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**Experiences of Persons with Sensory Disability
and their Vulnerability to HIV and AIDS in the
year 2013**

(The Case of Ethiopian Associations of People with Disabilities)

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Abstract

This paper explores phenomena of sensory disabled persons with the aim of understanding their vulnerability to HIV/AIDS. The study was undertaken utilizing an in depth interview and ten participants were purposely selected and interviewed. Methodologically the research is informed by phenomenological approach. Thematic categorization and content analysis is used for analyzing data. The key findings of the research indicate that first; the participants have multifaceted challenges: shortage of income due to lack of equal job opportunity that leads to commit sex for survival; social inferiority when viewed as liability and environmental legal constraints. Second, participants exposed for several risks including low income status, social and legal related challenges that increases susceptibility of persons with sensory disability to HIV/AIDS. Third, participants demonstrated lack of attention by different bodies' for their special needs. Fourth, participants were devoid of different services. The aforementioned findings suggest the need for special interventions. The interventions should be designed and implemented to ensure the empowerment of SDPs, as well as developing mechanisms that enable to explore and build up the strength of individuals and communities, which would ultimately help to prevent and manage HIV prevention and control.

ACRONYMS

AIDS	Acquire Immunodeficiency Syndrome
BCC	Behavioral Change & Communication
CSA	Central Statistics Authority
EFPD	Ethiopia Federation of Person with Disability
ENAB	Ethiopia National Association of Blind
ENAD	Ethiopia National Association of Deaf
FDRE	Federal Democratic Republic of Ethiopia
GO	Governmental Organization
HAPCO	HIV/AIDS Prevention and Control Office
IEC	Information Education Communication
MOLSA	Ministry of Labor and Social Affairs
NGO	Non Governmental Organization
PDLHAs	Person with disability Living with HIV/AIDS
PWD	Person with Disability
SDPs	Sensory Disabled Persons
UN	United Nations
UNAIDS	United Nations Program of AIDS
UNDP	United Nations Development Program

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APPENDICES

Appendix-1

Informed Consent Form to the Study Participants

I am Etabezahu Negussie; I came from Addis Ababa. I am here to interview persons With Sensory Disability (the deaf and the blind). The study is for the requirement of Masters Degree in Social Work. The general purpose of the study is to know the study participants' experience related to their social and economic challenges in terms of their vulnerability to HIV/AIDS. The research generates information from sensory disabled persons using in-depth interview guideline. The interview will be conducted in two parts. The first part is developed to see the life histories of the participants. The second part of the interview guide deals on understanding and feelings of participants on their present and past experiences related to disability and its consequences in addition to their coping responses. The data collection process fully considers your right of asking questions, and you have the right to withdraw from the interview at any time and for any reason. Then, the information you provide will not be utilized. Refusal to participate will not have loss of benefits to which you are entitled (Padgett, 2008). You have also the right not to respond to questions that seems uncomfortable to you. The confidentiality, risk and benefits of the research will be handled in the following way. The information you provide is fully confidential. All shared information is free from any personal identifier and it will be used only for research purpose. To ensure confidentiality and anonymity, the informants will be only identified using pseudo name. The study might have potential risk such as creating psychological disturbance. If in case participants face psychological disturbance while sharing their past experience counseling session will be arranged.

Based on your willingness, tape recording and note taking will be carried out. This is to facilitate transcription and keep the quality of the data. If you don't want the audiotape I would like to thank you for your time and you will not be part of the study since it will affect the quality of the data to be collected. This in-depth interview guide is prepared to explore the understanding and feeling of persons with sensory disability who are a member of ENAD or ENAB in Addis Ababa. As the research is part of the efforts to

alleviate the problem of disability by attracting attention of concerned bodies in the country, you are contributing this end by sharing your life experience related to disability.

Appendix-2 Guiding question for sensory disabled persons

Interview one: Life History

1. Tell me about your biographical information, e.g. age, religion; date and place you born, and your level of education?

2. I would like you to take me back to your childhood and share with me all the details you can remember about it.

Possible probes: *Tell me about your families, friends, school life and your relationship with them, how did you feel about the experience? Why do you think you felt that way?*

3. Have you married so far? if yes, would you share me about your married life, both good and bad times?

Possible probes: *age at your first marriage, first sex, your husband's age, occupation and educational status, current marital status. How did you feel about the experience and why you feel like that?*

4. How do you compare life before and after marriage? What meaning does it have in your life?

Possible probes: *What do you think made it better (or worse)? How are the two stages of life different?*

5. How do you describe your effort to promote and/or protect your own health as girl/women? Probe for:

Possible probes: *Visiting health post for antenatal care, asking information from friends, the contribution of your husband, families, friends and relatives*

6. What is your experience with giving birth? How do you describe it?

Possible Probes: *the age at first birth, the kind of birth preparation, visiting time of health institution after labor started, who made decision about where to deliver, delivery place, mode of delivery, attendant at delivery.* Interview Two: Past and Present experience

7. Would you share me how you finally got obstetric fistula?

Possible probes: *tell me how the understanding evolved? How did you feel about the experience? Why do you think you felt that way?*

8. What is your experience with obstetric fistula? What meaning does it have in your life?

Possible Probes: *physical, economical, fulfilling your roles in the family and*

9. How would you describe obstetric fistula? 10. Tell me for whom you are sharing your emotions? Why? How about your obstetric fistula case?

11. from whom, how, and where did you get support in relation to your disability problem? Did the assistance meet your expectation? If no, why?

Possible Probes: *families, friends, neighbors and relatives; financial, informational, emotional, accompanying while you take public services*

12. How did you cope with challenges you faced because of disability?

Possible Probes: *Seeking financial support; seeking emotional support and from whom? What was their response?*

13. How do you feel about the support given to you during your stay in this kebele? What does that mean to you?

14. Would you share some specific differences in getting opportunities nOndisabled has made in your life?

Possible probes: *What difference did it make in your relationship to significant others?, What difference did it make in your day-to-day routines?*

15. Have you shared to people your problems? If no, why? If yes? For whom you shared? (Probe for: *What was their reaction to your problems?*)

16. How do you feel about life in your home and outside? What does that mean for you?

17. Tell me how you reintegrate to the urban community?

Possible Probes: *income, stigma, acceptance by the community*

18. Have you faced challenges in joining the community what are the major challenges you faced because of your disability?

19. How is your relationship with your families, husband and friends?

20. How do you describe your current life as compared to the previous one?

Possible probes: *How did you feel about the experience? Why do you think you felt that way?*

Thank you for your Cooperation

CHAPTER ONE

1. INTRODUCTION

The thesis is composed of six chapters. The first one defines, explains and locates the distribution of HIV/AIDS and disabled person. Then the chapter highlights the problems and the key research questions that it envisages to address and demonstrates the objectives, the significance and the limitation of the study. The second chapter critically examines the literature on disability and HIV/AIDS, and conceptual frame work with its description. Chapter three provides the methods and methodological approaches used to undertake the research. The fourth chapter presents the findings of the study. The fifth chapter also presented the discussion part of the challenges of sensory disabled person, and the final chapter provides conclusive remarks and translates the key findings into concrete implications.

1.1 BACKGROUND OF THE STUDY

The Ethiopian National Association of the Deaf blind, as the official title of this registered legal entity reads, was legally established on 6 July 2006. It is a national association, its structure comprises the Board headed by the Chair (there are 7 deaf blind persons in the Board) and the General Assembly consisting of people experienced with disabilities.

The Association is national and should thus work in the five regions. Even though they have identified disabled children in other regions, the Association does not have the capacity to reach outside Addis. The Association of the deafblind has great difficulties in getting data about deaf blind in Ethiopia. They do not know how many people are in need.

The organization works collaboratively with other organizations to promote and facilitate “disability inclusive development” in Ethiopia – the inclusion of disability issues and persons with disabilities in mainstream government and non-governmental service delivery and development programs. The organization is also engaged in many different services such as:- inclusive health services (family planning, sexual and reproductive health services, HIV/AIDS education, prevention, treatment, care and support program, inclusive education (sign language, formal education). The target population of the organization is all aged group people with sensory disability.

1.1.1 HIV/AIDS AND DISABLED PERSONS

United Nation Program on AIDS indicate that Sub Saharan Africa is now home for a vast majority (66 percent) of people living with HIV/AIDS- with 7400 new infections each day out of these 96 percent are from low and middle income countries(UNAIDS, 2008). In Ethiopia an estimated 1.1 million people are living with HIV virus. Adult HIV prevalence in 2009 is estimated to be between 1.4 and 2.8 percent as a new single point estimate of HIV prevalence will be generated following the completion of a population-based sero-survey in late 2010 Federal Democratic Republic Ethiopia (FDRE) & Federal HIV/AIDS Prevention and Control Office (FHAPCO), 2010.

According to Global survey on Disability and HIV/AIDS, 2004 estimate, there are about 600 million persons with different types of disabilities in the world. That means about 10 percent of the world population is with disability. Together with this prevalence, the nature of problems and challenges encountered by disabled persons. There are an estimated 7 million people living with some kind of disability in Ethiopia. Visual impairment accounted about 42.2% of all disabilities while hearing impairment and disability from leprosy contributes 7.8% and 6.5% respectively. (A. & Edwards, K. (2004))

The Japan International Cooperation Agency (2002) produced a country profile in Ethiopia on disabled people. It estimated that 7.6-% of the population lives with a disability (approximately 5 million). A separate WHO study estimates that it is 10%, meaning that 7.7 million people are living with a disability.

Housing and Population Survey conducted in 2003 in Addis Ababa indicates that there are about 54,030 disability cases among 1,423,111 people. According to the survey, about 988,853(1.86%) of disability cases were reported in the 1994 population census of the country (Daniel, 2000). Persons with disabilities are part of the social categories that are usually neglected in HIV/AIDS prevention, management and care. Many HIV/AIDS programs and projects do not target the disabled persons. However, it is evident that the disabled like other groups are also at the risk of contracting HIV/AIDS and therefore should be targeted (Groce, 2004).

There are 5 associations of persons with disabilities and 1 federation of which the 5 associations are members. The 5 organizations are the Ethiopian Association of the

Physically Handicapped, the Ethiopian National Association of the Blind, the Ethiopian National Association of the Deaf, the Support Organization of the Mentally Handicapped, and the Ethiopian National Association of Ex-leprosy Patient.

Involving the disabled adds value to the programs, as they not only become beneficiaries but also participants in the fight against AIDS. This study focused on investigating the experience of disabled persons mainly about how they are exposed to HIV virus and the risk factors that make them vulnerable to the disease. It is found essential to look at the status and prevalence rate of HIV/AIDS from the global to local context. It is expected that people with disabilities are exposed to HIV risk factors as equal to or at higher rates than their non-disabled counterparts. This necessitates the need for disability specific HIV/AIDS related interventions. Thus, so as to address this gap in the literature, this research is critically important to get essential experiences from the hearing and visually impaired persons.

1.2 STATEMENT OF THE PROBLEM

In many African countries, organizations that work in the area of HIV/AIDS and even organizations of persons with disabilities fail to recognize that people with disabilities are at risk of HIV/AIDS. For instance, these organizations do not consider this population in HIV/AIDS programs (Secretariat of the African Decade for Disabled Persons and Handicap International, n.a). However, realities show that compounded with their disabilities, poverty and illiteracy, HIV/AIDS is assaulting persons with disabilities like the non-disabled population (World Bank & Yale University, 2004; Yousafzi, & Edwards, 2004).

It should be noted that disabled person are disabled not only by the causes of disability but they are mainly disabled when they are denied the opportunities generally available in the community (WHO (2008). Disabled persons are denied opportunities for employment because the employers are unwilling to employ them even in jobs which they are actually capable to performing (Lakech Hailemariam, 2006). Lack of access to resources is an obstacle to the development and implementation of projects and programmes of rehabilitation services required to meet the needs of the disabled in the country. Very little has been done so far concerning dissemination of information and public awareness campaigns with a view to bringing about a positive public attitude about persons with disabilities.

Persons with disabilities are denied equal opportunities in society and are subjected to various forms of discrimination and segregation. Disabled persons are thought as economically dependent and treated as irrelevant to development. Ethiopia is one of the most severely HIV affected countries in Africa as a workshop report, by Ethiopian Federation of Persons with disabilities GFED (2006), on Disability and HIV/AIDS, has reflected the high susceptibility of this population for HIV infection risk factors. Population mobility, poverty and gender relationships are mentioned as factors at the macro level.

Almost all services are prepared for able bodied persons. Person with Disabilities (PWDs) therefore have little access to HIV/AIDS information and services. HIV prevention messages and communications are often inaccessible to people who have visual or hearing impairments, and health services have limited access to people with physical disabilities. Because of the above facts the life of sensory disabled persons is still marginal. Therefore a lot should be done even in the capital where violence on Sensory Disabled Persons (SDPs) are rampant, where there is a large gap in job opportunities between SDPs and none SDPs, where large difference in educational enrolment at higher level are common and where other attitudinal gaps are still not bridged.

A number of researches have been done on the HIV/AIDS related issues. These researches, however, have overwhelmingly focused on people in general and the youth and women in particular. But the fact that this segment of the society is the most marginalized and triple-burdened (HIV/AIDS, disability and poverty), there is a need to conduct practical research to fill up this huge gap.

1.3 SIGNIFICANCE OF THE STUDY

There is an urgent need for evidence generation and utilization about the known and emerging high risk groups including disabled persons. Prevention interventions targeting the general population are done at scale but there is limited scale of HIV prevention programs targeting the vulnerable and most at risk population groups has been extremely low.

In a country like Ethiopia, where an estimated 10 percent of the total population of 77 million lives with some kind of permanent disability, failure to accord this vast community in connection with the issue of HIV/AIDS has negative impact on the process and intended outcomes of the mainstream prevention and control undertakings.

People with disabilities (PwDs) are among the most socially and economically disadvantaged segment of the population. Besides their physical suffering from pain and disability, these individuals are socially distressed from various forms of stigma and discrimination, mental anxiety, dependency and rejection. Generally there is lack of epidemiological data on the prevalence of HIV among people with disabilities. However, a study conducted to assess the HIV/AIDS and disability situation in Ethiopia suggested that people with disabilities could be among vulnerable groups.

It is hoped that the study will initiate the concerned bodies to redirect their attention towards SDPs and indicate best experiences. It also shed light how these best experiences can be incorporated in the broader poverty alleviation programs. As a result benefit SDPs in particular and the society at large. The study will also have the benefit for those who are the subject of the study by providing the real experience to different interventionist stakeholders like the sub city and woreda offices, non-governmental organizations, civil societies and other concerned bodies in the study area.

1.4 OBJECTIVES OF THE STUDY

The general objective of this research is to assess the extent to which persons with disabilities (the deaf, and the blind) are vulnerable to HIV/AIDS. This will be accomplished through the following specific objectives:

- Understand situation of persons with sensory disabilities
- Identify the risk factors of persons with disabilities to HIV infection.
- Assess HIV/AIDS mainstreaming programs in relation to disability issues.
- Identify the HIV/AIDS related services available for persons with Disabilities.

The research questions to be followed are the following:- the study intended to

- ✚ What is the existing situation of persons with sensory disabilities?
- ✚ What are the risk factors of persons with disabilities to HIV infection?
- ✚ How far HIV/AIDS mainstreaming programs are linked to disability issues.
- ✚ What are the HIV/AIDS related services available for persons with sensory Disabilities in the study area?

1.5 LIMITATION AND DELIMITATION OF THE STUDY

1.5.1 DELIMITATION OF THE STUDY

The study will be conducted in Addis Ababa bole sub-city. The key concern of the study is SDPs. The study excluded physical and other disabilities such as mental disabilities completely. The study intended to assess the challenges of SDPs in the study area by giving special emphasis on HIV risk factors. Solutions and justifications will be demonstrated in the study based on the findings from the study area. These study targets persons with disabilities (PwDs). The selected members of the study subjects include the person with hearing loss and the blind. In addition to this, organizational level assessment will be made with community based organizations and two SDP's related associations in Addis Ababa.

1.5.2 LIMITATION OF THE STUDY

Despite all the efforts going to be made to accomplish this study, some practical limitations are expected to inevitably be part of it. The sensitive nature of both HIV and disability has some challenges for the researcher during data collection. The first challenge is related to the hearing loss participants. In this regard, the researcher's inability to use sign language will create problem to get complete message through interpreter. The use of the third person for sign language interpretation can also affect the confidentiality of the data. This results in limitation of the data collection. Second, the high expectation of incentives from SDPs for interview sessions will challenge full access to the data. This problem will be compounded with the weak finance ability of the researcher. But, the researcher will exert the utmost effort to minimize these sources of bias by employing all the possible mechanisms to contact the study subjects more than once and ensuring the necessary data needed without compromising their interest and time.

CHAPTER TWO

2. REVIEW OF LITRATURE

2.1.1 DISABILITY AND HIV/AIDS;

The three concepts Impairment, Disability and Handicap are defined by WHO as follows: impairment is defied as "any loss or abnormality of psychological, physiological or anatomical structure or function" (WHO 1980: 27). Disability is defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO 1980: 28).

Handicap is defined as "a disadvantage for a given individual, resulting from impairment or a disability that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual (WHO 1980: 28)

Disability is a condition caused by an accident, trauma, genetics or disease that may limit a person's mobility, hearing, vision, speech or cognitive function (Ethiopian Federation of Disabled Persons with Disability (EFPD, 2005). Sensory Disabilities are those people who are visually handicapped, deaf or unable of hearing (DPA, 2003). Disability may be temporary, lasting for a limited period, or permanent, not expected, or later on, acquired. It can also be progressive, or regressive, leading improvement or complete recovery. A Handicap is defined as "a disadvantage for a given individual, resulting from an impairments or disability that prevents fulfillment of a role that is normal depending on age, sex, social and cultural factors, for individual. Vulnerability is a dynamic concept that reflects socioeconomic environment and their resilience towards it. Vulnerability captures the sense of threat and the pressure felt and experienced by particular groups those belonging to the group are spatially at risk (Banda T., 2007).

The concept of disability and handicap emerged in particular historical circumstances in Europe. As a social identity the concept "disabled" is a recent phenomenon in most nonwestern societies: through surveys, research projects and government policies. The significance of impairment depends on the values and assumptions that people have about the nature, functioning, and goals of persons with disability. It involves the ideals and expectations against which people measure them. In other words answers to the question:

What is human or inhuman?" are determined by the values of different cultural groups (Ingstad and Reynolds, 1995).

Ecological model helps to understand human health behavior by focusing on the nature of people's transactions with their physical and socio-cultural surroundings (Stokols, 1992 cited by Glanz, Rimer & Lewis, 2002). There are four explicit assumptions of the ecological model. First, health is influenced by multiple components of physical and social environments including personal attributes. Second, environments themselves are multidimensional. Third, human-environment interactions can be described at varying levels of aggregation (individuals, families, work and cultural organizations, communities and whole populations); and fourth, there is feed back across different levels of environments and aggregates of persons (Sallis & Owen, 2000).

The model depicts that human health behavior is influenced by the interaction of personal, situational, socio-cultural and environmental factors including built environment. The inclusion of all these types of analysis in ecological models provides an opportunity to see the influence of intra-personal behavioral factors (level of individual knowledge, attitudes, and beliefs on obstetric care) and inter-personal behavioral factors (level of support from spouses, families, neighbors and traditional birth attendants) on Experience of Participants' experience particularly on their health and social situation. It also assists to understand the influence of socio-cultural (early marriage and socioeconomic status of SDP) and environmental factors (accessibility of obstetric and transportation services) to the occurrence and consequence of disability.

According to the religious model, the root of understanding the bodily difference on disabled persons was grounded in the 'Biblical References'. Clapton and Fitzgerald (1996) argued that disability has been seen as a result of 'evil spirits', 'the devil', 'witchcraft' or God's displeasure'. The social model of disability emphasizes the promotion of social change to incorporate persons with disabilities in the larger social context. The model affirms that disability is not only the medical issue but the social restrictions emerging from discrimination. According to this model, therefore, active participation of disabled people is essential to address disability problems. For them, it is not the impairment but the social response that has much more influence on the lives of disabled people. According to this

model, people with disability face different types of discriminations, such as 'institutional, environmental and attitudinal' (DFID, 2000). I used social model for my study.

2.1.2 POVERTY AND HIV/AIDS

At the global level there is a positive correlation between HIV/AIDS prevalence and poverty (Fenton, 2004). Fenton also describes as there are two by-causal relationships between HIV/AIDS and poverty. On one hand poverty fosters the spread of HIV/AIDS; on the other hand HIV/AIDS increases the poverty of affected people.

The socio-economic statuses (being poor, uneducated, stigmatized and marginalized) of persons with disabilities within society present a unique challenge for them to access basic social services including HIV/AIDS related messages. As a result, they are exposed to all known risk factors of the HIV/AIDS infection (Groce & Trasi, 2004; World Bank & Yale University, 2004). The hearing and visually impaired also face significant disadvantages in most societies. Too often, they are not considered as a target group for HIV prevention education and AIDS outreach efforts because there is a misconception that they are not sexually active and exposed to risk HIV infection (D'Aubin, 2003; World Bank & Yale University, 2004).

People with disabilities are among the poorest, less educated and most stigmatized people. The stigma experienced by PwDs creates a feeling of insecurity that drives them to risky sexual behavior such as having multiple sexual partners. Furthermore, PwDs are vulnerable to violence and sexual abuse, including rape – situations where they are less likely to negotiate safer sex, such as condom use. The prevailing social discrimination places women, children and the elderly with disabilities at even higher risk due to greater possibility of physical and sexual abuses.

2. RISK FACTORS.

Risk factors are activities that increase the likelihood of HIV/AIDS infection. There are no definite statistics which show the percentage distribution of risk factors (as that of the hearing impaired) in the visually impaired population. This clearly indicates that an important problem has been over looked for a long period of time in the country. Risky behaviors of HIV/AIDS infection are largely pronounced in the disabled population in

general and in the visually impaired individuals in particular. Thus it will compound the infection rate of the visually impaired persons more than the general population.

Studies made in Uganda and Rwanda revealed that persons with disabilities are exposed to all known risk factors of HIV/AIDS. They tend to have many sexual partners, be involved in unstable relationships, are likely to be victims of sexual abuse and rape, have a low awareness and knowledge of HIV/AIDS, engage in unprotected sex, suffer from poverty, lack persons with disabilities targeted programs and access to HIV/AIDS related services and face discrimination and stigma (Yousafzi, & Edwards, 2004; Malindwa, 2003).

Individual sexual behavior, the numbers of sexual partners, use of protection during sexual intercourse are taken as factors at the micro level in determining HIV infection (Fontanet & Piot 1997 cited in Bernardi, 2002).

This implies, it is not only necessary but also mandatory to have target specific HIV/AIDS intervention programs for sensory disabled populations. Currently, preventing the spread of HIV/AIDS through IEC and behavioral change communication (BCC) remains as the top intervention strategy. More recently, to facilitate the response to the questions of what, who, how and when, while undertaking BCC interventions, the National HIV/AIDS Communication Framework has been developed (HAPCO, 2002).

There is evidence that the rate of sexual abuse committed against disabled people is far higher than that suffered by the wider community. In line with this, The World Disability Report (1999) stated that disabled individuals experience sexual abuse and they are much more at risk than the general population for HIV/AIDS infection and the report further explained that most are sexually abused in a cycle of violence from which they cannot escape. For the sexual abuse of visually impaired individuals, the report gave such reasons as they are more dependent on others for assistance and are unable to differentiate between appropriate and inappropriate physical contacts. Persons with disabilities are at high risk of HIV infection due to the various factors like poverty, disability, lack of information, inaccessibility of HIV educational materials and social exclusion, and stigma. This implies urgent need to incorporate disability issues in HIV/AIDS and poverty reduction policies.

2.3 EFFORTS TO HELP DISABLED PERSONS

The constitution of Ethiopia under Article 41 states that “The Government shall, according to its economic capacity, do its best to rehabilitate and support persons with physical and mental disabilities, the elderly and children without parents or foster parents”. The fact that the issue of disability has been addressed is an important step forward and there is no doubt that it will have a tremendous impact on future actions.

Persons with disabilities are usually discriminated with respect to recruitment, salaries, benefits and training opportunities. Realizing this, the Government has enacted a law on the rights of disabled persons regarding employment i.e. proclamation No. 101/1992, with the objective of curtailing discrimination.

There is a national HIV and Disability Taskforce with members from government, UN agencies and associations working on issues of disabilities in Ethiopia. Currently there are 17 organizations working on issues of disabilities that at the same time have HIV/AIDS awareness raising programs. However there is lack of information on the magnitude of HIV among PwD, capacity to provide HIV/AIDS services as well as poor capacity to mobilize PwDs. Furthermore, there is insufficient coordination among the different associations working on disabilities to deal with HIV/AIDS.

CHAPTER THREE

3. METHODOLOGY

The study used qualitative research method and phenomenological research design. Non probability sampling techniques is used to identify participants of the study and in-depth interview is used as the main tool for data collection. It also indicates how data collection instrument is developed, procedures for data collection and analysis, and ethical issues.

3.1 WHY QUALITATIVE RESEARCH METHOD?

Experience is the source of all knowledge and the basis of behavior. It is the foundation of knowledge. Without human experience there would be no human world.(Becker, 1992). The assumption in this study is that participants' experience richly illuminates and thus it is this experience that serves as the primary source of knowledge on the subject of the study. This research is consistent with this premise, reflecting the belief that studying the specific and individual details of the participant's experience.

This study employed qualitative research method. According to Padgett (2008) qualitative research method is best suited for a topic which is sensitive and emotional depth that requires empathy and understanding. In addition, qualitative method helps to understand the meaning of situations, events, experiences, and actions of participants (Maxwell, 2005). Qualitative research approach helps to study a social phenomenon within its natural context. It also enables to have in-depth understanding of a few numbers of cases rather than a general understanding of many cases or people (Grinnel, 2001).

3.2 RESEARCH DESIGN

Phenomenology in Greek which means to show itself was the methodological basis for this qualitative study. This approach is one of discovery and description, and emphasizes meaning and understanding in the study of the lived experience of individuals (Cresswell, 2007).

The research participants of this study are hearing and visually impaired and living in Addis Ababa. Scholars propose the range of participants to be studied in phenomenological research. For instance, Padgett (2008) recommends, “From six to ten participants”. In fact, the number of participants in qualitative research depends on the saturation of the data hence; ten in-depth interviews conducted until data reach the level of saturation.

The study used non-probability sampling technique as a sampling method. Purposive sampling method is employed to trace the first participant. This involved conscious selection of a participant by the researcher based on the inclusion criteria and purpose of the research. This has been done with ENAD and ENAB members. Then, snowball sampling which relies on referrals from initial participant to identify additional participants was used.

For the purpose of this study, the researcher recruited ten respondents who satisfied the following inclusion criteria, considering the method and the resources available to conduct the study. Through setting boundaries on the Experience of sensory disabled persons Were willing to participate in the study, and able to give consent by themselves, Inclusion criteria, the homogeneity of the sample was increased. So, participants with age range of 18-45 who: a) person who is living in Addis Ababa for a minimum of five year; b) are willing to be part of the study and their voice to be recorded, c) lived with disability for at least five years.

3.3 DATA COLLECTION TOOLS

Formulation of the in-depth interview guide was guided by the literature review and the objectives of the study. It has two major parts that aimed to capture the experience of participants in relation to their social relationship and health issues. Part One: Life history part of the interview guide included the background characteristics of the participants such as their childhood memories, marital situation and sexual initiation. It also deals on disability history of the respondents. Part Two: Participants’ experience this part sheds light on participants’ present and past experiences, understanding and feelings about their social relationship and health situation. Also, the meaning they provided for what they experienced. A pilot test was held with two sensory disabled persons who fulfilled the inclusion criteria. This helped to make the guiding questions more compatible with the objective and the setting of the study.

3.4 DATA COLLECTION TECHNIQUES AND PROCEDURES

In-depth interviews were used as the main technique for collecting data. Data collection in the interview is interactive, where by the researcher describe as accurately as possible ones' understanding and interpretation (Creswell, 2007).

Two interviews per participants guided by two major parts of open ended questions were conducted with the voluntary participants who fulfilled the inclusion criteria and confirmed their participation in a written and verbal form. In the first interview, participants were asked questions this interview promoted the next interview through creating easiness and developing trust. In the second part, participants' present and past experiences related to difficulties they had met with their problems and the meaning they provide for their experiences were explored between four to six days of the first interview. Interviews were conducted over two weeks. The interviews were taken in a place preferred by the participants; mostly in their private houses. The selected setting was also checked how much it is free from background noise and interruptions. The researchers role during in-depth interview was probing in order to get the core of the reality about the phenomenon under study. Forwarding open ended questions and asking for clarification from the interviewees were the techniques I used for probing. I was also encouraging participants to speak using techniques like nodding.

3.5 ETHICAL ISSUE

Written and verbal consent was obtained from women who fulfilled the inclusion criteria to let them know that they will be researched and also protect them from participating involuntarily. The informed consent has incorporated information such as the voluntary nature of the research, purpose of the research, extent and procedures of confidentiality and anonymity.

The informed consent also indicates the associated risks and how it was planned to handle it though none of the participants were demanding such kind of arrangements. Participants who completed the two interviews successfully received a 'thank you' card and

refreshment costs are covered in order to indicate the appreciation of their valuable time and contribution to the existing literature through sharing their lived experience. The right to withdraw from the interview at any time with no loss of benefits was also part of the consent form. Tape recording and note taking was carried out taking in to consideration the willingness of each participant.

3.6 DATA ANALYSIS PROCESS

The following procedures and activities were taken during data analysis process. The audiotape was transcribed using rules of transcription for the blind respondents and write contents explained by the deaf participants through sign language translator. Every page had the pseudo name of the participants, dates of interview and transcription; every guiding question was followed by participants' answer; and nonverbal signals, clarifying phrases and words that need translation are put in the way it could reflect the interview as fully as possible by being verbatim (Padgett, 2008). The transcription which is written in Amharic, then translated in to English as accurately as possible. Identification numbers were assigned to audio files and field notes in order to keep the link of various data sources for each particular case.

Coding is according to Coffey and Atkinson (1996) cited in Padgett (2008, p.151) coding breaks the “data apart in analytically relevant ways in order to lead toward further question about the data”. To do so, a new document was created with two parallel columns: units of information and code. In column one (units of information) data forming specific descriptions of the phenomenon was inserted. In column two which is entitled code, brief and descriptive codes that are helpful to easily understand and see the content of the data were assigned to these significant statements. Codes which are large enough for division are divided and sub-codes are assigned.

Categorization and Thematic Development

Finally, the main themes were identified and the categories brought together and rearranged under those themes. Accordingly, the interpretation was done based on: the common points and/or something new emerged, and conceptualizing and explaining issues interrelated to one another in the themes and codes emerged.

Interpretation

The significant statements and themes are used to write what the participants experienced and the context or setting that influenced how the participants experienced the phenomenon. Ideas developed through transforming participants' experience and meaning in to appropriate scientific discussion.

3.7 TRUSTWORTHINESS OF THE STUDY

In order to ensure the trustworthiness of a research it is important to know the possible threats and how to deal with that. Reactivity, researcher biases, and respondent biases are the major challenges for trustworthiness of qualitative studies. In order to minimize respondents' biases and the risk of reactivity in which participants hold back information due to the presence of researcher, prolonged engagement is used as strategy (Padgett, 2008). Prolonged engagement is the investment of sufficient time to achieve certain purpose. To have prolonged engagement two interviews per participant was conducted. The first interview enables to build rapport and promote for the next interview. The next interview brought engagement and has participants' experience evidently (Morrow & Smith, 1995 cited in Padgett, 2008).

A researcher bias was handled through 'bracketing out'. Creswell (2007) stated that to fully describe how participants view and feel the phenomenon, and counter early categorization researchers must bracket out their own preconception and experiences. This enabled to suspend belief throughout data collection and analysis.

CHAPTER FOUR

4. MAJOR FINDINGS

This portion of the study has five parts. The first part shows background characteristics of the participants. The second part describes understanding of participants about the predisposed challenges in relation to their disability and vulnerability to HIV/AIDS, deals with the first objective. The third part presents findings related to risk factors encountered by disability and HIV victims. This part addresses the second objectives of the thesis. The fourth part deals with the links of HIV/AIDS prevention and control programs to disability issues and speaks to the third objective of the thesis the last part of this portion examine the basic service available for persons with sensory disability based on their experience in coping the background of the participants.

4.1 Characteristics of Respondents

Table 1: Background of Respondents

Informant	Sex	Age	Religion	Place of Origin	Education	Marital S.	Occupation
1	F	30	Orthodox	AA	8 th Grade	Single	Unemployed
2	M	24	Orthodox	Gojam	5 th Grade	Single	Unemployed
3	F	29	Protestant	Gojam	8 th Grade	Single	Unemployed
4	F	34	Orthodox	Tigray	6 th Grade	Single	Unemployed
5	M	41	Orthodox	Tigray	Illiterate	Divorsed	Pity trade
6	F	25	Protestant	AA	8 th Grade	Single	Unemployed
7	F	39	Orthodox	Gonder	Illiterate	Married	Unemployed
8	F	35	Muslim	Wollo	Illiterate	Single	Unemployed
9	M	45	Orthodox	Jima	Illiterate	Divorsed	Pity trade

10	M	18	Muslim	Jima	8 th Grade	Single	Unemployed
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Sensory disabled persons Selected for the study

Purposive samples of PwD who are vulnerable to HIV/AIDS were participated in this study participants were between the ages of 18-45 years and lived with disability at least for five years. Six of the respondents are orthodox Christian others are Muslims and protestant Christians. Six of them are females and males are four. All are Ethiopian from different place of origin. No one engaged to high school and formal employment opportunities

4.2. UNDERSTANDING CHALLENGES OF SENSORY DISABLED PERSONS

When asked what challenges the participants encountered because of their disability most participants noted that their first ranking problem is lack of income. Most of their problems are intrinsically linked to poverty; lack of information about the messages on HIV/AIDS because of their disability.

In connection with the challenges to PwDs to access HIV/AIDS messages, care and support services, the respondents admitted that their low literacy intimidated their understanding of the messages. They added that the inaccessibility of messages for the blind and the deaf (Braille and sign language skills), and the inaccessibility of health service facilities for the disabled persons further complicated access to HIV related messages. Above all, the failure of HIV prevention and control messages expose sensory disabled persons. This information gap highly contributed for the vulnerability of PwDs to HIV infection. It is likely that the spread of the virus escalates with increasing availability of information for the non-disabled people. In this regard, complete absence of information for PwDs worsens the spread of the virus among the disabled.

The other response shows shortage of income because of lack of income generating jobs. The main causes for their joblessness were lack of adequate academic qualification and profession that the present labor market requires.

The participants confirmed that their limited education skill and information are the primary root cause for their inability to get job.

One respondent said:

“Vacancies disclosed only for non-disabled job seekers, do not consider blinds. If jobs are hanged on notice boards how we the blind can read it and how can we compute with non-blinds?”

The other challenge presented by all respondents was unbalanced (biased) social attitude in the labor market.

Most employers assumed disabled persons to do less than assumed disabled can do. Some employers do job recruitment in favor of non-disabled persons therefore sensory disabled persons are marginalized in job markets.

The attitude of the society is also manifested in the form of lack of sending to higher education. All the respondents reveal that:-

“The society including our family consider me as a “cursed” person, some people feel fright to have disabled partner (sexual)” (the deaf respondent)

All the respondents associate the discrimination by the society to their lack of income.

In this regard four participants witnessed that they are forced to be involved to have sexual practice to get money and survive. They reflect that they opt to have sexual relation but the non-disabled who could give those gifts or money on the will of their partner

Two respondents involved in begging at night not to be seen in day time to get money. This exposed them to be raped. They have no knowledge about who actually raped them. It could be a person with HIV to make them vulnerable to HIV/AIDS being victims of sexual abuse.

It is their sexual partners who make decision either to use condom or not. This could increase persons with sensory disabilities (the participants) probability of getting infected with the virus.

On the other hand three women with sensory disability responded that:-

“I aspired to have children from the non-disabled men without checking the HIV status of the men”

One respondent stated that:-

“I rushed to get children, I prefer to have non-disabled child to be assisted I like to see this world through the eyes of my child.”

Here the purpose is only to have child. The issue of sexually transmitted disease (HIV) is underestimated. Such unsafe sexual practice could increase the likelihood of contracting HIV.

The result depicts that the income/ poverty situation determines respondent's sexual choice. Their primary intention is supporting their daily subsistent life ignoring attention to the risk of contracting HIV. This ignorance escalates the vulnerability of the persons with sensory disability.

In this study the respondents do not participate in commercial sex openly but indirectly they are engaged in sex without their interest to survive. Thus problems have been identified as driving force for respondents to be engaged in sex without consideration of reproductive health problems which increase the sustainability of persons for HIV infection.

4.3 RISK FACTORS

When asked to highlight their understanding of the risk factors, the main risk factors mentioned by all participants are categorized in to four themes such as economic factors, social factors, environmental factors and legal factors. In the first theme two respondents stated:

“It is a puzzle for me... I thought some people viewed me as a liability... I have no fixed or other asset. I need money to survive had no power have sex with no consent, with risk of

pregnancy and HIV. I always think how money is important? to me” (an informant age 25, blind)

One of the participants argues that:-

“Poverty for disabled people is not only monetary it is also a question of powerlessness which accelerates the situation of further discrimination and violence.”

This was related to an incident she experienced when she commit sex with her sexual partner she explained the event as follows:

“I asked my friend to use condom but he refused and resist having sex without condom he agreed to use condom but he reject the condom during sex and forced me to get naked sex, I cried for that moment but... our relation continues with his interest because I can't live without his help”

Several participants stressed lack of income and decision power as contributing factor to influence decision on sex matters as a means to get enough money for their survival.

In the second theme social factors are mentioned as a risk factor. Participants experienced isolation, discrimination, stigma, and despair especially during their childhood. Three participants explained this situation as:-

“I was protected at home and could not get basic services even to go health centers and attend education. When I asked to go school or health center no one responds to me. I was totally ignored. It was not possible to me to participate in social life (meeting, seminars, musical consorts' etc)”

The participants experienced emotional challenges because of lack of social values. All the respondents confirmed that:

“Most people favor the non-disabled than the disabled person. Disabled persons have less opportunity for marriage. It is because of the fact that society gives more value for physical (external) beauty than beauty of the soul when choosing spouse”

The findings under this theme indicate that social inferiority is manifested by the participants. This was mainly due to the lack of power to do their wishes when they were children (in ability to participate in family issues and avoid being married off).

The third and fourth themes are environmental and legal factors

Another participant experience described

“The social service infrastructural environment is arranged for non-disabled. The buildings stairs, the streets and the entire physical environment is not conducive for disabled. This exclusion to different services lead sensory disabled persons to miss opportunity for education, health and legal services as a result. We are forgotten unconsidered in most services: all the physical, mental and social barriers exposed us for different problems and we are feeling hopelessness”

The other respondent disclosed also:

“I was sensitive when I was child but I am becoming senseless in my opinion now I am a real sensory disabled person it is not because of my disability but because of the barriers that hindered me to go forward.”

The above views of respondents strengthened by the argument of the social model as disability are socially constructed problem rather than disease by itself (DFIO, 2000). Persons with sensory disabilities experience difficulties in getting married and setting up family as a convention all participants blame its practicality.

All the participants agreed on the poor access to sensory disabled persons to get legal services especially on the stigma and discrimination. Persons with sensory disabilities often need support from the legal bodies to protect them from sexual abuse but neglected (Choruma (2006)).

On the other hand, eight of the respondents have had sexual partner with persons with disability. It was reflected that they do this because they often have social interaction within PDs and they have little chance to contact the non-disabled. Besides, they can maintain good relationship with those with the same kind of persons with disabilities.

Nevertheless, they do not opt for SDPs for sexual partner due to the disability and failure to get financial and other related support from the SDPs. The need to help their daily subsistence limits their choice of making sexual partner.

It is evident from the above finding that SDPs choice of sexual partner is associated with their need to get their daily subsistence. Sexual relationship is not just for reflection of actual sexual behaviour but to fulfil their basic needs through financial resource. This indicates that failure to have a consistent sexual partner may lead to unsafe sex and thus expose them to HIV infection. In addition, SDPs consider the sexual practice as source of income and this makes them to have sexual relation with somebody whom they do not have any information about his or her sexual experience.

The above finding indicates that the sexual life or behaviour of SDPs is very risky in exposing them to HIV infection. On one hand, the rape practice by the perpetrators highly increases their infection rate to the virus. They have no knowledge about who actually raped them. It could be persons with HIV, who might wish to cleanse their sero- status. On the other hand, some SDPs like the physically disabled fail to protect themselves from their perpetrators, thus, are easily become victims of the sexual abuse.

The interview results appear to be sad for the disabled people who are unable to get appropriate legal provision. It shows that these people are not in a position to get legal protection as victims of sexual abuse. The problem is also correlated with social and economic consequences. Shortage of income may hamper their capacity to report the case. On the other hand, the report and follow up of the case could result in further discrimination from the non-disabled people in the community. It is, therefore, more likely that PSDs could easily be exposed to persistent sexual abuse and this may increase their infection.

On the other hand, four of the respondents reacted that they some times get services like counselling by task forces organized by Ethiopian National Association of the Blind (ENAB). But six of the respondents are totally non-beneficiaries of any service available in the city. They could not get any reference to service organizations and associations simply

because they are not registered or known by those service sectors. Even they do not know where these organizations are placed in the city.

Participants described childhood memories, most of them have sad memories of their childhoods. When they talk about the way how they brought up and the educational opportunities they missed, lack of freedom and lack of free discussion on different issues including reproductive health matters.

One of the respondents described his childhood memories:

“As a deaf child I had no chance to discuss with my family members language barrier was a challenge for me. I always wish to go to school (alpha sign language school) to get my friends who can communicate with me with sign language. When we come back to home I was so late and intended to stay in school not to be departed from my friends with same disability the time I spent there was interesting.”(An informant aged 25)

Another participant recalled her childhood with unpleasant memories

“All the family have gone to wedding ceremony except me, I never forgot that day not because of missing the ceremony but our door was latched over me all the neighbors were also absent. I cried loudly to help me I need to pass urine I shouted! no one helped me. I complete everything inside my trouser. At night when the family came back to home my mother washed my clothes, my brother and sisters laughed over me; my eyes can't control tears. It took me long time to recover and regain my happiness “(an informant, are-blind)

While describing their childhoods, all participants expressed disappointment at their social life, and they identified it as major factors explaining their current status. All participants except one blamed their parents and the tradition that discourages sensory disabled persons.

4.4 FOCUSES TOWARDS SDPs

Several participants argued that HIV prevalence cannot be reduced unless the social conditions are transformed. If any progress is to be made in fighting AIDS inequality of special interest must be tackled. HIV prevention and control programs should be linked with disability issues. All participants identified the gap between the programs held and the

challenges of disabled persons because of the unfilled gap in prevention and control of HIV/AIDS. Sensory disabled persons consider themselves as a high risk groups.

Four participants stated unavailable services. Lack of access to information especially HIV related materials for the deaf and the blind. For instance, there are no sufficient Braille materials for the blind, there are no brushers written in sign language for deaf.

All participants stressed “the lack of special attention for disabled persons”. Coherent policies are designed and institutionalized to prevent the spread of HIV/AIDS. However persons with multiple burdens like disabled are ignored to have special programs in control and prevention of HIV/AIDS. Most of the programs designed for non disabled persons could not properly address the problems of the disabled.

One informant explained these mismatch by stating her own experience:

“Lack of knowledge about the way in which HIV can and cannot be transmitted is my major problem to protect my life from the epidemic. The awareness creation work mostly is by distributing brushers even for blinds. I remember in one meeting on HIV/AIDS issues I was a participant I collected the papers and I asked him to read the brusher he refused to read and give me condom. It was my first time to touch condom”

There is no brusher written in Braille, no method of familiarizing condom for visual and hearing impaired. Another participant describe the absence of attention for disabled persons in the following way:

“My teacher asked me with sign language that how I active in sex and weather I have sexual experience or not. I asked him his own question to him again and told him the same is true for disabled people “

All participants were asked whether they have sexual experience or not. All except one disclosed that they had sexual experience. Likewise, question addressing the intervention of the government in provision of services related to HIV/AIDS was presented to the interviewees. Regarding this, all of the respondents did not get direct services from the government.

There is no special service provision for them as disabled. The following story was recorded from one of the blind respondents during the interview.

“I heard that there are a lot of media campaigns particularly through radio, television and printed materials like posters. On one hand, I can not afford radio and television to listen to the information. On the other hand, I can not see the visually based information in the television. So, I can not deny that the government has made effort on disseminating HIV information. But the disabled like me use none of the information.”

The result clearly depicts that the government has put in much effort in promoting awareness on the people by using various methods of information materials. Nevertheless, these materials are not disabled people friendly. They fail to consider SDP.

On the other hand, a contextual factor like poverty further impedes SDPs from getting the information sources. These people may not afford the costs of transportation, visual and reading materials like television and magazines and brochures respectively. But they recognize that some of them have been visiting the service sectors in the nearby government organizations. It was mentioned that two of the respondents have made contact with Sub-city HIV/AIDS prevention and control office. But they could not access information designed to their needs. They simply take part in service provision programs designed for all people in general. However, the visual and hearing impaired people in the sub-city are still non beneficiaries of such services due to their disability.

CHAPTER FIVE

5. DISCUSSION

In an attempt to illuminate the feeling and understanding of sensory disabled persons commonalities were found in different participant's experience. An analysis of thematic categories is examined along with the literature. This enabled the identification of participants understanding of risk factors that escalates their vulnerability to HIV infection, as well as their challenges. This discussion is organized based on the findings presented above.

5.1 Understanding the challenges of sensory disabled persons

Misconception

One may understand from the above findings that the visual and hearing impaired are facing difficulties in getting HIV information. A significant number of visually and hearing impaired people have very limited options for overwhelmingly increasing information materials related to HIV for those people who are unable to see and hear. They have special needs with regards to HIV information. Though it might be understood publicly that the visual and hearing impaired people require communicating through these specially designed materials, it is not recognized by service sectors. Thus, if these people are not getting access to such formatted materials, it is likely they may not have enough information about the virus. Let alone absence of information on HIV, even those non-disabled people are suffering seriously by the virus despite the recently booming information materials on HIV/AIDS. This shows that PwDs like the blind and the deaf, in this case, are denied access to sufficient information on HIV which contributes for their exposure to the infection. The research identified that HIV/AIDS related need of PwDs have not yet been clearly known and thus no special programs are designed to help them.

The following sections try to establish a link between the views of the targeted population and how it fits into the social, medical or socio-medical models. Given the limitations of both the medical and social models of disability, the alternative explanatory

model is a construct that combines the positive features of both models. The assumption here is that an individual's human nature, his/her position in society, and life chances are neither exclusively determined by his/her innate biological characteristics and abilities, nor are they totally prescribed by social, economic and political structure of society. Both medical and social approaches assume that all human beings are essentially passive, in the sense that they are unable to influence the courses that their life will take (Thomas and Thomas, 2000: 4). There is thus an inter-dependent and dynamic relationship between an individual and his society. Conversely, the socio-medical model approach posits the integration of biological and social factors in determining human condition.

The possible explanation for the overall low level of comprehensive knowledge about HIV prevention and transmission could be that the current efforts being done by governmental and non-governmental organizations to deliver HIV/AIDS messages to this population of society, are not effective. Another possible explanation to consider based on research conducted in other countries (Mulindwa, 2003; Munthali, Mvula & Ali, 2004; Patrick & Matonhodze, 2004; Yousafzi & Edwards, 2004; World Bank & Yale university, 2004) is that individuals with sensory disabilities in our community may be the most disadvantaged group to access HIV/AIDS messages. Although this study could not proof or disproof these two assumptions, the overall result of the study seems to demand evaluation of current HIV/AIDS messages delivering schemes to persons with sensory disabilities. All in all, the low level of comprehensive knowledge concerning HIV transmission and prevention among the studied population is an alarm to organizations that work in the area of HIV/AIDS prevention, to give more attention to increase the knowledge among persons with disabilities.

In terms of the availability of HIV information in accessible format, a report by the South African National AIDs Council in 2002 depicts that the prevailing disability related stereotypes often undermine the campaign programmes to exclude PwDs in the HIV/AIDS message. The Peoples' perception shows that disabled persons have poor sexual relation with other people and thus are less likely to be victims of the virus. This prejudice makes the inclusion of PwDs in any HIV related message campaigns challenging. In addition to this, the information often does not consider the different disability groups. AIDS educators are not trained to be sign language interpreters. Moreover, the materials like Braille are not

considered and distributed to the blind during the campaign. This indicates the huge gap in access to HIV information for SDPs in accessible format. This results in SDPs susceptibility to HIV infection only because they do not have appropriate information on how to use condom, likewise, the deaf cannot access trained or professional sign language interpreters for HIV information.

Lack of income

The respondents were also asked for the influence of their income level poverty to their sexual behaviour. They explained that their low level household income limits their choice of safe sex and opt for sexual intercourse to get money for their survival. Simultaneously, it is their sexual partners who make decision either to use condom or not. Thus, use of condom is not a big deal but the only thing essential at the time is getting paid for the sexual practice. This could increase SDPs probability of getting infected with the virus.

On the other hand, women with disability responded that they aspire to have children from the non-disabled men and they cannot be sure of HIV status of the men. They rather rush towards sex to have child. They prefer it because they want to be like the non-disabled mothers who have their own children to be assisted. Here, the purpose is only to have child and the issue of sexually transmitted diseases is underestimated. This unsafe sexual practice could increase the likelihood of contracting HIV.

The result depicts that the income poverty has influenced the sexual choice of SDPs particularly the young ones. Since their primary intention is supporting their daily subsistent life, they do not give attention to the risk of contracting HIV. This ignorance may escalate the likelihood of infection by the virus. In Addis Ababa over majority of establishments with sex workers reported that they had one to five non-regular sexual partners per day and nearly 60 percent of the sex workers forced to commercial sex for economic reasons (FHI, 2006)

It is also important to know the sexual partner of SDPs to identify their sexual behaviour. The respondents have varying responses in this regard. Among the respondents, 8 replied that they have occasional partnership with the non-disabled persons. According to the respondents, it is the non-disabled who are often engaged in sexual relation with them.

Though they are not consistent sexual partners, they are the ones who sometimes pay for them.

Social inferiority

Generally, as a historical and cultural construct, the notion of disabled is heavily charged with implications of social inferiority or stigma (Talle: 1988. Furthermore, Ingstad (1991) argues that *“The focus in stigma and severe maltreatment of disabled people may well be a product of our lack of understanding of other fundamental social processes that shape the lives of the disabled”*. The findings under this theme indicate the social exclusion experienced by the participants. Respondents confirmed their exclusion from disability oriented HIV prevention programs, unequal participation in awareness creation activities and sensory disabled persons are devoid of HIV related materials like Braille and messages in sign language. With regard to question addressed to SDPs in relation to their families’ control, they replied that their family prefers to restrict them at home rather than moving out like the non-disabled people. According to the respondents view, their families are not willing to give them responsibility at home. They are often ordered by the non-disabled members of their family.

All in all, the presence of misconceptions about HIV transmission and lack of comprehensive knowledge on prevention methods together with low level of consistent condom use, perceived susceptibility to HIV/AIDS as well as perceived benefit towards the effectiveness of condom to prevent HIV necessitates intervention programs have affected the disabled members of the respondents.

5.2 Risk Factors

Regarding their current comprehension of the contributing factors almost all of the participants mentioned the connection between the risk factors and HIV prevalence and its severity on the presence of sensory disability. The factors categorized in four themes such as economic, social, environmental and legal factors. This findings are similar to those of Chroma (2006)

Participants experience as the hypothesis of social and ecological model revealed economic, social, environmental and legal factors might have influenced susceptibility to HIV/AIDS. Biological factors are not considered in the study. Experiences of the participants were meaningful and valuable information was collected analyzed and interpreted.

The participants understanding of risk factors are interpreted in light of social and ecological models if encompasses from intrapersonal to physical environment including the economic, social, environmental and legal factors all levels of factors can influence behaviors of the cases. The intention of this study is to explore the understanding of these known factors on sensory disabled persons. It implies participants current understanding was supported by the literature as well as the conceptual framework which indicating that vulnerability to HIV/AIDS is related to multidimensional risk factors particularly higher in sensory disabled persons. The findings under this theme indicate the social exclusion experienced by the participants. Respondents confirmed their exclusion from disability oriented HIV prevention programs, unequal participation in awareness creation activities and sensory disabled persons are devoid of HIV related materials like Braille and messages in sign language.

Sexual abuse has also been one of the major risk factors found to be increasing the probability of PwDs to be infected by HIV. A research finding by Nganwa (2002) highly supports this finding. He states that “while the physically disabled women cannot run away from their abusers, the deaf, dumb and blind cannot shout or protect themselves from their abusers”. The study points out that they cannot even insist on having protected sex and faithfulness from their partners. In addition, high levels of poverty, rape and non-use of contraceptives are the most common factors, which predispose disabled women to HIV/AIDS.

The finding on the risk factors that expose SDPs to HIV infection depicts that the limited social interaction of SDPs affects their level of interaction with others and thus fail to get HIV related messages. As pointed out by Nganwa (2002), PwDs isolation and confinement based on culture and traditions, attitudes and prejudices often affect disabled persons’ access to information obtained from communication. This isolation leads to low self-esteem and negative feelings. As a result, they become away from HIV related information. In other

words, missing the opportunity to get relevant information expands their ignorance on HIV prevention and control mechanism. This indicates the contribution of poor social interaction in exposing SDPs to lack of knowledge on the disease.

The results on the risk factor related to poverty indicate that SDPs are much more exposed to unsafe sexual practice due to their poor living condition. The fact that disabled people are more likely to have received little or no education and to be out of employment, places them among the world's poorest, most stigmatized and most marginalized (Choruma, 2006). According to this study, most disabled people accept financial promises from the opposite sex due to ignorance about the consequences of unwanted pregnancies and HIV/AIDS. This is related to their desire to get financial resource for their survival. In the attempt to earn their living, SDPs are increasing the likelihood of doing sexual intercourse with the non-disabled, whose HIV status is not known.

5.3 Focus towards disabled persons

HIV related service organizations and disability organizations failed to incorporate this service in their programmes. This could inevitably create a gap in addressing both the sexual abuse and perceived HIV related discrimination of the disabled. The national HIV/AIDS policy documents reviewed to assess the inclusion of PwDs indicate that both PSDs and PDLHAs in particular are non-existent. Both the policy and the strategic plans of HIV/AIDS exclude SDPs from the perceived risk groups such as the youth, women, truck drivers and commercial sex workers. It is clearly evident from this finding that this segment of society is neglected from HIV policy arena.

Despite the presence of policies and programmes, HIV/AIDS has been killing thousands of non-disabled people. Whereas people with special needs without related policy could seriously be forgotten and thus be victims of the virus.

Worst of all, absence of HIV services in disability specific programmes further deteriorates the situation of disabled people in Addis Ababa and in Bole sub city in particular. There has not been any action plans developed to address HIV related special

needs of SDPs in the selected associations. This could inevitably contribute for reluctance of HIV related policy and programmes to include SDPs.

Though there is a handful of HIV service organizations in Addis Ababa, most of them fail to include PwDs in their programmes. The finding indicates that respondents complain that the problem is associated with the national HIV/AIDS policy. The absence at the national policy affects the effort at the service sectors in the city.

In connection to the legal service to the disabled, who are suffering from HIV related stigma and discrimination, Choruma (2006) argues that it is essential for the disabled to get appropriate protection from the police and court whenever they are victims of the perceived discrimination and sexual abuse. It is their right to access such provision. But this right to access the service is often inhibited by perception of the police and the court that the disabled are considered as subordinate in social relations and are less likely to be exposed to sexual abuse. On the other hand, the disabled often fail to know their right to have legal protection from the concerned parties. Thus, though it is found to be important for the disabled to get legal services.

CHAPTER SIX

6. CONCLUSIONS AND IMPLICATION FOR SOCIAL WORK

6.1 CONCLUSION

This section of the paper presents the major findings and points of discussion presented in the previous sections. Broadly speaking, this research has been dealing with the vulnerability of persons with sensory disabilities particularly the deaf, and the blind. The research finding mainly focused on HIV related service packages available for PwDs, the efforts made by social service organizations, and risk factors for exposure of PwDs to the virus, and the contribution of income level poverty in exposing PwDs to the infection.

According to the finding, such inaccessibility of HIV related information materials is compounded with the disabled peoples poverty are the major challenges for exposing to HIV. The finding shows that lack of income often makes the disabled to opt for sexual practice as a means of income. They are hardly ever decision makers on sexual intercourse. It is the one who has bargaining power could make choice on this matter. This condition inevitably exposes the disabled people to HIV infection.

The research finding also depicts the influence of some risk factors that accelerates SDPs vulnerability to HIV infection. First, their dependency to get income for their survival leads them to opt for sexual intercourse as source of income. Second, families of the disabled children make serious control at home and the disabled could not access social interaction, which is believed to be one of the important social skills to get HIV related information through communication. Third, the challenges to reach the disabled in HIV messages make the situation of SDPs risky. Fourth, the sexual abuse PwDs experience and their failure to react on the abuse further increases the risk of contracting the virus.

Above all, the absence of disabled people policy strategies in national HIV/AIDS policy worsens the situation. Not only is the national policy but the disability associations in the sub city having no HIV related programmes designed to address HIV related needs of SDP. The results of the study reveal that social work practice programs must include prevention of HIV/AIDS which should include the use of appropriate means of communication to address the needs of sensory disabled populations. In this study the composite indicators on HIV prevention and transmission have disclosed the presence of a low level of knowledge among the studied population. Therefore, the delivery of HIV messages pertaining to HIV transmission and prevention, using appropriate modes of communication channels by organizations is indispensable.

The low level of risk perception, which is one of the prerequisites for behavior change demands social work interventions to increase the level of awareness, especially among persons with hearing impairments. In order to accomplish this, the organization needs to design strategies to influence the attitudes of individuals with sensory disabilities.

The majority of respondents were sexually active and a quarter of them reported having multiple partners. Premarital sex was prevalent. This activity can be supported by inclusion of societal norms that encourage delaying sex before marriage. Such interventions will encourage individuals, especially those who had never experience sex, to maintain their safe behavior. In addition, strategies to promote informal discussions among family members, friends and sexual partners that are interacting with persons who have sensory disabilities.

In conclusion, the findings have revealed the presence of misconceptions about HIV transmission. More actions are needed to save the lives of the visually and hearing impaired from HIV/AIDS.

Therefore, to curb the problem continued research among this population will be needed to enable the profession of social work to be proactive toward solutions to improve the quality of life for those individuals who are sexually active and have a sensory disability.

6.2 POLICY IMPLICATION

The research finding has a lot of implications for all relevant stakeholders to alleviate the vulnerability of SDPs to HIV infection. First of all, the result calls for policy level intervention to address HIV related needs of the sensory disabled people. Here it is the role

of social worker to advocate and aware HIV policy makers to reconsider the inclusion of SDPs in special package in all prevention and control programmes.

- Policy level intervention needs to be considered the national growth and transformation plan.
- There is a need to incorporate SDPs in this strategy to meet their special needs. This could be achieved if the social worker is involved in lobbying and advocacy activities to persuade the **policy makers**.
- Support the development of community-based support systems, i.e., transportation and health services, required by persons with disabilities to secure and maintain open, competitive employment.
- Programmes need to incorporate **local community members**, community social workers, traditional associations (*Edirs, Mahibers, and Equibs*), school teachers, and traditional leaders. The networks within these local people enable the implementation of the programmes easily. This is because disability as shown in literature section is more of social construction rather than disease.

If SDPs are understood by these people, provision of HIV related services will not be difficult. Thus, with regard to direct access to HIV related information:

- **Local administrations** should deal with GOs and NGOs in the production of materials in accessible formats. These include. Braille scripts for the blind and provision of professional training for sign language interpreters for the deaf.
- The integration of disabled and non-disabled people into the overall system. The involvement of disabled people in all aspects of the system, including design and development of programs and the hiring of disabled people as trainers and teachers in these programs;
- There need to be a comprehensive research on the prevalence of the infection rate at the national level. Social worker has to supplement the practical interventions with applied research on the relation between HIV/AIDS and disability, and the accessibility of HIV services to disabled people. Identify services in the community that can provide help and support to target sensory disabled persons.

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