University of Eastern Africa Baraton, Kenya

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Master's Degree in Global Health Care

Empowering HIV positive women in Nepal

Master's Thesis

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Name of Study Unit:	Master's thesis
Assignment name and/or number:	
Date:	20–11–2017

ABSTRACT

Kormilainen, Aino. Empowering HIV positive women in Nepal. 47p, 5 appendices. Language: English. Helsinki, Fall 2017. Diaconia University of Applied Sciences. Master´s Degree in Global Health Care.

Thesis' goal was to clarify how empowering women with HIV will impact on their life and stigma and discrimination towards them. Thesis was done in co–operation with Nepalese NGO working with HIV positive women, Shakti Milan Samaj. Participants of the thesis were participants of EWCAH–project, established by Shakti Milan Samaj to empower HIV–positive women and raise the awareness of HIV.

Thesis was qualitative research based on the research questions. Data was collected from focus group discussion of 8 HIV positive women. Collected data were analyzed using content analysis. The results show that HIV positive women in Nepal face stigma and discrimination in many aspects of life. Empowering HIV positive women through projects like the EWCAH, will also help to reduce stigma and discrimination against them.

Theoretical background of the thesis was based on literature review done using four electronical databases.

Keywords: Nepal, HIV, women, empowerment, stigma, discrimination.

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List of Abbreviations and Symbols

HIV	Human Immunodeficiency Virus
AIDS	Acquired Immune Deficiency
ART	Antiretroviral therapy
WHO	World Health Organization
FHI 360	Formerly Family Health International, non-profit human development organization working with health, education, environment, economic empowerment and nutrition.
SMS	Shakti Milan Samaj
NGO	Non-govermental organization
EWCAH	Empowering women and children against HIV/AIDS-project implemented by Shakti Milan Samaj
MDGs	Millenium Development Goals
QOL	Quality of life
STD	Sexually transmitted diseases
UNAIDS	The Joint United Nations Programme on HIV/AIDS

1 INTRODUCTION

In the last three decades, The Human Immunodeficiency Virus (HIV), has turned into a global epidemic. WHO estimated that there were 36.7 million HIV positive persons worldwide in the end of 2015. Worldwide HIV is one of the leading cause of death. In Africa, it is the number one cause of death (WHO, 2015).

In Nepal, HIV prevalence is low compared to other South-Asian countries, however prevalence is high and epidemic among some certain group. These groups are such as female sex workers and people who inject drugs (Government of Nepal, 2004). UNAIDS (2015) estimates that there are 39 000 people living with HIV in Nepal, but due to lack of proper registration and health surveillance, the number might be much higher.

Throughout the history of HIV, it has been a heavily stigmatized disease (Mondel & Shitan, 2013). There are several reasons behind the HIV related stigma such as lack of proper knowledge and education about HIV and its's transmission, beliefs and mis-conceptions (Nepal & Ross, 2010). Women are biologically more vulnerable to get HIV-infection and they also face more HIV related stigma and discrimination than men (Ho & Holloway, 2015).

HIV related stigma in Nepal is mostly due to cultural beliefs and general perception about HIV and its transmission. Level of education and economic status also effect on the stigmatizing. Women with HIV face more stigma and discrimination than men in Nepal. This is due to the women's role in society as mother and caregiver of the family. Also, the beliefs of HIV in Nepal effect the stigma (Nepal et al., 2010). In Nepal, HIV positive woman might be seen as a prostitute or unfaithful to her marital husband (Jha, Plummer & Bowers, 2011).

In this thesis, I aim to clarify how empowering women with HIV will impact on their life and stigma and discrimination towards them. This thesis was done in co-operation with Nepalese NGO working with HIV positive women, Shakti Milan Samaj. Theory is based in literature review, which was done using four different electronic databases.

Example of the literature review done on women and HIV can be found in appendix 1. The results of the thesis are based in group discussion, where 8 women participated.

2 HIV/AIDS as a global and individual factor

2.1 The Human Immunodeficiency Virus (HIV)

The Human Immunodeficiency Virus (HIV) is a virus infection, which targets the immune system and impairs the human's defense systems against infections and some cancers. Individuals with HIV will eventually become immunodeficient, because the virus weakens and destroys the function of immune cells, mostly the CD 4 cells (T–cells). Even though there is no cure to HIV, with antiretroviral drugs, the virus can be controlled and transmission prevented (WHO, 2016).

The symptoms and signs of HIV varies depending on the state of infection. Some individuals don't have any symptoms on the early stage of HIV and because of the lack of symptoms, might be unaware of the infection. Some individuals experience common cold or influenza type of symptoms, such as sore throat, fever, muscle aches and fatigue (CDC, 2016a).

HIV transmits to other persons by exchanging certain body fluids of infected, such as blood, breast milk, semen, pre-seminal fluid, rectal or vaginal fluids. The body fluids must be contacted with damaged tissues or a mucous membrane, or injected directly to blood flow by using a needle or syringe. HIV can transmit during sex or sharing infected needles or syringes. HIV doesn't transmit by air, touch or sharing the food or drinks (CDC, 2016b).

HIV does not only effect on the individual's health, it also effects to the person's social life, mental health and financial aspects (Liping; Peng; Haijiang; Lahong & Fan, 2015). HIV can develop into Acquired Immunodeficiency Syndrome (AIDS) which is the most advanced stage of HIV. HIV will develop to AIDS within 2–15 years, depending on the individual. The lifespan after the AIDS stage is diagnosed, varies from 2–3 years without treatment (WHO, 2016).

2.2 The global HIV/AIDS epidemic

Since the first identification of HIV in the early 1980s much has been learnt about its transmission, its symptoms and how it is the cause of AIDS. In the last three decades HIV, has become a global epidemic. Countries, where the HIV prevalence is high are facing huge socio-economic problems due to the infection. Cases of HIV are being discovered worldwide, but most of the cases (97%) concentrate on the low and middle income, specifically in the Sub-Saharan Africa. Most of the HIV positive people or people in a risk to be infected with HIV, don't have access to preventing, testing, medication or other care. Worldwide HIV is one of the leading causes of death and in Africa, it is the number one cause of death. HIV infection does not only affect the individuals and their health, it also effects on the community the individual is living, development and economic growth of the nation (Mondel & Shitan, 2013, 301–302).

The global HIV/AIDS epidemic has taken different forms; in some nations or areas HIV is spreading generally, where as in other parts of the world, however HIV is mainly spreading among different groups of population, such as men who have sex with men or inject drug users (Gaile & Hill, 2001, 327).

About half of the new HIV infections are been diagnosed with people under 25 years old. Specifically, young women are biologically more vulnerable to get HIV than young men. Also, the gender inequalities, such as sexual violence and not been able to access the treatment increases women's risk for HIV. Young women have two times more bigger chance to get HIV infection than young men. Globally, around 50% of the HIV positive are women and in Sub-Saharan Africa, 60% of the HIV positive people are women (Mondel & Shitan, 2013, 302).

WHO (2015) estimated that in the end of 2015, there were 36.7 million HIV positive worldwide. Total 2.1 million new HIV infections was discovered and 1.1 million people died because of AIDS. The growth of incidence of new cases seems to be stabilized.

Worldwide there are fewer deaths related to AIDS and the number of new HIV infections are slowly decreasing. The incidence of HIV has fallen by 25% in 33 countries between 2001 and 2009. 22 of these countries are in Sub-Saharan Africa (Sultan & Adler, 2001, 1–2).

United Nations declared eight Millenium Development Goals in 2000. These goals range from fighting the extreme poverty to halting the spread of HIV/AIDS and providing universal primary education by the target date in 2015. The MDG number 6 is to combat HIV/AIDS, Malaria and other diseases. Target 6A is that by 2015, the new infections of HIV will be halved and the spread of HIV/AIDS begin to reverse. By 2013 the new HIV infections fell approximately 40 percent since the declaration of MDGs (UN, n.d.).

MDG target 6B is also about HIV and AIDS. It targets to achieve, by 2010, universal access to treatment of HIV/AIDS for all those who need it. By 2014, there were 13.6 million people living with HIV globally, who received Antiretroviral therapy (ART). In 2003 the some number of people receiving ART was 800,000, so there was an obvious increase in the number of people on ART (UN, n.d.).

In 1996, The Joint United Nations Programme on HIV/AIDS-UNAIDS was created to response to the need for concentrated and focused efforts of wide range sector of factors to battle HIV. UNAIDS is the leading delegate for global action against HIV/AIDS. Its aims are to guide, strengthen and support worldwide efforts to bring down the epidemic (UN, n.d.).

2.3 HIV/AIDS in Nepal

The first case of AIDS in Nepal was reported in 1988. HIV prevalence in Nepal is low compared to other South Asian countries. UNAIDS (2015) estimates that there are 39 000 people living with HIV/AIDS in Nepal. Out of this 35 % (14 000) are women at a ge 15 years or older. The prevalence of HIV of adult population is 0.3% out of Nepal's 28 million population (UNAIDS, 2015). Due to the poor public health surveillance systems in Nepal, the prevalence of HIV is likely to be higher, than the given prevalence (Pokhrel, Regmi & Piedade, 2008). In Nepal HIV/AIDS is emergent, major threat in the health and socio-economic sectors (Nepal & Ross, 2010).

Even though the prevalence of HIV is generally low in Nepal, it is high and epidemic among certain groups of population such as; people who inject drugs (PWID), Men who have sex with men (MSM), transgender people, female sex workers (FSW) and male labor migrants and their families (Government of Nepal, 2014). Until the late 1990s HIV infections were mainly common among female sex workers and injecting drug users, but recently HIV is becoming more generalized health issue, mainly because of the high rate of male migration to India and Arab countries (Nepal & Ross, 2010, 22).

Poverty, low socio-economic status of women, prostitution, high rate of male migration and illicit drug traffic are all vulnerability factors, which worsen the HIV epidemic. Also, the sex trafficking of young girls from Nepal to India worse the epidemic (UNAIDS, 2004).

2.4 Women and HIV

Getting diagnosed with HIV is shocking to any individuals, but for woman it might be even more devastating than for men. Women must consider about her possible children, if they have been infected with HIV as well and also consider the possible future pregnancies and the fact, that due to HIV-status of the woman, it might have more complications than pregnancies of woman without HIV. For women, as natural caregivers of the family, might be hard to prioritize their health and seek for treatment for HIV (Wilkinson & Mercey, 2001, 87).

Women might face more fear and anxiety in the disclosure of their HIV-status than men. This is due to women's lower social status in many developing countries and the fact, that in most of these countries women has less power to decide for themselves. They might fear violence from their spouses or even rejection from the family and society (Wilkinson & Mercey, 2001, 87–88). Women might be blamed for bringing the HIV in the family (Nepal & Ross, 2010, 25).

2.5 Life with HIV

HIV changes people's lives in all of its aspects. Addition to the possible physical symptoms the disease causes, it effects on the mental health of individual, social life, appearance of individual and role in society. In addition to normal stress factors in life, HIV positive individuals has to cope with several other factors caused by HIV, such as managing the chronic medical condition, fear, uncertainty and anxiety towards future, changes in sex life and relationships and stigma caused by HIV (Hedge, 2001, 108–109). HIV effects and changes individual's life in psychological, physical and social aspect.

2.5.1 Quality of life

Quality of life (QOL) is a broad concept that includes perception of individual's physical and psychological wellbeing, social relationships, personal beliefs and individual's perception of the environment and society, where he/she is living. WHO has defined quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, n.d.).

As a result of improvements in clinical treatment and the increase in life expectancy of HIV-positive individuals, the quality of life of HIV-positive persons have become important subject to the researchers as well as for the healthcare professionals providing treatment and care for people with HIV. Addition to the physical symptoms due to HIV, it effects on other aspects of life of the individual living with HIV. Many HIV-positive person struggle with socioeconomic problems, such as stigma and discrimination.

These features beside the physical symptoms have an impact on the QOL of the HIV-positive individuals (Basavaraj, Navya & Rashmi, 2010, 75–76).

Individual's coping strategies and stance towards HIV impacts on the HIV-positive person's quality of life. Abnegation of the disease, hiding of the disease and disengagement from social relationships worsen the QOL and cause more stress. On the other hand, if the individual living with HIV has gained good coping methods and social support and acceptance from community or society, even though diagnosed with HIV, the QOL will be better than those without these methods and support (Basavaraj et al.2010, 75–77).

Studies have shown that HIV-positive persons in Nepal have lower quality of life, than those individuals not diagnosed with HIV. In a study by Smith et al.(2013, 279–281) it was revealed that the overall QOL of HIV-positive persons was lower than those persons who are not living with HIV. The lowest score of QOL was in psychological category, suggesting more interventions to improve this domain is needed.

2.5.2 Empowerment of women

Empowerment has various meanings, depending on the context where it is used. First and foremost, empowerment is about power; changing the power relation in favor of those who previously exercised less power over their lives. Power has two main control aspects; control of resources, such as health and financial aspect and control of ideology, including the control over beliefs and values. If power is control, then empowerment is the process of gaining control (Cornwall & Edwards, 2014, 3–5).

Empowerment can be defined as a process to improve individual's or group's capacity to make intentional choices or transform those choices into desired actions and outcomes (Alsop, Bertelsen & Holland, 2006,1).

Women's empowerment is defined to be an approach that aims to change the power relations in favor of women's rights and create more equality between men and women. Empowerment of women aims to ease the struggle of social justice for women and equality through modifying the economic, social and political structures in national

and international level. This can be seen as a journey or process, which woman travels alone or together in group to make changes in consciousness and collective power. Empowerment is something that can't be donated by someone else, but it is the acknowledgement of un-equality and demanding the right to have rights and acting individually so that the structures of society will become more equal for women (Cornwall & Edwards, 2014, 3–5).

2.5.3 Changes in mental health and physical well-being

HIV positive people's psychological symptoms varies from mild distress to major psychiatric illnesses, such as depression and post-traumatic stress reaction. In all of the stages of HIV raised level of anxiety, depression, suicidal thoughts, ideation and activation are reported. How severe these symptoms and psychological effects will develop, depends on the individual's past traumatic experiences, pre-existing vulnerability and current life situation and the experience of living with HIV (Hedge, 2001, 108).

Psychological symptoms may cause or worsen the physical symptoms such as fatigue or pain. Diagnosis of HIV or significant worsening in the stage of HIV can be especially stressful and aggravate the psychological burden of HIV (Hedge, 2001, 108–109).

The most stressful stage of HIV is usually the time of diagnosing with HIV. Most of the individuals will react to diagnosis with shock, but will later recover from it. Some of them will develop long-going, severe psychological symptoms or illnesses, such as post-traumatic stress disorder. In the stage of diagnosis, person has to cope and develop skills to live with chronic medical condition, that will effect on his daily life. Fear and anxiety of future and what it will bring are common feelings. Fear of being rejected, if found HIV-positive, is also very strong and common feeling among persons getting diagnosed with HIV. Anger towards the possible resource of the infection might rise. Shame and guilt of HIV diagnosis might make people to hide their HIV-status. Medication of HIV might also add or worsen the psychological symptoms. Medication can cause symptoms like changes in mood or changes in dreams, such as nightmares (Hedge, 2001, 108–109).

Addition to the symptoms caused directly by HIV, disease may cause some other physical symptoms or changes in physical well-being. Altogether, psychological and physical symptoms cause lowered quality of life. Changes in appearance of the individual, such as weight loss, might cause stigma and discrimination of HIV positive person. Changes in physical appearance have also connect to person's self-esteem and it may lower it (Hedge, 2001, 109).

2.5.4 Stigma and discrimination

Persons, who get stigmatized, difference somehow from the society's or community's definition of 'normal' or 'acceptable'. Stigmatization includes both social and psychological elements (Kleinman & Hall–Clifford, 2009, 418).

Throughout the history of HIV, it has been a disease with heavy stigma on it. The stigma and discrimination of people living with HIV effects on all of life's sectors including private life, family relationships, work and education and roles in society. HIV is often associated with despicable behaviors which differs from the society norms, such as injecting drug use and sex trade. HIV is often also associated with death. Addition to this, people might reject the HIV positive person, because of the fear being infected. Because of these conceptions, HIV positive people are often discriminated and rejected by the society they live in (Ho & Holloway, 2015 10–11).

In Nepal, HIV/AIDS is generally known as a disease, that will lead to death eventually. The general perception is that HIV/AIDS happens in sexual intercourse outside of marital relationships or to people, who seek to have sexual intercourse with prostitutes. In Nepalese society, premarital or outside of marriage relationships are not tolerated. Because of these perceptions people with HIV are facing huge discrimination from the society and HIV positive people struggle to live within their own communities, which will further force them to even leave their family and community (Jha, Plummer & Bowers, 2011, 22).

There are many reasons behind the HIV related stigma in Nepal. The general belief of HIV is that someone has been infected as a result of sin and it will cause untimely death. Death is seen also as a punishment for making sin (Nepal & Ross, 2010, 25).

Hinduism is the main religion in Nepal. Religion plays a major role in Nepalese society and daily life. According to Hinduism, untimely death is seen as a punishment for something, that has been done wrong in the past life. This will cause stigma to HIV positive people together with the beliefs of HIV (Nepal & Ross, 2010, 25). Some of the misconceptions about HIV and its transmission are also rooted in the Hindu cultural beliefs and practices, such as caste-related purity and philosophy of karma. HIV/AIDS can be seen as a cause of bad karma or God's punishment (Pokhrel et al.2008, 205).

Level of education and economic status effects on the stigma related to HIV. Lack of knowledge and misconceptions about HIV and its transmission causes fear, hate and rejection from the society. Study by Nepal & Ross (2010), revealed that educated HIV positive people face less stigmatization than uneducated people with HIV. Also, HIV positive people who have better economic status face less stigma than the lower economic status HIV positive people. However, in study by Jha & Madison (2009) it was revealed that, doctors and nurses had prejudices and stereotypes of HIV-positive person. Even though the education, healthcare professionals lack proper knowledge of HIV and its transmission, but they also lack sensitivity to treat HIV-positive patients with dignity. Some of the doctors refuse to treat HIV-positive persons, because of fear of getting infected or the fear, that they will be associated with HIV.

Community and society has a major role in the HIV related stigma. The communities' beliefs, behavior and actions might either reduce the stigma or increase it. In Nepal, joint families are common and usually women after marriage move to live with their in-laws. In these joint families, daughter in-law is heavily stigmatized if she is infected with HIV. In this case, she won't receive support or care from the in-laws or the husband, but if the male members of the family are infected, it is claimed that the daughter in–law will take care of them and support them (Nepal & Ross, 2010, 25–26).

HIV related stigma can also be seen as restrictions such as denying the access to kitchen, not sharing the same bathroom or bed and denying the participation in daily routines or activities. Rejection from the family or community might also a result of stigma (Nepal & Ross, 2010, 25).

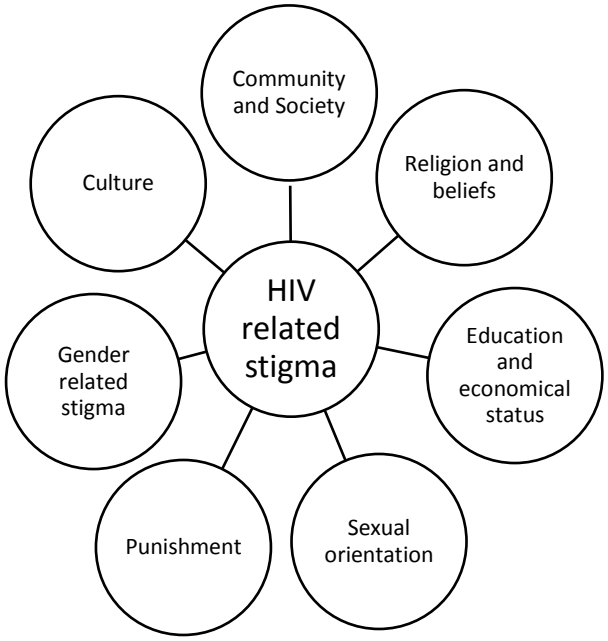

Figure 1. Summary of dimensions of HIV related stigma.

2.5.5 Women and HIV related stigma

When talking about the gender and HIV stigma, women often face more discrimination and stigma of being HIV positive. Women with HIV are seen immoral and failures in the roles given by society, such as mothers and care givers (Ho & Holloway, 2015). HIV positive women are often stereotyped for having the infection due to immoral sexual behavior even if the infection was transmitted by different means, such as injecting drugs (Nepal & Ross, 2010, 25–27).

In a study by Jha, Plummer & Bowers (2011) revealed that women with HIV in Nepal are often facing more stigma than the men. This is because of the perceptions of HIV in Nepal. After women is diagnosed with HIV, she might be seen as a prostitute or unfaithful to her marital husband. Also, the status of the woman in the eyes of husband's family, depends on the husband's health. If the husband is diagnosed with HIV, it might be seen as a wife's fault and husband's family members might think that wife is behind the HIV. If women are widowed they might lose right for their husband's

property, since in Nepalese society women are seen to be widowed because of sin and widowhood itself attracts social consequences (Jha et al.2011, 31).

Studies have revealed four various reasons relating to the stigma of HIV positive women in Nepal: (1) There are notable differences in the support provided to HIV positive men and women; (2) women with HIV are generally judged and blamed for their infection; (3) HIV-positive women lose their economic and social opportunities and (4) compared to the general population, HIV-positive have higher psychological burden (Nepal & Ross, 2010, 28). Example of the literature review done on women and HIV can be found on appendix 1.

3 PREVENTION OF HIV/AIDS IN NEPAL

Nepal's national response to HIV and sexually transmitted diseases are guided by the National AIDS strategies, which of the latest is the National HIV/AIDS Strategy 2011–2016. The framework for HIV strategies is given from the national development plan, which prioritize the HIV program the most important health related issue (Government of Nepal, 2015 1).

Government of Nepal, Ministry of Health and National Centre for AIDS and STD Control has published the National HIV Strategic Plan 2016-2021 called 'Nepal HIVISION 2020– Ending the AIDS epidemic as a public health threat, by 2030'. It has been planned together with Nepali government, civil society networks, international partners and services providers, under the leadership of the National Centre for AIDS and STD Control (Government of Nepal, 2015, 1).

The National Plan's aim is to build one unified, right-based HIV program, of which strategies are integrated in Nepal's public health services. The new National for 2016–2021 is based on the previous plan and lessons learned from implementing the previous plan. With the plan, Nepal aim at responding to the Fast-Tracking challenges towards ending the AIDS epidemic as a public health threat by 2030 (Government of Nepal, 2015,1–3).

The National Center for AIDS and STD Control is responsible for implementation of the National HIV Strategic Plan through the public health care in national, regional, district and village levels. The implementation of the National Strategy includes the coordination and co-operation between public actors and private sectors as well as with the NGOs and civil societies, which are working with HIV (Government of Nepal, 2015,3).

Key populations will stay in the focus of the National HIV Plan. These key populations in Nepal are; female sex workers, transgender sex workers, male sex workers, clients of sex workers, transgender people, gay men and other men who have sex with men, inject drug users, incarcerated people, mobile, migrant and displaced populations, young people and uniformed services. Addition to this, all pregnant women are also in the focus of the National HIV plan to prevent vertical transmission (Government of Nepal, 2015,4).

Because the HIV epidemic in Nepal is concentrated on the key populations, the national HIV plan and most of the HIV related programs are focusing on them. Even the concentrated epidemic, this is not enough to prevent the spread of HIV and raising the awareness of HIV and its transmission. According to the president of National NGOs Network Group Against AIDS-Nepal (NANGAN) Dal Bahadur GC (2017), much more should be done. The programs related to HIV and raising the awareness of HIV should be mainstreamed. Mainstreaming the information and education of HIV would reduce stigma and raise the awareness of HIV. It might also change the risky behavior of Nepalese migrant workers, as they are in risk of getting infected with HIV while working outside of country, mostly in India.

In the Nepal's school system, there is a certain curriculum of teaching about HIV and other sexually related issues, but most of the teacher don't get proper education for teaching these things. This is sometimes also seen in healthcare providers, who might have passed all the education needed to do their profession, but HIV and other transmitted diseases and prevention for those are skipped. Also, the hesitation to talk about HIV and/or other sexually related issues might arise from the community; in Nepal, talking about sexually related things is inappropriate. There should be more education

for the healthcare providers, teacher and mainstream about HIV and its' transmission, to battle the spread of the disease, but also to battle the stigma and discrimination related to it (GC, 2017). Mainstreaming of the HIV prevention and awareness of HIV is also crucially due to the fact that in Nepal, HIV is spreading fastest among individuals 15 to 39 years old and one fourth of Nepal's population is aged between 10 and 19 years. Furthermore, among the adolescents from rural area, there is a bigger risk for them to join the high-risk groups of HIV such as migrant workers or female sex workers, compared to the adolescents from urban areas (Pokhrel, Regmi & Piedade).

3.1 Shakti Milan Samaj

This Master's Thesis was done in co–operation with Nepalese NGO, Shakti Milan Samaj. Shakti Milan Samaj (SMS) is a Non–Governmental Organization, established and lead by HIV positive women. SMS was founded in 2003. SMS's primary mission is to facilitate health care, ensure access to resources such as health care, human rights of women and their children living with HIV/AID through advocacy, capacity building, care and support and referral service for treatment. SMS has been working with the on the issues with HIV/AIDS, human rights and violence against women, food and nutrition security and socio-economic development (SMS, n.d.).

3.1.1 EWCAH–Project

EWCAH–project (Empowering women and children against HIV/AIDS) is a project implemented by SMS. The project is carried out from January 2015 until December 2019. Financial donor for this project is German NGO 'Misereror'. This project's aim is to contribute to reduce to social discrimination and empower to women and children affected by HIV/AIDS.

The project has three objectives:

1. EMPOWER: Economically empower the HIV/AIDS effected women through vocational training and income generation activities.
2. AWARENESS: Raise awareness of stakeholders through behavior change communication (BCC).

3. CAPACITY BUILDING: build institutional and human resource capacity of agencies established by HIV/AIDS infected women, particularly Shakti Milan Samaj.

One of this project's activities was to find and identify 20 indigents, HIV positive women and through vocational training give them possibility to become employed or start their own business (Shakti Milan Samaj, personal notification, 2016).

4 AIM OF THE STUDY AND RESEARCH QUESTIONS

This study's aim was to clarify how empowering women with HIV will effect on their life and stigma and discrimination towards them. This study aimed to give tools on developing programs aiming to empower women with HIV and reducing the stigma and discrimination of HIV positive women in Nepal.

Research questions were:

-How the EWCAH–project effected on the HIV positive women's quality of life?

-How the EWCAH–project effected on stigma and discrimination of HIV positive women?

5 DATA COLLECTION AND ANALYZING

For this Thesis, qualitative research method was used. Qualitative research method investigates culture, society and social phenomena and behavior through people's actions or opinions. It is based on the lived experiences of participants of the research. Qualitative research method doesn't try to turn the verbal data into numerical, countable data. Instead, the data will remain in the verbal level. Qualitative research method gives researcher a chance to focus on the qualities rather than quantity (Hogan, Dolan & Donnelly, 2009, 9–11).

Qualitative research method was selected for this study because it is effective when researching immaterial factors, like social norms, socioeconomic status, gender roles, ethnicity and religion which role in the researching issue may not be easily seen (Kumari, 2010, 104). There is little research done about empowering HIV positive women, especially in Nepal. This is one of the reasons behind doing this particular study using qualitative research method.

5.1 Focus group discussion as data collection method

Data for the thesis was gathered by focus group discussions. Focus group discussion is a method to collect data in groups consisting participants with same background or experiences. Not only focus group discussion gives information about the research topic, it also gives the participants chance to comment on others experiences, change ideas and it also gives answers why and how participants think the way they do. When using focus group discussion, the group process can help participants to explore and clarify the topic more than in individual interviews (Kitzinger, 1995, 299–300).

In the first place, the data collection method chosen for this study was individual interviews, but it changed to focus group discussion after the discussion of Shakti Milan Samaj staff members. Individual interviews were chosen first for the data collection method, because I thought the topic of the research is intimate and it would be easier for the participants to share their experiences privately. After the discussion with Shakti Milan Samaj staff members and taking into account the time limitations for collecting the data in Nepal, data collection method was changed to focus group discussion.

5.2 Participants

For the data 8 women who participated in EWCAH–project, participated in the discussion Because of the time limitations for this thesis and especially the time limitation for the data gathering, I decided to narrow the number interviewees from the number of all participants in the EWCAH–project. Also, when doing a focused group discussions, more than 10 participants at one time will be too big group. Focus group discussion was audio recorded. Shakti Milan Samaj's project workers recruited the participants for this study. For the interview, staff member from Shakti Milan Samaj worked as an interpreter. The interview frame is in the appendices (Appendix 4).

5.3 Data analyzing of the focus group discussion

For analyzing the collected data, content analysis method was used. Content analysis is a systematic analysis method to describe to the text that is being analyzed. Its aim is to produce information about the research subject. Content analysis is the basic analysis method for qualitative research and with it the collected data can be systemically organized and described (Kylmä & Juvakka, 2007, 115).

The first step of the content analysis after the interview was to transcribe the audio record. The focus group discussion lasted 90 minutes. The transcript was written in font Arial and the size of the font was 12 and the space between the rows was 1,5. Altogether the transcript was 8 A4 sized papers. After the transcript was done the second phase of the analysis was getting familiar with the collected data and making simplified expressions from the raw data. After this, the simplified expressions were compared and grouped together with similar expressions to make categories out of it. In this phase, the collected data and researcher's interpretation will guide the grouping (Kylmä & Juvakka, 2007, 117–120). Example of the analysis of the data is in appendix 5.

6 RESULTS

6.1 Backround of the participants and previous knowledge of Shakti Milan Samaj

Most of the participants had some sort of employment before getting familiar with Shakti Milan Samaj. Mostly participants were self-employed in small businesses, such as sewing business or running a small shop. While talking about background, participants did not mention family or role in society. They focused on talking about their previous employment, before knowing SMS.

The experiences and knowledge of Shakti Milan Samaj and its work varied within the participants. The means of getting familiar with SMS varied as well. Some of the participants were advised to contact with SMS, when they were admitted to hospital, during the time they got diagnosed with HIV. One participant told the hospital, where she got diagnosed, advised her to contact SMS to get support.

One participant got diagnosed with HIV while staying with her husband in Delhi. After getting the diagnosis, she returned to Nepal and attended one seminar, where she was advised to visit SMS to get supported with HIV.

Part of the participants told they got to know SMS and its work through some other NGO. Some participants were told to contact some other NGOs, but these NGOs did not work with HIV positive women, so they were advised to contact SMS.

Most of the participants said SMS was the first NGO that they knew to be working with HIV and women.

6.2 The EWCAH–project and reasons for participating

All the participants of the EWCAH–projects are members of SMS, so they were given the priority to participate in all project arranged by SMS. Before the project, they were asked if they were interested to participate and they got in the project according to their interest. Participants were offered with seed money and economical support to

start or grow their own businesses. Some of the women got training for employment, such as computer training or training to start their own business.

Participants said the interaction with other members and sharing experiences with each other, helps on daily life and the life with HIV comes more bearable. Peer support was also found important and it was mentioned by many of the participants.

6.3 Empowerment and effects of the EWCAH–project

Empowerment and its meaning was explained and understood in various ways by the participants of the research. Some of them, experienced is as improvement in income or improvement in educational level. Many participants mentioned words like courage, confidence and activity while talking about empowerment. There was a separate question for the effects of the EWCAH–project later in the interview, but the participants told already the project's effects while talking about empowerment.

6.3.1 Economic empowerment

Economic empowerment was mentioned by most of the participants, while talking about empowerment and its meaning and experiences of empowerment. It was also mentioned by most of the participants for the effects and outcomes of the EWCAH–project.

Participants felt that they have got economic empowered through the training the project offered. Through the training participants were able to establish their own small businesses, such as running a small agricultural business or through the training they got employed by employers, not themselves or the families. One participant told she used to work in a village before the project and the training, but after the project, she got a new work in city.

Economic empowerment had also other effects on the participants' life than just improving the financial situation of them or raise in income. Participants told, that when they begin to earn their own money, they were no longer dependant on others and could themselves decide on where to spend the earned money. One of the participant

felt that her dignity level has raised, because she is earning her own money. Addition to this, participants felt that getting employed might reduce the stigma towards them. Participants feel that the society is changing and people begin to think that HIV positive women can work like any other persons.

6.3.2 Personal empowerment

Confidence, activity and courage were mentioned many times during the discussion about empowerment. Participants told experiences of gaining more courage to speak up for themselves or to defend HIV positive persons. One participant told about her experience of living with her husband's family, which discriminated her badly because she was diagnosed with HIV. She felt the EWCAH-project helped her to gain courage to say she wants to live on her own. She experienced empowerment as being able and brave enough to make her own decisions.

6.4 Quality of life and meaning of good life

Discussion of quality of life and good life raised lot of different thoughts and experiences among the participants. The most mentioned things that make good life were positive attitude, health and education.

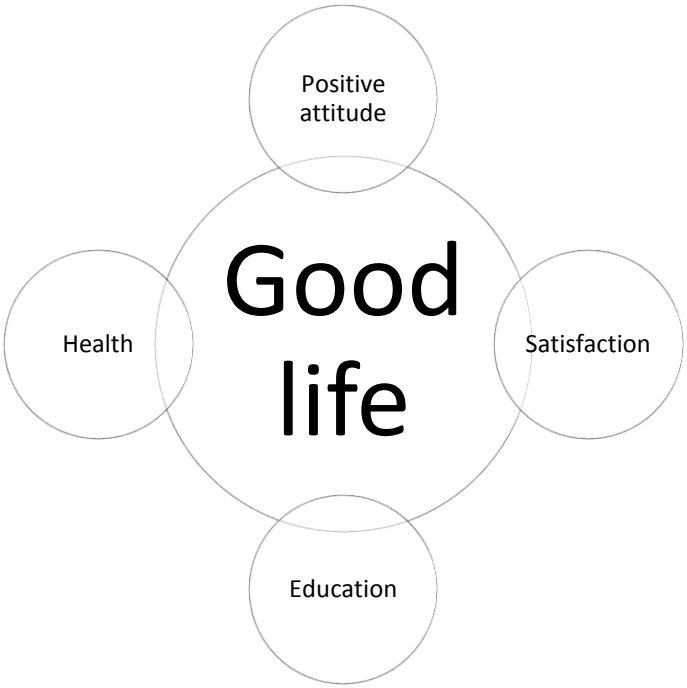

Figure 2. Meaning of good life for the participants

Positive attitude towards life, even though living with HIV, helps you to be satisfied with your current life and have a good life. Positive attitude and thinking was also related to good health, which was related to good life by the participants.

She said apart from other mental goodness, it depends on your lenses; depends what kind of lenses you are wearing, you can see all badly or good. It depends on your lenses.

You need to think positive to strength and not make your immune system more weak.

Develop positive attitude towards life. She doesn't feel sick even though she is taking medicine. She finds the life beautiful.

All the mentioned things related to good life and quality of life, were non–materialistic. One participant felt that materialism is not important and comparing what you have

with other people won't make you happy. Satisfaction with your life and what you have will make the life good.

6.5 Effect of HIV in daily life and stigma

All the participants had faced stigmatization due to their HIV diagnosis in some level. Stigma could be seen in participants' daily life as restrictions or restrains. Stigma and HIV restrained the participants from normal daily life activities, such as entering the kitchen or taking care of their daily tasks.

> *Stigma in social life and level; she went to shoemaker to repair her shoes, shoemaker won't sew the shoes if he knows she is affected with HIV. This kind of activities are discrimination in social levels.*

Stigmatization can arise from the family of HIV positive individual. Especially the participants told experiences of getting discriminated or stigmatized by their in–laws. This kind of discrimination happened, even though the husband was also diagnosed with HIV. The husband did not face discrimination from his parents, but the daughter-in-law did. In the discussion, this was explained by the Nepalese society and ignorance of the transmission of HIV.

> *In Nepal people think if woman is having HIV it's not from good reason, maybe she has been in some bad activities. Even though women are actually victims of their husbands of getting HIV.*

Due to the fear of discrimination and stigma, participants felt that they need to hide their HIV–status.

> *She wants to say that, her son is newly married, she is worried the new wife will leave the house because she has HIV. Her son told the wife she is diabetic and she is taking diabetes medicine. She wants to tell, but she doesn't want to tell now. She wants to tell some day, when they get emotionally attached-she doesn't want to hide either.*

6.6 Hopes and future

While discussing about hopes and future and EWCAH–project's part on it, the discussion focused on the economical aspect. Most participants hoped to expand their business which they had started with the seed money given by the project. Participants also mentioned in this discussion, that they are happy that through the project and their own businesses, they can take care of the financial side independently and they can decide where to use the money earned by their business. Participants were satisfied with the EWCAH–project and were hoping to continue with it in the future. One participant felt the future seems very beautiful and she is hoping to be healthy in the future. Another participant hoped that future will bring more satisfaction in life.

7 DISCUSSION

7.1 Discussion of the results

Participants were overall satisfied with the EWCAH–project and its' outcomes. They felt empowered by the program. Mostly the satisfaction and feeling of empowerment raised from the improvement in financial situation of the participants, but other outcomes, such as personal empowerment was mentioned. EWCAH–project offered seed money with/and training for the participants, such as computer training. Microfinance, combined with practical training of skills, which can be used for earning living, have been proved to improve the women's socio-economic empowerment and it's also related to the reduction of intimate partner violence. Addition to this, it has been shown that microfinance combined with group activities improves the overall well-being of women and reduces the stress related to poverty or health problems (Isangula, 2012, 81–82). This was one of the findings of this study as well; women felt the peer-support and sharing things and thoughts related to HIV helped them to cope with the disease.

Addition to the economic empowerment, the participants felt the EWCAH-project had increased their social- and self-confidence as well as it has increased activity of the participants. This finding is supported by the findings of Upadhyay (2015) who found that addition to economic empowerment, microfinancing programs combined with skills training, improve women's social, economic and self-confidence and it will increase the activity and positive thinking of the women. Self-confidence is one of the most important abstract related to the women's perception of their capabilities and also their actual level of capability and skills.

Stigma and discrimination due to HIV-diagnosis was familiar to all the participants and all of them had face stigma in some level. Most of the stigma raised from the social level, including family, especially in-laws, and community level. Women often face more stigma due to HIV in Nepal than men. This is because of the traditional vision of a woman as a mother and care giver in the family (Rai, 2008, 16).

Addition to the stigma from the social and community level, participants described the stigma also as restrictions for doing their daily tasks or denying participation in daily life routines, such as entering kitchen. According to Nepal & Ross (2010) this is common phenomena related to HIV stigma in Nepal.

The misconception and ignorance of HIV and its' transmission increases the stigma towards HIV positive women. There are several misconceptions of HIV's transmission and general belief is, that if women have got infected with HIV it is because of some sin she did, or some inappropriate activity, such as prostitution. This kind of misconceptions make women hide and lie about their HIV-infection (Nepal & Ross, 2010). This was also found in this study. Lying and hiding the disease will increase the disease related stress of HIV–positive persons (Wilkinson & Mercey, 2001, 88).

According to the findings of this study and previous studies, women living with HIV in Nepal face heavy stigma and discrimination due to their HIV-infection in many levels, including social and community level. Stigma and discrimination because of HIV impacts on women's daily life in many ways, such as restrictions to daily life activities or making women hide and lie to their family and community about the disease, because of the fear of being stigmatized.

Microfinance combined with training and group activities, will not only empower women economically, but also increase their self- and social-confidence, making them more satisfied with their lives and making them more independent. Projects, which aims to empower women, like EWCAH-project, are needed in Nepal to battle and reduce the stigma towards women living with HIV.

7.2 Ethical discussion

When doing a research, all persons who allow their information to be used as a part of research, permit the use of information in research (DIAK, 2012, 14). In this research, the permit from the participants, was collected written in the beginning of interview session. Permission to audio record the interview was also asked. In the beginning of the interview session, participants were told the meaning, aim and purpose of the study. They had free will to refuse from participating the study. When the data is

gathered, the author has to store the data so, that it doesn't end up in any other purposes than in the study it was permitted to (Kumar, 2010, 243).

Confidentiality was taken care so that single participants of the study can't be recognized and the information given by the participants was written in the report in a way that is essential to the researched issue (DIAK, 2012, 14).

Ethical approval for this study was applied from Shakti Milan Samaj's administration. Agreement of thesis was done between the student, Shakti Milan Samaj and Diaconia University of Applied Sciences.

Each participant was informed about the study, its aims and purposes before the interview by information letter (Appendix 2) and verbally before the interview. Participating to the interview was voluntary. Each participant signed the consent (Appendix 3) before the interview and allowed the interview to be audio recorded. The gathered data was treated so, that individual participants can't be recognized from the study. After the report was finalized, the gathered data was destroyed and it won't be used in any other purposed than this study.

7.3 Validity discussion

For any research done, discussion and consideration of validity is essential. Proving the validity of qualitative research, it might be harder than proving validity of quantitative research, because in qualitative study, the characteristic and background of the researcher is always present. For qualitative research to be successful its readers have learned something new about the phenomena being researched (Holloway & Wheeler, 2013, 299).

Audit trail of the research will help to evaluate the validity of qualitative study. Through audit trail the reader can follow the process of the research and reasons behind the decisions made before and during the research. Audit trail means detailed description of the contextual, methodological, analytic and personal response of the research. Contextual of the research describes the location and environment where the research was done. It also includes description of the people and social context of the study

(Holloway & Wheeler, 2013, 299–300). In this study, the contextual description can be found in chapters 2.3, 3 and 5.2. where the Nepal's HIV situation, Shakti Milan Samaj and participants have been described. Contextual description also includes the description of the interview situation, which is described in chapter 5.2.

Methodological description includes description of the chosen methodology for the study and justification behind the choice. Methodological description is also important if the research will be replicated. In qualitative research the study can't never be fully replicated, because the researcher is the main instrument in this study methodology and researcher can't be replicated. Also, other researchers might have different focus and emphasis than the researcher of the original study (Holloway & Wheeler, 2013, 300–301). Methodology for this study and the justification for using that method can be found in chapter 5 where the methodology is introduced.

Analytical description includes the introduction of the analysis method used to analyze the collected data, its results and theoretical insights arisen from the analysis. Analysis process is described in chapter 5.3 and the results of the analysis in chapter 6. Example of the data analysis can be found in Appendix 5.

Personal response describes researcher's self-awareness and its impact on the research and its results. This also includes description of the thought process behind the research. This is described in the discussion chapter of this study. Decisions, which have impact on the research or its results, should be presented for the reader in the final research report (Holloway & Wheeler, 2013, 301). Decisions and justifications for those choices and decisions regarding this study and its results are shown in this final report.

Through the description of the audit trail other criteria for evaluating the qualitative study can be shown. Internal validity of the research means the results of the study are real and true and they present the social reality of those who participated in the study. Internal validity of the study can be shown by taking the research and its results back to the participants and showing them the results of the study (Holloway & Wheeler, 2013, 300). This thesis was send to Shakti Milan Samaj when the report was

finalized. Validity can also be proved by comparing the results of the study to the findings of previous research.

Qualitative research should be loyal to the participants' experiences and it should be grounded in those. Researcher will always transform the original data and will take it to a different level than participants have described the phenomena. Researcher's ideas are more abstract and more theoretical than the experiences described the participants. After all the research is describing the interpretations of the researches, even though it's surrounded by participants' experiences (Lietz, Langer & Furman, 2006, 405).

Participants' responses and honesty of the responses will have impact on the research and its' validity. It is rare, but sometimes participants lie about their experiences. There is not a way to prove if the participants are speaking the truth or not, but the researcher just must trust the participants (Holloway & Wheeler, 2013, 301). In this research, due to language barrier between the researcher and participants, interpreter had to be used to translate the discussion. Interpreter was one of the staff of Shakti Milan Samaj.

Using interpreter in the data collection phase has some consideration the research should be aware of. These might be selective translating, when the interpreter makes his/her own interpretations of the participants' experiences and does not translate the participants' answers fully. This is related to impartiality of the interpreter as well (Murray & Wynne, 2001, 160). Because the interpreter was one of Shakti Milan Samaj staff members, participants' might have felt easier to talk to someone they already knew, but this could have also been hurting the results of the research, because the translation was not checked by another interpreter. There might be also a chance that since the participants knew the interpreter, they might have answered as they thought the interpreter wanted the answers to be.

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APPENDICES

Appendix 1. Example of the literature review done on women and HIV

Author and title of the research	Research design	Aim of the research	Results	Conclusion
Ho, Szu Szu & Holloway, Aisha 2015. ***The Impact of HIV-related stigma on the lives of HIV-positive women: an integrated literature view.***	An integrative literature review, using five databases.	Explore how HIV related stigma effects on HIV-positive women's lives and identify the contextual differences of HIV related stigma to HIV positive women.	Stigma towards HIV-positive women were found to be in four themes; individual, relationships, work and community. HIV-diagnosis will cause distress. Fear of being stigmatized make women to hide their HIV-status and because of that, they might not get proper treatment in health care services. By disclosing HIV-status women might be excluded from the social life, including being rejected by friends and family.	Women experiencing stigma due to HIV face several difficulties related to social and individual life, employment status and access to healthcare. Lack of support from friends and family will lead to psychological distress. Cultural and social norms and beliefs worsen the stigma and discrimination towards HIV positive women.
Jha, Chandra Kat; Plummer, David & Bowers, Randolph 2011. ***Coping with HIV and dealing with the threat of impending death in Nepal.***	Qualitative research, using modified grounded theory of 'Death Phobia' related to HIV. In-depth interviews with 20 participants.	The study aim to explore the life experiences of HIV-positive persons in Nepal and how counseling will contribute HIV-positive persons' coping strategies.	HIV-diagnosis will cause psychological distress and fear of the future and untimely death. Lack of support from family in the time of being diagnosed with HIV might lead to overuse of alcohol or drugs. Overuse of substances as a coping method is also interrelated with failure from the social norms or roles, such as women as a caregiver and man as a breadwinner of the family.	HIV diagnosis leads to several changes in person's psychological, social, economic and health aspects of life. Fear of being stigmatized make HIV-positive persons to hide their disease. Death phobia is highly associated with HIV and might cause suicidal behavior. In Nepalese culture woman is considered to be widowed due to some sin. Moral issues and misconceptions of HIV and its transmission will cause stigma.
Nepal, Vishnu Prasad & Ross, Michael W. 2010. ***Issues Related to HIV Stigma in Nepal.***	Qualitative research. Data was collected through focus group discussions and workshops with 70 participants.	Explore issues related to HIV stigma and mechanism of stigmatization experienced by people living with HIV and community members in Nepal.	HIV is heavily associated with untimely death, which is seen as a punishment for HIV-positive persons, for something "bad", culturally unacceptable done, such as extramarital sex. Fear of the transmission of HIV or ignorance of it will lead to stigma by rejecting or excluding HIV-positive persons form social life.	Blame is the key element in HIV related stigma in Nepal. Especially women and girls get blamed for bringing the HIV to the family, no matter the means of infection. Cultural beliefs and values play vital role in HIV related stigma in Nepal. HIV related

			HIV-positive women are often seen as prostitutes or promiscuous.	stigma in Nepal is interrelated with Nepalese culture, including the main religion Hinduism.
Jha, Chandra Kat & Madison, Jeanne 2009*. Disparity in health care: HIV, stigma and marginalization in Nepal*.	Qualitative study, data was collected by in-depth interviews from 20 HIV-positive and 10 participants, who injected drugs, but have never undergo HIV-test.	Explore health care related experiences and perceptions of HIV-positive persons/those, who are in risk to be HIV-positive.	Health care professionals, doctors and nurses, have prejudices and stereotypes of HIV-positive persons. HIV-positive patients are seen as violators to cultural norms of Nepal. Because of this, many health care professionals deny to treat people with HIV. Healthcare professionals, even though the education, fear the infection itself or being associated with HIV and by treating HIV positive persons, being thought as well HIV-positive. Untimely death caused by HIV was also one reason for denying the treatment for HIV-positive persons. Fear of stigma makes patients to hide their HIV-status, which will lead to complications in the treatment or getting insufficient treatment. By revealing HIV-status patients were treated hard handed or unfriendly.	Stigma related to HIV/AIDS in Nepal is mostly due to the cultural beliefs and norms. HIV is seen as punishment for violating these norms. In general, HIV is believed to be a disease, that will cause untimely death and someone have been infected with HIV because of violating cultural beliefs, such as having extramarital sex or injecting drugs. Stigma is heavily connected to the fear of being infected with HIV.

Appendix 2. Information of the study

Information of the study

You have been participating in Shakti Milan Samaj's EWCAH empowerment program. That is why I am contacting You. I am studying Master's Degree in Global Health Care in Diaconia University of Applied Sciences, in Helsinki, Finland. I am doing my Master's Thesis of HIV positive women and their quality of life.

This study's aim is to clarify how empowering women with HIV will effect on their life and stigma and discrimination towards them. This study aims to give tools on developing programs aiming to empower women with HIV and reducing the stigma and discrimination of HIV positive women in Nepal.

Research questions for this study are:
-How the EWCAH project effected on the HIV positive women's quality of life?
-How the EWCAH project effected on stigma and discrimination of HIV positive women?

Research data will be collected by group discussion, which will be audio recorded. In the discussion, Shakti Milan Samaj's staff member will work as a translator. The data will be treated so, that individual participant can't be recognized and the data will be destroyed after the final report is finished. The data won't be used for any other purposes than this study. Participating in this study is voluntary and confidential.

With best regards,
Aino Kormilainen
Contact information

Appendix 3. Consent for the study

Consent for the study

I have been informed about the Master's Thesis study, which I am taking part in. I have been informed about the study's aims and purposes. I have been informed of the study's data gathering methods.

I give my consent to be part of the study voluntary and the researcher to use my interview as a part of this study. I also give the researcher consent to audio record the interview.

Date and place

_____

Participant

_____

Researcher

_____

Appendix 4. Interview frame

INTERVIEW DRAFT

a) **Backround**, Describe your life before the EWCAH project.

(Life before the project, work, family, role in society)

b) **Effect of HIV in daily life**. How did the HIV diagnosis effect on your life? How life changed?

(Experiences of stigmatization, discrimination, effect of HIV daily life, family, work)

c) **Shakti Milan Samaj and other HIV related NGOs**, What kind of experiences or knowledge of NGO you had before the project? Knowledge of other NGO or services available for people living with HIV?

(Knowledge of SMS, services, support, experiences in previous projects)

d) EWCAH project, How did you get to know EWCAH project? Describe reasons for participating for the project?

(Knowledge, participating, reasons for participating, expectations towards the project)

e) Empowerment. How do you understand empowerment? What does it mean in your life?

(Understanding, experiences, meanings)

f) Quality of life. How would you describe good life? How do understand the quality of life? What does it mean in your life?

(Meanings, understanding, good life)

g) Effect of EWCAH project Describe your life now after the project, share experiences.

(Changes in daily life, quality of life, empowerment, effects)

h) Future How do you see your life in the future? What part EWCAH project has on it? (Hopes, wishes, goals)

Appendix 5. Example of analysis of the collected data

Raw data collected from the interview according to the interpreter	**Simplified expression**	**Sub category**	**Main category**
The economical income has raised, it affects also other aspects of life.	Economic situation has gone better.	Raise in income and effects in other aspects of life.	Economic empowerment
She has now work, because of the computer training.	She got work after training.	Became employed.	
She has been empowered in every level, like, when someone discriminates HIV positive persons, she can speak up now.	Has been empowered in every level in life, gain courage to speak up against discrimination towards HIV positive persons.	Raise in confidence.	Personal empowerment
She got the confidence to say that she wants to live on her own, after she got so much discriminated staying at with her husband's family.	Got confidence to say she wants to live on her own without discrimination of husband's family.	Making own decisions of personal life.	