location. Once government takes the initiative to implement policies for fisher folk communities, they will also have a change in their attitude towards and life style once they realise that their *freckles* and *risk taking* lifestyle is working against them and setting them apart from the other parts of the country.

Ruger (2010) states that, "health agency includes not only health knowledge but also effective decision-making about health, self-management and self-regulation skills, and the ability to control personal and professional situations to pursue health, among other important qualities" (Ruger 2010: 147). Thus the FFC in Kalangala district should refrain from harmful and careless practices that are exposing them to risk of contracting diseases. Furthermore they should participate in activities and programmes for HIVAIDS, and seek for help when necessary. Thus to ensure that everyone has the capability to be healthy, health norms must be scrutinised that bear on cultural and personal choice so that people can reject harmful practices that have a negative impact on the capability to prevent and treat diseases (Ruger 2010: 148).

Health agency is required at the collective level to "promote health norms that are scientifically valid and non-discriminatory. Health agency is necessary also to create an effective and accountable public health and health care system, one that interacts with individuals to build their health agency and provides medically necessary and appropriate care on a cost-effective basis" (Ruger 2009: 271). Therefore groups within societies should be given an opportunity to exercise collective health agency to demand for "conditions enabling good health especially through public health and health care systems" and to promote institutional reform through political process (Ruger 2009: 271). The various social determinants put some people in isolations which contribute to their inadequate access to health services. For example; access to antiretroviral drugs since It is too expensive to access especially in excluded locations and in turn it leads to

health inequalities where health services are mainly situated in easily accessible parts of the country. However this should not deter government's efforts to achieve its goals of universal access to antiretroviral drugs for those in need.

Chapter 4: The Multisectoral Response to Equal Access to Antiretroviral Treatment in Kalangala District

4.1 Introduction

It is well established that Uganda has a national obligation to respect, protect and to fulfil the right to health however, it is still debatable as to whether other countries have an international obligation to fulfil the right to health on behalf of other states although it is clear that poor or developing countries have the obligation to ask for international assistance (Sabine 2010: 53). It is stated that, countries with better health prospects should offer assistance to other countries in worse conditions in order to bridge the gap caused by health inequalities (Ruger 2009: 261). Multiple sectors in any country are important in bringing about positive health results. Strengthening health systems at country level needs synergies between governments and other multi actors. Thus this chapter will focus on how important the multisectoral response has been in achieving positive health results. Since the early onset of HIV/AIDS multiple sectors have joined forces to provide for those affected. Human rights based approaches are meant to empower the poor people to be able to know and demand for their rights but sector support on this is still lacking. There is a link between sectors be it in the water, environment, transport, infrastructure, education, or public services. Kalangala district may be isolated but it is not excluded, thus analysis will be drawn on what government and stakeholders are doing on ensuring universal access to antiretroviral drugs in such circumstances.

A multisectoral response to health is very crucial when it comes to HIV/AIDS. It is also common knowledge about the burden of AIDS care to duty bearers. Not forgetting that the cost of AIDS treatment triples any other health needs and with some countries like Uganda that cannot afford to independently cater for its HIV/AIDS patients hence the need for a multisectoral approach to Health. A multisectoral approach brings together all actors for a common good. Many HIV/AIDS health problems can be fully or partially solved by joint ventures from different sectors. Partnerships, teamwork and collaboration are needed in order to improve healthcare to vulnerable populations. Civil society plays a major role in bringing primary health care closer to communities but a larger and coordinated response is needed for lasting results. Bringing health care services closer to those that need them is the role of the government and failing to do so becomes a violation of the right to health. Even with the burden of AIDS service provision, these responsibilities should not be neglected (Maite 2012: 48).

4.2 Multisectoral Response towards Equal Access to ART

Moving "towards universal access is an extraordinary commitment by world leaders, signalling the political will to devote the resources and energy required to end AIDS" (UNAIDS 2006: 8). As a result, different projects and organisations have been set up to raise funds to be used in resource limited countries like Uganda and enable them afford essential drugs. For example, in 2002 the Global Fund to fight AIDS, tuberculosis and malaria was set up to raise funds through public and private donations and in "2003 President George Bush dedicated 15 billion dollars for the fight against AIDS, and the World Health Organization (WHO) launched the 3 x 5 initiative aimed to deliver antiretroviral treatment to 3 million people in low and middle-income countries in 2005" (Giuliano and Vella 2007: 315). All "state [parties] … undertakes to take steps, individually and through international assistance and cooperation, especially economic and technical, to maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means" (Sabine et al. 2010: 50). General Comment No. 14 in its Paragraph 43(d) clearly stipulates that, "*state parties are obliged to provide essential drugs, as from time to time defined under the WHO Action Programme on*

Essential Drugs and to ensure equitable distribution of all health facilities, goods and services" (UN Economic and Social Council 2000). This right is however said to be progressively achievable depending on the availability of resources within the country (Hestermeyer 2008: 103).

Over the years, Uganda's "annual spending for HIV/AIDS has [increased] from $270.2m in 2007/08 to $378.3 million in 2010/11" (Uganda AIDS Commission 2012: 12). However these amounts do not include contributions by the Government of Uganda. The Percentage contribution to the overall resource allocation is said to have increased from 5.2% to 10.5% between 2007/08 and 2009/10 (Uganda Aids Commission 2012: 13). As much as AIDS expenditure increases, also the number of people eligible for ARV treatment increases as well as the cost for treatment. For instance Uganda has 540,000 PLWHA eligible for ARVs yet to achieve this it will need about $270m annually. This is more than the current per capita spending on health of only $25 (Uganda AIDS Commission 2012: 14). In brief "80% of the national spending on HIV/AIDS is funded through bilateral donors" (Ibid: 14). I argue that this can be dangerous for the country as it puts it at risk of having less decision making powers when it comes to projects that are likely to affect the lives of the population in need of health services. The lives of people in need are at a greater risk especially if the donors decide to pull out or reduce on the funding. This was actually witnessed early this year '2014' when Uganda passed the Anti-Gay Bill. Almost half of the multilateral donors completely cut funding and others cut it by half. The Joint Evaluation National Response to HIV/AID Report commented that lack of Uganda's funding commitment, and over depending on PEPFAR resources was preventing the national AIDS response which has led to leaving out 3million people (Indevelop 2014: 15). (Ruger 2012:8) has criticised donor support saying that the assistance given only complies with their interests rather than the countries. She argues that different donors have their own set of goals and objectives which dominate and effectively control policies and resource allocation decisions for their own goals and objectives.

However donors cannot be overly criticised because the funds they donate to developing countries have to be accounted for according to agreement. Accountability can be measured in terms of results on the ground to satisfy the curiosity of the people of goodwill who donate to the cause. Also donor funds are regulated and have to be spent cent for cent, although due to lack of trickle down of donor agencies from north to south has seen these funds being embezzled by southern organizations. The north- south divide is however decreasing as more northern based organizations have partner organizations in the south. A multisectoral response requires the participation and monitoring of actions from the onset of support. Apart from experienced personnel, developing countries count largely on the monetary value that partners provide. The support provided is meant to empower public and private institutions in managing increased support. This however entails capacity building top-bottom and vis-a-vis. However it is the role of government to ensure that services trickle down to all corners of the country. Lack of services due to geographical exclusions is a violation of the code of conduct that governs the country. In health terms this will be termed as the violation of the right to health. Thus the kind of multisectoral response necessary for the trickle down of adequate health treatment to the Islands of Kalangala has to be consolidated with rights based approach and government preparedness. In such responses, there is a need for trained personnel in different sectors capable of representing and responding to all the needs of the island people. As a district, there has to be joint ventures coordinated at the district level and capable of responding at the national level.

Although Uganda's government is intensifying its efforts to achieve universal access to ARVs countrywide, the kind of multisectoral approach it will need to achieve bringing services closer to the PLWHA on Kalangala Island requires leadership and a set of partners to coordinate the different and interlinking sectors. Local communities have to be empowered but also there has to

be political will and agency for those in need to be able to advocate and demand for better health services. This kind of multisectoral coordination can be effective and sustainable if PLWHA are part of the team. These are times that Ruger (2012) says "need ethical and moral commitment" (Ruger 2012:7). Multilateral and bilateral donors work hand in hand in order to support the different sectors within countries. These sectors are all interlinked and failure for one to perform may cause a backlash in service provision. For example Education, sanitation, transport, water and nutrition are interlinked for improved healthcare services for people living with AIDS.

4.3 National HIV/AIDS Strategic Plan 2011-2015 and the Fisher Folk Community

A health policy is defined as "a set of rules that regulates the kinds of access individuals have to the means of leading what they would consider healthy lives, among other things" (Straehle 2014: 201). while formulating a healthy policy, 'human heterogeneity which calls for treating people differently under a health capability paradigm has to be taken into consideration because individual and social variations affect the relationship between resources and capabilities'(Ruger 2010: 59). States must respect the right to health by coming up with health policies based on human rights principle and also ensures that there are national health systems in place to enforce these policies. (Maite 2012: 48). Thus health policy makers have to be careful not to formulate health policies outside the human rights frame because health is a human right and not simply a charity service(London 2008:67). Paragraph 54 of General Comment No 4 of 2000 is to the effect that "*formulation and implementation of national health strategies and plans of action should respect, inter alia, the principles of non-discrimination and encourage people's participation*" (UN Economic and Social Council 2000). Success of HIV treatment depends on the full involvement and participation of people living with HIV (PLWH)(Barr et al. 2011:400). However, evidence has shown that there is lack participation in HIV/AIDS programmes by the people in the grass roots that are mostly affected by HIV. Policies targeting FFC as MARPs have to be formulated with a bottom-up approach if they are to be effective. FFC understand better what works and what does not.

Uganda after evaluating the five year National HIV/AIDS strategic Plan 2007/08-2011/12 whose overall goal "was to achieve universal access targets for HIV/AIDS prevention, care, treatment and social support by 2012" (Uganda Aids Commission 2012: xiii) formulated the National Strategic Plan of 2011-2015 which set out to address and guide the "key priority areas for the national response" to universal access target for HIV/AIDS prevention, care, treatment, social support and protection by 2015 (Ibid: xiii). Strategic objective 1 aims at increasing "equitable access to ART by those in need, from 50% to 80% by 2015" (Uganda Aids Commission 2012: 25). The specific goal of the NSP aims at building an "effective and efficient system that ensures quality, equitable timely services by 2015" (Uganda Aids Commission 2012: 30). However evidence has showed that there are no policies specifically drafted to address the issue of unequal access to antiretroviral drugs and prevention of HIV/AIDS in fishing communities (KMCC 2014: 7). Whitehead (1992) notes that, "national health policies designed for an entire population cannot claim to be concerned about the health of all the people if the heavier burden of ill health carried by the most vulnerable sections of society is not addressed" (Whitehead 1992: 4).

Policy formulation entails carrying out efficient research in order to assess the magnitude of the problem so that it can be efficiently planed for (Whitehead 1992: 225). Implementation of these policies is still lacking and minimal, even the monitoring and evaluation systems are said to be weak and inadequate. For example, it was reported that the NSP does not monitor and evaluate its objectives and defined goals or show how to measure the performance of the process for managing the epidemic (Indevelop 2014: 47). More evidence shows that health policies are inadequately circulated, causing an uninformed implementation of decisions to be made or

national guidelines not to be followed. (UAC 2009: 25). Some of the gaps and challenges of the previous National HIV/AIDS Strategic Plan 2007-2012 included lack of data, inadequate research evidence and "weak National AIDS Documentation Information Centres (NADIC) for "synthesized data that would guide [future] policy decision-making" (Uganda Aids Commission 2012: 14). Certainly this possesses questions on the legality and magnitude of the problem if there is inadequate documented information to help inform policy planning for MARPs for the next strategic plans. Furthermore, strategic plan is guided by the principles of human rights. For example, non-discrimination and equality. In this scenario, equality would mean that all people have equal rights and equal access to health services. However a description and guideline on how to implement and achieve equal and universal access is lacking and translation into an operational and practical manner is not visible because human rights are only rhetorically applied.

This being said, I believe that the policy drafting objective is to please the donors and that human rights activities raise false hope in unsuspecting members of society by giving them an impression that human rights principles will practically be adhered to while implementing such health policies. My belief is strengthened by Fortman (2006) who argues that as much as human rights exist, they are never implemented and the violations are hardly redressed. This is due to the "inadequacy of law as a check on power, and second, the lack of receptivity in many cultural and politico- economic contexts" (Fortman 2006: 35). However, Uganda has drafted different polices and strategic plans as a means of addressing the issue of HIV/AIDS prevention and treatment with the aim of delivering health services to the people. Implementation of these policies is still lacking and minimal, even the monitoring and evaluation systems are weak and inadequate. This leads to the inadequate provision of health services to the people.

Furthermore, General comment No 4 of 2000 paragraph 35 states that, "state parties should adopt legislation or take other measures ensuring equal access to health care and health related services provided by the third parties to ensure that privatization of the health sector does not constitute a threat to the availability accessibility, acceptability and quality of health facilities, goods and services to control the marketing of medical equipment and medicines by third parties*"* (UN Economic and Social Council 2000). Hence States have a duty to protect their citizens from any kind of infringement on their rights by third parties (Maite 2012: 46). In the same regard, states should guard against unreasonable prices for essential medicines and against other health practices that aim at excluding patients from accessing health services (Maite 2012: 47). Therefore Uganda has to adopt a legal framework aimed at protecting and ensuring that people have equal access to health services. Any kind of obstacle to the realisation and enjoyment of this right should be removed. Ruger (2012) warns against this when she talks about redistribution of resources and says that actors should have ethical commitment to making sacrifices and effectuating policies and programs that are beyond their self-interest (Ruger 2012:7). In this regard ethical commitment should not entail the profit oriented agendas of pharmaceutical companies and whoever stands to benefit out of the intellectual property to take into consideration of the right to health of people that need ARVs. Hence London (2008) calls upon "challenging injustices at all levels, local, global, micro- and macro-" … to "address the needs of the most vulnerable and most marginalized in their society" (London 2008: 72).

I am inclined to say that due to the above, there is poor health planning, participation, implementation and resource allocation of health services in communities since the government does not have a clear picture of what has been done, where it has been done and in what quantities so that they can measure what remains to be done. In my observation, human rights principles in health policies are rhetorically applied instead of practical implementation. Thus, I agree with (London 2008: 74) that a rights framework that recognises joint interests between states and their parties, communities and civil society is the way forward to building a consensus

with service providers for the realization of the right to health for those mostly affected by its violation.

4.4 Conclusion

In Conclusion, the above chapters have explored and analysed how important and unrealised is the right to health, even in countries that have ratified human rights treaties in regards to the right to health. Research showed that a lot is needed in order to achieve equal access to ARVs as a health right. Kalangala district fisher folk communities have been marked out for years as one of the most at risk areas to HIV/AIDS with a high HIV/AIDS prevalence. Throughout the years, Uganda has embarked on different projects to ensure universal access to antiretroviral drugs however, people in isolated places like that of Kalangala district have always missed out on the life saving treatment. Government and international stakeholder ought to take into consideration that, some policies adopted and favouring the realisation and exercise of the right to health. Thus, this has created health inequalities. Furthermore, government should devise means of policy formulation hand in hand with the people to whom the policies are being formulated for. To top it all, areas like Kalangala are already missing out due to their location which will further push them away. Furthermore profit driven and self-interest policy formulation should not supersede the right to health. De Schutter (2011) notes that "profit driven research serves the needs of the high value segments of the markets, while neglecting the real needs of the poorest and most marginalized groups"(De Schutter 2011: 349). Thus while redistributing resources one should have ethical commitment to making sacrifices and effectuating policies and programs that are beyond their self-interest (Ruger 2012: 7).

Chapter 5: Inadequate access to antiretroviral drugs in Kalangala Fishing Community: A Final Analysis

5.1 Key Findings

This paper aimed at exploring the question: *How has the inadequate access to antiretroviral drugs in Kalangala fishing community amounted to a violation of the right to health?* This question was answered through *three* interconnected analytical theories of rights based approach, global health justice and health inequalities.

In an attempt to understand how violations to health rights are being committed especially to geographically isolated communities like Kalangala Island, I explored and analysed the various circumstances that lead to some of these violations. However it remains quite unclear *how* and *what* the role of government, civil society and infected communities has been in ensuring that these fishing communities have adequate and efficient access to antiretroviral drugs. The research questions focused mainly on bringing out theoretical analysis on Human Rights Based Approach and Global Health Justice as the mechanism through which human rights violation can be addressed by the rights bearers and also how they can be claimed by the rights holders. Human rights are meant to be respected, promoted and fulfilled as stated in the Universal Declaration of the human rights (1948) and the International Covenant on Economic, Social and Cultural Rights (ICESCR), both of which are the most instrumental laws regarding the right to health. Also reviewed at an extent was the Global Justice Approach as advocated for by Jennifer Prah Ruger on understanding how health injustices and inequalities can be addressed and minimised (Ruger 2009, see also Ruger 2010, Ruger 2012). I also analysed the social determinants focusing on the fisher folk communities and trying to establish how social determinant like poor transport infrastructures, inadequate allocation of health service centres and creating favourable conditions for health service providers can result into health inequalities between different groups and such inequalities are the basis for health rights violations. To a small extent I look at how Fisher Folk Communities have been characterised and how their social behaviours are deemed as determinants to increased HIV/AIDS propagation within the district. However, important to understand and something that requires further research, is the kind of 'policy framing' needed for the integration of MARPs in the fight against HIV and how treatment can be accessed by these populations for the problem of inadequate access to antiretroviral drugs is escalading each year that goes by. For a clear understanding of actions necessary for the attainment of adequate HIV/AIDS services also an analysis on the multi-sectoral approach towards equal access to ARV treatment was explored.

Thus the final analysis and call for future research on health inequalities to isolated and hard to reach areas relies on three major themes as expounded below. These are all interconnected and help to search for an empirical study on the inaccessibility of treatment and services on islands geographically secluded.

5.2 Geographical Accessibility

Geographical exclusion has been researched in terms of indigenous people who are socially and geographically excluded in development programs. However due to the propagation of HIV to such closed groups, the culprit has been described as globalization. Globalization has made it possible for migration and social change to such isolated communities. And in response, the emergency of new and unknown diseases has been felt. For Uganda, Kalangala district as explained in chapters is geographically excluded with its 83 isolated islands and according to the

research findings, they are all inadequately supplied with health resources in that patients have to cross over to other districts. This isolation has made it difficult for provision of services. Also, this isolation has made it difficult for qualified health personnel and other health service providers to migrate from towns to such locations. Although the government of Uganda has made it possible to have minimal standards of health services at the mainland, people on the islands are still neglected. Also explained in earlier chapters, were the problems faced in accessing services on the mainland from the island. These included; schools, roads, and health centres. In wet seasons when the waters are turbulent, people at the island cannot access the mainland (Kibira and Hasunira 2012) in their research; they explained the geographical problems of living on an island like Kalangala. A boat ride that takes about 12hrs on a good day, may take days on a stormy day which leads to loss of valuable lives. The inadequacy of ARV drugs even on the mainland is more alarming as this causes more distress for PLWHA coming from the Island. Thus answers are minimal whereas many questions are unanswered. Questions to do with accountability measures put in place to monitor and respond to the suffering of people living on isolated islands. Questions about infrastructure, and what is being planned? How can the welfare of the people on islands be improved? How can communities be empowered to fight for their rights especially the right to health? In a geographically isolated and hard to reach area. Thus findings established that government still has a lot to do in order to fulfil its pledged obligation of respecting, promoting and fulfilling the right to health, to both the national and international stake holders.

5.3 Health Inequalities and Human Rights

It was proven without doubt in this research paper that the geographical location of people on Kalangala Island subjects them to health inequalities. The inadequate access to health services let alone the lack of ARVs in health facilities violates the right to health. There are certain instances when those in need search for unattainable services, however the Universal Declaration of Human Rights (UDHR) provides for the principle of universality of human rights. This entails the state to treat people equally and with dignity. To ensure that states are not pressured into achieving certain rights like the one in contest now, states are given a softer landing in a way that this right should be achieved progressively, depending on the status of the country and how much resources and external assistance they can get. However the findings have established how hard that will be without the proper monitoring and evaluation systems and information centres in place. To me such systems would be the starting points for analysing what missing, where is it missing and why is it missing thus I would say without such systems it will be hard not to violate the right to health because health resources will be allocated in the wrongs place. Furthermore, human rights are also inter-dependent, and interrelated in that the realisation or violation of one right may affect another inter related right.

It should be noted that the research never talked about non availability of ARVs in the country but rather accessibility of ARVs, so the fact that antiretroviral drugs are available in the country but they cannot be accessed by those that need them is leading to violation of the right to health and tarnishing the government's efforts of availing these drugs. Thus while the government is taking the initiative to ensure that ARVs are available within the country, it should also endeavour to see that the other interconnected and related obligations of accessibility, acceptability and quality are address throughout the country and not only in the easily accessible parts of the country. London (2008), Braveman and Guskin (2003), Starfield (2001), Maite (2012) all associate health inequalities to human rights. Health inequalities in my research and in relation to people living on Kalangala Island and district, further found that it pushes these populations to more injustice, where services are irregular and unsystematic which does not guarantee any adequacy and equality to health care. Research on islands of Uganda and health care services is still raw,

and data is mainly unavailable. However the fact still remains that the geographical location of PLWHA on any Island makes it harder for them to attain the minimum health services and any claim to human rights violations maybe justifiable by location, circumstance and in-motion. In-motion in this view will be the speculated response from the government on policies and plans to come. Such responses are known to abate the rage of citizens and a wave of hope sets in as those living with AIDS succumb to their early graves. Research on Health inequalities has to be amplified in terms of geography. Any circumstantial evidence on health inequalities has to be fully researched in order to inform future studies on health inequality in geographically isolated locations.

5.4 Human Right Based Approach towards access to ARV Treatment

A Human Right Based Approach (HRBA) towards access to ARV treatment in my research analysis is one that puts PLWHA first. This approach is meant to empower PLWHA with knowledge on their rights and mainly on health rights. The right based approach from shifting for the traditional ways of waiting for services to be brought to them and encourages people to also engage in these processes of policy formulation and implementation in their communities by participating in the processes that affect their health. Thus agree with the participatory approach as put forward by Yamin (2009). This approach will also eliminate and change the top down method of policy formulation to a bottom up where those that will be affected by the policies are part of the policy formulation process. Thus involving fisher folk communities in policy formulation affecting them would help them also understand why there is inadequate access to antiretroviral drugs in their districts and they will join forces with the government and other stake holders to come up with policies and solutions that suit their life style. Furthermore, the existing support groups and service providers that are meant to help patients' access medical services are curtailed by poor remuneration, high transport cost and poor infrastructures in the district which as analysed in earlier chapters are some of the determinants to accessing health services. There their availability in good condition should be addressed by the responsible government bodies.

Furthermore, the research discovered that people's actions and agency is limited and it is mainly attributed to the life of the *Fisher Folk* community. This was explored in *Chapter three*. Thus, following Barr et al. (2011) there needs to be a "paradigm shift regarding the role of patients and communities in delivering health services" (Barr et al. 2011: 400). This two way shift gives focus and importance to issues that need propagation. As the number of AIDS patients increases so does the pressure on health ministries. A HRBA would not only empower PLWHA with knowledge on rights but it would also empower them on primary healthcare especially in places like islands. Such basic and strategic education explores the possibility of being able to withstand the inadequacy of health services and also devising meanings of mobilising what is missing. The researcher started with a perception that it was entirely the duty of the government to provide health care services and ensure that human rights are respected, protected and fulfilled. However by the end of the study it would I depart from that perception by following London (2008) and advocate for a rights-based approach to health that seeks to involve different players in achieving the right to health. Her theories depart from the customarily way of always talking the talk and never walking that talk, I would say its high time the rhetorical way of promoting human rights ended and practical implementation started. HRBA coupled with the support of stakeholders, partners and other multisectoral support will ensure continued defence and support in achieving the right to health in isolated places. Ruger (2010: 125) presses the need for states to reform and as such ensure the 'progressive realization of a right to health'. Putting people first does not exclude the state; rather it reinforces the work of the state by bringing the vulnerable people on the battle field towards achieving their goal. I found when collecting and analysing data that the *Fisher Folk*'s social behaviour can be used as a catalyst for change. It was noted that *Fisher Folk* community is more afraid of water than HIV/AIDS. Therefore, the HRBA would bring out

these behaviours for analysis through group appraisal while linking them to future goals and objectives. The fight against HIV/AIDS is paramount and achieving universal access to ARV treatment in Uganda should be paramount as well. Geographical exclusion of PLWHA will only create further discrimination and the situation on Kalangala Island is worse in a scenario where there are inadequate ARV drugs on the mainland and no health services on the island the gap between the people on the mainland and those in the island is widening and yet Uganda is being praised for being a success story in scaling up universal access to ARVs. Research should then be reinforced on how HRBA can be implemented in isolated locations.

5.5 Future research

Uganda has come a long way in fighting HIV/AIDS. On a global scale, Uganda is well recognised. However past success is blocking the present actions and as such HIV/AIDS indices in Uganda is on the rise. The future is still bleak and research should now focus on how Uganda can control the spread of HIV in MARPs. Especially MARPS in geographically excluded locations where services are unattainable and treatment is inadequate. Future research should be targeted to these populations in order to understand the changing dynamics towards AIDS propagation. We should also not forget that migration can clear the status of individuals from MARPS to ordinary people. Therefore research should target at how MARPS are evolving from space, place and time.

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