

**YANGON UNIVERSITY OF ECONOMICS
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**A STUDY ON THE CHALLENGES OF WOMEN LIVING
WITH HIV/AIDS IN SOCIOECONOMIC SITUATION**

**ZIN ZIN HTET
EMDevS – 60 (16th BATCH)**

DECEMBER, 2020

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MASTER OF DEVELOPMENT STUDIES PROGRAMME**

**A STUDY ON THE CHALLENGES OF WOMEN LIVING WITH
HIV/AIDS IN SOCIOECONOMIC SITUATION**

A thesis submitted in partial fulfillment of the requirements for the Degree of
Executive Master of Development Studies (EMDevS)

Supervised by:

Dr. Ni Lar
Visiting Professor
Department of Economics
Yangon University of Economics

Submitted by:

Zin Zin Htet
Roll No. 60
EMDevS (16th Batch)
(2018-2020)

DECEMBER, 2020

**YANGON UNIVERSITY OF ECONOMICS
DEPARTMENT OF ECONOMICS/APPLIED ECONOMICS
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This is to certify that this thesis entitled “**A Study on the Challenges of Women Living with HIV/AIDS in Socioeconomic Situation**”, submitted as a partial fulfillment of the requirements for the degree of Executive Master of Development Studies has been accepted by the Board of Examiners.

Board of Examiners

Professor Dr. Tin Win
(Chairman)
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Yangon University of Economics

Professor Dr. Ni Lar Myint Htoo
(Member)
Pro-Rector (Acting)
Yangon University of Economics

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(External Examiner)
Pro-Rector (Retired)
Department of Economics
Yangon University of Economics

Professor Dr. Khin Thida Nyein
(Member)
Pro-Rector (Acting)
Department of Economics
Yangon University of Economics

Professor Dr. Cho Cho Thein
(Member)
Professor and Head
Department of Economics
Yangon University of Economics

Dr. Ni Lar
(Supervisor)
Visiting Professor
Department of Economics
Yangon University of Economics

December, 2020

ABSTRACT

The daily lives of PLHIV are not easy. The stigma and discrimination are a major issue on PLHIV and it affected on social and economic. The person who is taking the treatment regularly and right time with right drugs will get the good outcome and he or she will achieve the good viral suppression situation. The objective of the study is to identify the common challenges and underlying causes of women living with HIV/AIDS that hindering the continuation of the treatment. The study was conducted to 120 of the female respondents who living with HIV/AIDS in Pyay. There are many factors affecting to the drugs adherence. They easily to missed to take the drugs when they face with the problem such as marital problem, financial problem, discrimination and lack of support from the family. These factors are the root causes to affect the adherence of the treatment. The method of the study is a mixed method of quantitative and qualitative approach. A study reveals that most of the respondents are struggling difficulty to get the treatment. The study highlights that providing psychosocial support and counseling is important and that can help to reduce the emotional unstable situation. The provision of psychosocial support and counseling can reduce the stress and reflect the way to manage the adherence and known how to balance the adherence and social problem.

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LIST OF ABBREVIATIONS

| | |
|--------|---|
| AIDS | Acquired Immuno-Deficiency Syndrome |
| APN+ | Asia Pacific Network of People Living with HIV/AIDS |
| ART | Anti-retroviral Therapy |
| CBO | Community-based Organization |
| CD4 | Cluster of Definition 4 (immune system, specifically the T cells) |
| FDC | Fixed Dose Combination |
| FHAM | Fund for HIV/AIDS in Myanmar |
| FSW | Female Sex Workers |
| GDP | Gross Domestic Product |
| HIV | Human Immuno-Deficiency Virus |
| HTC | HIV testing and counseling |
| HTS | HIV testing Services |
| LGBT | Lesbian Gay Bisexual Transgender |
| MSF | Medicines Sans Frontiers |
| MSM | Men who have sex with men |
| MOHS | Ministry of Health and Sports |
| NGO | Non-government Organization |
| NSP | National Strategic Plan |
| NTP | National TB Programme |
| PLHIV | People Living with HIV/AIDS |
| PMTCT | Prevention of Mother to Child Transmission |
| PrEP | Pre-exposure Prophylaxis |
| PWID | People who Inject Drugs |
| STI | Sexually Transmitted Infections |
| SHG | Sub Health Group |
| SDG | Sustainable Development Goals |
| TB | Tuberculosis |
| UNAIDS | Joint United Nations Programme HIV/AIDS |
| UNDP | United Nations Development Programme |
| UNFPA | United Nations Population Fund |
| UNICEF | United Nations International Children's Emergency Fund |

LIST OF ABBREVIATIONS (Continued)

| | |
|--------|--|
| UNODC | United Nations Office on Drugs and Crime |
| USAID | United States Agency for International Development |
| US CDC | United State Center for Disease Control and Prevention |
| WFP | World Food Programme |
| WHO | World Health Organization |

CHAPTER I

INTRODUCTION

1.1 Rationale of the Study

Infected person's immune systems are attacked by the Human Immunodeficiency Virus (HIV). The body is unable to resist infections caused by bacteria, fungi, and other viruses due to lowered immunity. Acquired Immunodeficiency Syndrome is the early stage of this illness (AIDS). HIV multiplies in the body if it is not handled. If the infected person is not treated, he or she becomes frail, ill, and eventually dies (WHO, 2018).

Health can be considered as a fundamental human right and a worldwide social goal. A healthy person would easily asset to any of society. On the other hand, the illness caused by Human Immunodeficiency Virus (HIV) and its possible fatal consequences is a major health challenge. Could not finding to be cure or vaccine is the enormous number of debilitating illnesses and deaths that will be caused by the rapid spread of HIV in globally, is a main developmental problem with far-reaching effect beyond the health sector. Acquired immunodeficiency Syndrome (AIDS) is becoming a major cause of adult mortality that challenges conventional views of public health progress” (Myo Mie Mie Tun et al., 2019).

In the past decades, Edward and Klatt (2017) stated that HIV infection has been a major public health challenge contributing to high disease burden globally. In 1996 the researchers could invent Antiretroviral Therapy and this treatment is helpful for health and it can improve life expectancy of People living with HIV (PLHIV) worldwide Death case that related with AIDS have been reduced by more than 51%. Similar trend in Myanmar, between 2010 and 2017, the number of AIDS-related deaths has fallen by 49%. However, in 2017 the number of PLHIV persist of 0.7% among adults ages 15–49 years (UNAIDS, 2019)

HIV is not curable and it can be affected on life expectancy and all of the people who living with HIV must need to take the treatment for life long that directed prescribe by medical doctor. There is much discrimination in some of the issue especially in Education, Employment, Health, social communication, cultural issue, and mental health issue. Stigma and discrimination are barriers to get health assistance because of some of the norms and dignity portion. Some of the women are facing with stigma and discrimination in health seeking process and some working environment. For example, during the delivering period they have got discrimination from family as well as in hospitalization duration, gossiping and cheating in working environment. There has some domestic violence in our country related with HIV and this status become the problem for the marriage life. Women are play a role in house wives, bread winner, also be the care taker for the families so they are facing many difficulties than other person.

According to the data of USAIDS 2019, 36.7 million (34.0-39.8 million) people were living with HIV at the end of 2015 globally. An approximation of 0.8% (0.7-0.9%) of adults aged 15-49 years worldwide is living with HIV, although the burden of the epidemic continues to vary considerably between countries and regions. Sub-Saharan Africa is still most heavily affected, with nearly 1 in every 25 adults (4.4%) living with HIV and accounting for nearly 70% of the people living with HIV worldwide. HIV is the most powerful known risk factor for developing tuberculosis (TB). People co-infected with both the TB bacterium and HIV are up to 50 times more likely to develop TB than people infected with the TB bacterium but not with HIV (Myo Mie Mie Tun et al., 2019). In Myanmar, according to the USAIDS 2019 Data round about 88000 women were living with HIV in Myanmar. They are vulnerable groups and being neglected although they get the treatment. They still facing with difficulties in many areas such as finding the job, denied from the health assess and severe clinical situation. This is a huge amount in Myanmar and this is the reason to study this title.

1.2 Objective of the Study

The objective of the study is to identify the common challenges and underlying causes of women living with HIV/AIDS that hinders the continuation of the treatment.

1.3 Method of Study

The method of the study is descriptive method to elaborate the survey result in order to meet objective of the study. A sample size of 120 HIV patients who received HIV patients receiving Anti-Retroviral Therapy (ART) treatment at government hospital and other local site to follow by purposive sampling method. The interviewee is from peer member of Sub Health Group (SHG) that is focus only on infected female in Pyay Area and they all are taking the treatment. Secondary data also be used for getting more information for qualitative data. This is purposive sampling method to focus on hospital under care clients and meet with the clients when they come and collect the drugs at their appointment day in respective ART site and second stage is focus on positive network and meet with client on their group work activity and meeting days.

1.4 Scope and Limitation of the Study

The study Area is only focus on the some of the Sub Health Group (SHG) and some of the HIV positive women network especially from Pyay. Because HIV infected cases have big confidential issue and discrimination for the lifelong. The participation and cooperative of the clients are majority of the interview to answer the questioner. The scope cannot be covering the data of all positive women in Pyay.

1.5 Organization of the Study

This thesis is organizing with five chapters. Chapter one is the introduction of the chapter with rationale, method, scope and limitation, the organization of the study. Chapter two includes global overview of HIV, Culture of Women and HIV, Social wellbeing among PLHIV, HIV treatment and other comorbidity and previous empirical study overview. Chapter three follows as over view on Myanmar HIV situation, background information of epidemic situation of HIV in Myanmar, Health care system and strategic plan for HIV and Treatment, socioeconomic situation and impact of HIV, factor influencing in quality of life. Chapter four includes profile of SHG for positive women network in Pyay and finding points from the survey and interview record. Chapter five consists of the conclusions of finding and possible recommendation.

CHAPTER II

LITERATURE REVIEW

2.1 Global History of HIV/AIDS

Human immunodeficiency virus (HIV) is a kind of lentivirus that causes acquired immunodeficiency syndrome (AIDS) in human beings and it damages the immune system of that infected person. If the person who was infected with HIV virus will become suffering from the life-threatening opportunistic infection like Tuberculosis (TB), Pneumonia, cancer, wasting syndrome. The main mode of transmission to person-to-person is by unsafe sex, sharing the needle and mother to child (Barasa, 2011).

The main task of HIV is to destroy the immune system of the body and the person will become very sick and getting worse and worse. The nature of the immune system is to resist the human from several types of illness. The immune system CD4 cells and T lymphocyte is the majority of complete process in blood supporting stream and to get better system in health.

There is the primary stage and secondary stage in nature of syndrome, the primary stage is that (80 to 90) percent of individuals are influenza or mononucleosis called acute HIV infection. This sign is like flu, fever, rash, malaise, esophageal sores and include severe headache, etc. The secondary stage is depending on the individual resistance being of keeping positive living in their day-to-day life style. The final stage of HIV is AIDS and in that time the person face many opportunistic infections and difficult to treat to recover to get better (Barasa, 2011).

The definition of ART is antiretroviral therapy and standard antiretroviral therapy (ART) consists of the combination with at least three antiretroviral (ARV) drugs to maximally suppress the HIV virus and stop the progression of HIV disease. Huge reductions are seen in rates of death and sufferings when use is made of a potent ARV regimen, particularly in early states of the disease (WHO, 2013). The nature of treatment is need to take lifelong with right time and right treatment. If there is stop

taking the drugs, the viral implication will be increasing again and to become treatment failure.

The type of the drugs groups is classified according to the nature of inhibited step to the virus lifecycle. In 1987, the first drug came out and called AZT (Zidovudine) that is a class of nucleoside reverse transcript inhibitor (NRTI) and it can affective to control the virus. However, there are many challenges like pills burden, side effect and limitation in treatment. In the middle of 1990, there are 2 other groups emerged and call (NNRTs) nonnucleoside transcript inhibitor and (PIs) protease inhibitor. Treatment pattern include the two drugs form NRTI and one drugs from NNRTs or PIs group (Tseng et al., 2014). Weak point of the treatment is taking the drugs for lifelong and adherence is important. If there are missing doses or late to take the drugs there will be occur the resistance virus in the body and difficult to control the virus again. More than 80% of adherence can be control the virus very well and the combination of drugs are main factor of the treatment. Treatment is more advance after the follow up research and trial stage.

2.2 Health and Development in HIV/AIDS

Health and education are close related in the economic development, the greater health may helpful to the greater investment in development. Health and education levels improved in both developed and developing countries (Mushkin, 2015). Health, education and development is link with each other. In the WHO explains that, a health system is all the activities whose primary purpose is to market, restore, or maintain health. Health system include the components of public health departments, hospitals and clinics, and office of doctors and paramedics (Mushkin, 2015).

Health is majority for wellbeing and it is leading factor of the sustainable development and income distribution. Because economic development is continuous progression and also effect on many decades. The basic principle of development is health and education. Health is majority for wellbeing and it is leading factor of the sustainable development and income distribution. Because economic development is continuous progression and also effect on many decades. Human capital productive investments embodied in human process that include the skill of the human, abilities and capacity of the human, thinking of conceptualize in economic development and health. In the early stage most of the people view as health is the consumption and not an investment but more and more research by doing the economists, health is

majority in human capital. Expenditure on health is an investment for the human resourcing to contribute to the productivity on economic on development (Sab, 2001). If there is not good in health that can affect on the society development as well as in economic development. The person who suffers from HIV/AIDS and would not get the proper treatment to be taken the drugs, that family must be face with financial and social problem as well as in living situation. Health situation and labor force is direct relation on productivity.

The health care cost effect applies to increased spending on health care by individuals and governments (public and private) to help AIDS patients and their families cope with declining health. The direct result of higher medical costs, which aim to limit saving, as well as the rise of per capita wages, life expectancy, age structure, and population healthiness, all have an impact on saving. The reduce in domestic saving will involve a reduction in capital formation, and if it were consequences, it would have a potentially large adverse effect on per capita income over the long term. On the other hand, the steady increase in AIDS-related death rates would have two major demographic and macroeconomic implications. First, there will be a decrease the population growth rate, which will result in a smaller population at a future date. Second, a rising number of deaths from AIDS will shift the age structure of the population towards the younger age cohorts (Ijaiya et al., 2012).

In every country, the HIV / AIDS epidemic generally has two consequences. First, the life expectancy is reduced, which reduces the incentive to invest. Second, epidemics increase premature death in adults. The death of parents will have detrimental consequences on the development of human resources/offspring. When adult household members reduce family income, children are forced to leave school to contribute to family income. Moreover, the transfer of human capital formation is undermined when one or both parents die, as these adults cannot transfer human capital to their offspring. Poor education of children leads to a decline in posterity. Declining education reduces the resources available to children in adulthood, as household income is a function of adult human capital.

This will reduce your investment in education for your child. The less education parents receive, the less transfer of human capital to their children. The result of this process is the deprivation of poverty and orphans and their offspring will be caught in a cycle of low educational outcomes. In addition, since the formation of human capital is one of the most important determinants of happiness and economic growth affecting

human capital, in the long run, it is important for the well-being of the people and the development of the country have an impact (Ijaiya et al., 2010).

2.3 Women Participation in Prevention of HIV/AIDS

The participation of the women against to the HIV/AIDS program and HIV prevention project has still challenges because in some of the countries, women didn't get the chance to participate in main role and still have gender issue.

The theoretical perspective on gender and development part, since for a long time, many of feminists were dissatisfied with traditional Marxism, which assume that women are need to be played in a subordination as the primary form of subordination role that "Engles,1970" stated as theory (Engels, 1884)

Socialist feminists argued that class and women's subordination were of equal importance and had to be challenged simultaneously (Parpart, 2000). In each of the family every woman has to be done to unpaid work and they are less chance to make a decision rather than the man. The role of women is really important for the HIV and AIDS awareness and treatment outcomes because woman is the first care taker for the family as well as for themselves. They can be the only one person to take care of family not only for the treatment but also for the other house work.

If there are the children in family the role of the women is majority to run the daily activities smoothly and effectively. Because they have enough knowledge and experiences person and also be, they are the mother of the family. The men assume that they are the main incomer and they are the main responsible person to make the decision in family matter. If there is less chance to participate the women in HIV prevention and treatment ongoing process there might not be reach the certain goal of reduce the HIV transmission on globally. Now a day there are many sub health group and peer group initiating process especially for the women empowerment.

In African countries, more and more women's empowerment groups emerge within year by year, the role of participation in women is much greater, and women-led groups have the ability to make choices and have better transformation processes. Is greater action and consequences. In all countries and cultures, there are differences between men and women in making these choices. The meaningful engagement and leadership of HIV-infected and HIV-infected women is an important factor in ensuring effective and sustainable responses. HIV-infected young women are involved in policy and decision-making at all levels, including on behalf of the policy-making advisory

group and as members of parliament to implement, monitor, and evaluate HIV policy should be represented. Women's empowerment affects their ability to build human capital (Sidibé, 2015).

2.4 Global Impact of HIV/AIDS

The Human Immunodeficiency virus (HIV) had also notified and have been known in Asia few years after the first case emerge US. It quickly spreads and transmitted human to human. After 1990, many cases emerged and reported as globally in every country. Thailand is the highest and major epidemics situation. After two decades later round about 9 million people in Asia have been infected and round about one million people with AIDS related syndrome. Even the number of dead cases was higher, there was the no words to express the felling emotion for those pain and infectious. All of the people have been painful and getting shock for those painful situations. They face with sudden failing in health and unnamed illness, shame, humiliations and most of the other people are condemnation to infected person and then rejected in socially.

In Western and Central Europe, as well as North America, an estimated 2.2 million people were living with HIV in 2019. Annual new HIV infections peaked in 2008 at 82,000, but have dropped by 12% to 2018 since 2010. In the United States, more than half of all new HIV infections occurred, with more than a quarter occurring in six countries: France, Germany, Italy, Spain, Turkey, and the United Kingdom (UNAIDS, 2020). In 2019, 88% of people living with HIV in the region were aware of their status, of whom 92% were accessing antiretroviral treatment (ART). Among those on treatment, 82% were virally suppressed. However, late diagnosis remains a challenge: approximately a quarter of people diagnosed with HIV between 2014 and 2016 were diagnosed at an advanced stage of infection (UNAIDS, 2017). As a result, 12,000 people died of AIDS-related diseases in 2019. In 2014, primary infected groups and their intimate partners accounted for nine out of ten new infections. HIV prevalence is also considerably higher among key affected populations. However, the populations most affected by HIV differ between countries (UNAIDS, 2016).

The human immunodeficiency virus (HIV/AIDS) epidemic has destroyed many individuals, families and communities. Because of AIDS epidemic, millions of children were orphaned, disrupting the lives of villages and communities and increasingly contributing to the erosion of civil order and economic growth. According to the World

Health Organization (WHO) and the United Nations Joint Program on HIV/AIDS (UNAIDS), there were approximately 34.3 million people living with HIV/AIDS worldwide at the end of 1999, estimated at 15,000. People infected daily. 95% of the world's total population living with HIV live in developing countries. As the epidemic progresses, prices will continue to rise in communities and countries where poverty, social inequality, and poor healthcare infrastructure allow the spread of the virus (Helene, 2001).

HIV/AIDS pandemics take different forms in different parts of the world. In some areas, HIV transmission has rapidly spread to the general population. In other regions, the distribution remained in high-risk subpopulations, including sex workers and their clients, men having sex with men, and injection drug users (IDUs) giving injections. The prevalence of adults is 1.07% of the world's population and 47% of infections occur among women. AIDS is the fourth leading cause of death in the world, and is the leading cause of death in sub-Saharan Africa. An estimated 18.8 million adults and children have died of HIV/AIDS since the epidemic began. As the number of people infected with HIV continues to grow, the number of deaths per year worldwide may increase. In 1999, one-fifth of children were death due to AIDS and more than half of the adults who died from HIV-related causes were women. As of November 1999, a total of 2,201,461 AIDS cases have been reported to WHO. This total represents an increase of 214,244 AIDS cases since November 1998 (Helene, 2001).

One of the students from Cammeron observed that “Socioeconomic Status, Women and HIV: Do the determinants of Female vary by socioeconomic status in Cammeron” for her doctor of philosophy. The objective of the study research was to develop a model that can predict and individual’ HIV status and getting early treatment and to reduce the transmission. In practically, husband behavior is the most important way transmit infection to get the HIV positive. Sexual behavior is main determinant of the women HIV situation. The knowledge level of the women is helping to reduce the risk and they can evaluate their situation. This study shows that there is a link between SES and HIV is very complicated and cannot confirm the traditional assumption that there are women with low SES the risk of contracting HIV increases. This study shows that women have lower overall SES the HIV infection rate is low, although it is still much higher than in the United States. Most of them, women with higher socioeconomic status have obtained expected benefits from greater economic resources

in Cameroon (e.g., higher levels of formal education, more knowledge about HIV increase access to healthcare services, and more progressive ideas about roles Women in marriage). However, being in a higher SES situation cannot be assumed that they have useful in discussing power with their respective relationship. To tackle with HIV crisis in Cameroon, mainly needs is to be shift in some of the cultural norms and formed in society. This shift is mainly exceptions foe both of men and women. Even though high SES women in there is seem a specific at risk for HIV and it means that the significant policy approach is required (Mumah, 2011).

AIDS Epidemics in ASIA

HIV incidence in Asia continues to be low as a proportion of the region's vast population, but absolute numbers are high. According to UNAIDS and WHO estimates, there were 4.9 million people in 2007 (with a range of 3.7 million to 6.7 million), with the HIV population in Asia, including 440,000 (210,000-1.0 million) people newly infected in that year. About 300,000 (250,000–470,000) people died from AIDS-related illnesses in 2007. In total, round about 9 million Asians have been infected with HIV since from the beginning in the region over 20 years ago. About 2.6 million men, more than 950,000 women, and nearly 330,000 children have died from AIDS-related illnesses (WHO, 2013).

In the Asian societies there is weak in observing to do research for the patterns and trends of HIV transmission, these weak points are the main factor spared out the HIV transmission rate. In The very beginning of the period, most of the people thought that the transmission is not related with every one and it can transmit to the person who engaged with taboo behavior. This mis concept is the driven factor to become epidemic in Asia. At the same time in East and Southern Africa, the transmission rate is incredible high due to lack of knowledge and bad attitude with careless behavior. Over the past decade, our understanding of HIV epidemics in Asia has improved and more understand on how we can say and point it out to be stay in safe (Marais, 2008).

Epidemics differ widely from country to country, they have important characteristics, namely that they are primarily centered: paid sex without a condom, sharing infected needles through drug users, and unprotected sex between men. However, men buying sex, most of whom come from 'mainstream' societies, are the biggest force in the HIV epidemic in Asia and constitute the largest group of the infected population. Because most men who buy sex are married or are about to marry,

a large number of 'low-risk' women who only have sex with their husbands are exposed to HIV. Effective means of preventing HIV infection in female partners of these men have yet to be developed in Asia, but these are clearly important.

Some women in Asia have sex with more than one partner. The chain of HIV transmission tends to end once their wives and girlfriends are infected. Some may pass HIV to their unborn or newborn babies. But the chances of women transmitting HIV to other men are generally very small.

This means that it is currently unlikely that the HIV epidemic in Asia will persist in the 'general population', apart from commercial sex, drug injection and sex between men. And most importantly, it appears that efforts to drastically reduce HIV transmission among and among these populations that have the greatest risk of controlling the epidemic. HIV-related stigma and discrimination weakens Asia's response to the epidemic, causing people to use a number of essential services. For example, the use of HIV testing and counseling services is still low. Discrimination against people living with HIV affects their access to jobs, housing, insurance, social services, education, health and inheritance rights for women and men. In some countries, there is strong prejudice against people living with HIV in health care. Furthermore, these groups have been discriminated against, marginalized, and in some countries criminalized the groups most at risk of becoming infected with HIV (Ijaiya et al., 2010).

2.4.1 Consequence of HIV/AIDS and Factors Influencing in Treatment

The effects of HIV/AIDS can be identified into two categories; those are linking with rising morbidity rates and those associated with rising mortality rates for particular age cohorts, especially sexually active adults and children infected at birth. The rise in morbidity has three immediate effects: (a) reduction in labor productivity, (b) increase in health care spending and (c) reduction in savings.

The negative labor productivity effect will arise because sick or worried workers are less productive than happy and healthy workers. The productivity will fall because of there is link between family, co-worker, need to taker for the person who suffering chronic disease. There are many factors influencing on HIV treatment to get good adherence and good economic status. Living standard situation, self-stigma, cultural situation, family support and disclosure status and marital situation, educational back ground, health care assess, demographic situation, treatment nature and other

psychological factors. All of above these factors are under the umbrella of the socio-economic status (SES). Because SES is the major component for all of the human being and no one could not escape from these factors.

Education is the important aspect in SES. The higher educational and academic person can produce the better outcomes in economic structure as employment loyalty, income. Education is the basic factor to improve in technical skill that to produce the output effectively and efficiently, increase skill and knowledge (APA, 2006).

Asses to service for women especially young women and young pregnant women living with HIV is import for getting treatment. The adolescent and young pregnant mother have less chance to get the proper Post exposure prophylaxis (Pep) treatment because there is a disclosure issue and assumed that they have low risk group. Adhering to treatment is complicated for pregnant and youth girls due to violence stigma and discrimination, poor support from family and duration of the trimester of pregnant. In some countries among of the group of adolescent girls have been living as vulnerable situation and they don't have right to get the treatment because of, cultural issue. Many factors are surrounded to get the proper and right treatment due to sexual orientation, law and gender issue; far from the health care centers and waiting time in clinic are main challenges to get the treatment assessment and that can affect on the treatment adherence and to maintain the good adherence (Sidibe, 2019).

People living with HIV/AIDS (PLWHA) are often confront with discrimination in health care setting. Being isolation in medical setting, divided in seating plan, confidentiality and denied to do operation procedure or double charges when doing the procedure for any operation. And other possible factors are neglect by the family, referred to other hospital, physical abuse, force to resign or blackmailing from the employer, physical abuse and power manipulation from working environment. Self-discrimination is a kind of factors that influence to adherence sometime most of the person are assumed that they are the burden for the family so they have been assumed as they are worthlessness (Myo Mie Mie Tun et al., 2019).

2.5 Common Challenges of Women Living with HIV/AIDS

The main challenges of women living with HIV/AIDS are clinical situation, disclosure problem, side effect of the drugs, criteria of the treatment provided organization or health department, working situation. Resistance, anxiety to disclosing HIV-positive status, and fear of being rejected and discriminated against, are evidence

of the continuing nature of AIDS-related stigma in communities and families. AIDS-related stigma is one of the barriers to preventing the disease from spreading further among people who are aware of their HIV status (Cloete, 2010). Once diagnosed of the HIV positive result is the big challenge for the person.

Decision about disclosure is depend on the perception on stigma and awareness of the family member. Using to separate fork, spoon and personal things must be different that indicates the danger of delusion, those living with HIV increase the rest family. Inaccurate beliefs about HIV infection causes more fear and discrimination, which is even more so stigmatization of people living with HIV (Stephenson, 2009).

Some of the women duress and forced to do sterilization and not try to get child because of their result. It can be deeply felt and devastated for women and its effect on mental health issue. According to the delivering process HIV positive situation is need to take the universal precaution and taking systematically infection control procedure, this is good to follow each and every of women but on the other hand there can be faced the disclosure and confidential difficulty for the respective person and family (Orza, 2015).

2.6 Review on Previous Empirical Studies

Maung Maung Kyaw (2009) found that the main mode of transmission of HIV infection through sexual contact and women transmitted than men through heterosexual contact. The attitude of the family member was shocked and shamed because of the route of transmission and do not want to accept. In the beginning of the time the knowledge of the community is poor and they assumed that this is not cure and no a chance to treat to recover and the positive person will be died. Community stigma and discrimination lead to difficult to get assess of the treatment in that time. Stigma and discrimination faced by the PLHIV in different setting, namely as family, community, education, institution and work place. Women were more being discriminated than men and against as compared with men. Stigma and discrimination contribute to the socio-economic vulnerability of PLHIV. Existing misconception regarding the spread of the infection have led to high prevalence of the discrimination and negative responses and attitude of people towards PLHIV.

Htay Thet Mar (2015) study found that in Myanmar many of stigma and discrimination still dominant in adherence. It leads to delayed to disclosed for the status and the possible implication is getting the treatment very late time and getting wasting syndrome is difficult to treat in HIV. In the health care setting Key population has been

discriminated by the service provider, mis trusting relationship between the clients and providers. PLHIV also meet stigma and discrimination in formal and informal workplaces, which is causes for the effect on the employment status and job seeking process. Unemployment or low income is the main factors for the insecure of finance for basic needs and indirect costs and unfulfillment on the living conditions. The effect of this factors is hit the treatment adherence. Some of the clients are emotionally not stable and suffer several mental health disorders such as anxiety and depression due to their positive result. Depression is the significant issue of non-adherence.

Min San Tun (2019) studies peer to peer counseling help to reduce the tension of the clients and almost all of client told their true history on treatment. Disclose about their missed to taking the treatment, relationship between service provider, family member, relatives, spouse/partner. Although some of the staff are working in hospital, they do not have sympathy and empathy on the situation of the clients. some of the clients have experiences on do not want to touch by the medical person and they do not want to take care or providing the services because of retro positive. By providing the counseling service, clients have got the emotional support and advice from the peer counselor to coping the idea for the problematic situation and unhealthy emotional state. They found out the possible solution by discussing with the counselor. Psychological support is a way to help the thinking process by learning and sharing of experience with peer counselor and making to help better understanding on individual situation.

CHAPTER III

WOMEN LIVING WITH HIV/AIDS IN MYANMAR

3.1 Prevalence of AIDS and HIV in Myanmar

The first HIV case was detected in Myanmar in 1988. The peak of new infections occurred in 1999. The trend of the epidemic is decreasing, but the burden of disease is still large. HIV prevalence is concentrated in key affected populations (KAP) and low in the general population. According to the 2013 HIV Sentinel Surveillance, the prevalence is 0.47% in the adult population (15 years and over). The prevalence among KAP is high: Female Sex Workers (FSW) (8.1%), Men Having Sex with Men (MSM) (10.4%) and Drug Users (IDU) (18.7%). That's 0.6% among pregnant women. There are 189,000 PLHIV, of which 37% are women. AIDS-related deaths are 15,000 and new infections exceeded more than 7,000 in 2013. PSI an agency in the Ministry of Health that primarily carries out HIV care and prevention activities in Myanmar under the National Strategic Plan II (NSP II) (2011-2015) with three priorities.

- a) Improvement of the quality and length of the life of people living with HIV through treatment, care and support.
- b) Mitigation of the social, cultural and economic impacts of the epidemic.
- c) Reduction of HIV transmission and vulnerability particularly by people at highest risk

Service availability was low during the first decade of the epidemic. Although Myanmar is one of the developing countries in Asia, it is underfunded by international development partners due to political isolation. Sex work, homosexuality and drug abuse are criminalized. The coverage and depth of HIV prevention and treatment services in KAP is low. Promotion of 100% targeted condoms, prevention of mother-to-child transmission and harm reduction programs have been implemented since 2000.

Médecins Sans Frontières (MSF) Holland launched ART services in Myanmar in 2003. The government launched an ART program with free drug payments and laboratory tests in 2005. Since 2011, the program has addressed the continuity of care for PLHIV. HIV testing and counseling services (HCT) have been decentralized since 2013. Tasks have been transferred from laboratory technicians to other health workers. Community-based HCT is being implemented in the non-government sector with the target of KAP having more access to testing 6 services.

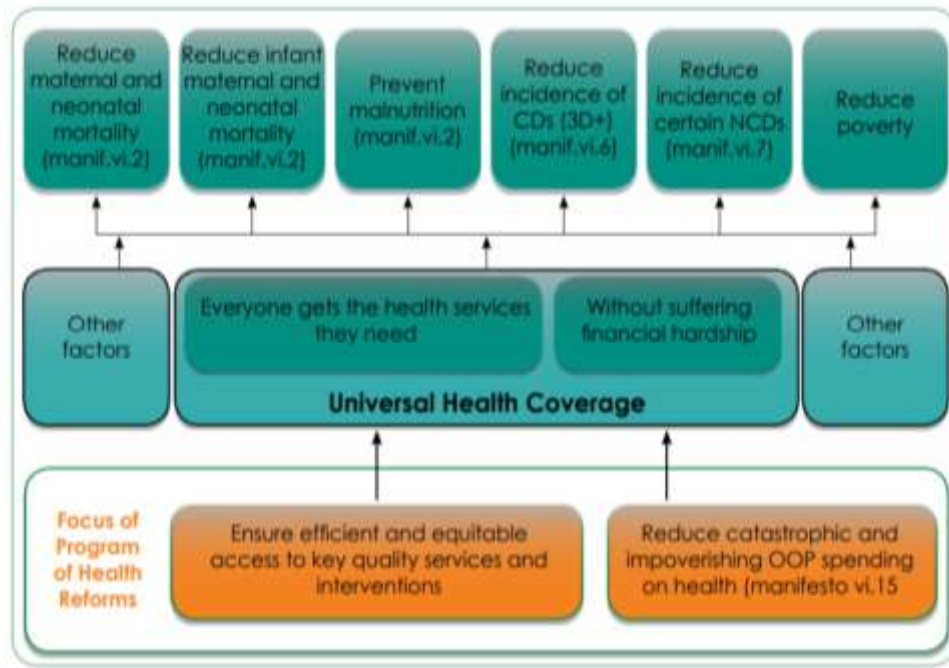
At the same time, the number of ART centers is increasing from year to year. About 140 ART centers are located in government hospitals and STD clinics. In addition, construction of a decentralized ART site started in 2013 to operate ARV drug compounding. As of June 2014, 75,000 people with HIV were taking ART in line with previous WHO guidelines. By starting ART for people with HIV with CD4 counts of 350 to 500 cells / μ l, the number of people eligible for ART will increase. The intensification plan is intended to cover more than 100,000 patients by 2015 and 111,000 patients by the end of 2016.

In September 2015, the General Assembly of the United Nations adopted Resolution 70/1 Changing Our World: The 2030 Agenda for Sustainable Development. Under the Millennium Development Goals (MDGs), the Sustainable Development Goals (SDGs) tie governments around the world to the 2030 Agenda to end poverty, fight inequality, protect human rights and gender equality, and achieve lasting equality for protecting the planet. The SDGs lay the groundwork for a significant increase in the level of ambition for HIV, moving away from the MDGs target of ending the epidemic and ending the epidemic by 2030. In October 2015, the United Nations Program on HIV / AIDS (UNAIDS) released its strategy for 2016-2021 In the Fast Track to End AIDS with the goal of ending the AIDS epidemic by 2030 with “Zero new infections, zero discrimination and zero AIDS deaths”.

UNAIDS has identified Myanmar as a fast-moving country with a serious epidemic and Yangon as a major city in the Asia-Pacific region. HIV NSP III Myanmar was developed in the context of a recent world strategy that aims to end HIV as a threat to public health by 2030. Despite its ambition, countries around the world are struggling to achieve the same vision. There is no doubt that investing in a frontal tax will help reduce the total cost of achieving this strategic goal as early as possible. As government contributions increase, sustainable financial assistance abroad is needed to ensure that Myanmar can invest in cost-effective and cost-effective coverage expansion for

prevention and treatment needed to achieve its rapid targets. The 2014 census put Myanmar's population at over 51 million, with two thirds living outside urban areas.¹ It is estimated that at least 25% of people live below the poverty line and that nearly 85% of the poor live in rural areas (MOHS, 2015).

Figure (3.1) Universal Health Coverage Vision in Myanmar



Source: National strategic plan 2016-2020 page 21

According to the figure (3.1) government effort to reassess the health inequities, improvement of the quality in service and technical, accountability and sustainability of the palliative care and HIV to cover the National strategic plan III.

Myanmar has demonstrated a strong political relationship with HIV, which has been identified as one of the priority diseases in the 2011–2016 National Health Plan. In 2016, the government provided US \$ 15 million for HIV treatment, including ARVs and other commodities, and US \$ 1 million for the acquisition of methadone. The Myanmar Health Coordination Committee (M-HSCC), formed in 2013 as part of the Nay Pyi Taw Agreement, has a broad mandate as a coordinating body for all public health sector matters. The M-HSCC, chaired by the Minister of Health and Sports, oversees implementation NSP and has participation from other ministries, United Nations organizations, non-governmental organizations (NGOs), development partners and civil society organizations. The HIV Technical Strategic Group (TSG), chaired by

the Director for Disease Control and the National Aids Program Manager, is responsible for implementing the national strategy and includes a large number of international, local, private sector, people living with HIV and community partners. NSP supports (NAP, 2016).

The Ministry of Health has announced a systemic plan for the next five years and a road map. The plan includes a roadmap on how to rapidly track the national HIV response and end the AIDS epidemic as a public health threat by 2030. Myanmar is one of 35 countries in the world responsible for 90% of new cases. HIV infection. The new plan adapts global Fast Track targets to the local context to ensure an effective, cost-effective and high-impact HIV response. Locations are prioritized based on the HIV epidemic and risk of new HIV infections and service delivery approaches are tailored to reach priority populations and accelerate access to services.

In 2018, nearly 240,000 people living with HIV/AIDS live in Myanmar. An estimated 7,800 people died of AIDS-related illness this year. Myanmar has the second highest incidence in Southeast Asia and is one of 35 countries accounting for 90% of new infectious diseases worldwide. (UNAIDS, 2020). “In 2018, Myanmar reported 11,000 new infections (approximately 30 infections per day). Although this number remains steady compared to the two years before, observations show the annual rate of infections is no longer declining at the same rate it did between 2000 and 2010” (UNAIDS, 2019)

Myanmar's HIV epidemic is concentrated among certain key populations, particularly those who inject drugs (sometimes called IDUs), but also men who have sex with men (sometimes called MSM), transgender and sex workers. More than 70% of new infections in the country occur between these groups each year.⁹ About 65% of all key populations are estimated to live in five regions and states (Mandalay, Yangon, Sagaing, Kachin and Shan North), mostly in urban areas, where most new infections occur.

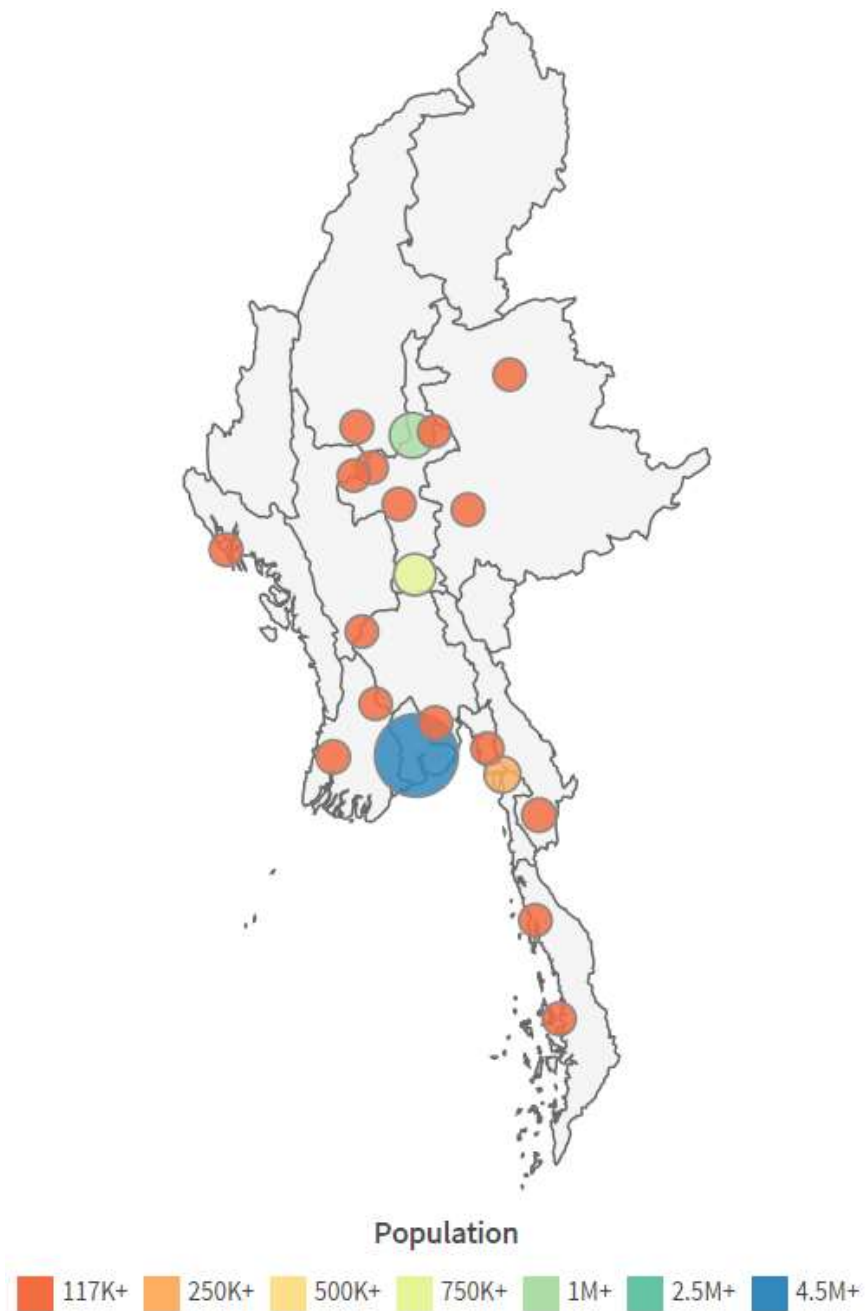
Myanmar is facing a serious epidemic - an estimated 240,000 people are infected with HIV. Myanmar's authoritarian military regime is widely condemned for human rights abuses, and in 2005 this global fund led the fight against AIDS, TB and Malaria, withdrawing a proposed \$ 98.4 million grant to the country. Prevention services for injecting drug users are lacking with needle exchange programs operating in several locations. Drug users are treated harshly and suppressed drug production has resulted in opium and heroin shortages. As a result, inhaling drugs has been replaced

by injections, as a more cost-effective way of using drugs, with a greater risk of HIV transmission. In 2006, methadone substitution therapy was introduced in a small number of government buildings. Furthermore, HIV prevalence among MSM (men who have sex with men) is very high in several cities, with 23.5 percent of MSM infected with HIV in Yangon and 35 percent in Mandalay. However, in 2011 Myanmar implemented a four-year plan to use the mass media to aid HIV education and reduce discrimination around HIV and AIDS (UNAIDS, 2020).

Regarding the demographic situation of the country is very ethnically diverse, with 135 ethnic groups approved by the government. Myanmar has at least 108 ethnic groups. Bamar is about 68% of the population, followed by Shan (10%), Chin (7%), Rakhine (4%), and overseas Chinese (3%). National minorities are preferably referred to as ethnic nationalities to combat the predominant expansion of the Bamar population. Other ethnic groups are Mon (2%), foreign Indians (2%), Kachin, Karen, Anglo-Indian, Nepalese and Anglo-Burmese. Myanmar's relatively modest population growth is expected to continue its current trajectory. The current growth rate is just under 1%, but it is likely to reach near zero by 2050. The projected population for 2020 is 54,808,276. According to the 2014 census, Myanmar's population increased by approximately 16.2 million, or 46%, according to the census from 1983 to 2014. This means that the country's population has increased by an average of more than 500,000 in each of the 31 years between the two censuses. With an average annual growth rate of 0.9% during this period, Myanmar is one of the slowest growing countries in Southeast Asia (World Population Review, 2020).

Figure (3.2) show that Yangon is the highest population in Myanmar round about 4477638 people are living, the second highest population is living in Mandalay and there is estimated 1208099 people are living in there and the third highest population city is Nay Pyi Taw and there is round about 925000 people are living.

Figure (3.2) World Population Review



Source : <https://worldpopulationreview.com/countries/myanmar-population>

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3.2 Key Affected Population in Myanmar

3.2.1 People with Injection Drugs User (PWID)

In 2018, 93,000 people in Myanmar were estimated to inject drugs, 19% of whom were living with HIV. This makes people that inject drugs the population group most suffering from HIV within the country. Although urban areas in Myanmar report the highest HIV prevalence rates in the country, prevalence is also high in the more rural northern and north-eastern areas where injectable opium is produced and its use is endemic. Distribution of medicine from this region has also contributed to new HIV infections developing in additional remote areas of the country, providing additional challenges to expanding the coverage of harm reduction and HIV services (UNAIDS, 2019).

3.2.2 Men Who have Sex with Men

“In 2018, 6.4% of gay men and other men who have sex with men in Myanmar were estimated to be living with HIV. Myanmar’s National Strategic Plan on HIV and AIDS 2016-2020 recognizes that these rates are alarming and has presented an idea to proportion targeted services for men who have sex with men in geographical locations where HIV prevalence is high” (UNAIDS, 2019).

Stigma and discrimination continue to contribute to low levels of access to HIV services, with between half and three quarters of men who have sex with men estimated to have taken an HIV test in 2015. Consequently, in 2017, just over half (52.4%) of men who have sex with men who were living with HIV were conscious of status.

3.2.3 Sex Workers

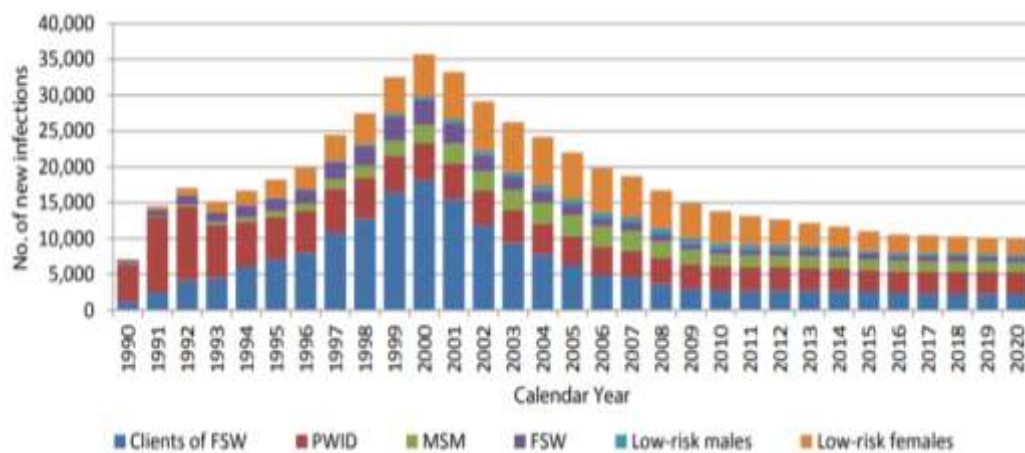
HIV prevalence among sex workers was 5.6 percent in 2018. Around 45% of HIV positive sex workers were conscious of their status. In Myanmar’s major cities, HIV prevalence among sex workers is far higher, estimated at 24.6% and 13.7% in Yangon and Mandalay respectively, representing a number of the very best. HIV prevalence locations in the Southeast Asia and Pacific region (UNAIDS, 2019).

3.2.4 Young People

“In 2018, young people (aged 15-24 years) has been calculated for 26% of new infections in the region but a higher proportion in Myanmar at around 55%. Because

Myanmar’s HIV epidemic is deliberated focus among certain groups, 15 to 24-year-olds from these key populations are most affected. For example, speed of HIV spreading among young men who have sex with men is five times that of the general population. Social norms concerning same-sex relationships and the criminalization of homosexuality, coupled with prohibited regarding young people’s sexuality, combine to result in poor access to essential HIV services and information” (UNAIDS, 2019).

Figure (3.3) New Infection Rate According to the Key Populations 1990 - 2020



Source: National Strategic plan 2016 – 2020

Figure 3.3 shown the data of new infection rate according to the key population between 1990 to2020. The highest infection rate was in 2000, in this time there is lack of treatment in Myanmar and ART treatment program was not easily to assess in health care setting on that time. National AIDS program starts the anti-retroviral treatment in 2005. After the initiation of the treatment the transmission rate was gradually decreased.

3.3 Barriers to HIV Responses in Myanmar

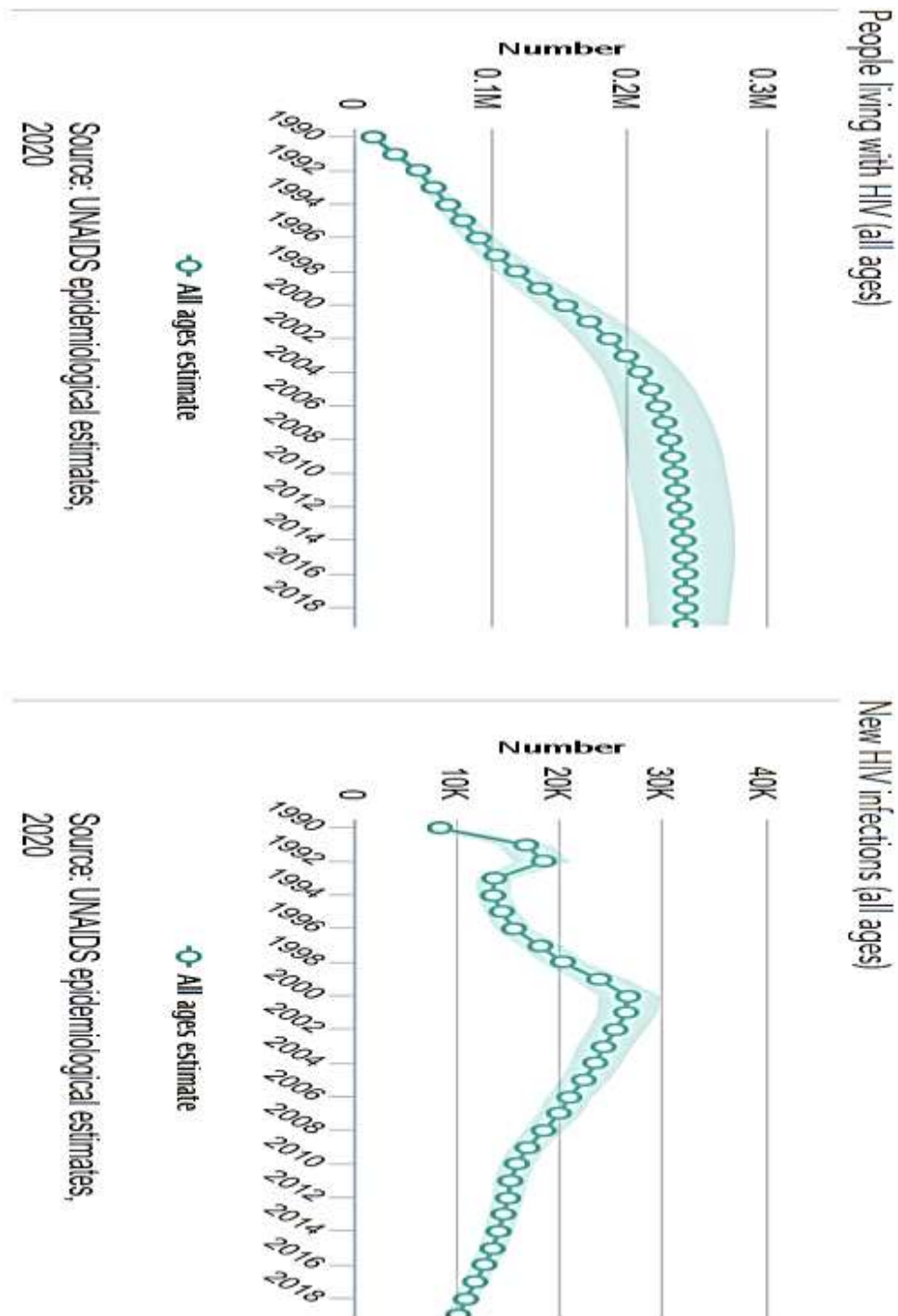
3.3.1 Financial Barriers

Barriers to HIV response can be defined as financial barriers and structural barriers. Myanmar's total health care cost is (2-2.4% of GDP) is entitle of lowest in Southeast Asia and the Western Pacific, and is a good way to explain the country's HIV prevalence. Similarly, an analysis of countries with different epidemic patterns in different regions shows that Myanmar is one of the countries that be short of funding for effective and focused primary HIV prevention (UNAIDS, 2016).

3.3.2 Structural Barriers

There are plans to move HIV treatment services to government-run facilities, but the mainly supply chain and human resource needs that drive such transition have not yet been paid attention to. This means that the most at risk groups, such as those who inject drugs, are left behind in terms of service coverage. In addition to these constraints, service delivery and supply chains are set up to function independently within the healthcare system. This means that human resources, such as community health workers, and service provision at medical facilities are different from each other. (UNAIDS, 2016). HIV resources and allocating part the results of the National Aids Expenditure Assessment (NASA) 2012–2013 show that more than 20 donors are supporting these programs although the number of donors in this sector, most HIV funding is solely HIV funding.

Figure (3.4) People Living with HIV in All Ages



Sources: UNAIDS epidemiological Estimate 2020

Figure 3.4 showed that the number of people living with HIV in all ages between the year of 1990 to 2018. According to the data, that can be assumed that the number is increasing year by year although compare with the next figure the new infection rate is

gradually decreased. It means people of the figure in all ages is still alive and infection rate is reduced.

3.4 Health Care System of HIV in Myanmar

At the beginning of the new decade, many organizations have begun to work on HIV and AIDS, even though not yet in usual coordinated way. Myanmar's Joint AIDS Program from 2003 to 2005 was an effort to share HIV services through a planned and have the same opinion with strategic framework. Donors have established the Myanmar HIV/AIDS Fund (FHAM). It provides a merger mechanism for financing and significantly boots the resources available in Myanmar. By 2006, there has been significant progress in terms of coverage and variety in service delivery, including addressing most of the population risks of HIV. More organizations provide more services to more people. Services across from providing HIV prevention messages through mass media and peers in high-risk groups to providing, treating and supporting people living with HIV.

However, the data also show that it was not enough to scale this to the greater part of people who needed HIV and AIDS services. The HIV surveillance system has been introduced since 1992. In 1993, it was found that 1.4% of pregnant women in the sample who joined in prenatal care services were infected with HIV in 1993. From the first nine surveillance locations, the system was gradually increased to 30 facilities in 2005 to monitor women receiving prenatal care and those receiving sexually transmitted disease services. HIV close supervision is also being conducted for certain high-risk groups such as drug users (4 sites), tuberculosis patients (9 sites started in 2005), and female sex workers (2 sites). Current monitoring systems do not provide institutional analysis because the sample size is too small. Therefore, regional differences in epidemics cannot be evaluated any further. In 2007, the protocol was introduced to include men who have sex with men, to add sites for sex workers, to increase sample size, and to improve sampling methods. (Williams et al., Conflict and Health, 2008).

The country's response to HIV and AIDS was so delayed in the 1990s, despite increasing evidence of an increasing prevalence of HIV. During the first decade of the epidemic, there were many factors limiting the scope of services available for HIV activity. Myanmar has a well-funded public health system and limited political support to support HIV services. There are few national civil society organizations that carry

out HIV programs, and civil society formation remain and same with generally problematic, except for those related to government. Among the limited number of international non-governmental organizations in Myanmar, some have launched a limited-scale HIV prevention program since 1995 and have made critical advocacy. UNICEF has been supporting HIV services since 1994.

As one of the few donors in Myanmar during that time, UNICEF supported various HIV prevention interventions. The World Health Organization (WHO) provides training and technical assistance to monitor HIV, manage sexually transmitted diseases, and prevent HIV transmission in children. The United Nations Development Program (UNDP) supports the National AIDS Program and local civil society organizations. Activities supported include the promotion and supply of condoms, the provision of test kits for national blood safety programs, the creation of information, education and communication materials (Williams et al., Conflict and Health, 2008).

The commence of antiretroviral therapy (ART) in Myanmar dates back to 2003 when Medicine Sans Frontier is the first organization in terms of treatment for care and support. Since then, they have expanded steadily, providing treatment to additional organizations, including the public health sector, which was started in 2005, bringing significant sharpening. Home care and community-based care also grew from 3,800 living with HIV to 10,900 at the end of 2004 and 2005 with some support. In recent years, many self-help groups and networks of people living with HIV have come out and now there are model of people living with HIV in the planning of events and coordination forums. However, further progress of localized self-help groups and networks is needed to ensure a structure in which role of people living with HIV can effectively communicate with their constituents (Williams et al., Conflict and Health, 2008).

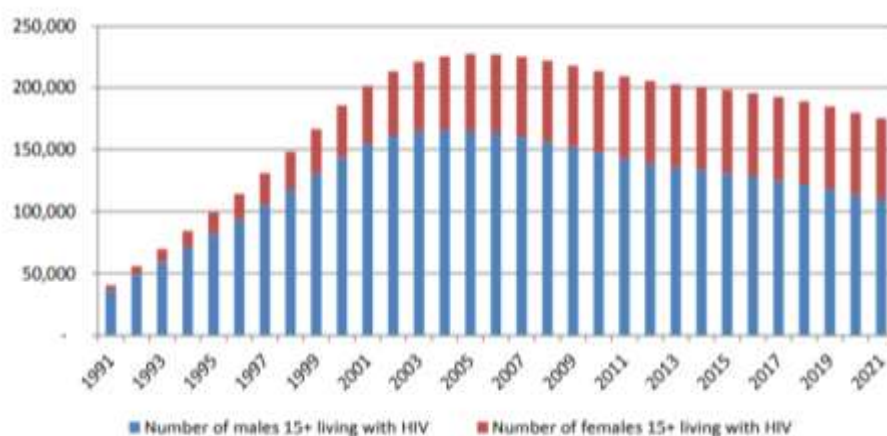
3.4.1 Antiretroviral Treatment Availability in Myanmar

According to UNAIDS 2018 data, 70% of adults and 80% of children living with HIV in Myanmar were on antiretroviral (ART) treatment in 2018. It is attention that this rate more than two times in 2012 (from 24%) and that the country achieved higher treatment coverage than the regional average (54%). As a result, the number of AIDS-related deaths has decreased by 30% since 2010 to 7,800 in 2018 as ART coverage has enlarged.

Although men are more transmitted by HIV than women in the country, HIV-positive women in Myanmar are more prone to treatment. In 2018, 81% of all women living with HIV were treated in the country, compared to 63% of men. This is largely due to Myanmar's successful PMTCT program.

Historically, most health care facilities in Myanmar have been founded or supported by NGOs. It is also estimated that at least 25% of the people in Myanmar live below the poverty line and those living with HIV may resist to get money for the necessary ARV treatment. As such, there is a strong argument for the transition from private and non-governmental organizations to public provision, with the hope of making treatment easier for vulnerable groups across the country.

Figure (3.5) Projection of Number of People Living with HIV by Sex (1991-2021)



Source: HIV Estimates and Projections Myanmar, AEM Dec 2014

Figure showed HIV estimated number and projections number of people living with HIV by sex in Myanmar (1991 to 2021). National Aids Program estimate the projection of HIV/AIDS people in Myanmar by using the 1991 to 2019. Figure has been shown in figure 3.5 in this data the projection number is decreased. The number of PLHIV is gradually increase between 1991 to 2007, in that time treatment criteria is strict and could not provide much amount. ART program is stated at 2005 in government site and increase the number of providing. And also changing the treatment criteria is the main reason to decrease the transmission rates. Increasing in providing the treatment number is good and help for the transmission rates.

3.4.2 Further Challenges for Program Implementation and Scaling Up

As a result, the actions of the Ministry of Health and the national AIDS program and the maintain of the international actors have allowed expanding to their AIDS control. At the same time, overall operational settings generally remain and still limited in some area, without being prohibit. The implementation of health and humanitarian programs in Myanmar is characterized by a high degree of administrative control. Approval of organization and program settings, whether international or international, can take over a year. A notation agreement of understanding on detailed work plans should be negotiated annually to the town level. Cabinet agency approval requires post from all international staff in Myanmar. All trips by foreigners need to get the permission, usually by at least 3 weeks in advance, both from the Department of Technology and from the Department of Defense. Foreigners are not allowed to visit project sites or sites under their direct control without being come along by a government official. Approval for the import of goods is late and international and domestic non-governmental organizations do not benefit from the excused offered in other countries for tax-free imports of vehicles and other project supplies. Much of the funding from international sources came from various members of the United Nations system. Issues related to role coordination and the timeliness of acquisitions have in some cases further delayed program implementation (Williams et al., 2008).

3.4.3 New Directions in HIV Programming

While partners are gradually enhancing their services, several motivational and complex factors are further evolving HIV's strategic planning and coordination efforts. In line with the "Three Ones" ¹principle of advocating AIDS programs around the world, governments advocate a sole leadership role in the country's response to AIDS, while international standards make more participation design and development use to day-to-day activity and introduced the strategy coordination for the further management. The joint program and FHAM's independent short-term review also animate the establishment of more complex procedure that separate leadership roles from ownership of national plans, the provision of technical support by international organizations, and investor decision making. Prior to the end, compliance with the

¹ Three ones principle, the first one is an agreement on the requirement of AIDS action frame work, second one is agreement of participation of the organization, the third one is agreement on country level monitoring and evaluation system.

requirements of the Global Fund Round 3 also motivated the creation of a participatory coordination structure. The end of August 2005 involved a deliberate effort in the turmoil that required further coordination. In early 2006, the government was called for an external review of the health sector by a team of international and national experts. The review advised some recommendations to address the identified shortcomings. The United Nations assisted the Government in developing the 2006 National Strategic Plan and a targeted, prioritized and budgeted operational plan for 2006-2008 (Williams et al., Conflict and Health, 2008).

3.5 Decentralization of ART Treatment in Myanmar

Myanmar is one of the countries in the Asia-Pacific region heaviest hit by the HIV epidemic which is focused among urban areas and key populations. In 2014, the National AIDS Program (NAP) introduced a new model of decentralized service delivery with the establishment of an ART satellite site with care provided by HIV partner workers. The ART satellite site is controlled by non-governmental organizations to serve high-burden HIV areas and populations with stigma or services that have public sector access. It equipped continuity of HIV care from testing outreach, counseling, links to care and retention in care (Kyaw Myo Htet et al., 2019).

Anti-retroviral initiation is starting at a specialist doctor in a health facility. The Ministry of Health and Sports of Myanmar recognizes HIV as a priority public health issue and implements the response through the National AIDS Program (NAP) in collaboration with national and international non-governmental organizations (NGOs). The Myanmar National Strategic Plan (NSP III) for HIV and AIDS (2016-2020) intend to end HIV as a high hazard to public health in Myanmar through speedy access to a continuum of high-quality, integrated human rights services protecting and promoting all people. In Myanmar, HIV treatment and care services were initially introduced and upgraded by NGOs from 2002. NAP began providing ART care in 2005. (NAP, 2016). The public sector aims to support 2020 75% of the total national cohort by 2020. The World Health Organization (WHO) 2013 has consolidated ART guidelines to recommend integration of HIV services and decentralization of HIV care, based on systematic reviews showing that decentralization improves patient access to and care retention (5, 6). In 2012, the NAP started a decentralized ART (DC) site to reduce the workload of ART centers and provide access to patients. Key population suffer from

stigma and discrimination and it may be difficult to access ART centers in the public sector.

In 2014, NAP created and introduced a new service delivery model can be easily to assess in urban PLHIV and key populations through clinic-based testing and treatment sites in partnership with INGO called the ART satellite site. Several studies continue to keep control caution, with rates ranging from (30 to 90%). No previous study has checked out the outcome of HIV-positive individuals on ART at the ART satellite site in Myanmar. As the country is rapidly tracking its HIV response according to the new national plan, we reported on a group of PLHIV who were under the observation at five ART satellite sites in Yangon from 2015 to 2016, and assessed the programmatic results of this model. Specific objectives were to describe the demographic and clinical characteristics of UNAIDS to determine retention of care during the period from January 2015 to March 2018, and to determine the time from enrollment to initiation of ART, and to determine the factors. associated with reduction defined as death or loss to follow-up (LTFU) (MOHS, 2015).

CHAPTER 4

SURVEY ANALYSIS

4.1 Survey Profile

The study focused on the women living with HIV/AIDS (WLHIV) who lived in Pyay township. Pyay is the administrative center of the Pyay district in Myanmar's Bago Region. Pyay is located on the Ayeyarwady Delta in Myanmar's Central and Upper Regions, as well as Rakhine State. The district of Pyay encompasses the valley of the Irrawaddy, located between Thayetmyo, Hninthada and Tharyarwaddy districts. Along the western side of the Pyay District are the Rakhine hilly and the Bago range is located the eastern side of Pyay. Pyay District's main towns are Pyay, Shwe Taung and Pongde. Total population in Pyay is 251643.

The Ayarwaddy river is the majority of Pyay which intersects the district from the north to south; next in importance are the Thani and its tributaries and the Naweng system of rivers. Pyay General Hospital, Aung Zaw Oo Hospital, Myo Thuka Hospital, Aung Tharaphu Hospital, Lawkaparla Hospital and Pyi Myanmar Hospital are public and private hospital in Pyay.

There are 6 local organizations and sub help groups and they are initiated to help the people who living with HIV/AIDS. The name of the network that organized in Pyay is Strength for Survival sub help group, Top center, Myanmar positive women network, Sex Worker in Myanmar, New life forward and Tawwin Khayae network. Survey was conducted in the hospital appointment days and activities days. The structured questionnaires were used during in depth face to face interview (See Annex). The survey period was from November and December 2020, Data about personal identity were not asked. The recruitment was voluntary with consent of an individual.

4.2 Survey Design

To achieve objectives, the quantitative and qualitative approach was used, which include primary data collection through well-structured questionnaires with the group such as who are living with HIV/ AIDS and taking the anti-retroviral therapy in Pyay township. The questionnaire was reference from the study conducted by Delhi Network of Positive people, Positive women's Network of South India, 2003. In this study they used the questionnaire to study the Socio-economic impact of HIV/AIDS on people living with HIV/AIDS and their family. And before using the questionnaire edited and modulated to use more applicable in Myanmar.

Primary data collected were analyzed by descriptive methods. The survey was including 9 sections (i) general information (ii) information on HIV/AIDS status (iii) stigma and discrimination (iv) impact on women and children and family member (v) HIV/ AIDS and employment status (vi) indirect cost (vii) house hold experience (viii) medical expenditure (iv) factors to effect towards adherence. The peer leader from the Strength for Survival group the interviewers of the survey.

Two part in the assessment session one is to explore the common challenges and underlying the causes of women living with HIV/AIDS that is hindering the continuation of the treatment, clinical situation, disclosure problem, side effect of the drugs, criteria of the treatment enrolment are the common challenges. But the level of the coping skills is not the same on each of the respondents, so some of the common challenges became the barrier to continue the treatment. Some of the structural related factors are leads towards barriers to continue to the treatment such as communication of the patients and providers, long waiting time for the follow up and frequent visit for the blood investigation. According to the drugs dispensing guideline, providers can dispense the drugs 6 monthly. Actually there is limitation in drugs storage and not ready to keep the drugs for 6 months per person for each of the under-care clients in the health care setting.

4.3 Survey Analysis

The section below is the presentation and analysis of data from the responses obtained from face-to-face interview. The collected data set has been statistically analyzed by using SPSS- Statistical Package. Descriptive method also was used to present the result of study. The results were based on the various data obtained from the use of questionnaires.

4.3.1 Area and Age

The data was collected from Pyay and the other rural, urban and semi urban area to hang about Pyay. The range of the respondents was between 16 to 58 years. The mean age of the respondents was (38) years. 45 out of 120 respondents were live in rural area and (75) respondent was live in urban.

4.3.2 Education and Religious

Table (4.1) describes the education level of the respondents. There are four categories in education part, no formal education, school education, graduate and post graduate. 6 respondents are not teaching any kind of education, the other respondents have a chance to join the education, 89 percent are going to school for primary to high school education and 25 percent of respondent are graduated and post graduate.

Table (4.1) Education Level of the Respondents

| | Educational Qualification | | | | | |
|-------------------------|---------------------------|---------|--------------------------|---------|----------------------------|---------|
| | No Formal School | | Primary or Middle School | | Graduate and Post Graduate | |
| | No. | Percent | No. | Percent | No. | Percent |
| Above 40 years | 0 | 0.0 | 33 | 37.1 | 15 | 60.0 |
| Between 30 and 40 years | 4 | 66.7 | 26 | 29.2 | 10 | 40.0 |
| Under 30 years | 2 | 33.3 | 30 | 33.7 | 0 | 0.0 |
| Total | 6 | 100.0 | 89 | 100.0 | 25 | 100.0 |

Source: Survey data November – December 2020

When educational attainment of respondents checked, majority of respondents are primary or middle school finished. Their educational attainment has been shown in Table 4.1. As showed in table, 85 percent of respondents have been finished primary or middle school. Graduates and post graduates are 21percent and the rest of the respondents do not have formal school.

4.3.3 Family and Occupational Status and Marital Status

Table (4.2) presents the occupational status of the respondent and all respondents with different level of education. 76 respondents are living together with extended family such as parents and relative. Only 11 respondents are living together with their own family. 14 out of 101 respondents are living alone and struggle with difficulties in their day-to-day activities. 67 respondents are married, 8 out of 101 are divorce, only one respondent is abandoned from family. 27 percent of respondents are widow and most of their partner were expired due to AIDS syndrome. Only 2 respondents are single and these two are getting the diagnosis is transmit from the parents.

Table (4.2) Occupational Status

| Occupational Status | Number | Percent |
|----------------------------|---------------|----------------|
| Employed | 34 | 28.3 |
| Unemployed | 14 | 11.7 |
| Self employed | 72 | 60.0 |

Source: Survey data November -December 2020

The result showed that the majority of respondents are running own business, own firm and working as daily worker. They are running the own business like selling the cloths, government lottery, doing traditional snacks, tailoring and designing for cloths. Only one respondent is totally depending on the community and sub health group support due to permanent health not recover problem. All of the post graduate respondents are employed. The nature of Myanmar society in most of the family are stay live as a big family and they show that the unique of family is great value in society. They handed over the spiritual norms and value of family nature to elder to younger. There are 95.3 percent respondents are working in both public and private area. Among of these 32.8 percent are form the rural, 67.6 percent are from Urban. 28.6 percent of respondent from both rural and urban are unemployed and 72 percent of respondent are self-employment both are from rural and urban.

4.4 Discovering HIV Status of Respondents

Table (4.3) indicates that the discovering condition of all respondents. According to the survey, Health condition of the respondent who took the test in 2002 is still good. Around 30 percent of respondents discovered their HIV status by voluntary testing. Of those 4.2 percent of client were founded HIV result in testing in blood donation. The patient who was prolong illness and getting the result were 20.0 percentage of the data. 17.5 percent of the women were getting the result during pregnancy. The rest are getting result from the unexpected situation in work place and force to testing in workplace.

Table (4.3) Mood of Blood Testing and Discovering Status

| | Under 30 years | | Between 30 and 40 years | | Above 40 years | |
|--------------------------------------|----------------|---------|-------------------------|---------|----------------|---------|
| | No | Percent | No | Percent | No | Percent |
| Voluntary testing | 12 | 37.5 | 5 | 12.5 | 19 | 39.6 |
| While donating blood | 0 | 0.0 | 3 | 7.5 | 2 | 4.2 |
| After prolonged illness, symptomatic | 3 | 9.4 | 5 | 12.5 | 16 | 33.3 |
| During pregnancy | 4 | 12.5 | 13 | 32.5 | 4 | 8.3 |
| Others | 13 | 40.6 | 14 | 35.0 | 7 | 14.6 |
| Total | 32 | 100.0 | 40 | 100.0 | 48 | 100.0 |

Source: Survey data November -December 2020

As shown in the data, the voluntary testing was round about 30 percent and the second highest testing nature was followed by 20 percent as after prolong illness, entry point from as other categories is higher than prolong illness. Of the 17.5 percent of the respondents known their status during the pregnancy.

Table (4.4) describes the amount of the client who joined the counseling session for their blood testing. The pre- and post-counseling session are providing in both government hospital and private sectors.

Table (4.4) Counseling Session for Blood Testing (n = 120)

| Test Place | Patients | Counselling Sessions | Number | Percent |
|------------|----------|----------------------|--------|---------|
| Government | 80 | Joined | 68 | 66.7 |
| | | Not joined | 12 | 15.0 |
| Private | 40 | Joined | 38 | 95.0 |
| | | Not joined | 2 | 5.0 |

Source: Survey data November – December 2020

After doing the questionnaire, the result at government sector percentage were 80 and the rest of checking in private hospital were 40 percentage. 80 percent of testing are come from Public hospital and 85 percent of among these respondents are taking the counseling session for HIV testing in hospital. 40 respondents are taking the investigation for the blood testing at private clinic and among of these testing 95 percent are taking the counseling for both before and after testing. Because most of the private clinics especially NGO are providing the treatment as soon as possible and they already set up the protocol and criteria to provide the treatment for all vulnerable. In the private sector ART treatment is easily to assessable and they provide the comprehensive care and support for other screening and also providing treatment for opportunistic infection with free of charges. So, most of the people are used to going the private sector for HIV treatment. almost 85 percent of the respondents are joined the counseling session and they have got information of the disease and treatment from the government site and from the point of the private it also joined the counseling session for pretest and posttest.

4.4.1 Disclosure Status

Table (4.7) is the information of the disclosure status and disclosed person. Almost 97.5 per cent respondents disclosed their HIV status to someone or the other. The confidants were the spouse, sibling, parent/s, friends, co-workers, neighbors or any close relative. The percentage of not disclosed to no one is only 2.5 percent and they are really afraid of being discriminated. Among those who did not disclose their results, fear of stigma and discrimination was the main reason. They said they did not bare of their identities when they went to private clinics to catch a common cold or cough because they feared being rejected to get the treatment or asking for extra money. They also excited the fear of losing their job and fear of harassment and persecution in society. All of the positive parents and person do not want transmitted the virus to their children and to the partner. So, if they their result they follow the instruction as much as possible.

Table (4.5) Disclosure Status and Disclosing Groups (n=120)

| Disclosing Groups | Number | Percent |
|--------------------------|---------------|----------------|
| Disclose | 117 | 97.5 |
| Not disclose | 3 | 2.5 |
| Spouse | 90 | 76.9 |
| Parents | 76 | 67.0 |
| Siblings | 50 | 42.7 |
| Close friends | 16 | 13.7 |
| Co-workers | 12 | 10.3 |
| Neighbors | 13 | 11.1 |

Source: Survey data November – December 2020

As shown in figure 4.5 the disclosure level of respondent was high 117 respondents are disclosed about their status to their rely person as mention as above. According to the table disclosed to spouse is the highest and disclosed to coworkers is the lowest percent.

Of the eligible respondents, about 92.5 per cent said that they took precautions to protect their partner/spouse from getting infected that of all respondents who took precautions. 4.3 percent of the respondent are not taking action because their partner root causes to get the HIV result and they have other sex partner. 55.2 percentage of the respondent's partner are getting the HIV result before they don't know their result are being positive. Disclosure level of the respondents were high 117 of 120 respondents disclosed about their status to spouse, parents, sibling, close friends, co-worker and neighbor. According to the precents 76.9%, 65%, 42%, 1.7%,10.3%, 11.1% are follow by the group of spouse, parents, sibling, close friend, co-worker and neighbor.

In the questionnaire the protection of spouse or partner was applicable in only, the person who have known their status in the early time of before married or before having sex. During the face-to-face interview and focus group discussion revealed that most of clients use to condoms.

116 respondents out of total 120 respondents answered the information for the mother to child transmission. Among these 40.5 percent of mother were taking the action for the precaution not to infect to infant. 4.3 percent of mother are late to take the precaution and the other 55.2 percent of mother decided not to take more child and the rest of 61 respondents knew the result when the children are become sick and getting the positive result. In the earliest time the prevention of mother transmission to child

treatment (PMTCT) is not much advance and not easily to assess in hospital. After the government setting has been changed all of the pregnant are easily assessable and transmission of mother to child rate is reduce and PMTCT program was achieved in the continuous years in ahead.

4.4.2 Discrimination of the Infected Women

Table (4.6) expresses that the discrimination condition among all types of relation. The respondents also stated various situation through which they felt discriminated. These included disregard family and relatives dissent of the treatment by restorative people, alluded to other healing center, physically mishandle behavior, verbal mishandle, children were rejected and were not permitted to play with other children, deprivation of cherish and care, faulted of spreading infection, moving absent when the contaminated individual passed by, not permitted in social get-together, inquired to take off the place.

Table (4.6) Discriminated Percentage in Women Living with HIV/AIDS

| Place of Discrimination | Number | Percent |
|-------------------------|--------|---------|
| Discriminated | 49 | 40.8 |
| Not discriminated | 71 | 59.2 |
| Family | 20 | 40.8 |
| Hospital | 3 | 6.1 |
| Neighbors | 19 | 38.8 |
| Community | 5 | 10.2 |
| Education | 4 | 8.2 |
| Work Place | 5 | 10.3 |
| Others | 3 | 6.1 |

Source: Survey data November – December 2020

According to the data, 49 out of 120 respondents face with discrimination from family, relatives and community. They try to survive and think about themselves how to struggle and meet with peer support to express their emotional support. As shown in Table (4.6), 40.8 percent of the respondents were faced with discrimination from the family, relatives, friends, coworkers and community. As high as about 40.8 per cent of the respondents said that they faced discrimination. Family is integral part of the society and it provided to the family member to get emotional bounding and a sense of being secured. Ironically enough, discrimination mainly occurred at the family level (40.8%)

and in hospitals (6.1%). At the next level was discrimination by neighbors (38.8%), in community (10.2%), other (14.3%) was from the educational institutes, relatives and workplace.

Non discriminated percent was higher than the being discriminated percent. Stigma is cause to discrimination against infected people and their families in some of the situation. Discrimination is the main cause to take the prevention and care efforts of the illness. Discrimination lead when people or institutes take negative actions that result in the unfair or unequal treatment of a person affected by HIV. Some of the respondent share rejected experience of being HIV positive and bad manner from the medical person. Some of the patients are afraid to discrimination so they stigmatized to themselves. It can effect on the psychosocial wellbeing of the human and which leads to the depression and psychosomatic trauma issue. Generally, there was observed in different society with uncontrollable and unexpected discrimination.

There are 59.2 percent of respondents have got the good communication from spouse, family, relative. They can create the satisfied environment and better understanding in each other. That is the good to share to know other environment and try to get more secure palace in community level.

4.4.3 Possible Economic Impact on Family Member

Almost 65 per cent of the respondents had other HIV+ members in their family. Of them, 55 per cent respondents said their spouses were also infected. Siblings of about 3 percent were infected. 15 percent of children were infected from the parents and 1 percent of other relatives was also being infected. After studying the HIV status of respondents, the first reaction of the family was shocking (27.5%), and then negative respond was following by (39.1%). At the same time, it's nice to see that about 81.7% of families accept them and helping when necessary and needed situation. They know their status very lately and the disease was transmitted to their children. The psychological situation of family members is also being effect on this situation. Family members are afraid of the transmission but they support and taking care of them.

Approximately 95 per cent respondents said they got the support from the family member and spouse. About 63.2 percent of respondents are getting taking care and support from the spouse. 27.2 percent of respondents got the support from their children and taking care to them when they have been sick. Roughly 34.2 percent of respondents got the support from the parents when they were sick and severe illness.

In most of the family, the client is only one bread winner for the family. When the client is being sick or suffering chronic illness, the other family members are taking a responsible to earn money to help the family and to support the client. They face with financial problem when client could not work. Of 45 percent of care taker lost the money that use to treat to recover from the severe illness and support the family because of the health is not good and could not effort to earn money due to the health situation. The loss of income ranged was from MMK. 50000 to MMK10000000 due to the chronic ill and intensive treatment. Average MMK 160000 was loss of income in the family.

Monthly income is depending on the type of the working nature and it was varied from MMK 20000 to 3500000. The average monthly income of the respondents was about 350000 kyats, which suggests that it is very difficult for single women to live independently without financial support. Coincidentally, after the death of her husband, their money and property were confiscated by relative and the husband's parents. Round about 7.5 respondents were earning money 0 Kyat to 150000. 25.8 percent of respondents were earning money between 150001 to 300000 and the rest of 17.5 percent could earn above 300000 per month.

The attitude of the family and behaving to the infectious person is not the same, some are really empathized and try to help. Some of the communication was too bad most of the people are being neglected and avoidant from the family, friends, working environment. Some are facing with deprived of using basic amenities at home accessories, being taking away the properties after spouse was passed away and force to leave from home. It signifies that even highly-educated people are ignorant about the modes of HIV transmission. Interventions must be planned to change the existing behavior of people.

4.4.4 Support of the Care Taker During Illness and Getting Trouble

Table (4.7) convey that the situation of the condition of the contribution of the family member's supporting. By doing the focus group discussion and interview sessions most of the respondents report that actually their husbands do not want to infected to them and they have concerned for their wives and children, they wanted to be a supportive person for family. Husband wanted to protect the family but it was too late and where there was already positive in some of the case.

Table (4.7) Caretakers Support

| Caretakers | Number | Percent |
|-------------------|---------------|----------------|
| Spouse | 72 | 63.2 |
| Children | 31 | 27.2 |
| Parents | 39 | 34.2 |
| Sibling | 30 | 26.3 |
| Others | 8 | 7.0 |

Source: Survey data November – December 2020

According to the table (4.7) that almost all of the respondents has got the support. The support got from the spouse was the 63.2 percent, got the support from the children was 27.2 percent, support from the parents was 34.2 percent, 26.3 percent and 7 percent are followed by the sibling and others. There is less cases which was not transmitted and get a chance to protect of spouse and it was relevant only in cases where the person had got to know his status either before marriage or before having unsafe sex with spouse after marriage or they do have open relation.

After getting the result women were prepare their mind to be brave and think about that to continue the life with HIV and to support for family not only for the health but also to get the happy and healthy family life. After observing the interview session, they said that the scenario of being infectious the first emotion is really difficult to accept and most of the vulnerable persons was shown the sign and symptom of AIDS and need the treatment but they have not ready for that and the support from the family is much effective to continue for the future. The initiation stage of family acceptance level is not much smooth but after well understanding on the AIDS they know and begin to accept and help. In one case, property was taken away from the spouse of the infected person. In some cases, children faced with bad discrimination from the both of family member and community. Children get trauma for that issue and difficult to communicate with community and loss of self-esteem.

4.5 Employment Status and Attitude of the Employer

Table (4.8) shows that the employment status and the attitude of the employer towards the respondents. Some of them face with difficulties in the working environment, the employer was not supportive, demotion, froze the position, force to resign and disclosure problem.

Table (4.8) Disclosure Status, Support from the Employer and Effort by Patients

| Disclosure and Support | Number | Percent |
|-----------------------------------|---------------|----------------|
| Disclosed to Employer (n=120) | 34 | 41.2 |
| Not Disclosed to Employer (n=120) | 86 | 58.8 |
| Support from Employer (n=34) | 14 | 41.0 |
| Not Support from Employer (n=34) | 20 | 59.0 |
| Using Past Saving (n=86) | | 35.0 |
| Borrow from Others (n=86) | | 55.8 |
| Mortgage Assets (n=86) | | 29.2 |
| Sales Assets (n=86) | | 24.2 |
| Loan from Employer (n=86) | | 03.3 |
| NGO Support (n=86) | | 30.0 |
| Stopped taking Medicine (n=86) | | 03.3 |
| Others (n=86) | | 11.7 |

Source: Survey data November – December 2020

As above the Table (4.8) of the employed respondents, employers of 41.2 per cent people knew about their HIV status. Of the respondent of 22 percentage are from the government sector and 12 percent are from the private sector. Each of the group round about 27.3% percent have got the support from the employer of government staff and 66.7 percent of the private sector have got the support from their manager. So, the employee from the private sector have got the support then government sector.

It seemed to be there have more humanitarian and transparency between organization and staff. Some have force to checking the blood test and keeping the authorize power. Some are finding the new jobs and during the gab not getting the job they had used their past saving, sell their entire assets, borrow the money from someone, some are stopped to taking the treatment and some has got the medical expense from the organization and it was depending on the rules and regulations of organization. Some of the medical cost was very high and it's depends on the clinical situation. Some are getting paid leaves and some are unpaid leaves. Some of the respondent said that they received the immaculate support from the working environment that was really invaluable and priceless for them.

In the case of non-support from the employers or in self-employed, the infected persons had to meet their medical expenses on their own. About 35 per cent used their

past savings to meet the increased expenditure. About 55.8 per cent had to borrow from the others. In some cases, it was so difficult to manage the increased expenses that they had to sell (24.2%) or mortgage their assets (29.2%). 3.3. percent of respondent had to take a loan from his employer to meet his needs. There are 30 percent of respondent has got the support from and NGO and It was viewed that NGOs are playing a significant role in this field.

4.5.1 Discrimination from Co-worker and Attitude of Co-worker

Table (4.9) refer to the situation of the discrimination at work place. Stigma and discrimination were faced by PLWHA at every place and the workplace was no exception. The other also have got the discrimination, the scenarios are depending on the workplace, some of the employer and colleagues are much supportive and some are giving enough space for both spiritual and physically safe.

Table (4.9) Discrimination at Work Place and Attitude of Coworker

| Discrimination and Attitude | Number | Percent |
|------------------------------------|--------|---------|
| Disclosed to Co-worker (n=106) | 7 | 07 |
| Not Disclose to Co-worker (n=106) | 99 | 93 |
| Neglected, isolated, avoided (n=7) | 4 | 57 |
| Verbally abused, teased (n=7) | 3 | 43 |

Source: Survey data November – December 2020

The behavior of co-workers is an important issue as one spends a major part of one's day with co-workers. Total 7 respondents were after disclosing and by knowing the status of HIV+ they face with discriminated. Roundabout of 57percent is being negligence and isolated, 43 percent were teasing, verbally abused and acidly in working environment. That is why most of the respondents have not disclosed about their status in the working environment because of fear to be discriminated. They don't want unpleasant situation and insecure feeling.

As shown in above figure, the data can be assumed that Total 34 respondents answered this question and among these 5.9 percent (2 person) has been discriminated at work place as denied the promotion and force to take the voluntary retirement. But no one were not changing the new jobs and working environment. They afraid of getting the new challenges from the new environment and they worried about if they change the working environment, they have to negotiate about leave and clinic appointment for

the regular follow up. Even though the working situation has been discriminated, the other procedure for the regular follow up is harmonize with the oldies.

4.6 Economic situation and Impact of Infected Person

Only 5 of the respondents were taking the leave due to their illness and delivery period. They have loss income due to their illness the amount was not much higher and this is entitled with unpaid leave in some cases only one case loss 1000000 kyats and the other. The other has doing work regularly in both private and public sector. Of the 2 respondents are changing the job after recover from their health. One respondent does not get the fringe benefits for overtime charges. Only the rest of the other are taking the support both family, NGO and community base movement organization.

Table (4.10) explain about the economic impact on the beneficiary and their family. The amount of earning money and consuming amount was depending on the economic situation of respondents.

Table (4.10) Household Income and Expenses

| | Minimum (Kyats) | Maximum (Kyats) | Mean (Kyats) |
|--------------------------|----------------------------|----------------------------|-------------------------|
| Monthly income | 20000 | 3500000 | 359108.11 |
| Family income | 20000 | 4500000 | 4500000.00 |
| Food expense | 150000 | 700000 | 172123.89 |
| Expense on clothing | 0 | 50000 | 13425.53 |
| Expense on Education | 20000 | 350000 | 25542.19 |
| Expense on Accommodation | 20000 | 350000 | 17183.86 |
| Expense on medicine | 150000 | 200000 | 9158.86 |
| Expense on convenience | 20000 | 200000 | 20075.53 |

Source: Survey data November – December 2020

Table (4.10) shows that the monthly income of the respondents different from Myanmar kyats 150000 to 3500000. The averages income of the respondents was round about 350000 Kyats. The family income of the respondents was different from 0 kyats to 4500000. The average family income for monthly was 430000 kyats. Some of the respondents not working to earning money but main responsible for those people was house wives and taking care to the family members not only for the HIV but also to run everything is functioning well within family.

Some of the family members was doing extra work to cover the compensate of the vacant of the sick people. Because no one could not guess they will be face with the horrible disease in their life time. They do not prepare for that in advance, by knowing this result they take a break and preparing about how to accept and how to live together with HIV for a lifelong. It was really difficult and hard to fit in with life and it took a time to become stable. All of the vulnerable people try to set up their normal life with the chronic disease.

The average money usage for food was between 150000 to 700000, for the household expense for clothing is between Zero kyats to 50000, most of the family are not using money for clothing regularly and the usage was depending on the regularly income. The usage for the education was varied from the 20000 Kyats to 350000 Kyats. The renting for the accommodation was 200000 to 350000 their accommodation cost was not much higher in both rural and urban. The monthly expense on medicine was between 15000 to 200000. The average household usage for the conveyance and entertainment difference from 20000 to 200000 it was depending on the working nature and some of the respondents were using the money because of their working nature is consuming the money.

4.7 Before and After HIV Detection Condition

Table (4.10) provides the information about before and after HIV detection condition of the respondents. The situation is relying on the clinical situation of individual respondents.

Table (4.11) Difference of Expenditure Before and After Detecting HIV

| Items | Average Monthly Expenditure Before (Kyats) | Average Increase/ Decrease (Kyats) | Increase/ Decrease |
|----------------------------------|--|------------------------------------|--------------------|
| Expenditure on food | 170000 | 40000 | Increase |
| Expenditure on Entertainment | 200000 | 20000 | Decrease |
| Medicine Expenditure on medicine | 10000 | 25000 | Increase |
| Expenditure on Education | 25000 | 15000 | Decrease |
| Expenditure on Debt | 0 | 150000 | Increase |

Source: Survey data November – December 2020

The data shows that in the figure (4.11) the impact of before and after HIV detection is different from the mode of the expenditure on the household. The 48 respondents have increase in food expenditure and basic needs because of the nutrition is important for those people the average amount is increased 50000 from 150000 for the whole family. They need to taking care for the appetite. The medical expenditure was also increased in the 15 percent of total respondents the amount is increased in some of the family the range is within 80000 to 550000 because of the severe health situation. Expenditure on education was decrease in only 4 percent of the respondents. The rest of other respondents are not decrease. For the entertainment expense there were 33 percent of respondents decrease and they try to balance the income and expenditure. Some were not trying to use extra money for the entertainment.

Of the graduate and postgraduate respondents, about 25 per cent reduced their expenditure on entertainment. Of the respondents who had only been to school, about 89 per cent cut their entertainment expenditure. 6 per cent of the illiterate respondents reduced their expenditure on entertainment. By observing the data, most of the people been to school were much less the extra money use age of entertainment because they do not have enough money and could effort for that. If they increased in debt that not to sort out easily in their life. According to the data the educated person is give priority the health, food then the other non-educated person. 24 respondents were increased debt minimum 200000 Kyats to maximum 5000000 Kyats some of the respondents have treating the opportunistic infection treatment.

4.8 Medical Expenditure

Table (4.12) provides the data of the medical expenditure of the respondents. Some of the respondents need to effort the medical expense due to their clinical situation. Normally they need to effort for the treatment of ART and opportunistic treatment costs. But some of the situation, if the clinical situation is severe and not to wait for free of charge the start the treatment as self-funded.

Table (4.12) Medical Expenditure

| Types of Medical Expenditure | Number | Maximum cost (kyats) |
|--------------------------------------|---------------|-----------------------------|
| Cost for the opportunistic infection | 31 | 250000 |
| Checking for viral load and CD4 | 4 | 150000 |
| General medical cost | 1 | 20000 |

Source: Survey data November – December 2020

The data shows that 31 respondents were effort for the treatment the opportunistic infection. 4 respondents have invested to check the viral load and CD4. Only 1 respondent give the general medical cost. The rest of 89 respondents do not have the medical expense for the treatment of opportunistic infection. It was varied from the 20000 Kyats to 250000. Only the 2 respondents were given the cost for viral load and CD4 checking. Only 1 respondent was given the money for the general drugs. HIV-infected people have to go for regular check-up of viral loads and CD4 counts. But in most of the government hospital was given a chance to check viral load testing to every patient for free of charge. All of the patients waited until their routine due date to check the CD4 count and viral load. Now government hospital provided the drugs for non-communicable diseases treatment after taking the antiretroviral. In the government hospital there was appointment date for the specific diseases like diabetes, hypertension, dental, cardio vascular disease, tuberculosis, maternal service. Among these OPD days cost sharing for the normal person and free of charge for HIV clients. Because some of the drugs side effect are intentionally suffer from diabetes, cardio vascular diseases, hypertension. So, for those kinds of patients do not need to give the charges for this treatment. Although they have received that kind of support from the government hospital, if they have faced with major problem and need to take an operation the charges for the procedure is increased to double. Some of the respondents can effort to continue to the operation and some are not effort and taking a time to chance to collect the money. For the anti-retroviral treatment is need to take life long and government provided for all of the clients.

4.9 Factors to Affecting towards Adherence

Table (4.13) illustrate that the factors that can affect to the treatment adherence. Psychological factors affect treatment adherence among PLHIV. Several mental health disorder such as anxiety and depression are associated with HIV.

Table (4.13) Factors Affecting towards Adherence (n =120)

| Factors | Number | Percent |
|--------------------|---------------|----------------|
| Social Factors | 65 | 54.2 |
| Emotional Factors | 84 | 70.0 |
| Behavioral Factors | 33 | 27.5 |
| Cognitive Factors | 19 | 15.8 |

Source: Survey data November – December 2020

The data shows that 65 percent of respondents are facing with social factors like facing with family problem, financial problem, economic unstable situation, being negligence from the family member and relative, lack of emotional and social support, disclosure issue and difficult to accept the difficult situation. 84 percent of the respondents reflect that they have emotional factors that is hinder problem for the adherence. They do have many problems in their life some of the practical of social problem is difficult to solve and sometime they do not want to continue the treatment but they told to the counselors about their situation and discussed about for the coping mechanism and balancing method. About 33 percent of respondents have face with behavior problem that effect to the adherence. 19 percent of the respondents are facing with cognitive factor, HIV itself has tend to effect to the central nervous system for some clients. some of the drugs have severe side effect on some of the people. Some have misconception on the treatment and they use to manipulate the drugs.

The key point of the adherence is to be accurate and right timing for each and every doses. For those kinds of the social problems became the root causes for the emotional unstable situation. All respondents face with social, emotional, behavior and cognitive challenges in their day-to-day activities to struggle to manage. Due to the discrimination, they do not want to continue to treatment. When to go appointment to take the drugs they face some like an inquisitive look even they have look in good condition because of the drugs collecting are that is already noticed. Being discriminated respondents said that they have insecure feeling when they taking the drugs in working environment even though they disclosed about their status. They have felt severe side effect of the antiretroviral drugs and their appearance is not look in good so they felt like fail to be human and loss of humanity even they have a chance to live by taking the drugs. After observing the interview session and group discussion of the women, they felt unfair feeling even they do not do any kind of invasion and bad manner in their lives. They have lost face and loss of dignity in life. Some of the people have behavioral problem like using illegal drugs, drinking alcohol, betel chewing, using the traditional and herbal drugs, take the drugs not right time due to social problem.

4.9.1 Missed to Take the Drugs and Adherence Maintaining

Table (4.14) represent the situation of the treatment adherence of the clients. Adherence is major issue for every person who took the ART treatment. If there is good adherence, they have less to get the failure and if they do not have good adherence, they will get the resistance virus.

Table (4.14) Missed the Drugs the Depends on the Situation

| Missed Drugs | Number |
|-------------------------------------|---------------|
| Late the drugs frequently (n=120) | 19 |
| Late the drugs occasionally (n=120) | 5 |
| Late the drugs sometimes (n=120) | 22 |
| Late the drugs very rare (n=120) | 2 |

Source: Survey data November – December 2020

Of the 19 respondents are history of missed to taking the drugs frequently due to their social and emotional situation. Some are missed and some are not late to take the drugs. Of 5 respondents are miss to take the drugs occasionally. 22 respondents are missed to take the drugs sometimes, 2 respondents are missed to take the drugs Vary rare. The rest of 72 respondents are taking the drugs on time with correct dosage.

4.9.2 Managing the Adherence and Unexpected Situation

Table (4.15) shows that, managing pattern of the adherence in unexpected situation. This is the key points of the treatment result and it reflect of the difficulties of the real situation of the day-to-day activity.

Table (4.15) Managing the Drugs Adherence

| Managing | Number |
|--|---------------|
| Taking the drugs by reminder | 36 |
| Taking the drugs by self-care | 86 |
| Taking the drugs by remind from some one | 22 |
| Total | n=120 |

Source: survey data November – December 2020

The above data show that there is total 120 respondents answer the survey questionnaire, 77 of the respondents said that their adherence is priority in their life and 42 respondents are priority to the situation the rest of the other are solve the problem according to the situation. 36 respondents are taking the drugs with alarm and reminder.

86 percent was taking the drugs by themselves and the rest of 22 percent was reminded from the 2nd person. The result of the viral load is depending on the adherence level and it would be regularly checking. 72 respondents have good viral suppression and the other 48 respondents have experience on increasing the viral load and after getting the viral load increasing result, they tried to correct the adherence and avoiding and managing the risk factors. Because they afraid of to get the resistance virus and change the treatment to 2nd generation of the drugs.

According to the interviewed, the common challenges of the respondents in social factors are, financial unstable situation and increasing the debt, facing with discrimination from different groups as family, community and co-worker. The children of the respondents are also being negligence and rejected and this is one of the challenges for them. The condition of being infected due to concealment can cause of the stressful situation and infected to other family members is also instability in struggling. One third of the respondents are widow and they face with many problems like not enough income and reduce some of the expenses, stop some of the treatment. These social factors are effect to the emotional state of beneficiary, they felt depress, stress, worry and concern on how to survive. They just focus on the practical situation and sometime they missed to take the drugs because of the stressful situation. The meaning is that common challenges of social factors are the linking with the emotional unbalancing situation and it can also beat the behavior like not taking the drugs right time. Therefore, social factors, emotional factors and behavior are related each other's. The affect of social and emotional barriers leads to the adherence problem.

CHAPTER 5

CONCLUSION

5.1 Findings

In this study, structured questionnaire with face-to-face interview to the women living with HIV/AIDS in Pyay township, Bago region to study the challenges of women living with HIV/AIDS in socioeconomic situation that can affect to continue the treatment. The study was conducted at the hospital and peer group gathering meeting at sup help group and interviewed to the 120 respondents. Finding from the study may not be correspond to the whole situation of the HIV positive community.

As the finding of the think about all of the respondents are female from Pyay who lives the provincial and urban zone close the township of Pyay. 45 respondents are from the country and 75 respondents are from urban region. Among of these respondents one third are widowed and accomplice were terminated and caused of passing is related with HIV and deft contamination and other comorbid illness. The relocation rate was as it were 24.4% and the reason are due to social, financial, hitched, family matter. As it were 2 people are relocated to other town since of the shame and separation. 90 respondents are live with extended/ joint family, 12 respondents live with claim family and the other 12 were living alone. Nearly all of the respondents are working in open, private and running the possess the commerce. The rest of 14 numbers are not unemployed

Discovered to reason of the result was depending on wellbeing conditions, aimed pregnant, unremitting ailment, blood checking for the giving, intentional testing and other reason. But from the checking for the giving, the rest of the other have complicated issue to urge treatment evaluate. But most of the respondents have known their partner/spouse tested positive.

The earliest discovered date of the respondents was 2002 and the latest discovered year was 2020. For the accommodation issue the most of the respondents have no problem for the accommodation but they have feeling unsecured when the

go and take the drugs at respective center because the government allow to take the drugs according to their address it means the person who lives around Pyay must be taken the drugs at Pyay General hospital. That's one of the components to influence the adherence since of the confidential and stigma issue. If possible, they prefer to take the drugs from other town ship.

Stigma and discrimination 49 (40.8) of respondents were face with stigma and discrimination. Among them 3 to 4 was faced with higher level of discriminated like not get the personal property, force to leave from home after bereavement of their husband and dispossess of assets. They start the life from the very beginning without support. They told that sometimes they do not want to survive and they missed and late to take the drugs because of stressful situation. When they feel stress and emotion was changed, they disclosed about this feeling to the mental health counselor or peer counselor discussed about coping mechanical for the stressful situation.

Among of the respondents 70 (58.3%) respondents are married and 40 (33.3) respondents are widow and they have faced with more difficulties than other respondents because they are the only one person who takes the responsible of the family. They psyched themselves up for the life and they do not want to give up the HIV. So, they try harder than the other person even though they live together joint family or not. There is a huge amount, 114 respondents (95.1 percent) were need somebody to take of them when they were sick. They have got the support from the family, parents, spouse and from their children also. The very beginning of time getting to assess the treatment is complicated criteria from both government and private sector (INGOs). One of the major challenges is that the client needs to move the designated area to get the treatment because most of the treatment are accessible in Yangon and after six months of treatment or the clinical condition is better, they allowed to go back to native town. In that time care take has lost the income and to prepare take care of the clients. 54 respondents (45 percent) have lost income due to take care for the respondents. Round about 23.1 percent of the children of the respondents were face discrimination from the community and relatives. They experienced negligence, physical abuse and refuse to use basic material. From the points of the mental health and psychological aspect, they have got trauma and mentally abused. Most of the children have felt low self-esteem, difficult to express emotion and difficult to form the healthy relationship with other. Mother felt guilty for their children.

About 41.2 percent of the respondents disclose their status to the employer and among of these 41percent has got the support from the employer. The rest of other did not the support and face with discriminate. One highlighted point is that even they face with discrimination they do not try to change the work place. After the face to face interviewed the said that they afraid to face the same feeling at new environment and if they would change, they will be negotiated with new employer disclosed again to them so they do want this unsecure felling again. 150000 to 3500000. The averages income of the respondents was round about 350000 Kyats. The married respondent's income is much then the widow and the income range of the married respondents was between 40000 to 400000 and the income range of widow was between 20000 to 360000. Only the 11.7 percent of the caretaker did the extra work to compensate for illness of the respondents.

After getting the result the of being positive 24 respondents (48 percent) were increased in debts, 48 respondents (40 percent) were increase the food expenditure, 33 (27.5 percent) respondents were reducing the money that use for the entertainment, 15 (12.5) respondents were increase the medical expense. Its means that HIV status was effect on the living situation of the person. The charges for the antiretroviral treatment and relative investigation procedure were free of charge in every unit of government hospital and INGO. But here there are some of the money that use in viral load checking, the taking the treatment for the opportunistic infection and operation cost. They have to paid the double charges for the operation and some of the health care provider denied the treatment and referred to the HIV specialist hospital even the health condition is not related with HIV.

The possible points of the factors the not taking the treatment were social, emotional, cognitive and behavioral dimensions. In the social dimension, common challenges and factors to continue to the adherence are, their health condition, psychologically unstable between their status and difficult to struggling in day to day activities, complication of the treatment, stigma and discrimination, family problem, financial problem, disclosure issue, health condition of other family member, regular follow up and employment status, loss to assess of the family properties, loss of income in the sickest situation because they are the only bread winner in some of the family. The treatment nature, side effect of the drugs, pills counts are one of the factors that effect to the adherence, self-reporting of the respondents in the interview, some of the

drugs have awful smell, some of the drugs effect the physical appearance, some of the medical factors are the kind of the adherence problem.

In the face to face interviewed the most respondent mentioned that when they face with social problem, they just focus on that problem situation rather than the adherence of the treatment. Because the social problem is needed to be solve depend on the situation and the adherence cannot affect at once so they prior the social problem. Social dimension and emotional demission are related if there is not stable in social situation, the emotion was change and fluctuated. In the questionnaire 54.2 percent of respondents have social factors to affect the adherence. 70 percent of the respondents have face emotional unstable situation and effect the adherence. 33 percent have behavioral related issue to affect the adherence. 15.8 percent of respondents have cognitive impairment and that is effect on adherence. According to the self-report at the questionnaire 39.6 respondents have late and missed to take the drugs, 10.4 percent of the respondents have missed to take the drugs occasionally, 45.8 percent were missed to take the drugs some of the situation and the rest of 4.2 is rare to affect the adherence.

5.2 Suggestions

According to the finding and the results of the survey analysis, these following points are the recommended. Stigma and discrimination are still having in the community level, so the local organization and international need to enhancing the awareness activity in the community not only for the civil society but also for the rural and district level. And the people who do not have the HIV + also need to participate in all kind of activities in community level and sometime give a chance to lead the session. The nature of the subhealth group all of the group member is the PLHIV, some of the HIV negative person have concern and interest to join and participate to the activity, this is the good chance to start the change to interchange the new segment.

In the previous study was focus the transmission and prevention part, advice for the risk reduction plan, enhance the risk reduction behavior, providing health education to the community and potential risk area. Another study was focus about risky groups and disclosure problem of this group are delay to get the treatment.

In this study, there are three points that have need to be changed to get the better situation for drugs adherence and drugs providing process. First point is suggested to improve the government infrastructure and service providing process, second point is

the participation and coordination of the government sectors and NGO is need to be more enhance. The third is the involvement and openness of the of clients.

For the first part, infrastructure at government building, the better suggestion is not to separate the place to provide the drugs with signboard. By using the same building and same procedure like non communicable diseases is a kind of the stigma and discrimination activities. Drugs providing center at government level there are many limitations, they could not dispense the drugs every day and the responsible person of on that drugs dispensing time he or she have need to do other activities so there also have time limitation. If possible, to expense the drugs at every week days during every working hour is better to reduce the tendency of the stress reduction for the both medical and patient's site. It is also affective to the misunderstanding between medical focal person and patients. Taking massive duties for one person is lead to the mistake and error for the medical person. So, government authorize person is need to think about to the regular focal person for each of the health care setting.

There is still limitation in the testing procedure for the viral load checking and blood testing issue. Government provides the free of charge for the blood testing but they have quota issue in daily running coverage for every hospital and decentralize side. Patients need to wait until arrived their turn. If there was possible to increase the human resource and upgrade to running the machine is better service for the clients to reduce the transportation charges for drugs collection time and investigation visit. And it also effects to reduce the burden for the lab technician and medical person also.

The service center is available at the nearest place with the patients is good point but for the confidential and stigmatize issue, give a chance to take the drugs at their prefer township.

From the individual point of view from the patient's side, they have been taking the drugs for a long time of duration and sometime they feel boarded and they negligence the adherence some of the situation, they assumed that they don't felt any kind of poor health condition even miss the drugs sometimes. They are not well informed about the virus duplication before starting the treatment in some of the clients. So, one important thing is that, before starting the treatment client and care taker have got full information of the treatment, nature of virus, process of the treatment, the meaning of viral suppressing process and duplication process. If not, there will be occur the adherence problem in a short period of time and becomes the resistance virus.

For the second the participation of the NGO is really important for the psychosocial support aspect, all decentralized site and government are must have peer support and psychosocial support counselor to provide the mental health and psychosocial support of the clients. Counseling support is really effective and supportive for the client adherence. To explore and identify the possible barrier of adherence is key component in mental health and psychosocial support of the clients. To get the good adherence outcomes result is not only important for the client but also for to reach the goal of the national strategic plan. According the objective of the national strategic plan 2011 – 2015, the target objective was improving quality of care and accessibility for the ART, ensure viral suppression for all PLHIV, improve the enabling environment to support the national HIV response. To be reach this goal is to implement to the above points and it would be the helping points for reaching goal and also support to the patient's holistic life and adherence issue.

The third and last part is involvement and openness of the clients is, because some of the clients are not enough involvement and they are not telling about their adherence history because of they afraid to be blamed and they assumed that they are good in health even late or missed the drugs. So, the second part and last part are linking and if there is enough psychosocial support with quality counseling is supportive to change the mindset of the clients.

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APPENDIX

Sample Questionnaire

Classification Data

| | | |
|-----------------------|-----------|---------|
| 01. Respondent ID# | | |
| 03. Interviewer Name | | |
| 04. Date of Interview | | |
| 05. Sex | 1. Female | 2. Male |

Section - I: General Information

| | |
|---|--|
| 101. Age | Yrs. |
| 102. Educational Qualification | 01. No formal school 02. School up to _____(standard/level) 03. Graduate and post graduate |
| 103. State of Residence | Origin Current |
| 104. Since when you are staying _____ (current place) | Yrs. (if staying since birth skip to 106) |
| 105. What are the reasons for coming to _____ (place) | |
| 106. Location of Current Residential Area | 1. Rural 2. Urban 3. Semi-urban |
| 107. Religion | 1. Hindu 2. Muslim 3. Christian 4. Others |
| 108. Current Martial Status | 1. Married 2. Separated/Divorced 3. Abandoned 4. Widowed 5. Living together 6. Unmarried/No live-in partner |

| | |
|--------------------------|---|
| 109. Family Status | <ol style="list-style-type: none"> 1. Living with parents/joint family 2. Living separately with spouse/partner 3. Living alone |
| 110. Occupational Status | <ol style="list-style-type: none"> 1. Employed <ol style="list-style-type: none"> a. Public b. Private 2. Unemployed 3. Self employed |

Section - II: Information on HIV/AIDS Status

| | |
|--|---|
| 201. How did you discover your HIV Status? | <ol style="list-style-type: none"> 1. Voluntary testing 2. While donating blood 3. After prolonged illness, symptomatic 4. During pregnancy 5. While seeking employment abroad 6. Others (specify_____) |
| 202. When was it detected? | (/ /) |
| 203. Where was the test done? | 1. Govt. 2. Private Place: _____ |
| 204. Did you have pre and posttest counseling? | 1. Yes 2. No |
| 205. What was cost of testing | Kyats. _____ No cost involved |
| 206. Have you disclosed your HIV status to others? | <ol style="list-style-type: none"> 1. Yes 2. No (skip to q. 208) |
| 207. If yes, to whom? | <ol style="list-style-type: none"> 01. Spouse 02. Parents 03. Siblings 04. Close friends 05. Co-workers 06. Neighbors' 07. Others (specify_____) |

| | |
|---|--|
| 208. If no, what are the reasons for not disclosing your HIV status? | 01. Stigma and discrimination 02. Rejection 03. Others (specify_____) |
| 209. Did you take any precaution to protect your spouse/ partner from getting infected? | 1. Yes 2. No (Skip to q.211) 3. Not Applicable (Skip to SECTION III) |
| 210. If yes, what efforts did you take? | 01. Abstain from having sex 02. Started using condom consistently 03. Stopped sharing needles 04. Stopped donating blood 05. Others (specify_____) |
| 211. Did you take any precaution to protect your children from getting infected? | 1. Yes 2. No 3. Decided not have a child (skip to SECTION III) 4. Not applicable (skip to SECTION III) |
| 212. If yes, what efforts did you take? | 01. AZT/Nevirapine during pregnancy 02. C-section during delivery 03. AZT to the infant 04. No breastfeeding 05. Decided not to have a child |
| 213. Apart from you, are there other family members who are HIV+ ? | 1. Yes 2. No (Skip to SECTION III) |
| 214. If yes, who are they? | 1. Spouse 2. Siblings 3. Children 4. Others (Specify_____) |

Section - III: Stigma and Discrimination

| | |
|---|--|
| 301. Have you faced any discrimination or stigma? | 1. Yes 2. No |
| 302. If yes, then from whom/where? | 1. Family 2. Hospital 3. Neighbors 4. Community 5. Educational Institution 6. Others (specify_____) |

| | |
|---|--|
| 303. Please mention three instances when you faced discrimination? | 1. 2. 3. |
| 304. What was the initial reaction of your family members to your HIV status? | 01. Shocked 02. Denied/Disappointed 03. Empathized 04. Embarrassed 05. Not disclosed to family (Skip to SECTION IV) 06. Others |
| 305. Did your family accept you? | 01. Yes 02. No |
| 306. If yes, how long did they take to accept? | |

Section - IV: Impact on Women and Children and family member

| | |
|---|---|
| 401. Have you needed anyone to take care of you, while you were sick? | 1. Yes 2. No |
| 402. If yes, who takes care of you? | 01. Spouse 02. Children 03. Parents 04. Siblings 05. Others |
| 403. Did your care giver lose income due to lose of work time? (in case if they have one) | 01. Yes 02. No 03. Non-earning member (Skip to q.405) |
| 404. If yes, how much income did they lose? | Kyats. _____ |
| 405. What additional responsibilities were taken to support the family by the spouse/ children of the infected? | 01. Quit job in order to take care 02. Had to take-up job in order to support the family (wife/children) 03. Had to take up additional job to meet the increasing expenditure 04. Others 05. Not applicable |

| | |
|---|---|
| <p>406. What was the attitude of the family members towards the infected/ affected spouse?</p> | <p>01. Neglected, isolated, avoided 02. Verbally abused, teased 03. Physically abused 04. Deprived of using basic amenities at home 05. Property taken away 06. Asked to leave home 07. Never discriminated</p> |
| <p>407. How were the children treated at home?</p> | <p>01. Withdrawn from the school 02. Had to take up job 03. Were denied basic amenities 04. Others 05. Not applicable</p> |
| <p>408. Were you or your children treated badly or differently by others in the community because of having HIV/AIDS in the family?</p> | <p>01. Yes 02. No 03. Status not known to others (Skip SECTION V)</p> |
| <p>409. If yes, how did they treat you or your children differently</p> | <p>01. Neglected, isolated, avoided 02. Verbally abused, teased 03. Did not allow your children to play with their children 04. School authorities were compelled to expel the child from the school 05. Others</p> |
| <p>410. Who took care of the deceased?</p> | <p>01. Spouse 02. Children 03. Parents 04. Siblings 05. NGO 06. Hospital 07. Others</p> |
| <p>411. Did the care giver lose income due to lose of work time?</p> | <p>01. Yes 02. No (Skip to q.304) 03. Non-earning member (Skip to q.304)</p> |
| <p>412. If yes, how much income did they lose?</p> | <p>Kyats. _____</p> |

| | |
|---|---|
| <p>413. What additional responsibilities were taken to support the family by the parent/ spouse/ children of the deceased?</p> | <p>01. Had to take-up job in order to support the family 02. Had to take up additional job to meet the increasing expenditure 03. Others 04. Not applicable</p> |
| <p>414. How were the children of deceased treated at home?</p> | <p>01. Withdrawn from the school 02. Had to take up job 03. Were denied basic amenities 04. Others 05. Not applicable</p> |
| <p>415. Were you or the children of deceased treated badly or differently by others in the community because of HIV/AIDS death in the family?</p> | <p>01. Yes 02. No 03. Status not known to others (Skip SECTION IV)</p> |
| <p>416. If yes, how did they treat you or the children of deceased differently?</p> | <p>01. Neglected, isolated, avoided 02. Verbally abused, teased 03. Did not allow your children to play with their children 04. School authorities were compelled to expel the child from the school 05. Others</p> |

Section - V: HIV/AIDS and Employment

A - Only if employed

| | |
|---|--|
| 501. Does your employer know about your HIV status | 1. Yes 2.No 3. Self-employed (skip to q. 504) |
| 502. Do you get support of your employer? | 01. Yes 02. No |
| 503. If yes, specify the form of employer support | 1. Medical expenditure 2. Paid leave 3. Others (Specify _____) |
| 504. If no support of employer / self-employed, how do you cope with the increased expenditure on medicines, maintenance etc? | 01. Use past savings 02. Borrow from others 03. Mortgage assets 04. Sale assets / durable 05. Loan from employer 06. NGO supports 07. Stopped taking medicines 08. Others |
| 505. Did you face any discrimination at the workplace? | 1. Yes 2. No |
| 506. If yes, how were you discriminated? | 1. Promotion denied 2. Forced to take-up voluntary retirement 3. Benefits were not given 4. Others |
| 507. What was the attitude of co-workers at the workplace? | 1. Neglected, isolated, avoided 2. Verbally abused, teased 3. Others |
| 508. Did you change your job in the last six months | 01. Yes 02. No |
| 509. How many jobs have you changed in last six months | Nos. _____ |
| 510. What was the reason for change / loss of job? | 01. Was asked to quit job 02. Discrimination by co-workers 03. Terminated 04. Ill health 05. Others |

| | |
|--|---|
| 511. How many days were you absent from work in the last six months due to illness? | Days/months: |
| 512. Did you lose wage/income due to leave/absence? | 01. Yes 02. No (Skip to q.601) 03. Not applicable (Skip to q.601) |
| 513. If yes, how much wage/income did you lose? | Kyats. _____ |
| 514. What was the amount of fringe (over time, paid leave etc.) benefits lost, if any? Please specify the nature of fringe benefits? | 1. 2. 3. Kyats. _____ (Approx) |

B – Only if Un-employed

| | |
|--|--|
| 515. How do you support your expenses? | 01. Family support 02. NGO/Network support 03. Community support 04. Others (Specify _____) |
|--|--|

Section - IV: Indirect Cost

| | |
|--|--|
| 601. What is your monthly income? | Kyats. _____ |
| 602. What is the source of income? | |
| 603. What is the monthly income of the family? | Kyats. _____ |
| 604. Did any of your household member (spouse/ children) does extra work to compensate the loss of income/time due to your illness | 01. Yes (Specify _____) 02. No |
| 605. If yes, how much of current expenditure does it cover? | 01. Covers only part of increased expenses 02. All increased expenses are covered |

Section - VII: Household Experience

A-Prior to HIV Status

| | |
|--|--------------|
| 701. What are the household monthly expenses on food? | Kyats. _____ |
| 702. What are the household monthly expenses on clothing? | Kyats. _____ |
| 703. What are the household monthly expenses on education? | Kyats. _____ |
| 704. What are the household monthly expenses on rent/accommodation? | Kyats. _____ |
| 705. What are the household monthly expenses on medicine? | Kyats. _____ |
| 706. What are the household monthly expenses on conveyance, entertainment etc? | Kyats. _____ |
| 707. Other expenditures | Kyats. _____ |
| 708. Total monthly expenditure | Kyats. _____ |
| 709. How much would you have earned if you were free from illness during the last six months | Kyats. _____ |

B-After the Detection HIV Status

| | | |
|--|--------------------|--|
| 710. How has HIV/AIDS impacted on the following: a. Expenditure on food has increased b. Expenditure on entertainment has decreased c. Expenditure on medicines has increased d. Expenditure on education has decreased e. Debts have increased | If. YES | |
| | 1. Yes 2. No | Increased from Kyats. ____ to Kyats. _____ |
| | 1. Yes 2. No | Decreased from Kyats. ____ to Kyats. _____ |
| | 1. Yes 2. No | Increased from Kyats. ____ to Kyats. _____ |
| | 1. Yes 2. No | Decreased from Kyats. ____ to Kyats. _____ |
| 1. Yes 2. No | Approx. Amt. _____ | |

Section VIII: Medical Expenditure

| | |
|---|--------------|
| 801. What is the cost incurred on treatment of opportunistic infections in the last six months? | Kyats. _____ |
| 802. Cost incurred on checkups of viral load & CD4/ CD8 Count | Kyats. _____ |
| 803. Cost incurred for ART | Kyats. _____ |
| 804. Other general medical costs/tests (specify) | Kyats. _____ |

Section IX: Factors to effect towards Adherence

| | |
|--|---|
| 901. What are the factors that not to take the treatment | <ol style="list-style-type: none">1. Social factors2. Emotional Factors3. Behavioral factors4. Cognitive factors |
| 902. Do you have miss to take the drugs right time. | <ol style="list-style-type: none">1. Yes2. No |
| 903. if Yes How many times | <ol style="list-style-type: none">1. Sometimes2. Occasionally3. Frequently4. Very rare |
| 904. how do you maintain your adherence normally | <ol style="list-style-type: none">1. by reminder2. by self-care3. by remind from someone |
| 905. how do you manage your timing when facing with social matter or problem | <ol style="list-style-type: none">1. priority the drugs anytime2. adherence is 2nd priority3.. manage depends on the situation |
| 906. What is your viral load result | <ol style="list-style-type: none">1. the lowest2. the highest <p>(please mention together with duration of the treatment)</p> |